Exploring the Wish Factory: Ethnographic Insights Into the Charitable Business of

Wish Granting

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Abstract

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In the last decade or so, the number of charitable organizations that offer various activities and programs dedicated specifically to "light up" the life of ill children through the granting of wishes has grown by leaps and bounds. In parallel, dozens–if not hundreds–of companies in various industries are collaborating with these charities through sponsorship and partnership programs. With their help, wish granting organizations now raise impressive sums of money and fulfill the wishes of children throughout the world.

Despite the importance of this major social and economic phenomenon, little research exists to date, that documents and reflects upon it. I studied this phenomenon by asking the following question: How can we conceptualize and understand ill children's wish granting and its impact on and relationship among the various actors, as they are deployed throughout the process? To do so, I used an 8-month full-time ethnographic fieldwork (complemented by 2 years of sporadic data collection) to immerse myself in the world of the Children's Wish Foundation of Canada. The Foundation grants approximately 1,000 wishes Canada-wide per year and granted its 15,000[th] wish in the summer of 2009.

This dissertation explores the phenomenon mainly from the perspective of *Actor-Network Theory*, as proposed by Bruno Latour (2005). It investigates which I call the Wish Factory through an in-depth analysis of the wish granting process (how wishes come to be developed), the actual fulfillment of the wishes, and finally the wish's after-life. Reflections on the relationship between charities, beneficiaries and the marketplace are woven into the analysis. The Wish Factory manifests itself as a process that engages a large and diversified network of actors, all

involved in the creation of an extraordinary event for families facing the turmoil of childhood illness. In creating the extraordinary wish, the actors (principally the beneficiary families, the charity and the marketplace) must deal with tensions arising from the opposing forces of the unique and the plain commercial. The notion of *regimes of value* (Appadurai, 1986) is proposed as a way to explain how such tensions are resolved at the micro and macro levels.

Acknowledgments

To my parents, who make the child in me live on.

To Yanan, who makes me the happiest man.

To Lynn-Lann, who makes me the proudest father.

To my informants, who gave me the gift of appreciation for life.

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1. Dreaming a New Society

Individuals, groups, and communities have always nurtured deep-felt wishes for a better society, for justice, and for social equality for the marginalized and the excluded. A contemporary example is Martin Luther King Jr's dream of a better America. In his speech delivered on the steps of the Lincoln Memorial on August 28, 1963, King said:

> *I have a dream that one day this nation will rise up and live out the true*
>
> *meaning of its creed: "We hold these truths to be self-evident: that all*
>
> *men are created equal." I have a dream that one day on the red hills of*
>
> *Georgia the sons of former slaves and the sons of former slave owners*
>
> *will be able to sit down together at a table of brotherhood. I have a dream*
>
> *that one day even the state of Mississippi, a desert state, sweltering with*
>
> *the heat of injustice and oppression, will be transformed into an oasis of*
>
> *freedom and justice. I have a dream that my four children will one day*
>
> *live in a nation where they will not be judged by the color of their skin but*
>
> *by the content of their character. I have a dream today.*

This speech has become, in many parts of the world, the defining symbol of non-violent struggle for social reform. In 1964, Martin Luther King was awarded the Nobel Peace Prize. In April, 1968, he was assassinated.

Among the many other dreams held by societies are the ecologists' green dream (Heller, 2003) and the romantic's longing for a return to nature (Tuan, 1998, Belk and Costa, 1998). Our contemporary world has been shaped by many of these ideals and aspirations. Many of these aspirations, however, are deeply rooted in the individual's private world.

2. Dreaming the Individual

Each of us has personal, private dreams. In what follows I highlight some of them. A ubiquitous dream in the Western world is one of getting a better job and climbing the social ladder. Since the advent of the industrial revolution and the shift to modernity, aspiring to higher economic and social status has become pervasive. Social emulation (Veblen, 1899; Douglas and Isherwood, 1979) of what others are doing to "make a living" (Schor, 1999) appears to be a factor in that dream (Campbell, 1987). So universal has it become in the West that a significant countermovement extolling the benefits of "slowing down," of downshifting, of living a simpler life (Elgin, 1981; Schor, 1998, Craig-Lees and Hill, 2002), has gained momentum over the last 20 years.

The ideals of masculinity and femininity also occupy the American imaginary as major forms of hopeful ideologies. In Holt and Thompson's (2004: 427) words, masculine ideology consists of the "tacit understandings regarding how a man earns respect, what makes a man successful, what it means to be a good father, what qualities

make a man heroic, etc." They argue that many American men conform to a model of masculinity that mixes two a priori contradictory forms – one as the breadwinner (hard-working, dependable, career-oriented, and fatherly), and the other as the rebel (uncivilized, anarchic, fiercely independent, courageous, physically skilled, and cunning). Thus emerges the man-of-action ideology: a man successful in "resolving the tensions between breadwinning and rebellion in a utopian revolution" (Holt and Thompson, 2004: 428).

Many women, on the other hand, struggle to maintain two competing roles in their attempted enactment of a feminist ideology: they continue to assume the major responsibilities of the family while at the same time trying to maintain their role as professionals (Thompson, 1996). The women in Thompson's research want to be good mothers, but they must juggle busy schedules, negotiate compromises within the competing desires of their family members, and cope with the tensions inherent between their idealized version of the "good mother" and their daily practice.

There is another dream beyond "Dreaming the Society" and "Dreaming the Individual" – the American Dream. American narratives and imaginaries resonate in this dream that, regardless of gender, economic position, or social class, "America is a land of boundless opportunity, free from the social barriers to individual mobility found in other countries, whereby individuals from all backgrounds (particularly immigrants) can grab the golden ring if they work hard and demonstrate initiative" (Holt and Thompson, 2004: 427). This dream is grounded in materialistic aspirations. Inspired by the Protestant (Weber, 1992) and Romantic ethics (Campbell, 1987), this aspiration has led individual Americans to strive for a better material world. It has a rich tradition in the history of the

United States and in its artistic representations. Moreover, after the Second World War, the dream broadened. Both military and homeland workers, aided by union jobs and a collective desire to reward Americans for their contribution to the war effort, gained access to secure jobs and higher wages. They could now focus their attention on a more extensive range of products and aspirations (Hurley, 2001).

Americans dream of objects that seem to promise a more satisfying life. Materiality and consumption occupy a prominent place in the daily life of modern (or postmodern) subjects and have become significant grounds upon which dreams can relocate and stabilize (McCracken, 1988).

3. Dreaming the Consumer

We are consumers. We create meaning, value, and symbols through the consumption of goods and services. We dream that such consumption will engender a better world. We also consume images and aspirations. We are bombarded by the media with images of the next generation of luxury cars and the most exotic tourist destinations. We are immersed in the world of millionaires, pop stars, and Hollywood celebrities. We embark on virtual tours of their magnificent mansions and gaze at their affluent lifestyle; vicariously, we live through them and consume their lives (Caughey, 1984).

Objects and brands have become primary sources for our aspirations. We long for the big house, the big car, the big trip, and the big money, the American Big Four (Fournier and Guiry, 1993). In the Western world, ideals and hopes have been to a large extent entirely displaced by consumer goods (McCracken, 1988). This is also becoming

true in developing countries such as Turkey and Romania, in which rapidly escalating consumer desires have become prevalent (Ger, Belk, and Lascu, 1993).

Thus, we live in dream worlds. Our consumer society has witnessed the "aestheticization of everyday life" (Featherstone, 1991). Companies offer consumers spectacles and experiences (Pine and Gilmore, 1999). They create "cathedrals of consumption" – theme parks (Disney World, Universal Studios, MGM), casinos (Las Vegas, Reno, Atlantic City), mega shopping malls (West Edmonton Mall), retail stores (Nike Town, Toys 'R' Us), hotels (Bonaventura Hotel), and carnival cruise ships – places in which spectacular, hyper-real lives (Baudrillard, 1983; Belk, 1996, Jameson, 1984) are constantly constructed and evolving in the quest for better consumer entertainment (Ritzer 2005). We are, furthermore, all tempted by this appealing, imaginary world.

Aspirations also serve political agendas in certain countries that hope to change their hitherto communist markets into capitalist models and to stimulate consumption. The People's Republic of China is a good example; political slogans under Mao Zedong focused on the communist ideal (peasant virtue, class struggle, and anti-capitalism), but, after his death, under the leadership of Deng Xiaopeng, this changed to a focus on aspirations of consumption: the glory of becoming rich and the joy of consuming (Belk and Zhou, 1987).

At the same time, however, we also aspire to more sacred lives. The secularized Western world still has its "temples." Modernity did not erase the sacred; even if religion has been "put aside" by laicized societies and secularized, disenchanted (in Weber's terms) imaginaries, religiosity still affects our lives (Eliade, 1965; Belk, Wallendorf and

Sherry, 1989).[1] Now, we develop cults for brands, such as Macintosh, Saab (Muniz and O'Guinn, 2001), Apple Newton (Muniz and Schau, 2005), and Star Trek (Kozinets, 2001), and build strong communities around them.

Overall, consumer dreams represent an important market for the corporate world. Many companies advertise their products or services directly through the context of dreams. For instance, the Royal Bank, Canada's largest bank, focused its 2002 ad campaign on how the bank could help consumers realize their dreams. The Caisse Populaire Desjardins was doing the same in 2005. Dreams also represent an important market in the sense that people invest a lot of money in lotteries and gambling; consumers "buy" hope. This market has grown significantly over the past few decades. In the United States, in 1987, lotteries and wagering represented around $17 billion in revenue (Clotfelter and Cook 1989). In 2002, the total was more than $68 billion (Ernst and Young 2004 United States Gaming Bulletin).

4. A Modest Researcher's Dream

I have argued that consumer dreams, along with our more general societal and individual aspirations, are part of the Western cosmology. We dream of a more equitable society and aspire to become better individuals. Dreams help us to understand our past and present, and give us hope for a better future (McCracken 1988, MacInnis, and de Mello 2005). They therefore play a central role in our lives and affect the way we think and behave. Consumer dreams specifically also play an important role in our society. We aspire to purchase sometimes inaccessible – or barely accessible – goods. We long for these idealized consumer goods and experiences and organize our lives in ways that

could help us achieve those ideals. We save money and work harder. We stop consuming non-dream-related activities to save even more. We construct our dreams by buying dream-related products like magazines, miniatures, and books (Belk, 2001).

Although dreams are central to our world, the topic has been largely ignored in the field of consumer research, or tends to be presented as indistinct from similar yet somehow different concepts such as goals and desires. Moreover, its exploration has been largely limited to what people say about their aspirations, leaving the praxis of dreams relatively unexplored. My goal (my dream!) is to further the tradition of motivation research and explore these consumer dreams.

5. The research context: A particular wish industry

In North America, over the last few decades, a significant amount of charitable organizations, such as *Starlight Starbright Children's Foundation, Make A Wish, Children's Wish Foundation, Carolina Sunshine for Children, Cystic Fibrosis Dream Holidays, The Dream Foundation, Dream Come True, Wishes & More, Wishes Can Happen, Inc., The Wishing Well,* and *Children's Dream Fund,* have started to grow and to offer various activities and programs dedicated precisely to enlivening the lives of ill children through the granting of wishes (i.e. offering the possibility for seriously ill children to realize deep-felt dreams). Ill children, of course, have dreams. This idea has been popularized in popular culture by films such as *The Blue Butterfly* (directed by Léa Pool in 2003). Young Pete, terminally ill with brain cancer, realizes his dream of travelling to a tropical rainforest to catch the legendary blue morpho. Based on a true

story, this adventure transformed forever the lives of Pete, his mother, and the entomologist who took him on this fantastic quest.

These organizations are starting to regroup in order to professionalize their work. In 1995, in the United States, the *Association of Wish Granting Organizations* (http://www.awgo.org/) was created with the objective of "providing the highest standards in wish granting throughout the world." Nowadays, wish granting organizations are capable of raising significant amounts of money. For instance, *Make A Wish* alone reported over $200 million in fundraising activities, donations, lotteries, and other revenues in its 2007 annual report. Furthermore, the organization grants more than 13,000 wishes annually (one wish every 40 minutes).

These organizations are spreading throughout the world. For example, *Starlight Starbright Children's Foundation* has chapters in Canada, the United States, Australia, the United Kingdom, and Japan. *Make A Wish Foundation International* (http://www.worldwish.org/) serves 33 countries around the world and is represented in North America (Canada, the U.S., and Mexico), South America (Argentina, Chile, and Peru), Europe (Austria, Belgium, France, Greece, Denmark, Ireland, Germany, Italy, etc.) and Asia (Hong Kong, Japan, India, Pakistan, the Philippines, Singapore, Taiwan, etc.).[2] These organizations provide support for tens of thousands of seriously ill children. For example, the *Children's Wish Foundation* grants approximately one thousand dreams annually. In parallel, dozens – if not hundreds – of companies evolving in various industries, such as banking and financial services (e.g. TD Bank Financial Group, ING Direct, VISA), travel and resort (e.g. Fairmount Hotels and Resorts, Royal Caribbean, Disney), sports (e.g. Major League Baseball), jewellery (e.g. Swarovski), computers,

electronics, toys and gaming (e.g. Sony, Pogo, Nintendo, Toys "R" Us), food and beverages (e.g. McCain, Laura Secord, Starbuck Coffee), news and information (e.g. WIRED Magazine), and transportation (e.g. Avis Rental Car System, Air Transat, Delta Airlines, American Airlines, GM), are increasingly collaborating with the cause through sponsorship and partnership programs. The 21st century is witnessing the emergence and growth of the "Ill Children Wish Granting Industry."

Despite the importance of this major social and economic phenomenon, no research, to my knowledge, yet exists to document and reflect upon it. These organizations, mostly charitable, are evolving in an ever-more competitive market in which donations are more and more difficult to obtain (Andreasen and Kotler, 2008). The relationship between charities and profit-oriented corporations is also becoming increasingly intimate (Pringle and Thompson, 2001). Furthermore, our understanding of the charities' beneficiaries is still in its infancy (Bruce, 2005). Throughout all previous studies on the relationship between charities and the marketplace, most of the focus has been on how to generate more economic value, leaving the beneficiaries of the charities almost completely unexplored.

The scientific community possesses no information or theorization on the granting of the wishes, its impact on this specific population, or the role of the market in that process. In this context, it becomes necessary to delve into the phenomenon in order to evaluate the relationship between the ill children, their families, the wish granting organizations, and the other major actors, including the marketplace. There is, I believe, an urgent need for the scientific community to investigate this important type of wish granting and its effects.

The fundamental question that drives this exploratory research is: how can we conceptualize and understand the phenomenon of ill children's wish granting and its impact on the relationships among the various actors, as they are deployed throughout the process? More specifically:

- How can we describe the process of the wish realization of ill children?

- Who are the principal actors involved in the process? How are they affecting and affected by the process?

- What is the importance of the wish for the various actors involved, especially for the people affected by life-threatening illnesses?

- How does the wish evolve throughout the process?

- How is the illness affecting and affected by the wish and its realization?

- What is the role of the market? How does the market interact with a wish?

- Are there opposing views or forces involved in the wish process? How can we reconcile any such potential conflicts?

To answer these questions, I used the method of ethnographic fieldwork (Arnould and Wallendorf, 1994) to immerse myself in the world of the Children's Wish Foundation of Canada (www.childrenswish.ca). This foundation was the ideal collaborator on this project for two reasons. First, its core mission parallels my own research goals. The foundation is a charitable organization that "works with the community to provide children living with high-risk, life threatening illnesses the opportunity to realize their most heartfelt wish."[3] Consequently, direct and prolonged involvement with the CWF allowed me to explore diverse cases of ill children wish realization. Second, the CWF's extensive links with multiple actors in the community helped me to better understand the

entire process of wish granting. Thanks to this association with the CWF, I was able to participate in events (e.g. fundraising activities, wish granting preparation and planning, wish granting days, meetings, etc.) and meet with many of the actors involved in the process – beneficiaries (i.e. ill children and families), donors, volunteers, staff members, and some medical experts (e.g. physicians and therapists) – in order to develop an in-depth understanding of the process from all pertinent perspectives.

This research proposes to conceive dreams as a complex, evolving, multi-actor, multi-action process that is represented as the *practice of dreams*. We conceptualize and explore the realization of wishes not solely as dependant on the individual dreamer's will and skills but also on the high *interdependency* of a complex network of social actors (i.e. parents, friends, charity organizations, volunteers, donors, and medical experts) surrounding the dreamer (i.e. the ill child). Since my focus is on the wish granting process in its entirety – from the time the ill child has the dream until it is fulfilled – it forces a shift in analytic perspective from the psychology to the sociology of the actors (Latour, 2005).

The first chapter of this exploratory research will look at two important theoretical fields related to the phenomenon. The first is motivation research. I will introduce the study of consumer goals and desires and show their relevance to wishes as well as the limitations of the current research on the topic. Some improvements proposed by my research will also be introduced. The second field pertains to the current knowledge on the relationship between the marketplace and the world of charities. I will mainly argue that at micro and macro levels, the main focus of this field of research has been to develop and improve a mutually beneficial exchange of values. When one delves deeper

into the literature, one realizes that three major groups of actors are extensively studied: the charitable organization, the volunteers, and the marketplace, leaving the beneficiaries almost completely ignored. I will thus state how my research will attempt to provide a new perspective on the study of charities by adding the viewpoints of those beneficiaries.

Chapter 2 will be devoted to the description of the ethnographic approach that I developed in order to study the phenomenon. Chapters 3, 4, and 5 will present important findings of my ethnographic research and will be centred mainly on the three sequences of the wish granting process: the process itself (how wishes come to be developed, approved, and planned), the fulfillment of the wish (through a naturalistic description), and finally the wish's after-life. I will conclude by looking at how these multiple perspectives all come together and how the tensions resulting from the interaction between the marketplace, the charity and the beneficiaries can be solved.

Chapter 1

Problematizing the Research

I place this research in its historical context not only to acknowledge the work of other researchers, but also to emphasize the lacunae in the literature that calls for more work on the topic. This chapter will focus on the main elements scrutinized in this dissertation: the field of motivation research, charities and its beneficiaries, and the marketplace. In the context of the CWF, these three elements are intimately linked. First, according to its most basic definition, the CWF grants wishes. It is therefore relevant to examine the concept of wishes and some important related notions in the field of motivation research. I will explore the ambiguousness of terms related to the notion of wishes (mainly goals and desires) while at the same time looking at the definitions and distinctive characteristics of these concepts, definitions that I hope will prove to be sufficient but not necessarily final. Limitations of existing studies regarding dreams, desires, and goals will also be identified, and corrective propositions will be introduced as to how these limitations could be overcome.

In order to help its beneficiaries, a charity funds its operations in great part – if not completely – from associations with the marketplace: consumers purchasing cause-associated products or making donations, companies organizing fundraising events or doing philanthropic activities, and so on. I will therefore look at the current academic marketing research on charities and highlight what is, according to this research, their relationship with the marketplace. In the current research, the relationship is mainly

observed from the perspective of the creation of economic value, finding ways to make companies more profitable in a highly competitive business world while offering charitable organizations the chance to be more efficient at fulfilling their mission in an equally highly competitive charity world. I will then show that, in order to study this association, research has focused on a fundamental triad of actors, namely the marketplace, the charity, and volunteers, while almost completely leaving the reality of beneficiaries unexplored. Some explanation for this situation will be presented. Finally, I will explain how the approach developed in my research proposes to fill, partly at least, the gaps I identify in the literature.

1. The study of wishes in motivation research

The study of consumer wishes falls directly into the broader field of motivation research, currently in its second stage. The first stage began during the late 40s and 50s in the field of psychology (Levy, 1986). At that time, this field was dominated by Freudian theories of unconscious motivation (Berger, 2004). A prominent figure was Ernest Dichter, who defined motivation as "a composite of factors which result in a specific action intended to change an existing situation into a future one" (Dichter, 2004: 37). Dichter's approach was popular in its time. He worked with many levels of institutions (governments, charitable organizations, and companies) and applied his reading of the human mind to an understanding of motivation. In a Freudian context, the mind is composed of conscious, subconscious, and unconscious levels which all have different ways of expressing needs (Berger, 2004). The motivation researcher has to understand motivation fully in order to explain how one behaves. Dichter, along with motivation researchers in general, virulently attacked the rational view of human action and argued instead that most actions

are the result of irrational or unconscious mechanisms that are hidden from the awareness of the individual (Berger, 2004). Richter was committed to behavioural and attitudinal changes and attempted to answer questions that touched on all spheres of activities, such as, "How can we convince people that they should buy more of a brand of soap, chewing gum, or beer?"; "How are army officers taught to make decisions?"; "How can we stop the new wave of anti-Semitism?"; or "How can we create better understanding between races?" (Dichter, 2004: 17).

Motivation research depended on the use of qualitative methods, such as in-depth interviews, projective techniques such as Thematic Appreciation Techniques (TAT), sentence completion, word associations, and drawings (Levy, 1986). This approach faded away in the 1960s, partly because its scientific validity was challenged; the chief criticisms were its lack of replicability of results, subjectivity of analysis, and the presence of non representative samples (Arndt, 1986).

The 1980s saw a return to the study of consumer motivation, the second stage of motivation research. During the 1970s, some researchers criticized the lack of interest in motivational factors in consumer research (Rook, 1988). Scholars such as Sidney Levy observed that, despite consumers' frequent engagement in fantasy and imagination, researchers seldom attempted to explore such phenomena (Levy, 1978 and 1986). Hirschman and Holbrook's (1982) seminal article was one cornerstone in the popularization of this stage. In the article, they urged researchers to focus their attention on the neglected notion of hedonism in consumer research. They pointed out that many consumer behaviours are driven by a search for pleasure, fantasy, and multisensoriality, and this was a fruitful way to look at human motivation from a different point of view. In

the description of the theoretical background on which their paradigm is based, they explicitly acknowledge motivation research to be a precursor to hedonic consumption research.

In 2009, motivation research continues to occupy a prominent place in consumer research. Over the last 20 years, the field of motivation research has diversified and matured. Unlike the first stage, the second is not predominantly concerned with unconscious motivations. Many studies have explored the importance of goals, desires, needs, utilitarian/hedonic motivations, pleasure-seeking, pain avoidance, emotions, and materialism, at both conscious and unconscious levels. It even surmounted the epistemological dichotomy that limited its development in the first place. What seemed earlier to be a field restricted to qualitative methods expanded to include a wide range of techniques, including not only interpretive research but also positivist approaches such as surveys (Perugini and Bagozzi, 2001) and experiments (Chernev, 2004a).

1.1. A look at overlapping concepts

In the introduction of this dissertation, I purposefully used words such as hope, ideal, aspiration, daydream, desire, and dream interchangeably. I did this to draw attention to the fact that these terms are potentially confusing, and that they are commonly used interchangeably in everyday oral discourse. More importantly, I have found evidence that these notions are also occasionally used interchangeably in textual references. For instance, a dictionary definition of desire is "a strong hope or wish." This definition makes us question whether desires are distinct from hopes or wishes.

In philosophical circles, use of the term desire is even vaguer. For example, in his exploration of desires, Schroeder (2004) states the following: "When I write 'desire,' then the reader is encouraged to see whichever of 'desire,' 'want,' or 'wish' seems most appropriate in context" (p. 5). Desiring, wanting, and wishing are considered, by Schroeder, to be interchangeable. His conception is nonetheless more precise than other philosophical definitions of desire that, as he posits, suggest that "any state of mind that can succeed or be fulfilled counts" (Schroeder, 2004: 4). According to this broad view, "wants, plans, intentions, acts of will, cravings, goals, and more are all types of desires" (Schroeder, 2004: 4).

Psychologists also use motivational concepts ambiguously. For instance, Reiss (2000: 30), when describing his 16 basic desires, proposes no clear distinction between desires and goals. He simply declares, "When I discuss basic desires in this book, I am always referring to end goals." In his approach, basic desires are associated with end goals, but no further attention is drawn to how desires and goals are related or distinct. He further complicates the issue by arguing that vengeance, one of the basic desires, can be an end goal in itself. Is desire a goal? Is it distinct?

Consumer researchers also tend to use the terms in a somewhat confused manner. An example is the preliminary work of Leonard (2005) on consumption fantasy. In her attempt to define the notion of fantasy, she refers to desire as a related but distinct construct. Referring to the Belk, Ger, and Askegaard (2003) article, she states:

> *Clearly, consumer fantasies are related to consumer desire, yet important*
>
> *distinctions exist. Consumer desire is described as passionate*

consumption, explained as 'overpowering, something we give into, takes

control of us and dominates our thoughts, feelings and actions.' Fantasies

on the other hand are consumer imaginations of and cravings for

consumer goods not possessed, and returning to the dictionary definition,

defined by their improbable and fictional quality. (p.229)

Although her attempt is interesting, she fails to adequately distinguish between the two constructs. First, nothing in the Belk article states that consumers desire things they already possess. In fact, the idea that the object is "not possessed" is a major factor in the source of desire. Second, as with fantasies, improbability can also be a factor of desire, since it creates distance between the desirer and the object. Belk et al. refer to Simmel's *Philosophy of Money* to express the importance of distance in the creation of desire: "We desire most fervently those objects that transfix us and that we cannot readily have. Objects' distance and resistance to our pursuit intensify our desire" (Belk, Ger, and Askegaard, 2003: 330). Third, there is no evidence that the desires described by the Belk, Ger, and Askegaard informants are not also an important source of craving (Belk et al. describe how desires are associated with permanent longing). Fourth, fantasies, like desires, can also take control over us, for instance by assuming hallucinatory proportions (Rhue and Lynn, 1987) or by undermining an individual's relation to reality (Akhtar, 1996). Finally, at an earlier point in her paper, she refers to fantasies as being closely related to daydreams, by positing that Singers's (1966) "definition of daydreaming relates closely to Klinger's [1971] definition of fantasy" (p. 229). However, she does not draw a clear distinction between the two concepts. Are they similar or distinct? To what extent are they both valid and necessary since they are similar in significant respects? Most

importantly, to what extent do they need to be valid to be considered scientific constructs? It seems to me that Campbell (1987: 82) best summarizes the problem of definitions in research related to desires. As he forcefully states in somewhat humbling terms:

> *It is not too easy to distinguish clearly between the various mental processes and activities which are relevant to this discussion, and terms like illusion, fantasy, day-dream, make-believe, imaginative speculation and stream of consciousness all appear to be pertinent in one way or another. In addition, the usage of these words is not standardized, and various influential writers, most especially Freud, have given very distinctive interpretations to some of them.*

My objective, therefore, is not to provide a set of final definitions. I don't believe that the discussion should revolve around what is or is not the final definition of desires, goals, or wishes. Everyone is, after all, likely to have a personal definition of what dreams, desires, or fantasy are. Focusing on definitions could ultimately lead to a semantic imbroglio that diverts attention from the true interest in exploring motivational phenomena. Furthermore, imposing definitions in opposition to what my informants are likely to say would violate a primary rule of inductive research and grounded theory (Glaser and Strauss, 1967).[4]

However, at a strictly intuitive level, these concepts, though having a lot in common, appear different. Some researchers have attempted to put an end to the definitional vagueness of these concepts by reflecting on their nature and respective qualities. I will

present their conclusions and attempt to show how they relate to the phenomenon under study. To do so, I will look primarily at two different constructs – goals and desires – to show the *somewhat* particular nature of consumer dreams and wishes.

1.1.1. Consumer goals

A basic dictionary definition of a goal is, "Something that you hope to achieve in the future; aim." Aim is defined as, "What you are hoping to achieve by plan, action, or activity." From these definitions, we see that a goal is highly related to a set of actions, for the person who sets the goal is likely to actively strive to achieve it. In scholarly work too, a goal is associated with expected fulfillment (Bagozzi, Dholakia, and Basuroy, 2003). We are unlikely to set goals if we don't expect to realize them. An individual may have many goals (Sirin, Diemer, Jackson, Gonsalves, and Howell, 2004). They can be classified on the basis of criteria such as ease of implementation (Bagozzi and Edwards, 2000), level of abstractness (Bagozzi and Dabholkar, 2000), and goal hierarchy (Bay and Daniel, 2003; Guttman, 1997). We can factor in time (short-term, mid-term, long-term) and means versus ends (instrumental vs. terminal) as ways of classifying goals (Reiss, 2000).

Bagozzi and his colleagues showed that goals differ from reasoned behaviours. The theory of reasoned behaviours presented by Fishbein and Ajzen (1975) assumes "(1) that action is preceded by a deliberative process culminating in a conscious decision to act and (2) that, if the individual tries to act, no impediments are likely to stand in the way" (quoted in Bagozzi and Warshaw, 1990: 127). It presupposes that virtually all behaviours are goals. In fact, Bagozzi and Warshaw (1990) and Fishbein and Ajzen

(1975) consider that some behaviours are subject to environmental impediments and that these constraints affect the nature of the behaviour. Hence, an important distinction appears: goals, contrary to reasoned behaviours, are by definition subject to performance impediment (Bagozzi and Warshaw, 1990). A goal exists when there is an obstacle (time, money, distance, scarcity) that hinders the realization of the behaviour, which then has to be planned in order to be achieved. Bagozzi, Dholakia, and Basuroy (2003) developed a complex model predicting how a goal is enacted. The process is first initiated by a goal desire, which is then transformed into a goal intention. Once the intention crystallizes, the next step is the formation of a desire to implement the goal, which then becomes another intention. It is at this point that the plan is enacted and the goal realized. We can assume that the goal seeker is likely to have a high level of control over the activity of imagining the goal (which goes through many steps of desire and intention) as well as over the goal achievement itself.

Fischer, Otnes, and Tuncay (2007) push Bagozzi's perspective further and propose that cultural aspects intervene in the process of goal striving. They argue that, in Western societies, cultural discourse such as scientific rationalism can affect the appraisal of the means to achieve a goal. The prevalence and status of science can cause one's feelings of self-efficacy to be eclipsed by the power of technology. A reliance on statistics in the appraisal of goal success is also derived from scientific thought, which encourages thinking in terms of probabilities.

1.1.2. Consumer desires

In the literature on desire, we find three significantly different approaches: 1) desire as a causal factor in the decision-making chain, 2) desire as a moderator of human behaviours and attitudes, and 3) desire as a substantive topic.

1.1.2.1. Desire as causal factor

Desire as a causal factor is principally represented by the work of Bagozzi and his colleagues. Using self-report surveys, they explored the importance of desire in the causal chain of goal striving.

Bagozzi and his colleagues developed a general model of Goal-Directed Behaviour (GDB), which involves desires, intentions, and behaviours (Perugini and Bagozzi, 2001). In their view, desires are different from intentions in at least three dimensions: perceived performability, action-connectedness, and temporal framing (Perugini and Bagozzi, 2004). More precisely, according to Perugini and Bagozzi (2004), intention to perform an action will occur only when one has a high level of confidence in the performance of that action. On the other hand, one can have a desire without having real confidence in its possible operationalization and realization (perceived performability). Secondly, intentions are more directly connected to goals or outcomes than desires; desires are less specific and leave open, or imply more ways of achieving, fulfillment (action-connectedness). Thirdly, desires are less time-specific and can even have an indefinite timeline, or entail postponement (temporal framing). Intentions, on the other hand, tend to be more now-oriented and perhaps more scheduled and planned in detail. For that last dimension, Perugini and Bagozzi's example is instructive: "My intention to scuba-dive in

the Red Sea next August, unlike my desire to do so, involves multiple timing issues with respect to opportunities forgone, planning, and implementing plans" (2004: 72). Thus, in the causal chain of goal striving, desires are said to be strong predictors of intentions, which are in turn predictors of behaviours (Bagozzi, Dholakia, and Basuroy, 2003; Perugini and Bagozzi, 2004; Perugini and Bagozzi, 2001). The relationship between desires and intentions can be summarized as follows: "Goal intentions, defined as the intention to achieve a certain goal, are commonly the end result of the deliberation of wishes and desires into a predecisional phase of decision making, and mark the transition to the pre-actional phase" (Perugini and Bagozzi, 2004: 70). Finally, this perspective also suggests that desires are functions of attitudes, positive and negative anticipated emotions, subjective norms, and perceived behavioural control (Perugini and Bagozzi, 2001).

1.1.2.2. Desire as moderator

Desire as moderator is the second approach. It consists of manipulating the mental state of the individual by priming a "desiring mode" and measuring the effect of this unconscious state on various consumer attitudes and behaviours. This approach is often associated with the work of Tory Higgins of Columbia University. It tries to offer a more systematic look at the age-old approach-avoidance theory of the pleasure principle (hedonic principle), which stipulates that "people are motivated to approach pleasure and avoid pain" (Higgins, 1997: 1280). This perspective proposes that there are two fundamental types of goals: ideals and oughts. Ideals refer to hopes, wishes, and aspirations while oughts concern obligations, duties, and responsibilities (Higgins, 1987). Associated with these two goals are the two main principles regulating the pleasure

principle: self-regulation with a promotion focus and self-regulation with a prevention focus. Promotion focus is tailored by nurturance needs, strong ideals, and gain/non-gain situations, whereas prevention focus is driven by security needs, strong oughts, and non-loss/loss situations (Higgins, 1997). The interest in this approach lies in the fact that either state can be primed below the awareness level, and once primed can globally affect the individual's psychological responses and, hence, behaviours. For instance, people in the former state will be likely to take more risks and try new things in order to improve the chances of achieving their goals, while those in the latter case will tend to be more conservative and more risk-averse, in order to maintain the status quo or to avoid loss. As one can imagine, this approach has been explored mainly using experimental methods. The priming task can be as simple as asking individuals to report on either how their hopes, desires, and goals had changed over time or how their sense of duty and obligation had changed over time (Higgins, 1997). The effects of self-regulatory focus have been documented in many areas, including preference for the status quo in decisional contexts (Chernev, 2004a); persuasion (Pham and Avnet, 2004; Aaker and Lee, 2001); product attributes evaluation (Chernev, 2004b); repurchasing intentions (Louro, Pieters, and Zeelenberg, 2005); and sports performance (Kitsantas and Zimmerman, 2002).

1.1.2.3. Desire as substantive topic

Desire as a substantive topic, the third approach, is embodied in the work of Belk and his colleagues (Belk, Ger, and Askegaard, 2003). They explore the notion in its unity (as a substantive topic) with interpretive methods such as depth interviews and projective techniques. While the first and second approaches look at desires from a psychological perspective, Belk et al. widen the exploration by looking at desires from a

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phenomenological-psychological as well as a social-cultural standpoint. For instance, they explore the cultural differences of desires (Belk, Ger, and Askegaard, 1997; Ger, Belk, and Lascu, 1993) and the impact of social-political changes on their evolution (Belk and Zhou, 1987), in addition to individuals' understanding of their own desires and the effects of desires on the consumer.

In their attempt to define desire, Belk et al. propose that desires are different from *needs* and *wants*. According to Belk, Ger, and Askegaard (2000), desire and need are two categorically and qualitatively different phenomena. For instance, by trying to realize a desire, one may choose to repress one's own needs in order to pursue the desire. Also, needs are often included under psycho-motivational models such as Maslow's (1954) hierarchy, which, contrary to desire, does not take into account the passion involved in consumption or longing for consumption (Belk, Ger, and Askegaard, 2000). Furthermore, the desire is focused on a specific "something" that is shaped by social and historical circumstances (Belk, Ger, and Askegaard, 2003). More precisely, a desire will concern a specific person (for example, a movie star), a particular brand of product, or a specific house. On the other hand, a need has a more generic nature; that is, we all generally need social relationships, cars, houses, and so on.

They also propose that desires are different from wants. In Belk, Ger, and Askegaard's (2003: 328) words:

> *The notion of want is too reassuringly controlled by the mind for it to*
>
> *cover the passionate aspects of desire. Furthermore, a want is normally*
>
> *taken as an expression of a personal, psychological preference structure.*

We see desire as deeply linked to the social world both through the

mimetic process (Girard, 1977) and through the pool of available value

systems and lifestyles that constrain the freedom to desire.

Moreover, as they put it, the concept of desire shows an "infinite initial openness" – anything can potentially become an object of desire. They argue that desire emphasizes "exotic and luxurious travel destinations, sexy and desirable people, couples dancing or embracing ardently, passionate activities such as bullfighting, and luscious and delicious foods and beverages." (Belk, Ger, and Askegaard, 2003: 333). Hence, a human being (as a sexual object, a romantic lover) as well as a chocolate bar or a trip around the world can be turned into desires. In their attempt to understand how consumers mentally represent desires, they found that informants use three major metaphors (Belk, Ger, and Askegaard 1996) to articulate their desires: eating (starving for something), sex (desire as lust), and addiction (implies both devotion and obsession). More generally speaking, they refer to desires as "burning passions," hard-to-resist impulses and urges. According to their findings, resisting desires seems to be an important issue for consumers; failing to repress or control the desire can be associated with negative feelings such as guilt or even sinfulness (Belk, Ger, and Askegaard, 2003).

Desires do not happen independently from one another and can potentially conflict. Conflicting desires mean that "one particular desire or cluster of desires causes trouble by interfering with our other desires" (Irvine, 2006: 21). Hard-to-resist desires like drugs, sex, or any addictions, and hunger, thirst, or other "visceral factors" (Loewenstein, 1996) can impact one's quality of life.

Although resisting desires can, of course, be necessary, one should not forget their positive side. Desiring can, in itself, be an enjoyable activity, and the desire to desire can be the source of positive emotions (Belk, Ger, and Askeegard, 2003; Campbell, 1987). Ultimately, the mere state of desiring suggests a certain balanced state of mind. Losing desires or the ability to desire is called a "crisis of desires" and can be a source of boredom or a symptom of a larger issue, such as an existential crisis – when one no longer sees any point in desiring (Irvine, 2006).

Related desires do not always lead to conflicting situations. Like goals, desires can also build on one another. As Irvine (2006) argues, instrumental desires can serve terminal desires. A desire to end hunger pangs (a terminal desire) might explain instrumental desires, such as the desire to eat in a restaurant (p. 57).

1.2. Specificity of consumer wishes

We have seen in the last two sections how goals and desires have been explored in the relevant literature. Despite initial definitional ambiguities, we have seen that these two notions are distinct from one another. A goal implies the idea of consciously planned implementation of an action and reflection on the means and capacities to achieve the goal, as well as expectations about the probability of realizing it. Goals are intimately linked to desires, which represent the original impulses behind the goal formation. Desires are related to longing, burning, and imagining. When in a desiring mode, one's self-regulating mechanism can be affected, which can result in changes in behaviour. In addition, desires are often represented as hard-to-control urges that can create discomfort when at least two of them conflict. Desiring can, however, also be pleasantly enjoyed,

and a lack of desire can be a symptom of existential malaise. We've also seen that desires differ from intentions, needs, and wants. We will now look at consumer wishes.

1.2.1. Consumer wishes

For the purpose of simplicity, "consumer dreams" and "consumer wishes" are used in this dissertation interchangeably. This decision is based on my interest to respect my informants' use of the two terms. For instance, the CWF frequently refers to the two expressions in their communications. Their website features turns of phrases like, "Jordan's dream," "Bryden's wish," and "Darcy Lee's dream team" in their descriptions of the fulfillment of wishes. In addition, other wish granting charities use either term in their organization's name, for example "A Wish with Wings," "A Wish Comes True," "Dare to Dream Foundation," "The Dream Foundation," and so on. Finally, similarities between dreams and wishes are also expressed in everyday language. "I have a dream," "May your dreams come true," "May your wishes come true," "Make a wish," etc., are frequent expressions used to convey the same concept. Although I will treat these two terms as equivalent in this dissertation, I will most often refer to a "wish," as this is the term featured in the name of the CWF.

As such, the present use of the terms "consumer wishes" and "consumer dreams" is consistent with that of Fournier and Guiry (1993) and d'Astous and Deschenes (2005), which are, to my knowledge, the only two studies that have directly addressed the notion of consumer dreams. Up to now, this phenomenon has indeed received limited attention. Fournier and Guiry (1993) investigated the content of the wish lists of 170 American consumers using survey data. They found four different types of dreams, and they are (in

order of occurrence): possessions (cars, houses), experiences (travels), ideals (career, family) and money. They also found that the number of wishes was negatively correlated with life satisfaction and positively correlated with income, education, and frequency of dreaming. Finally, they observed that materialism was positively correlated with dream frequency and that attitudes towards consumer dreaming were negatively correlated with education, income, and age.

d'Astous and Deschenes (2005) explored consumer dreams from a more global psychological perspective. Combining unstructured in-depth interviews with surveys of 195 consumers, the authors looked at the dreams, their antecedents, and their consequences. They first observed that a dream can be described using eight categories: content, origin, evolution, level of self-centeredness or inclusiveness, perceived level of uniqueness, relative and absolute importance, clarity, and accessibility. In line with Fournier and Guiry's study, they found that houses and travel were the most popular dreams. The authors tested the relationship between the dreams and psychological variables such as propensity to have consumption dreams, materialism, pragmatism, and a need for cognition. They also explored emotions as well as dream-approaching strategies (such as searching for information, increasing one's income, and communicating).

1.2.2. *Currently accepted specificities of wishes, desires, and goals*

I do not seek to argue that dreams are completely distinct from goals or desires, but that they do have specific characteristics that merit pointing out. As d'Astous and Deschenes (2005) put it, "the concept of consumer dream borrows from several notions; that is, it is

conceptually akin to goals, desires and fantasies, but it cannot be completely explained by any of these concepts separately" (p. 5). The following table highlights some of these particularities.

Table 1.1: Distinctions between desires, goals, and dreams[5]

	Temporal horizon	Degree of control	Quantity
Goal	Variable	High	Large
Desire	Short-term	Variable	Large
Dream	Long-term	High	Small

This breakdown suggests that dreams are normally the object of long-term visions. They also represent a "creative and deliberate activity based on a relatively stable but evolving mental representation that is accessible on demand" (p. 5), which illustrates a degree of mental control greater than in desires. As we previously discussed, desires are sometimes experienced at a visceral, "burning" level and are difficult to control. One can have a burning desire for chocolate, an irrepressible urge to indulge in eating a favourite chocolate brand. We can hardly associate that controllability issue with the dream of a swimming pool or the wish to be reunited with estranged family members. People will also normally have a limited number of dreams compared to desires and goals. Since everything is potentially desirable, a person is likely to desire a lot. In fact, in the modern context, desiring consumption goods is a necessary condition for the development of a

consumer culture (Campbell, 1987). The modern individual is overwhelmed by consumption goods and constantly craves new things. Modern consumers are trapped in the circle of desires (Campbell, 1987; Belk, Ger, and Askegaard, 2003). They constantly desire new things, motivated by the notion that the new things will ultimately provide more pleasure than the previous ones; they fail to realize that true pleasure is derived from the mere act of desiring. Dreams, on the other hand, are not necessarily subject to this phenomenon. Consumers, as just stated, usually only have a few dreams compared to the number of desires they can sustain. In a study conducted in one of Canada's largest cities, 88% of the 195 respondents had only one or a few dreams (Deschenes, 2002). This finding is consistent with Fournier and Guiry's (1993) study which revealed that people had on average five items on their wish list.

1.2.3. Additional elements of specificity

Keeping in mind the context under study as well as the general relationship between wishes and desires, I propose to look at three additional criteria that may highlight the specificity of wishes: their level of inclusiveness, their stability, and the concept of hope.

1.2.3.1. Level of inclusiveness

One of the major points made in the desire literature is that a desire represents an all-encompassing notion. As we have seen, for Belk and his colleagues, everything can potentially be desired, from human beings to chocolate bars. Moreover, Higgins's approach does not take into account what desire is. In his view, the only thing that matters is to activate the "desiring mode," regardless of what the person is actually desiring or dreaming of. Finally, in Bagozzi's approach, desires are also vaguely defined.

In his case, desires loosely refer to wishes: "the concept of desires, typically referred to as wishes, is explicitly distinguished from intentions in the literature on goals" (Perugini and Bagozzi, 2004: 70).

One can legitimately ask whether desiring to eat a chocolate bar is the same as desiring to meet one's most idolized pop singer. Following d'Astous and Deschenes (2005), we can propose that, "whereas a desire is implicit in the notion of a dream – that is, the dream object is an object of desire – a desire is not necessarily a consumption dream" (p. 5). In other words, both the chocolate and the idolized pop singer can be objects of desire, but the chocolate bar is less likely to be the object of a dream. The differences in horizon and probability of fulfillment (d'Astous and Deschenes, 2005) can further illuminate this distinction. The chocolate craving is likely to be satisfied on the very day of the emergence of the desire. The probability of fulfillment is expected to be high. On the other hand, one can struggle throughout an entire life to meet his or her favourite singer without ultimately being successful. Here, the odds, although difficult to estimate, are most probably lower, and the horizon of realization may be longer.

1.2.3.2.   Stability

Consumer desires are likely to have a more tumultuous life than consumer dreams. In fact, a central element in the concept of desire is novelty. As Campbell (1987) states, "The modern consumer will desire a novel rather than a familiar product because it enables him to believe that its acquisition and use can supply experiences which he has not so far encountered in reality" (p. 89). He adds:

Their [in reference to modern consumers] basic motivation is the desire

to experience in reality the pleasurable dramas which they have already

enjoyed in imagination, and each 'new' product is seen as offering the

possibility of realizing this ambition. (p. 89-90)

Consequently, most consumer desires are subject to mutation, change, accumulation, and oblivion. Consumer dreams show the opposite pattern. Most consumers will have only a few dreams and will stick to these dreams for life or at least for many years. In d'Astous's and Deschenes's (2005) study, more than 55% of the respondents declared to have had the same dream for many years, if not since childhood. In this research, these authors also found that the dream did not change at all, or went through only minor modifications over time, for more than 80% of the respondents.

1.2.3.3. Hope

As we can now imagine, desiring and dreaming might imply different psychological mechanisms. Hope is one of them. Hope has been defined as "a positively valenced emotion evoked in response to an uncertain but possible goal-congruent outcome" (MacInnis and de Mello, 2005: 2). In the case of wishes, hope is a necessary condition. Since probabilities of realization are expected to be somewhat low, one needs hope in order to preserve the dream. With desires, on the other hand, hope might not be a necessary component. In the case of the chocolate bar, there is no real need for hope since probability of realization is high. (When having a desire for sexual intercourse, however, hope might be more likely to be experienced if the probability of fulfilling the desire is

lower.) On the other hand, in the case of the singer, hope is most probably necessary in order to continue the fight and not to give up the project.

Due to its importance and central role in Chapter 5, hope will be introduced here in greater detail. Hope is a recent concept in consumer research and a focus of newly increasing interest in other disciplines, such as psychology and medicine. Despite some disagreement over whether to qualify hope as an emotion,[6] a large number of psychologists consider it as such and have studied it mainly from cognitive and social constructivist traditions (Corneluis, 1996).[7] From a cognitive standpoint, hope has its roots in appraisal theory, which proposes that hope depends on one's assessment of future events and potential scenarios (Lazarus, 1991). Goal congruency (is the environment consistent with my goal?), agency (what can I do to achieve the goal?), and certainty (what are the odds of fulfilling the goal?) are among some of the factors considered to constitute hope (MacInnis and de Mello, 2005). From a social constructivist perspective, hope is a historically and culturally relative term. In a famous exploration comparing the concept of hope in American and Korean cultures, Averill, Katlin, and Chon (1990) found that the American concept of hope is based mainly on Judeo-Christian intellectual and religious traditions – and more specifically the work of Thomas Aquinas – while the conceptual make-up of hope in the Korean population can be explained by Confucian intellectual and religious traditions.[8]

De Mello and MacInnis conceptualize hope along three lines: having hope, being hopeful, and hoping (de Mello and MacInnis, 2005). *Having hope* is to enjoy the feeling that a goal-congruent outcome is possible; *being hopeful* is to assign a probability value to the occurrence of such an outcome; and *hoping* is to yearn for an outcome believed to

be possible, while the degree of hoping is a factor of the extent to which the goal is valued. In order to illustrate these three facets, de Mello and MacInnis propose the following example in the case of cancer patients: two people could *have hope* for surviving cancer and hope (yearn) to varying degrees for this outcome; however, one may *be* more *hopeful* than the other with respect to his chances of overcoming the disease, depending on the odds of survival (p. 48).

Hope must be distinguished from optimism. Optimism is an attitude that everything will turn out for the best. Hope, on the other hand, is rooted in reality. Jerome Groopman, a renowned haematologist and oncologist, reflects on the concept of hope in his New York Times best seller *The Anatomy of Hope* and proposes that it represents "the elevating feeling we experience – in the mind's eye – a path to a better future. Hope acknowledges the significant obstacles and deep pitfalls along that path. True hope has no room for delusion" (Groopman, 2005: xiv). In that sense, hope must also be distinguished from faith. According to Reading (2004), faith, like hope, involves positive expectations about the future; however, faith is based on belief rather than knowledge. It involves prayer and rituals and requires the "intervention of a deity to achieve [people's] desired outcome" (p. 8).

Hope has been viewed as something we acquire and that evolves developmentally. Reading (2004) suggests that children show their first signs of nurturing hope at around the age of four, which corresponds to the time when "they acquire a rudimentary capacity for abstract thought and reasoning" (p. 7). Snyder (1994) proposes that, as children grow, their capacity to set goals becomes more elaborate – from desiring nearby objects, to

asking a bigger person to do something for them, to wanting to get together with friends –
and their experience of hope evolves accordingly.

1.2.4. A global look at the three concepts

In the previous sections, I compared three main concepts in motivation research: goals,
desires, and dreams or wishes. Table 1.2 summarizes the comparison. In a nutshell, goals
are characterized by their high level of probability of realization and by the high degree
of control that one is likely to have over the imagined activity as well as over the content
and process of realization. Hope is not a necessary or critical emotion for the goal-seeker,
as he or she is likely to envision a high probability of success and to develop a concrete
realization plan. Moreover, individuals are expected to have a variable quantity of goals
with specific temporal horizons of realization (since an enactment plan is often associated
with them). The stability of goals may depend on how accustomed the individual is to
setting goals.

Table 1.2: Distinctions among goals, desires, and dreams

Type of aspiration	Degree of inclusiveness	Temporal horizon	Probability of realization	Hope	Control over the activity	Stability	Quantity
Goals	Any accessible, realizable, planned, and desirable thing	Specific	High	Not critical	High	Variable	Large
Desires	Anything that can potentially be desired	Variable	Variable	Variable	Variable	Unstable	Large
Dreams	Things that would be barely realizable, yet desirable	Long-term	Low	Critical	High	Stable	Small

Desires have a more variable level of probability of realization (desiring a chocolate bar will have a higher probability of realization than desiring to have sexual intercourse or a

romantic relationship). In that sense, hope might sometimes be felt and sometimes not be felt by the desirer. In addition, desires encompass potentially everything and hence can have various temporal horizons of realization. Depending on the desire, the importance and degree of control over the activity will also be variable. Craving a chocolate bar can have a different level of importance than desiring a sexual encounter. Moreover, the capacity to control the urge also depends on the activated desire.

Consumer dreams are more likely to embrace long-term, low-level probability, high-level importance aspirations. The stability of dreams may be higher on average than that of goals or desires. The number of dreams, conversely, is likely to be lower than that of either goals or desires.

I am aware that this a priori differentiation may not work in all cases. To what extent can we be sure that one particular aspiration (in the generic sense of anything one would like to do, possess, or experience) can be categorized as a goal, a desire, or a dream? Can the search for a soul-mate or romantic lover be considered a dream or a desire? There is no systematic way to accurately sort that out. What is the object of desire for one person can be experienced as a long-term dream by someone else. An essentialist distinction, therefore, does not hold in this case. What matters is people's personal experience of things, and this is influenced by factors relating to their nature as individuals, their culture and economic situation, and time factors (Douglas and Isherwood, 1979). A wealthy, jet-setting entrepreneur might only dream of having the time to read the entire collected works of a popular writer, while an artist struggling to make a living, who reads the entire set twice over, might rather wish to win big at the lottery some day. Furthermore, I don't believe that an aspiration necessarily belongs only

to a single category throughout its entire life. I think it would be more honest to conceptualize these three notions as intertwining and dynamically co-evolving over time. For example, after a certain time or evolution, a dream (something highly desirable but somewhat improbable) can become a goal, if some conditions are met, such as the unexpected accumulation of money and/or explicit and progressive implementation of actions in order to achieve it. Desires can also potentially evolve. For example, what was strongly desired at first could gradually turn into a dream if one realizes that the probabilities of realization are lower than expected.

We can derive from the existing literature that studies on desire tend to include dreams (Belk et al. do not distinguish between the craving for a chocolate bar and a trip around the world) and to a certain extent goals (in the case of Higgins's notion of ideals). In fact, desiring is a necessary condition for having both goals and dreams. If one does not desire something, one will not plan a set of actions to achieve it (Perugini and Bagozzi, 2001), nor will one spend energy on mentally imagining what it would be like to do, possess, or experience something longed for. Consequently, one has to accept desire as a necessary condition in motivation research.

1.3.   Studying consumer dreams from a new perspective

Despite their intrinsic interest, current investigations in the body of work on dreams, goals, and desires in general have important caveats that need to be addressed. These limitations, combined with my personal interest in the topic, represent major elements that motivate and legitimize my research and that shape and determine its conceptual,

theoretical, methodological, and philosophical orientations. These limitations are summarized in Table 1.3.

1.3.1. Limitations of the psychological approach (Limitation #1)

Motivation research is important because it provides insightful information concerning the dream, goal, or desire, its antecedents, and its consequences. However, the scope of its contribution is limited by its psychological perspective. For instance, in motivation research, goals are likely to be affected by self-efficacy, outcome expectations, and affect (Bagozzi and Edwards, 2000), three variables represented in the psychology literature. In the literature on desire, the principal antecedents are attitudes, anticipated emotions, perceived behavioural control, and subjective norms (Perugini and Bagozzi, 2001), more psychological variables. D'Astous and Deschenes (2005) also locate the antecedents of dreams within the individual. In fact, all these authors principally consider the individual (materialism, pragmatism, need for cognition) and dream-based individual variables (frequency of dreaming, expertise on dreamed objects) to influence dreams.

What about the impact of marketing on dreams, desires, and goals? Companies propose a dream world to consumers (Williams, 1982, Crisp, 1987; Ritzer, 2005). Movies create hope (Haskell, 1999). Aren't parents, friends, and other reference groups involved in the creation, preservation, and evolution of dreams? After all, goals are said to be contagious (Aarts, Gollwitzer, and Hassin, 2004). A more sociological and anthropological perspective is definitely needed to broaden our understanding of consumer dreams.

1.3.2. Limitation of surveys (Limitation #2)

A second major limit is the methodology used. Most consumer motivation research relies on surveys and a limited knowledge of the aspiration (goal, desire, or dream) itself. For instance, in the case of research on dreams, the dream is described by the respondent in a few words, either as a simple element on a wish list (Fournier and Guiry, 1993) or as the result of a short, open-ended questionnaire (d'Astous and Deschenes, 2005). Are a few words sufficient to fully describe a dream?

We can also question whether nominal, ordinal, or interval scales are suited to an exploration of the complexity of dreams. When and how did the dream form in the person's mind? How did it evolve over time? How is this dream related to other dreams, desires, and goals in the person's life? What is the importance of this dream? What is the meaning of this dream? How is this dream affecting the people surrounding the dreamer (e.g. family, friends, and work colleagues)? Can a Likert scale of 1 to 7 capture the depth of these issues? Definitely, the use of more flexible, more exploratory, and more qualitative methods is needed.

1.3.3. Limitation of "average" informants (Limitation #3)

In order to gather information, motivation research on consumer behaviour commonly focuses on laypeople, "normal" individuals (college students, housewives, male and female white-collar workers). This representation of the subjects is consistent with the representation of subjects in the larger field of consumer research, which tends to focus on average white Americans (Burton, 2009). Can we really believe, however, that "ordinary" consumers are representative of all individuals in Western society? To what

extent are we exploring concepts and constructs to their full depth and documenting phenomena widely enough by focusing solely on the "middle of the curve"? Over the last 15 years or so, some scholars have started exploring phenomena and behaviours that fall outside the range of what is "common," such as plastic surgery (Schouten, 1991; Langer and Beckman, 2005), high-risk leisure (Celsi, Rose, and Leigh, 1993; Arnould and Price, 1993), and compulsive purchasing (Faber and O'Guinn, 1988; O'Guinn and Faber, 1989, Rindfleisch, Burroughs, and Denton, 1997). They have also begun to study particular populations such as teenagers (Ritson and Elliott, 1999), children (Schor, 2005, Linn, 2004), homosexuals (Kates, 2002), immigrants (Oswald, 1999), physically disabled people (Vezina, d'Astous, and Deschamps, 1995), delinquents (Ozanne, Hill, and Wright, 1998) and fairly illiterate consumers (Adkins and Ozanne, 2005). Couldn't (shouldn't) consumer researchers be concerned with social issues and vulnerable populations? Some researchers, for example Murray and Ozanne (1991), have proposed that we should develop extensive research programs in order to help solve specific social problems. This idea has just recently broken into the news in the field of consumer research.[9]

The study of dreams should be no exception. Isn't focusing the study of consumer dreams on "average" people limiting our understanding of the concept? One problem we currently have is our failure to go beyond common sense and the post hoc explanation of certain findings, such as the relationship between age and consumer dreaming. For instance, Fournier and Guiry (1993) found negative correlations between age and anticipated attainment, dream frequency, and dream attitude, and a positive correlation between age and the relative proportion of experiences in consumer dreams. This suggests that the older the consumers, the less likely they are to expect to realize their

dreams, to indulge in the dreaming activity, or to have a positive attitude towards consumer dreams; and they are more likely to long for experiences (rather than for possessions). How do we explain such results? Should we be satisfied with post hoc rationales, such as "older consumers are more realistic" or "as consumers move through life and acquire consumption packages, the range of possibilities remaining open to them becomes limited, which reduces the need for consumption dreaming" (Fournier and Guiry, 1993)? Are adults really too busy to dream (Singer and McCraven, 1961)? Certainly more thorough empirical data is needed in order to better understand how consumer dreams evolve over a lifetime and how consumers perceive them.

One way to potentially shed new light on this issue is to focus on cases in which the individual's self-perception of finitude is at the forefront. For instance, a recent study revealed that consumers dealing with life-threatening illnesses, and in the early stages of illness, tend to be highly now-oriented and to use consumer goods to help cope with the threat and uncertainty of their future (Pavia and Mason, 2004). According to this work, and congruent with Terror Management Theory (Greenberg, Pyszczynski, and Solomon, 1986), a return to future orientations is usually only possible once the individuals perceive themselves as permanently cured or as being in sustained remission. Obviously, this particular context offers an alternative to the age variable in understanding how individuals perceive their dreams and their evolution; anyone, both young and old, can face a major life challenge at some point. Are these vulnerable people dreaming? Are they postponing their dreams until better days come? Research shows that critically ill patients whose psychological needs are met experience lower levels of anxiety (Kent, Wills, Faulkner, Parry, Whipp, and Coleman, 1996). Couldn't dreams serve the same

function? Does dreaming mean something different for those particular populations? Furthermore, it would be interesting to explore how the ill person's family and friends relate to those dreams, and how the dreams help them to deal with the eventual death of a loved one (Bonsu and Belk, 2003). It seems certain that studying the consumer dreams of vulnerable populations will improve our understanding of consumer dreams in general.

1.3.4. Limitation of retrospective and prospective discourse (Limitation #4)

To my knowledge, most of the existing literature in consumer research dealing with the issue of motivation focuses mainly on the analysis of formal discourse (what people say in interviews, self-report surveys, our projections) from a prospective standpoint. At the prospective level, the objective is to understand how the individual anticipates the aspiration. According to that perspective, researchers will try to sort the different goals, desires, or dreams according to their importance, temporal horizon, terminality, and/or instrumentality. They will question consumers about their expectations for fulfillment and their anticipated emotions.[10] Despite the importance of the prospective approach, there is also some evidence of a retrospective perspective in motivation research. According to that perspective, consumers will look backward. They will remember what happened when they realized the aspiration. They will also discuss what came next, what happened after the realization of an aspiration.[11]

One can question these two approaches. In the prospective approach, to what extent can we match the actual realization of the aspiration with what the consumers tell us they were expecting? Isn't there a potential modification along the way? Can't the individual or the aspiration change? Can a one-shot, cross-sectional analysis be

representative of such a complex phenomenon as the realization of an aspiration? Moreover, can a discourse detached from its context (there is a time distance between the realization of the dream and the interview with the consumer) fully account for the realization of the dream? What happens when a wish suddenly becomes achievable? On the other hand, can a retrospective look at the past realization of an aspiration be sufficient to provide accurate information for the analysis of the phenomenon? In either case, the critical middle part is missing. We have no single unit of information stemming directly from the crucial moment of the achievement. We need to document the realization of dreams during their realization. How do people realize their dreams? How does the actual fulfillment diverge from the expectation, and how does that discrepancy affect the dreamers, their friends, and their family?

Finally, one can ask whether the reliance on formal discourse at large (including interviews, surveys, and projective techniques) is sufficient to understand this process. Words in interviews can capture part of the phenomenon, and projections can certainly add to that knowledge. But the fulfillment of a wish is more than the words and images used to express expectations about its fulfillment. It is more than the words and images used to recount a past experience. It is a process by which a series of actions and evolving thoughts and feelings will (consciously or not) be put together and affected by each other. It is a process in which many potential actors are likely to play various and evolving roles, sometimes without the awareness of the dreamer. We have to look at the praxis of dreams, not only at what people say about them during an interview. We have to witness how the dream is enacted. We have to be observers or participant-observers of its realization.

1.3.5. Limitation of reification (Limitation #5)

A fifth limit can be globally derived from the four previous ones. It concerns how the researchers conceptualize the relationship between the dreamer and the dream. In the existing literature, the aspiration seems to be considered as a still picture, a fixed object that can be examined on its own. According to that perspective, the consumer can say, "My dream is ..." or the researcher can say, "The consumer's dream can be defined as..." The dream or the desire is isolated, removed from the individual, and treated independently in order to be analyzed. This viewpoint inspires questions, such as, what is the nature of the dream? What is its probability of realization? How often does the dreamer rehearse the dream? It can be placed in a causal chain: having a dream will generate a set of expectations, cause specific emotions, and lead to particular behaviours. Also, the existing perspective entails that consumers talk about dreams (or desires) that already happened in the past or are likely to happen in the future. In that sense, consumers are temporally separated from their dreams. By taking this approach, the researcher objectifies the dream and studies it, out there, as an independent object, separable from the consumer. It is so independent that it becomes possible to transfer the dream into a database by quantifying its dimensions, and to study its relationship with antecedent and consequence variables.

One can question that view. To what extent is it possible to isolate the dream from the dreamer? To what extent can we consider the dream as something "out there," something observable in its totality? To what extent can we conceptualize the dream as being fixed in time and removable from its context? I believe that another approach is possible, an approach that would not force a separation of the dreamer from the dream;

would preserve the dream's complexity and context; would conceptualize the dream as being constantly evolving and constantly negotiated through actions, feelings, thoughts, and social interactions; would theorize the dream in its practice; and would look at the process of dream realization, assigning the same weight to the dream, the dreamer, and all other persons and objects involved in the process.

1.3.6. Limitation of morality (Limitation #6)

As far as I know, motivation research largely neglects the relationship between morality and motivation. Indeed, morality is likely to play an important role in goals, desires, and dreams. Is this dream/desire/goal good for me? What would people think if they knew about my desires? I have already noted that we are likely to have many desires and that some of them may be hard to control. I also added that we sometimes feel guilty in those situations, and that we even consider some of our desires to be sins (Belk, Ger, and Askegaard, 2003). Belk, Ger, and Askegaard (2003) conceptualize desires as the interplay of seduction and morality: the thing that seduces can cross the dangerous border of what is acceptable.

Morality may be experienced differently in the case of dreams. We have fewer dreams, and they are usually of greater importance. Do we restrain ourselves in terms of the type and the number of dreams that we have? Do we perceive them as good or bad? We can expect that people don't usually feel guilty about their dreams or about when they are dreaming. Let's return to the American Dream, a dream associated with the foundation of the United States that resonates throughout the world. The power of this dream makes me wonder whether it could not be perceived as a right by the population:

everyone has the right to hope for a better life, and America is the place to fulfil that hope. Can we apply that rationale to all dreams? There is a need to explore the relationship between morality and dreams. It could also be insightful to investigate how desires, goals, and dreams differ with regard to moral imperatives.

1.3.7. Limitation relating to the image, the imaginary, and the body (Limitation #7)

Most motivation studies don't consider the importance of mental imagery processes when studying goals, desires, or dreams. As suggested under the limit of objectification, most research considers the dream (or desire or goal) "as is," without paying attention to the fact that one's capacity to articulate an aspiration is related to one's capacity to imagine it. In fact, the dream can be conceptualized in terms of imagery. Imagery is defined "as (1) a process (not a structure) by which (2) sensory information is represented in working memory" (MacInnis and Price, 1987: 473). It is an evolving construction, the result of the instantiation of information already encoded (as schema or script) and activated depending on the context and on internal (e.g. emotions, mood, etc.) and external cues (e.g. TV advertising, discussion with friends, etc.). This process is powerful. It is said to influence people's affect, cognition, and behaviour (MacInnis and Price, 1987). For instance, the mere act of imagining an event can increase significantly the perceived likelihood of the realization of the event (Carroll, 1978). It also affects people's physiological responses. For example, imagining fearful scenarios can increase people's respiratory responses (Lang, Kozak, Miller, Levin, and McLean, 1980). It can even pose political or legal concerns in certain societies. For the Temiars of Malaysia, "receiving songs" during night time dreams, another context within which imagery abounds

(Hilgard, 1981), helps activities such as naming the land, identifying borders, and determining property rights (Roseman, 1998).

In the context of this research, one can ask, what is the power of the consumer dream? Can that image be communicated to others, and if so, how? How does it evolve through various relationships and contexts? The current literature does not pursue answers to these questions. The only attempt to understand the image of an aspiration was made by Belk, Ger, and Askegaard (2003). However, in their case, the objective was to explore the general notion of desire (i.e. how consumers picture the concept of desire), rather than the process of understanding mental images representing specific consumer desires.

The absence of focus on the imagination overshadows the place of the "imaginary" in the study of consumer dreams. The imaginary is the set of schemas, scripts, representations, and mental images concerning one's personal identity and that of others, one's past, present, and future, as well as one's sense of the environment (e.g. objects, locations, etc.) (Bouchard, 2003). As Martin (2004) observes, there are different strategies that one can take to evoke the imaginary, such as extrapolation, ornamentation, historicization, complementary addition, and replacement.

Furthermore, imagery is a mental process that involves the senses. As MacInnis and Price (1987) note, "imagery processing includes perceptual or sensory representations in working memory that are used in much the same way as perceptions of external stimuli" (p.474). The senses are triggered through synaesthesia (Zakia, 2002), which is the capacity of the senses to be activated without exposure to their physical

counterpart (e.g. imagining the smell of the sea while living far away from it). Some marketing researchers are currently exploring the senses and atmospherics (for instance odors; Morrin and Ratneshwar, 2003, Spangenberg, Grohmann and Sprott, 2005) and the implications for consumer behaviour. This is not surprising given the experience economy (Pine and Gilmore, 1999), our capitalist society that constantly triggers our senses to the point of over stimulation (Howes, 2005). Despite that, the sensoriality of aspirations remains obscure. Following Howes's (2003) reflection, we should use an anthropological approach to the study of the senses in relation to consumer dreams.

Finally, imagination also has to be linked with the body. Recent work in cognitive psychology and neurology shows that it is impossible to separate the body from the way we think. Indeed, mental elements such as categories and concepts are inseparable from our experiences of the world – experiences that are always mediated by our senses and body (Lakoff and Johnson, 1999). Joy and Sherry (2003), combining the work of Merleau-Ponty (1945), Lakoff and Johnson (1999), and Fauconnier and Turner (2002), provide evidence of the interconnection between the body and the imagination in aesthetic experiences. They show, for instance, how museum visitors feel like they are going back in time while walking from one room to the other. They also show how consumers express their experiences through metaphors related to the body. When applied in the context of consumer dreams, one can wonder what the place of the body in consumer dreams is.

Table 1.3: Limits of existing literature on motivation research and a proposed corrective

Limit	Description	Corrective
#1:Psychological approach	Focus on individual-centred explanation of antecedents and consequences.	Social-cultural and historical approach: consider the role of society, advertising, friends, reference groups, etc., in the antecedents and consequences of dreams.
#2:Surveys	Lack of detailed description of dreams in the studies. Impossibility to grasp all the complexity of dreams and social-cultural and psychological phenomena that are associated with their realization.	More flexible, more exploratory method such as qualitative research.
#3:Average informant	Average informants offer a limited view for looking at the notion of dreams. Post-hoc, common sense explanation of relationship between aging and dreaming.	Explore "extreme" populations and extreme behaviours. In the present context, deal with ill individuals in order to understand the importance of time. Time over age.

	Age over time.	
#4:Retrospective/ prospective perspective	Focus on past and future in the exploration of dreams has major caveats. Impossibility to access the "real story" of the dream realization (either based on speculation or on impaired reconstruction of the event). Important gap between discourse and practice. Lack of details due to single focus on verbal reports (e.g. unconscious behaviours, hidden actors or actions, etc.) Cross-sectional investigation does not account for the dynamic nature of the process of realization.	Explore the "middle part," the realization of the dream in real time, a dynamic perspective, as it comes to be realized. Use of prolonged participant observation in order to witness discourse and practice.
#5:Reification	Consideration of the dream as still, fixed. Decontextualization of the dream	Consider the dream as complex and evolving. Consider the dream as inseparable from the dreamer and his/her context. Consider the dream in

	by studying it in isolation from the dreamer. The temporal distance of retrospective and prospective perspectives causes an objectification.	its practice.
#6:Morality	Absence of research on the importance of morality.	Introduce the notion of morality in motivation research and explore its relationship with dreams, desires, and goals.
#7:Imagination, imagery and the body	Consideration of the dream as a fixed image. No investigation of the image of the dream in the dreamer's mind. No focus on the imaginary of the dream. No exploration of the relationship between the senses, the body, and consumer dreams.	Investigate the dream-as-image. Explore the imaginary from which it is derived as well as the evoking strategies. Delve into the relationship between the dream, the senses, and the body.

2. Relationship between the marketplace and charities

In the context of charities, the marketplace has traditionally been acknowledged for its economic association with causes. Companies are pressured to become good corporate citizens and are increasingly expected to "do at least some good" in their daily activities. What used to be seen by managers as an obligation, however, is now seized as an opportunity, as an increasing number of strategic textbooks and scientific articles written on the subject show the potential benefits of corporate social responsibility and try to guide corporations from a strategic perspective (Kotler and Lee, 2005). In this relentlessly growing competitive market, companies are constantly searching for new differentiation strategies in order to avoid the dreadful spectre of commoditization (Pine and Guilmore, 1999). As a result, non-profit organizations (NPOs) in general, and charities in particular, have become a key element in today's for-profit strategies. In order to position themselves differently, corporations are becoming proficient at finding ways to associate themselves with charitable organizations and/or causes, for instance through corporate social marketing, philanthropy, community volunteering, and cause-related marketing (Kotler and Lee, 2005). The objective of these strategic associations is to create value in the eyes of the firm's stakeholders.[12] In so doing, they devote effort to deploying vast marketing campaigns, involving their employees (often on a volunteer basis), and generating large amounts of money which they reinvest in the non-profit sector through carefully managed public relations activities. As we will see, the creation of this value can be explored on an individual level, that is, from the perspective of how a company relates to a charity on an individual base.

2.1. A micro look at the exchange and creation of value

In seeking to define the current relationship between the marketplace and the charitable world, we find a good summary of the situation in Daw (2006). Her approach is anchored in cause-related marketing (CRM), which she defines as "mutually beneficial collaboration that aligns the power of a company's brand, marketing, and people, to a charitable cause's brand and assets to create shareholder and social value, connect with constituents and publically communicate values" (p. 26). Her view proposes that the advantage of a partnership between a charity and a corporation lies in the relationship between *value* and *values*. A corporate-compatible cause's *values*, when properly addressed and communicated with and/or through a corporation, can prove beneficial to both the charity and the corporate partner by creating *value* for stakeholders. Value comes in many forms and depends on the partner. On the one hand, it can help charities achieve their mission, legitimize their activities, create brand awareness, help implement social change, or bring corporate expertise to their activities. On the other hand, it can help corporations by disseminating corporate values, helping attract and appeal to employees, consumers, and shareholders, developing brand awareness and positioning, improving corporate image, increasing sales and market shares, and reducing costs (Daw, 2006; Kotler and Lee, 2005). This relationship can be visually represented as follows:

Figure 1.1: Creation of value through communication of values in a CRM[13]
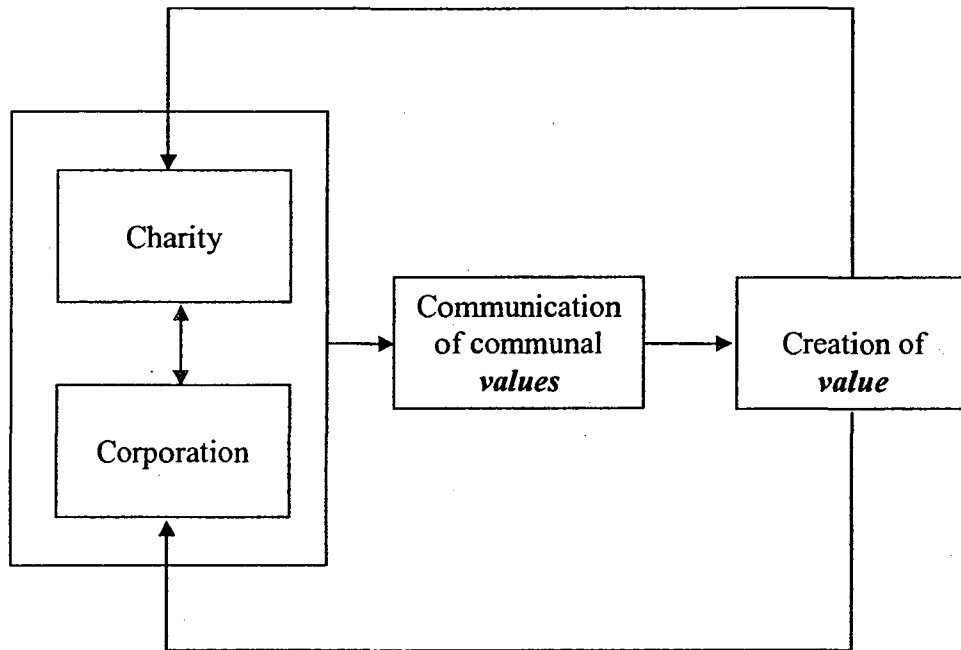
As the figure shows, a partnership develops between a corporation and a charity that share common values. By mutually agreeing on the communication of these values through diverse means,[14] they can create beneficial forms of value.

2.2. A macro perspective of the value(s) framework

The one-on-one relationship between a corporation and a charity previously described can further be extended and adapted to larger relations between charities and the marketplace. Like for-profits, charities also face an increasingly competitive reality, as the battle for donations grows fiercer year after year. In order to survive the increasing competitiveness of the fundraising battleground, they have had to open themselves up to the necessity of following the example of the private sector and developing a *business-like* philosophy. Since the early 80's, a number of books have been written, including the seminal *Strategic Marketing for Non-profit Organizations* by Alan R. Andreasen and

Philip Kotler, urging charities to adopt marketplace values. Although differences are acknowledged between for-profit and non-profit organizations,[15] there is strong pressure on charities to perform like private businesses. Consequently, charities have attempted to internalize and appropriate corporate values, such as competitiveness, differentiation, strategic planning, market-driven analysis, and performance monitoring (Andreasen and Kotler, 2008). By constantly adapting to the changing for-profit world (Brinckerhoff, 2003) and applying profit-driven techniques, they aspire to become more efficient, accountable, and trust-worthy, and to generate greater interest in their cause, which can translate into more money from philanthropists and corporate alliances (Brest and Harvey, 2008). The adaptation of the marketing orientation has been praised as the key philosophy to adopt in order to achieve success (Clarke and Mount, 2001; Alvarez, Santos, and Vazquez, 2002; Andreasen, Goodstein, and Wilson, 2005, etc.).[16] In order to further non-profits' knowledge of the for-profits, books and articles explore the internal functioning of the corporate funding structure and the philanthropist's mind (e.g., Holland, 2006; Brest and Harvey, 2008; Cantrell, Kyriazis, Noble, and Algie, 2008).

Hence, the relationship between for-profits and non-profits is not solely based on the individual values-based partnerships we introduced in section 2.1. At a macro level, *marketplace values* as a whole have been injected into the daily practices of the non-profit world. We can therefore adapt the previous conceptualization of the value(s) framework into a larger system, as shown in Figure 1.2.

Figure 1.2: Macro relationship between value and values

Marketplace

Charities

Creation of value

Values
Surviving in a competitive world
(efficiency, competitiveness, analysis, planning, strategy, etc.)

For-profit value: disseminate corporate values, attract and appeal to employees, consumers, and shareholders, develop branding, increase sales and market shares, reduce costs, etc.

Non-profit value: Help achieve their mission, legitimize activities, create brand awareness, help implement social change, etc.

Values
Fulfilling a social and humanistic mission
(helping, providing, caring, devoting, etc.)

In this relationship, the marketplace develops a connection with the values associated with the missions of charities, while the charitable organizations learn to become business-like by adopting marketplace values. This mutual relationship generates value for various stakeholders: consumers, beneficiaries, shareholders, donors, funding and regulating governmental agencies, public opinion, and the media. We will now look at how this system of value creation is studied in the academic field.

2.3. Towards a broadened understanding of the relationship

2.3.1. Three common substantive domains of investigation

In order to understand the general idea of this creation of value, researchers have developed in-depth exploration of three substantive domains that represent three of the fundamental constituents of the charitable world: charities and NPOs, the marketplace,

and volunteers. Charities and other NPOs broadly refer to organizations pursuing non-profit-oriented missions (e.g. fostering social change, helping target groups, etc.). The volunteers grouping refers to the unpaid workforce that contributes to the NPOs by offering free labour. Finally, the marketplace refers to companies, individuals, products, and services stemming from for-profit businesses or the marketplace as a whole, which are involved in one way or another with charities and NPOs. When analyzing the focus of the research in these three domains, we can further observe that studies mainly pay attention to the relationship between two elements of the triad at a time,[17] creating three dyadic fields of investigation: charities-marketplace, charities-volunteers, and volunteers-marketplace. The following figure presents examples of topics explored for each dyad.

Figure 1.3: Research topics at the centre of studies on the world of charities and NPOs

Charities and NPOs

- Satisfaction and motives
- Segmentation of volunteers
- Contexts of volunteering
- Choice of charity
- Etc.

- CRM
- Marketing orientation
- Segmentation and understanding of donors
- Branding
- Database marketing
- Etc.

Volunteers   Marketplace

- Work/volunteering negotiation
- Comparison of paid/unpaid workers
- Career opportunities
- Corporate benefits
- Board of directors
- Etc.

The *charities-marketplace* research is mainly concerned with questions regarding interactions between the charitable organization and the individuals, products, services, or companies within the marketplace. As we mentioned before, a great deal of attention has been devoted to applying knowledge of the marketplace to charities, for example by applying the market orientation philosophy (e.g. Alvarez Gonzalez, Santos Vijande, and Vazquez Casielles, 2002; Duque-Zuluaga and Schneider, 2008; Shoham, Ruvio, Vigoda-Gadot, and Schwabsky, 2006), and exploring the concepts of branding (Hankinson, 2001), brand personality (Sargeant, Ford, and Hudson, 2008; Voeth and Herbst, 2008), and brand communities (Hassay and Peloza, 2009). In addition, life cycle (Drye, Wetherill, and Pinnock, 2001) and database (Key, 2001) analysis as well as consumers' response to, for instance, CRM (Hoek and Gendall, 2008) and social entrepreneurship (Hibbert, Hogg, and Quinn, 2002), have also been explored. Within this dyad, researchers have also looked at segmenting and understanding the market of donors (e.g., James and Sharpe, 2007; Brown, 2004) and studied the importance of individual variables such as religious affiliation, age, volunteerism, education, gender, race, social desirability, and gender and moral identity (e.g., Gittell and Tebaldi, 2006; Louie and Obermiller, 2000; Mesch, Rooney, Steinberg, and Denton 2006; Schlegelmilch, Love and Diamantopoulos, 1997; Winterich, Mittal, and Ross, 2009); of charity variables such as administrative efficiency (Tinkelman and Mankaney, 2007) and accountability (Sloan, 2009); and of specific donation markets such as major donors (Cermak, File, and Prince, 1994), legacy donors (Sargeant, Wymer, and Hilton, 2006), diasporas (Brinkerhoff, 2008), giving circles (Caster, 2008), venture philanthropists (Wagner, 2002) and young professionals (Kottasz, 2004).

The *charities-volunteers* dyad research, on the other hand, looks at the relationship between the charity and the volunteer workforce. The exploration of this association has been analyzed mainly from three angles: volunteering itself, the impact of volunteering, and the managerial and strategic implications of volunteering for charities and NPOs. In order to understand volunteering, various studies have investigated the reasons for volunteering as well as the characteristics of volunteers (e.g., Bussell and Forbes, 2002; MacNeela, 2008; Yavas, Riecken, 1985: Yeung, 2004). They have also attempted to segment volunteers based, for instance, on motivation (Dolnicar and Randle, 2007; Mayer, Fraccastoro, and McNary, 2007), to compare volunteers in different countries (Hwang, Grabb and Curtis, 2005), to differentiate people who volunteer for different causes (e.g., Beerli, Diaz, and Martin, 2004; Wymer, 2003), and to explore contexts of volunteering, such as charity retailing (Broadbridge and Horne, 1994), the Olympics (Kemp, 2002) and overseas volunteering (e.g., Hudson and Inkson, 2006; Thomas, Newell, Baral, and Byanjankar, 2007). In exploring the impact of volunteering, researchers have looked, among other things, at causes of satisfaction and burnout in volunteers (Kulik, 2007), the relationship between volunteering and personal and neighbourhood well-being (Mellor, Hayashi, Stokes, Firth, Lake, Staples, Chambers, and Cummins, 2009), and the effects of volunteering on longevity and health (Post and Niemark, 2007), social capital formation (Isham and Kolodinsky, and Kimberly, 2006), and empowerment (Cohen, 2009). To understand the managerial and strategic implications of volunteering in the context of charities, scholars have reflected on the challenge of managing volunteers (Wilson and Pimm, 1996; Shin and Kleiner, 2003), on labour demand (Handy and Srinivasan, 2005), and on improving volunteers' performance

and effectiveness (Adams and Sheperd, 1996; Zweigenhaft, Armstrong, Quintis, and Riddick, 1996). Researchers have also attempted to quantify the added value of volunteerism for organizations (Mook, Handy, Ginieniewicz, and Quarter, 2007), explored how organizational changes can impact volunteers (Lie and Baines, 2007), and compared the perceptions of volunteers and their managers (Liao-Troth and Dunn, 1999).

Finally, the *volunteers-marketplace* investigations have examined the relationship between private corporations and the volunteer workforce. For instance, studies have compared volunteers and paid workers (Catano, Pond, and Kelloway, 2001; Elshaug and Metzer, 2001), assessed the impact of volunteering on paid employees (Geroy, Wright, and Jacoby, 2000; MacPhail and Bowles, 2009), and examined how employees could be managed like volunteers (Smith and Greeb, 1993). They have also explored the relationship between employment, family life, and volunteering (Gomez and Gunderson, 2003; Rotolo and Wilson, 2007; Taniguchi, 2006).

In summary, the current academic and managerial discourse on creation of value in non-profit and charitable marketing focuses on three major domains of the charity world. In these examinations, the charity is mainly conceptualized as a rational agent that adopts and appropriates values borrowed from the marketplace in its creation of value. It also develops extensive managerial ties with volunteers. For its part, the marketplace is also conceptualized as a rational agent that provides monetary, technical, human, and material assistance to charities and NPOs in order to create value. Volunteers are unpaid resources used by charities, and they have complex ties to both the charities and the marketplace. The three components work together, exchange values, and seek to create value in order to fulfill their respective needs and objectives.

2.3.2. An important, yet overlooked, aspect

Despite the vast amounts of research devoted to the three groups mentioned above, ironically, few studies directly address the issues, reality, and complexity of the beneficiaries of charities. I say ironically because beneficiaries are the *raison d'être* of these organizations. In fact, their missions explicitly identify the object of their assistance: "Helping low-income families meet their basic need for safe, decent and affordable shelters" (Habitat for Humanity); "Delivers emergency aid to people affected by armed conflict, epidemics, natural or man-made disasters, or exclusion from health care in more than 70 countries" (Doctors Without Borders); "Works with the community to provide children living with high-risk, life threatening illnesses the opportunity to realize their most heartfelt wish" (The Children's Wish Foundation of Canada). In an attempt to situate the debate with beneficiaries, we will first look at the scarce body of academic literature that explores the issue. We will then observe that the lack of attention on beneficiaries is also present in managerial textbooks.

2.3.2.1. Limited body of academic literature

A very limited body of literature has focused on those who benefit from a charity's mission. In one such exception, Ronel (2006) aimed to understand the impact of volunteers on street youth receiving services from an outreach van service. This ethnographic study concluded that both positive and negative consequences existed. On the positive side, volunteers led street youth to change their world view by opening their eyes to the possibility of indirect, non-material gratification associated with the act of volunteering. On the negative side, a limited engagement on the part of the volunteers,

which manifested in frequent absences or cancellations of services, made it difficult for them to break down the barrier of teenagers' hesitation to build trusting relationships with them. Du, Sen, and Bhattacharya (2008) explored the returns of a cause-related partnership between the Boys and Girls Club of America (BGCA), the American Dental Association (ADA), and a major brand of oral hygiene products, on groups of disadvantaged Hispanic immigrants. They showed that less acculturated immigrants were more likely to adopt proper oral care attitudes and behaviours in their search for self-confidence and social acceptance in the host country. The researchers also demonstrated that beneficiaries, in return, developed an emotional bond with the brand or companies defending their cause and become purchasers of their products. Hung and Wyer (2009) demonstrated that when a potential donor is "placed in the beneficiaries' perspective," it can, under certain conditions, positively or negatively affect their desire to help a cause. Hung and Wyer showed that putting the potential donors in the imagined situation of the beneficiaries can "conflict with their perception of themselves in the role of donors" (p. 422), depending on how the appeal is framed. Participants who were first primed to think about making donations did not react as positively to the appeal after being exposed to the condition of the beneficiaries, as those who were first exposed to the image of the people in need and only then solicited to make a donation.

This small group research has contributed to our understanding of beneficiaries but also has certain limitations. Ronel (2006), for instance, explored the relationship mainly from the volunteers' perspective, since it was hard to develop a rapport with the "suspicious teenagers." In addition, this study did not address the role of the marketplace in the relationship built between the organization and the young adults, which limits its

interest in the present context. Although they revealed the limits of empathy in donation, Hung and Wyer's investigation did not study beneficiaries directly, but simply asked research participants to picture themselves in the beneficiaries' shoes. Applications of their findings apply here only in a limited sense. Finally, Du, Sen, and Bhattacharya (2008) confirmed the long-held belief that CRM can be mutually beneficial to charities and companies but did not delve deeply into the beneficiaries' experience of the sponsored program. Consequently, from a scientific perspective, little is known about the beneficiaries of charitable causes and their reality. Who are they? How do they choose to become beneficiaries? Do they always choose? How do they experience the charity's service delivery? How do they perceive and react to its mission statement and values? What is the impact of their perception of the charity? Are there various ways of conceptualizing and categorizing beneficiaries? How do they perceive the relationship between the charitable organization and the corporate world? How does their perception of that relationship affect their appreciation of the charity's service? What is the impact of the charity's work on the beneficiaries? Can we explain the link between the beneficiary's well-being and the services offered by the charity? These are but a few of the questions that could be explored in order to better understand the reality and complexity of beneficiaries and their link with charitable organizations and the marketplace.

2.3.2.2.   Limited large-audience managerial references

Strategy books written about charities and strategic marketing also contain very limited discussions regarding the beneficiaries. For instance, when discussing the concept of "customers" in the context of NPOs, Brinckerhoff (2003) does not mention anything

about the recipients of the cause, even though the subject of the book is mission-based marketing. His conceptualization of customers is mainly restricted to employees, corporate partners, donors, and board members. Similarly, Daw (2006) defines the charity constituents as employees, community influentials, shareholders, suppliers, and customers with a strong emphasis on the corporate role in CRM. Her discussion of beneficiaries is vaguely encapsulated in the notion of "values" introduced earlier. In Holland's (2006) scrupulous analysis of the branding process for non-profits, her emphasis is mainly on the "producers" in the process. Her branding team includes the board of directors, the CEO, the staff, and the branding consultant. Never in the process is there mention of the beneficiaries' perspective. Her discussion about them is limited to her statement that the branding should "follow the mission." Finally, in the most recent version of their influential book, Kotler and Andreasen (2008) talk about "target audiences" mainly as groups which NPOs and government agencies wish to influence (which they see as the focal point of their marketing). They target two groups of behaviours for change: social behaviours (e.g., respecting the speed limit, quitting or not starting smoking, fighting drug use, creating healthy eating habits, etc.), and commercial behaviours (e.g., attracting and satisfying patrons of the arts), but give limited thought to the beneficiaries of charitable causes, who are likely in greater need of basic assistance (e.g., shelter, logistical, psychological, and/or social support, and medical attention) than of a change to their behaviour.

The absence of a beneficiary-centred approach in the marketing discussions found in the above textbooks is also reflected in the charities themselves. Ian Bruce, founder of the Centre for Charity Effectiveness at London City University's Cass Business School in

England, is among the few to have remarked on this situation. He proposed that, although charities extensively develop a *marketing orientation* in the way they deal with the marketplace and raise money, they tend to have a *product orientation* in the development of their own offer to their beneficiaries (Bruce, 2005). He advanced various reasons to explain this production focus, including a monopolistic situation, a demand that exceeds supply, the difficulty of some to get their voice heard by the charity, and the differences in world views between the "haves" (charity organizers) and the "have-nots" (beneficiaries), among others (Bruce, 1995). He goes on to condemn the absence of marketing research of beneficiaries – which he coins "needs research" – and proposes four explanations for its limited use (Bruce, 2005:163):

- As demand usually exceeds supply, there is no impetus to better understand beneficiaries' needs.

- Professionals working with disadvantaged groups often adopt an "I know best" attitude.

- Charities' policy-making committees are often expected to know the answers.

- More progressive charities that include beneficiaries on their committees may tend to assume that the perspective offered by this limited number of individuals is representative of the whole group.

This lack of emphasis on needs research is also related to a broader tendency among charities and NPOs to under-prioritize marketing research. Kotler and Andreasen (2008) attribute this situation to seven myths that prevail in the non-profit sector: the "big decision" myth, which is the belief that research is only valid for decisions involving major financial stakes; the "survey myopia" and "focus group" myths, whereby a reliance

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on surveys or focus groups is believed to be a sufficiently rigorous research process; the "big bucks" myth, consisting of a belief that research is too expensive; the "we can't wait myth", whereby research is believed to be too time-consuming; the "sophisticated researcher" myth, which involves a belief that charities need to possess extensive knowledge about research to undertake such endeavours; and the "most-research-is-not-read" myth, which states that research will lead nowhere or be rejected for political reasons. These myths show that charities have a limited understanding of the research process and of its potential value.

In summary, at present, we do not have a solid understanding of the beneficiaries' experience of the services they receive from charities. Charities tend to develop a dichotomous orientation in their operating philosophy: a market orientation with respect to their relationship to the marketplace and donors; and a product orientation with respect to beneficiaries. Furthermore, knowledge of the role played by the marketplace in this relationship is also very limited. This is consistent with the idea that the conventional role of the marketplace is conceived as a "constructive" one, insofar as it provides the material, money, human resources, and/or expertise necessary to assist the charity in pursuing its mission.

2.4. Putting the beneficiaries back in

From a value-creation perspective, acknowledging the beneficiaries may prove highly beneficial. Developing a deep, thoughtful, and lasting relationship with beneficiaries might pay off. As Bennett (2005) argued, adopting a relational (i.e. that encourages the development of deep and lasting relationships) rather than a mere transactional (i.e. that

develops a specific marketing mix) approach with beneficiaries can lead a charity to greater competitiveness on the charitable field and a better capacity to respond to their needs. More generally speaking, acknowledging the beneficiary imposes a different perception on charities. As illustrated in the next figure, the addition of the beneficiary adds a new perspective to the commonly studied triad.

Figure 1.4: Addition of the beneficiaries' perspective
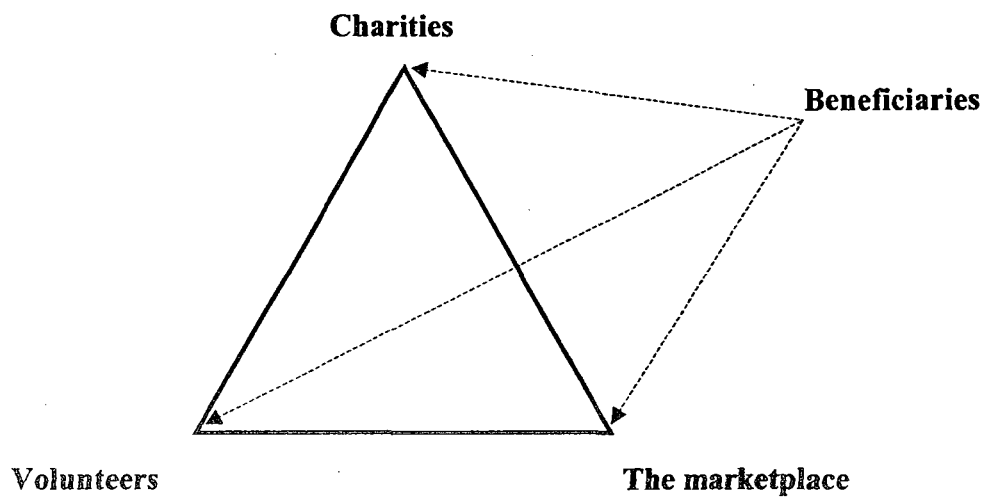
This addition adds new meaning to the actors' roles. The charity suddenly becomes accountable not only for optimizing its budget and limiting its administrative costs, but also for delivering a service and listening to those who receive the service. In this context, the market orientation becomes fully relevant. The marketplace cannot be seen merely as a supplier of money, people, and expertise. Its actors and their behaviours take a particular, more sensitive role, as they interact with potentially vulnerable people. In that regard, charities, depending on their level of involvement with their beneficiaries and the level of vulnerability of their clientele, must reflect on the very nature and role of the marketplace and on how to provide adequate mediation whenever needed.[18] The

marketplace also becomes accountable for its interfacing with beneficiaries, which can have various positive or negative consequences. When acknowledging beneficiaries, "looking good" is not enough. Donating money is not enough. Corporate social responsibility becomes truly significant. Social return on investment[19] (SROI) becomes more important than surface images of good corporate citizenship. When facing the beneficiaries, the marketplace cannot rely solely on communication skills, but must show *real results*. The link between volunteers and charity must also be revised. Not all volunteers occupy administrative functions or work on fundraising-related activities. Many are also involved in the direct delivery of the charity's services to the beneficiaries. These volunteers are unpaid resources with various backgrounds, training, interests, and agendas. Their knowledge of particular beneficiaries' situations and needs can sometimes be limited. The charity's awareness of the relationship between the volunteers and the beneficiaries hence becomes critical.

2.4.1. Concerning the condition of the beneficiaries of the CWF

Adding the perspective of beneficiaries leads to a new reality, slightly more complex to manage and likewise to study. My focus on a phenomenon oriented towards ill children necessitates a departure from the usual motivation research, which very often deals with healthy middleclass consumers.

CWF families are forced to deal with illness and the possibility of death on a daily basis. For some families, the illness of their child fell on them like a bomb, completely unexpectedly. Their child's battle with illness might last a few months or many years. For others, the diagnosis appeared early in the life of their child, and that child might have

been struggling for survival ever since. Some experience life-threatening conditions that are controlled, while others face slowly degenerative, ultimately fatal diseases. Each family has a different relationship with disease, and they all have something different to tell about it. One thing they share in common is the fact that they experience its overpowering presence, its cold and harsh reality. All of these families experience the instability caused by the transformation of their world, a world previously constructed around continuity and order.

Notions of continuity and order have received a certain amount of attention in the academic sphere. They are perceived as central cultural aspects of Western society. In fact, a significant aspect of the Western psyche involves the drive to create continuity and order in life. Storytelling is an interesting reflection of this coping mechanism, in that every story, be it in the form of a movie, fairytale, novel, or otherwise, has a beginning, middle, and end. In his exploration of order and continuity in disrupted lives, Becker (1997) sheds insight on this phenomenon. Order and continuity provide the framework for constructing and organizing meaning in our lives and help us to understand events as being part of an overall tradition. We create continuity through our daily routines, which help us to make sense of our lives and to establish expectations about future events. However, when these expectations are not met, people can experience malaise or even chaos, depending on the extent of the disruption and the course taken by the unexpected events. Illness is one such major disruption in a life story (Bury, 1982). When the body is assaulted by serious illness, one's sense of wholeness, on which a feeling of order depends, can crumble. One must first reconstitute a sense of wholeness in order to regain a sense of continuity (Becker, 1997 p. 39).

The unexpected exposure to a life-threatening illness sends a shock wave that deeply affects and dislocates one's relationship with time. Indeed, illness introduces disruption by defying orderliness; people experience the time before their illness and its aftermath as two separate realities (Becker, 1997). Furthermore, families who face the threat of a serious illness strongly focus their psychic energy[20] on the here and now of the illness and its potential ramifications. For instance, during what researchers have called the "acute illness phase" (i.e. diagnosis and early treatment), victims and those in their close circle tend to be sharply focused on the present moment (Leigh, 1994), hardly able to envision the future. Family members' psychic energies are all-consumed by the current moment, as they push aside mundane personal and family goals in order to care for the ill. Consequently, their self-identification as consumers takes on a different meaning – consumer goals are devalued. To merely plan future spending activities is an almost impossible task. To illustrate this phenomenon, Pavia and Mason (2004) use the "unwilling to buy green bananas" metaphor to express the challenge women with breast cancer face in trying to envision the future; their future outlook becomes as short term as "the brief time it takes for bananas to ripen" (p. 446).

On a deeper, more existential level, life goals and values can also be affected, even threatened, by this disruption. One such goal is the cultivation of parental identity. Parents are in part socially constructed as "shapers, the agents entrusted with molding their offspring's formlessness and potential" (Bluebond-Langer, 1978:214). Children are indeed often conceptualized in Western society as "adults to be" (Kellett, Robinson, and Burr, 2005), hence the importance of a forward-looking perspective in the role of parents. As such, a parent existentially defines himself not only in the now, but also in the

actualized future of his child becoming an adult. This internalized role has extensive repercussions on consumer behaviours. Parents invest money on specific future-oriented child-rearing products and services. This phenomenon, called *pathway consumption*, involves "spending on the opportunities that shape children's trajectories" (Pugh, 2009:178). Examples include the decision to invest in a private versus public school education for a child, or the choice to buy the more expensive hockey skates in the hopes that a child will become a successful hockey player. This occurs even in smaller, more trivial purchases, such as Disney's *Baby Einstein* DVD collection, of which the title evokes in parents' minds a vision of their genius-to-be. These rearing-related consumer products and services are designed to respond to parents' aspirations for their children's futures.

Illness potentially challenges this aspect of parental identity in its uprooting of the family system and continuity, causing established parental roles to progressively vanish. Parents come to perceive themselves as powerless before the disease, and also gradually lose their authority as the hospital takes on the parental role by becoming the "provider" of care (Bluebond-Langer, 1978). Furthermore, even traditional parenting roles with respect to healthy siblings are affected, as the latter are often somewhat neglected due to the critical nature of the situation (Bluebond-Langer, 1996).

The potential death of a child challenges not only parents' capacity to help and nurture, but also their capacity to envision the future with or of their child. They undergo somewhat of an existential crisis, whereby a central role[21] of their identity as parents – to give shape to their child's formlessness and potential – is jeopardized. Bluebond-Langer (1978) further argues that, in the face of terminal illness, the drive to rear a child towards

his or her future can ultimately lose its meaning, and consumer as well as other projects involving the child's future may be postponed, having possibly grown unappealing.

In parallel, ill children as young as three are reported to be aware of the threat to their lives and the challenge to the "normalcy" of their childhood imposed by the illness. They realize their incapacity to meet the hopes that parents and society alike may have had for their futures. They often react by developing new complex forms of interactions with their loved ones, such as mutual pretence,[22] in order to preserve some sort of social order (Bluebond-Langer, 1978).

In summary, by forcing family members to direct most of their attention, or psychic energy, away from the future and into the "disrupted now," and by dismantling deeply held conceptions of parenthood and childhood, illness effectively attacks the roots of our perceived sense of order and halts us on our expected path of life.

3. Position of the research

The abovementioned observations are all quite radical criticisms and ambitious questions that can potentially advance an entire field. An exploration of the Children's Wish Foundation can enable us to shed light on these issues. It is not my ambition to answer all these questions in this dissertation. The questions do, though, feed my interest in the topic and inspire my approach.

For the sake of this research, I conducted an ethnographic study of the wish granting phenomenon and, as stated in the introduction, focused on how we can conceptualize and understand the phenomenon of ill children's wish granting and its impact on, and relationship with, the various actors, as they are deployed throughout the

process. From a motivation research angle, the study follows the corrective rules proposed in section 1.3. By choosing to study the phenomenon from an ethnographic angle, I took a flexible, exploratory (Limitation #2), and more sociological (Limitation #1) approach to the study of the wishes and of their relationship to the dreamer (the child), his family, the CWF representative, and the other actors involved. Throughout this research, the wish was not considered a priori as fixed, but rather as evolving and negotiated throughout the process (Limitation #5). Real-time access to the phenomenon lent an additional naturalistic perspective (Limitation #4) to what people had to say about their past or future aspirations. Furthermore, it allowed a better phenomenological exploration of the mental and physical impact on the children and their families (Limitation #7). An investigation of these families takes us away from the average consumer normally studied in consumer research (Limitation #3), because they represent a very specific group of consumers facing highly difficult life-threatening situations. Finally, constant exposure to the family, the beneficiaries, and the marketplace opened the door to reflections on the place of morality (Limitation #6).

From a charity perspective, being immersed in the reality of wish fulfillment provided a way to delve into the intricate relationships between charities, beneficiaries, and the marketplace. The wish fulfillment context does offer a unique perspective from which to explore this relationship. From this viewpoint, the marketplace is not merely a rational agent in a carefully planned CRM campaign, but is instead a more pervasive, less structured, hard-to-grasp network of agents involved – consciously or not – in the delivery of a wish. Rather than being analyzed in a systematic way with a view to generating expected social and commercial returns, as in the case of CRM (Du, Sen, and

Bhattacharya, 2008), the marketplace is examined on an ad hoc basis. The fulfillment of a wish provides a situation in which the marketplace can have a boundless, almost free relationship with the beneficiaries.

This dissertation thus proposes an open-ended exploration of this reality in its complexity. In the following chapters, I will reflect on the notion of a wish and the intricate relationship between the main actors I have identified in this review of literature. We now turn to a description of the ethnographic method used to develop this study.

Chapter 2

An ethnography of the 'Wish Factory': Methodological

Considerations

In this chapter, I will introduce the ethnographic approach that I used to study the wish granting phenomenon as well as present some of its methodological specificities.

1. Why ethnography?

In light of the objective of this research, the ethnographic approach seemed the most suited for grasping the importance of the wish granting process at the Children's Wish Foundation. As argued by anthropologists and sociologists such as David Howes (1996), Arjun Appadurai (1988), Daniel Miller (1987), and Bruno Latour (1979, 1991, 2005), every social phenomenon is the result of a complex construction process composed by a series of actors, actions, contexts, history, and discourses. In other words, in order to fully appreciate a social outcome, one has to investigate the process that led to its current state. The social phenomenon is dialectically created through encounters with the various actors involved (who are to a certain extent also transformed by it). Close to one hundred years of theory building, epistemological debates, and empirical investigations in anthropology and sociology have shown that ethnography – that is, open-ended, direct, participatory, contextualized, prolonged, and intimate, contact with studied people (Arnould and Wallendorf, 1994) – is the most valuable and objective method to grasp the processes of social construction. Due to its prolonged character, this approach allowed

me to study the process of wish realization in its entirety – from the very beginning of the wish formation to the very end of the wish granting process, including the period following its fulfillment – and from all important perspectives: the wish provider (CWF staff and volunteers), the ill children, the families, the medical experts, the donors, etc.

Basically, an ethnographic approach allowed me to explore *the social life of the dream*: 1) how and why the wish originates from the ill child; 2) how it is discussed and negotiated within his/her family; 3) how the family approaches the wish granting organization to formulate a wish request; 4) how the organization evaluates the request; 5) how the organization gets the monetary, medical, legal, ethical, and human resources to be able to grant the wish; 6) what challenges and difficulties are encountered during the process; 7) how the wish granting is materialized and performed on the wish granting day; and 8) how the wish affects and is affected by the actors – directly or indirectly – involved in the process.

Ethnographies have been conducted in many fields outside sociology and anthropology, including political science, medicine, education, criminal justice, and marine biology (Van Maanen, 1988). It has also gained legitimacy in consumer research, with ethnographies of adolescents and their use of advertising (Ritson and Elliott, 1999), of flea markets (Sherry, 1990), of bikers (Schouten and McAlexander, 1995), of the gay community (Kates, 2002), of retail stores (Kozinets, Sherry, Storm, Duhachek, Nuttavuthist, and Deberry-Spence, 2004), of households (Coupland, 2005), and of house moving (Marcoux, 2009).

2. The contemporary ethnographic approach

My approach was influenced by the vision of ethnography developed by the Chicago School. Scholars at the University of Chicago established "urban ethnography" and described its purpose as the exploration of a familiar place "as if it were a remote and exotic setting" (Van Maanen, 1988:19). Being conducted in my own country, the ethnography of the Children's Wish Foundation forced me to adopt that perspective. The idea of "the stranger stepping into a culturally alien community to become, for a time and in an unpredictable way, an active part of the face-to-face relationship in that community," as Van Maanen (1988) put it, must be here reconsidered. In the context of contemporary ethnography, the terms "stranger" and "culturally alien" have a relativistic value. In fact, it is by no means expected that ethnographers will immerse themselves in a totally different cultural setting, but instead must accept that they will explore elements of their local world containing the known and the unknown, the familiar and the strange. Urban ethnographers "bring anthropology home by learning of the vigorous, dense, heterogeneous cultures located just beyond the university gates" (Van Maanen, 1988:19).

In studying one's own local context, one should practice a more "symmetric anthropology" Latour (1991). That is, one should stop building only two levels of human understanding, having only two readings of the culture, depending on which side of the "modern-pre-modern dichotomy" the scrutinized society falls. In other words, anthropologists should use all the concepts, frameworks, and skills they have gained as they explored foreign and exotic cultures to study their own society. After all, the "moderns" still have their myths, beliefs, and fetishes (Feyerabend, 1975; Latour, 1996).

It is in this context that my ethnography finds its legitimacy, in this need for a better understanding of our own society.

As is often the case with most contemporary urban ethnographies, my work entailed a prolonged – though frequently interrupted – immersion in the world of the Foundation in order to progressively develop a systemic understanding of its multilayered, multifaceted reality. I say prolonged because it was my intention to build a long-term relationship with the people in the foundation. I say interrupted because, contrary to the traditional anthropological ethnography of foreign cultures, it was not possible to have around-the-clock access to the foundation's environment because access was limited to their business hours and was dependent on my own work schedule. In addition, doing full-time volunteer work was not always an option in the context of my role and my personal life. Consequently, I was on or offsite, depending on my work schedule with the foundation and on any other unfolding events.

Like other contemporary ethnographers, one of my preoccupations was indeed to deal with the tension of making "the strange familiar and the familiar strange" (Glesne, 1999:46). To *make the strange familiar* means to understand what was previously unknown or incomprehensible. This can be done through constant interrogation, observation, and experiencing of unfamiliar phenomena. To *make the familiar strange* is a more delicate process. It demands that one look at the phenomena with fresh eyes, that one constantly question one's assumptions and perceptions of what is already known in order to avoid taking things for granted (Glesne, 1999). It asks one to be attentive to "breakdowns," a hermeneutic notion that signifies a "lack of fit between one's encounter with a tradition and the expectations contained in the schemas by which one organizes

one's experience" (Agar, 1982: 784). The experience of a breakdown signals a disjunction between the world of the researcher and the world of the informants (Agar, 1982). To "experience the strange," I tried to look for those breakdowns during the fieldwork: (un)expected emotions, differences, or feelings of strangeness, or of awkwardness, or of surprise, that were noticed by me, my informants, or both.

Ethnographies are more than method (Arnould and Wallendorf, 1994). They can be thought of as a combination of four building-block elements: fieldwork, culture, reflexivity, and writing. Through a discussion of these four components, I will further delineate my approach.

2.1. Fieldwork

Fieldwork is the essence of the ethnography. It is an indispensable way of seeking to understand others (Van Maanen, 1988). In order to perform the fieldwork, ethnography uses participant observation as the main source of data collection. Participant observation is the core of the method. It presupposes that the researcher will take an active part within the collective being studied. It constitutes a global field strategy in that it "simultaneously combines document analysis, interviewing of respondents and informants, direct participation and observation, and introspection" (Denzin, 1987: 183). In participant observation, experience is crucial (Arnould and Wallendorf, 1994). In fact, the researchers' firsthand experience of the phenomena can help them draw on personal knowledge during the interpretation and analysis of the findings (Patton, 2002). Moreover, long-term interaction and participation with an informant helps them to attain the status of a "trusted person" (Glesne, 1999). Participant observation is holistic. As

Malinowski (1922) notes, the ethnographer should patiently and seriously look at all aspects of the group. Ethnographers should make no distinction between the mundane and the extraordinary. Ethnographers deliberately "expect the unexpected" (Glaser and Strauss, 1967).

As an ethnographer, I stood as close as possible to the phenomenon. I got personally involved in the daily activities and routines of my informants in order to experience as much as possible the events in their lives, the various contexts, and the diverse emotions. By doing so, I developed a sensitive, human, contextualized, and respectful understanding of their lives. Most importantly, as Malinowski (1922) notes, "being there" through participant observation gave me the ability to witness "on the spot" the multitude of daily – and often unpredictable – activities, ceremonies, and transactions that naturalistically occur in the life of the wish granting community (e.g. the daily routines at work, the official and casual meetings or encounters between individuals and groups, the ways of preparing the logistics of events, the ways of performing during daily routines and extraordinary events, the emotional reactions and social interactions emerging during everyday life and special events, etc.). Being there also gave me access to the unsaid, to the daily routines taken for granted by the informants – if not unconsciously incorporated (Merleau-Ponty, 1945) – and which can become difficult, if not impossible, to verbally articulate. As Malinowski observed, researchers should not only rely on discourse and textual analysis of archives, but also on what individuals *do,* and on the *gap between what they say and what they do.* Arnould and Wallendorf's (1994: 486) differentiation between fieldwork, interviewing, experimenting and surveying is insightful in this regard:

Rather than asking people to comment about what they think they usually

do or say, recently did or said, and will do or say, as in

phenomenological interviews, ethnographers prefer to observe them

doing it; instead of observing people doing what they might do or say if

real-world complexities did not impose on them, as in laboratory

experiments, ethnographers observe actual people's behaviour in real

time; and rather than asking respondents to generalize about their

behaviour as in survey research, ethnographers record the particulars of

naturally occurring behaviours and conversations.

Indeed, the fulfillment of a wish is more than the words and images used to express expectations about its fulfillment. It is a process in which a series of evolving actions, thoughts, and feelings will be (consciously or not) put together, affecting each other. It is a process in which many potential actors are likely to play various and evolving roles, sometimes without the awareness of one another. In that sense, it is too multifaceted and complex to be explored through surveys, and implies too much naturalistic, taken for granted, unconscious actions to be studied solely with interviews.

During the fieldwork, I served as a full-time volunteer in a chapter of the foundation from May 2006 (upon receiving approval from the university's ethics committee) to December 2006. After that point, I continued to collect data sporadically until the middle of 2009. I first got involved at the CWF in order to become more familiar with the culture, activities, people, challenges, and so on at the CWF. It continued until the end of my fieldwork. My involvement at the CWF consisted of various activities and roles.

At the beginning of the fieldwork, my marketing expertise was sought for various tasks, including: gathering information on the competition and news related to charities; commenting on a private research report ordered by the head office; and analyzing the structure of obituaries in newspapers. I also produced a benchmarking report concerning competition in the charity sector.

In addition, for more than eight months I had my own office at the CWF and participated in daily activities and gatherings (e.g. lunch time, breaks, spontaneous and scheduled daily and weekly meetings). I participated in four fundraising walks between 2005 and 2008. I attended the 2005 walk (which took place before the start of my fieldwork) and the 2008 walk as a participant only. However, I was more actively involved in the organization of the two 2006 and 2007 walks (contacting people, planning the walks, training volunteers, etc.). As well, I took part in the preparation and organization of the events associated with these fundraising walks. Finally, I participated in the Annual Volunteers' Day, where I was present for the duration of the conference and played the role of the mascot during the greeting of the volunteers.

I and other CWF employees also represented the CWF at a variety of fundraising events organized by third parties, including benefit shows, fundraising dinners, parades, and bracelet campaigns conducted in shopping malls, among others. I also attended the Flight in Search of Santa organized by Air Transat.

I was also responsible for assisting whoever needed help in their daily activities (as per the direction of the CWF Director). This entailed calling families to invite them to participate in events, counting money raised at fundraising activities, entering data on the

organization's constituents into Raiser's Edge (fundraising software), and getting involved in evening volunteer training sessions to prepare them for their role at fundraising events. I also proofread letters and documents and gave my "marketing opinion" on specific documents, letters, and activities.

While getting around the CWF and subsequent to receiving final approval from Concordia's research ethics board, I progressively tried to become aware of the challenges and reality of dealing with the families. At first, I had various conversations with key informants: the wish coordinator (Wendy), an experienced volunteer (Debbie) and a social worker (Elisabeth). During these discussions, we explicitly tackled the question of death, illness and how to interact with families going through this difficult situation. The annual volunteers' meeting I attended also focused on this aspect of the work. I progressively started to attend meetings between the wish coordinator or volunteers and families. At first, I did not interact with the families and simply listened and observed. As time went on, I became more active in the conversations. Later, I further participated in the fulfillment of a number of wishes with Wendy, Becky (another CWF employee), and Debbie. These wishes consisted mainly of shopping excursions and performances. Finally, I was involved in the wish granting process for certain families, which entailed taking part in the planning of the wish, meetings with families, and ultimately accompanying these families to Disney by myself.

During the fieldwork, I gathered information concerning the foundation itself, the wishes and their process of realization, and the various actors' roles and perspectives. The objective was also to follow the realization of a variety of wishes in order to cover a

vast array of contexts: various illnesses (e.g. cystic fibrosis, leukemia, etc.), various ages (from 3 to 17), and various wishes (travels, items, and celebrities).

From my standpoint as a participant observer, I derived most of my data from the observation of behaviours, social interactions, environmental settings, and actors (donors, volunteers, ill children, their families and friends, and health care professionals). To complement these observations, interviews were also conducted. The interviews included informal, on-the-spot interactions as well as conversations in more formal, scheduled meetings. Interviews were necessary since they allow the ethnographer to collect information that would not be accessible otherwise (certain emotions or explanations of actions). During these privileged encounters, I explored various issues, such as the value of certain relationships, the notion of illness, the wishes, their fulfillment, their antecedents and consequences, the meaning of the realization of consumer wishes, the motivations to volunteer and to donate to the foundation, and information concerning the socioeconomic background of the informants. The following table presents a brief description of the main actors involved in my research as well as the methods used to collect data.

Table 2.1: List of actors

CWF actors			
Name	**Title or description of the actor**	**Age**	**Type of data collected**
Wendy	Wish Coordinator Key informant	Forty-something	Participant observation, long interview, informal

			conversation
Becky	First-party specialist Key informant Does not work for CWF anymore.	Twenty-something	Participant observation, daily informal conversations
Roger	Chapter Director Key informant Does not work for CWF anymore.	Forty-something	Participant observation, daily informal conversations
John	Corporate fundraising specialist Does not work for CWF anymore.	Forty-something	Participant observation, daily informal conversations
Jenny	Assistant Wish Coordinator Does not work for CWF anymore.	Twenty-something	Informal conversation
Meredith	Higher-level Wish Coordinator	Forty-something	Informal conversation
Dennis	Third party manager, mascot performer Does not work for CWF anymore.	Twenty-something	Participant observation, daily informal conversations

Eileen	Corporate fundraiser specialist Does not work for CWF anymore.	Forty-something	Participant observation, daily informal conversations
Aicha	Chapter Director Does not work for CWF anymore.	Thirty-something	Participant observation, daily informal conversations
Valery	Third-party manager Does not work for CWF anymore.	Thirty-something	Participant observation, daily informal conversations
Felicia	Communications and volunteer manager Does not work for CWF anymore.	Twenty-something	Participant observation, daily informal conversations
Norlaine	Receptionist	Sixty-something	Participant observation, daily informal conversations
Peter	Board member	Forty-something	Non-participant observation, informal conversation
Medical community			
Elisabeth	Key informant Social worker in a children's hospital Now retired. Specialized	Sixty-something	Participant observation (during the Annual Volunteers' Day), frequent informal conversations

	with children living with cancer.		
Various hospital staff	Doctors and nurses from various hospital departments.	Various	Participant observation and informal conversation

Volunteers			
Debbie (key informant)	Resource teacher	Forty-something	Participant observation, long interview, frequent informal conversations
Danna	School teacher	Fifty-something	Participant observation
Other volunteers	Various roles	Various	Participant and non-participant observation, informal conversation

Families			
Sonya	Wish child, Disney wish. Ruptured brain aneurysm	7	Participant observation, long interview
Kathrin	Sonya's mother	Twenty-something	Idem
Linda	Kathrin's mother	Fifty-something	Idem
Bobby	Wish child, Disney wish.	9	Participant observation,

	Physical disability and cognitive developmental delays		frequent informal conversations
Mary	Bobby's mother	Thirty-something	Idem
Susan	Mary's mother	Sixty-something	Idem
Jeff	Bobby's brother	11	Idem
Martin	Wish child, Disney wish. Leukemia	10	Participant observation, long interview
Martin's parents		Forty-something	Idem
Maria (plus mother and aunt)	Wish family, Disney wish. Leukemia	13	Non-participant observation, wish story (discussed at the CWF)
Simon	Wish child, trip to French Polynesia Muscular cancer	13	Participant observation, informal conversation, wish story (discussed at the CWF)
Anna	Simon's mother	Forty-something	Participant observation, long interview, informal conversation, wish story (discussed at the CWF)
Larry	Simon's father	Forty-	Idem

		something	
Lindsay	Wish child, wish to meet local celebrity Sarcoma	19	Participant observation, wish story (discussed at the CWF)
Janet	Lindsay's mother	Fifty-something	Idem
Emily	Wish child. Swimming pool wish Cystic fibrosis	12	Participant observation, long interview, informal conversation, wish story (discussed at the CWF)
Rose	Emily's mother	Forty-something	Idem
Jenny	Wish child, Disney wish. Brain tumor	12	Non-participant observation
Jenny's parents	Wish family	Forty-something	Idem
Nathaniel	Wish child, Disney wish. Acute lymphoblastic leukemia	4	Non-participant and participant observation, informal conversation
Nathaniel's parents		Thirty-something	Idem
Jeffrey	Wish child, Disney wish. Dandy-Walker syndrome	8	Non-participant and participant observation, multiple informal conversations

James	Wish child, wish to catch butterflies. Brain tumor	Twenty-something	Non-participant and participant observation, informal conversation
Alexandra	Wish child, wish to see family in Italy for the first time. Crouzon syndrome	14	Non-participant observation
Danny	Wish child, wish for PS3 and play station Renal failure	16	Participant observation

The following table also provides the description of some of the wish stories that were discussed at the CWF, publicized on their website or presented in thank-you letters sent by families.

Table 2.2: Examples of wish stories

Description	Age
Boy. Disney Wish. Popular wish in the media (sang to the Pope).	7
Boy. Disney wish. AIDS.	4
Boy. Disney wish. Burkitt lymphoma.	8
Girl. Dolphin wish. Cancer.	13
Boy. Disney wish. Leukemia	4
Boy. 63-inch plasma TV. Hodgkin's lymphoma.	10

Boy. Wish to design own personal guitar. Hodgkin's lymphoma.	13
Boy. Playground wish. Illness unknown.	6
Boy. Wish for Playmobile collection. Acute lymphoblastic leukemia.	8
Boy. Wish for personal recording studio. Cystic fibrosis.	16
Girl. Swimming pool wish. Neuroblastoma (brain tumor).	11
Boy. Toys "R" Us shopping wish. Heart failure.	5
Boy. Safari wish. Brain tumor.	17
Boy. Wish to go to a beach in Australia. Terminal illness.	18
Girl. Wish for Bahamas swim with dolphins. Cystic fibrosis.	18
Boy. Wish to go to a genuine cowboy ranch. Brain cancer.	7
Girl. Wish to see dolphins at Canada's Wonderland. Wilm's tumour.	4
Boy. Travel wish to the Caribbean. Cancer.	12
Boy. Travel wish to Hawaii. Osteogenic sarcoma.	17
Boy. Wish to visit video game design company. Cystic fibrosis.	14
Girl. Wish to meet local celebrity singer. Nager syndrome.	11
Boy. Wish to meet soccer player Ronaldo. Lymphoblastic leukemia.	8
Girl. Wish to meet local singer. Vater syndrome.	13
Boy. Wish to meet Spiderman. Acute lymphoblastic leukemia.	8

2.2. Culture

Culture has been defined in many ways and raises many passionate debates. It is, however, necessary to discuss it here because ethnography explicitly links fieldwork and culture (Van Maanen, 1988). In fact, ethnographers immerse themselves in a certain

socially bounded reality in order to explore its underlying mechanisms. It is that bounded reality that designates culture. I take culture to partly refer to "learned, socially acquired traditions and the lifestyle of the group of people, including patterned, repetitive ways of thinking, feeling, and acting (Arnould and Wallendorf, 1994:485). Not surprisingly, we expect people living and/or working together to share social-cultural elements. While acknowledging this, however, "culture" will mainly, throughout this dissertation, be considered loosely. It will not imply a "homogeneous population" (people who all behave and think alike). Neither will it be considered a tool that "preserves intact a given distribution of behavioural probabilities needed to keep the shape 'of the system' unchanged" (Bauman, 2005: 57). Rather, it will refer to aspects of shared commonalities. It will be considered permeable, as something moving and transforming, as a dynamic force that dictates behavioural and thinking patterns, but that is also shaped by them (Arnould and Wallendorf, 1994), as something potentially conflicting with the evolution of social order (Geertz, 1973), and as something that can be countered or subverted (Lasn, 2000).

This vision of culture, though, is still highly limiting in that it focuses primarily on human interactions. It does not account for the role that objects play. Studies in material culture have revealed the critical importance of objects and their capacity to affect human life. Douglas and Isherwood (1979), for instance, proposed that objects help define the world in which we live. They serve as social markers by helping us identify with, or oppose, certain social groups. Also, due to their socially-embedded meanings, objects help us to construct an intelligible, rational universe. Appadurai (1986) and Kopytoff (1986) argue that not all objects are mere commodities. Some of them carry

significant meanings over time and the possibility of their exchange is based on standard culturally-shared values, called regimes of value (Appadurai, 1986). They come to possess a "biography," a "social life" that can be recounted and transmitted to the next owner, whose relationship with the object will thereafter be affected by its history. Some objects are even "inalienable" (Weiner, 1992; Curasi, Price, and Arnould, 2004), that is, their biography is so strong that they become inseparable from their past. As Weiner states, inalienable possessions are "transcendent treasures to be guarded against all the exigencies that might force their loss" (33). Marcoux (2001) demonstrates that objects can also be socially constraining. They can become sources of negative feelings, for example when one tries to donate them but finds no potential recipients.

Consequently, a vision of culture that only considers human interactions creates an unbalanced representation of the relationship between human beings and the "nonhumans." Culture, in that sense, separates itself from "nature" (Latour, 1991). I suggest resolving that tension by proposing a conceptualization of culture that will also incorporate objects as "social actors." This approach borrows from Bruno Latour's summing up of the Actor-Network Theory (ANT). It is in his recent book, *Reassembling the Social*, that Bruno Latour precisely outlines his view. Latour depicts the actor as elusive, changing, unpredictable, and connected: the actor is "not the source of an action but the moving target of a vast array of entities swarming toward it" (p. 46). Observing the actor is consequently like watching a theatrical performance: you never know who will appear on stage next, what he will do, or how he will relate to the following or previous actors. ANT conceives the actor as inclusive. By its very definition, ANT's focus is on connections and associations, regardless of with whom or what they take

place; humans as well as objects can hence connect together and create a "social tie." By "social," Latour simply means a type of "momentary association which is characterized by the way it gathers together into new shapes" (p. 65). According to Latour, this vision of the social entity does not undergo any kind of reification. It can be found "nowhere in particular as a thing among other things but may circulate everywhere as a movement connecting non-social things" (p. 107). The concept of the social is at the heart of Latour's critique of the traditional field of sociology, which he posits focuses primarily on relationships between humans. Contrary to this approach, in his open-ended view of the social phenomenon, Latour defines the actor as "*any thing* that does modify a state of affairs by making a difference" (p. 71). Things can be either humans or objects, as long as they play an active role in an action. In that sense, he distinguishes *actors* from *actants*, in that the latter is a "dormant" actor, one without figuration *yet*. To be activated, the actant must make a difference in some other agent's action. Latour further emphasizes the unpredictable nature of the appearance of actors:

> *We don't know yet how all those actors are connected but we can state as the new default position before the study starts that all the actors we are going to deploy might be* associated *in such a way that they* make others do things. *This is done not by transporting a force that would remain the* same *throughout as some sort of faithful intermediary, but by generating* transformations *manifested by the many unexpected* events *triggered in the other mediators that* follow *them along the line.* (p. 107)

In order to study these actors and their deployment, Latour argues that we should study them in their *making*, not only after they are formed and appear to be crystallized in a specific way, routine, or context.

Generally speaking, I agree with this ontology of the actor and its epistemological counterpart. In fact, a wish, in the context of the CWF, is a fascinating subject for exploring an extensive manifestation of "social ties." Indeed, each time a wish is designed, processed, and fulfilled, a vast array of actors are likely to deploy, gather, and then split apart, only to perhaps later be redeployed if required or possible. In my exploration of actors, I therefore considered all kinds of actors without limiting my notion of actors to humans alone. I considered objects as part of my inquiry. I examined such objects as letters to donors and volunteers, advertising and donor campaign literature, CWF as well as other wish granting organizations' websites (mainly the Make a Wish Foundation, CWF's American counterpart and main competitor in Canada), newsletters, photographs, videos, thank-you notes from the CWF and from Make A Wish, press releases, books (associated with wishes and healing), and gifts, as well as the organization of space. Overall, I considered them at various levels to acknowledge their complexity in social interactions. They were treated as potential social actors (in the sense used by Latour), as they were able to play a significant role in the process of consummating wishes.

I also concur with Latour that a traditional approach consisting solely of interviewing people would not be sufficient to understand the network, as such a process would yield only a picture of the wish events as they appear in their "socially pre-constructed" form (in a traditional sociological sense). It would not allow us access to the

backstage construction process. As Latour argues, *local interactions* such as formal interviews, are made up of elements that were brought together by others or improvised on the spot without another person being able to witness their "social" (in a Latourian sense) gathering. The exploration of the wish granting process as it unfolds in many places and many points in time enables the witnessing of the deployment of actors to its fullest extent and fosters a broader account of the network *as it is constructed*. As Latour did in his exploration of the construction of science in his book *Science in Action*, I propose to shift "from final products to production, from 'cold' stable objects to 'warmer' unstable ones" (Latour, 1987:21). As such, I considered wishes first and foremost from the perspective of how they are constructed, and only secondly how they are reported.

2.3.   Reflexivity

Reflexivity plays a crucial role in the ethnographer's activity and transcends the mere doing of the fieldwork by reverberating through the writing. The significance of reflexivity lies with the fact that ethnography exists in the realm of interpretive research (Hudson and Ozanne 1988). This paradigm sees reality as being socially constructed, and hence only accessible through that construction. This rule does not pertain only to interpretive research, though. It applies to all kinds of scientific inquiry. The importance of reflexivity is a result of the fact that science and self are interrelated, if not co-created (Richardson, 1994). It is therefore important that ethnographers be conscious of the two main forces that drive the fieldwork: the data obtained, and the way it is obtained and analyzed. As Marcus and Fisher (1999: 26) put it, "interpretive anthropology operates on two levels simultaneously: it provides accounts of the worlds from the inside, and reflects about the epistemological groundings of such accounts." It is an "internal dialogue," an

"ongoing conversation" with one's self concerning the findings and its collection (Berg, 2001). Being reflexive does not mean only acknowledging the co-constructive nature of facts; it also means trying to be aware of the potential forces affecting that process. Reflexivity is a process by which ethnographers constantly try to be aware of "the cultural, political, social, linguistic, and ideological origins of one's own experience and voice as well as the perspective and voices of those one interviews" (Patton, 2002: 65). It also recognizes the prevalence of intersubjectivity in ethnographic research. That is, it acknowledges the fact that the fieldwork is the result of a dynamic combination of many subjectivities; it is the intersection of the researcher and the multitude of informants that gives the fieldwork its significance (Glesne 1999).

In an attempt to look at different views regarding reflexivity, Joy, Sherry, Troilo, and Deschenes (2007) identify three major perspectives in the social sciences: radical reflexivity, infra-reflexivity, and diffraction. *Radical reflexivity* is associated with Said (1979), Marcus and Fischer (1999), and Fabian (1983), to name a few. It forces researchers to acknowledge the limits of representation in research. The researcher is best viewed as a stranger in a strange land, whose stories will always remain partial in representing the other. However, it forces the researcher to be self-reflexive and to comment on his/her own biases during the fieldwork and writing. *Infra-reflexivity*, represented principally by the work of Bruno Latour, goes a step further by stating that the acknowledgment of the researcher's biases will not necessarily help him or her write better or more credible scientific texts.[23] It argues that dichotomies such as nature vs. culture and subject vs. object have to be overcome, and that the investigation should remain close to the observed phenomena. *Diffraction*, developed within feminist writing

(e.g. Haraway, 1991; Campbell, 2004) emphasizes the importance of power and unbalanced relationships during the investigation. It aims at revealing who wins and who loses in a certain situation, who possesses the resources and why, and who is prevented from access to these resources. It acknowledges that "the field is not neutral and the participants not equal."

On the whole, these three approaches of reflexivity informed my understanding of my role as a researcher, observer, and writer. I consider them to be largely complementary in the sense that they forced me to be conscious of the limits of my capacities to represent the phenomena, of my place within the research, and of the place of my informants and future audience. This reflexive spirit was the blueprint of this research and set its ethical standard. Considering the very specific nature of the population under study, it was crucial to undertake a reflexive approach that would constantly consider the role of the researcher in the fieldwork as well as the potential power relations that could create unbalanced relationships.

In order to maintain high standards of ethics and reflexivity regarding this delicate topic, I developed a procedure that I followed closely throughout my interactions with my informants. As stated before, ill children and their families represent a potentially vulnerable population. It was expected that some aspects of the interactions with the researcher would lead to strong emotions (i.e. when discussing illness). Interaction with vulnerable informants, furthermore, could have lead to unbalanced power relationships that would have benefited the researcher over the informants. For these reasons, I took measures to minimize potentially harmful situations and to redistribute the power between the researcher and his informants.

First, I was trained to maximize my interview and general social skills in dealing with seriously ill children and their families. In my training and personal evolution, I was supported throughout the fieldwork by a social worker, Elizabeth (who will be discussed later), who was employed in the oncology department of a children's hospital – now happily retired – and by Debbie, a resource teacher experienced in dealing with families in a wish granting context. Wendy, another of my key informants (who happens to be the wish coordinator of the CWF chapter I got involved with), also provided enormous critical insights about how to approach families respectfully. She offered me her support, shared with me her thoughts, and guided me throughout this research. Before becoming involved with families, I immersed myself into the environment at CWF, until I became familiar enough with its mission and values. I did my utmost to honour the families, their integrity, and their privacy. At the beginning of the interactions, I simply accompanied Wendy and volunteers such as Debbie, to various meetings with families as a non-participant observer, in order to take notes of the situation and analyze it through reflexive discussions with my guides following the meetings. Progressively, as I came to understand the lives of the families, and as my confidence increased, I took on a more interactive role. Also note that, following Masson's (2004) strong caution, I never sought to play the role of a therapist during my encounters with participants. I planned instead to recommend participants to consult experts, such as Elizabeth, and to provide a list of resources if needed, although this situation never occurred.

Throughout my interactions with the families, I always had the Foundation's mission at the forefront of my mind. I sought a balance between asking questions and participating in the wish experiences. Moreover, I came to realize that some situations

were more suitable for questioning than others. It was indeed important to be very careful in choosing the appropriate moment to ask questions, not only because of the sensitivity of the families' situations, but also, and most importantly, because some moments of the wish granting process are to be *experienced without thinking*. For instance, the time of wish fulfillment is meant to be filled with wonder and joy, and not with inquiries and reflection.

Participants were recruited on the basis of a convenience and snowball sampling as they came in contact with me during the fieldwork. There was no a priori criteria for selecting informants during this research. I respected the principle of *justice* (i.e. everyone's voice has the right to be heard) as well as the grounded-theory principle of *emergence* (i.e. to include any significant actor in the process without a priori framework). I developed supportive, subject-centered, collaborative research that informed and empowered ill children and families by including – and strongly considering – their voices throughout the research process. The *United Nation Convention on the Rights of Children* (General Assembly, 1989) recommends that children should be informed, involved, and consulted about all activities that affect their lives. So I made sure that, whenever possible, the children I interacted with were aware of the situation and of my role.

Participation was always on a volunteer basis: official written consent was requested prior to conducting any formal investigation, and withdrawal from the research was allowed at any time without negative consequences. Explicit parental or legal guardian consent (through the signing of a consent form) was also requested prior to formally approaching (for instance through formal interviews) any participant under 14 years old. As often as situations allowed, I had someone from the Foundation talk about me to the

families before each first encounter. I wanted to be sure that the families felt comfortable speaking to a researcher. I also made a lay abstract of my research available to each family. The families with whom I interacted (during observation sessions or interviews) all seemed genuinely happy to talk with me, and to share aspects of their lives. Formal interviews were tape-recorded following participants' approval. Formal interviews were conducted in a comfortable environment previously approved by the participants. Whenever possible, they were tape-recorded, with informants' approval. It seemed to me to be easier to interview the families all together, so children were not interviewed alone.

I also came to realize the importance of the ending of interactions when dealing with some families. In fact, although my fear was at first that families would feel intimidated by my research status, and feel forced to comply with the research, I realized that the real issue pertained to how I should end a relation, after developing lasting and intimate access to a family's life. Children tended to consider me an "older brother." Therefore, my research status had to be clarified, and a conversation with parents and the children was organized to acknowledge the transient nature of our encounters. This is not to say that I completely stopped seeing all families after the research. I was fortunate enough to keep active relationships with some of them, and I hope these relations will last...

In order to avoid any potential conflict between the Foundation and the informants, and/or any exploitation of informants by the Foundation, as little information as possible regarding my informants' identities was communicated to the Foundation, except when families were openly willing to share their views (like Sonya's family, who kindly allowed pictures of their Disney trip to be included in this dissertation). In order to ensure

confidentiality, the names of the participants, as well as any other information that could potentially lead to the disclosure of their identities, has been altered. For information concerning ethics, see the Summary Protocol Form (Appendix 3) submitted to the University Human Research Ethics Committee (UHREC) in February 2006. Please note, however, that due to its exploratory nature and its specific focus, this dissertation covers only some aspects of what is presented in the SPF.

2.4. Writing

Reflexivity is an ongoing process that has to be performed throughout the fieldwork. However, reflexivity is not a procedure that can be executed solely at the level of thought. It also must be evident in the writing. In fact, an important place to observe reflexivity is in the written records. They are the primary output of the ethnographer (Glesne, 1999). I used two types of record: the field diaries and the field notes. Briefly, the field notes are the descriptions of observed phenomena. I aimed to create accurate descriptions and to avoid personal interpretations. I jotted down the information from the fieldwork as it happened. The field diaries, on the other hand, contain analysis, personal impressions, and judgments. They represent the privileged moment during which the observer tries to build connections between phenomena, raise questions stemming from emerging concepts and problems, and so forth. Most importantly, all the entries in both records were scrutinized to assess the evolution of the fieldwork as witnessed, and also to reflect on my evolution during the fieldwork (to perform the reflexive work). Hence, in addition to observation, interviews, and artefacts, I also relied on personal feelings and introspection (Gould 1991, 1995; Wallendorf and Brucks, 1993), note taking, and

reflexivity. I took note of any potential discrepancies between discourse and practice (what is said versus what is done), power relations, and normalization protocols.

The writing of the ethnography is the final step; it makes public the results of the ethnographer's work. As Van Maanen (1988: 1) puts it, an ethnographic study is a "written representation of a culture (or selected aspects of the culture)." I will in this dissertation describe the world of the Children's Wish Foundation in its complexity.

Since the actual writing of the ethnography is accomplished after the fieldwork is finished, all descriptions and analyses of the phenomena denote an actualization of the past (Fabian, 1983), or of *a* past (the past that the ethnographer has chosen to (re)present or reveal). Reflexivity remains an important issue during the writing. The writing process demands choices: Which elements should be included and which should be ignored? What type of narrative should be used? Which metaphors will best convey the essence of the fieldwork and of the analysis? To what extent should reflexivity be present in the text? In this chapter, I tried to develop a *confessional tale* (Van Mannen, 1988). *Confessional tales* focus more on the process and the ethnographer than on the culture. In the next chapters, I tend to adopt more of a *realist approach* (Van Mannen, 1988), to stay centered essentially on the phenomena and the processes in order to account for the complexity of the situation. My focus on the process and on the actors follows Latour (2005), who proposes that a good account is one that traces a network. In his opinion, a good account is "a narrative or a description or a proposition where all the actors do something and don't just sit there" (p. 128). My realist approach follows this spirit.

I do not pretend, however, that this narrative structure, which really only represents a personal choice, will create a more "objective account" of the situation. I do not equate realism with objectivity. As mentioned before, the descriptions, after all, come from the perspective of my own worldview and understanding of the phenomena. This is not to say, however, that I relied solely on my own judgement. In my analysis of the processes and the development of my thoughts, I regularly "tested" my ideas, sought feedback from informants, and shared my reflections with academic peers (Lincoln and Guba, 1985). My approach, moreover, allowed the development of a rapport with various informants, which lead to the development of a high level of mutual trust. I hope this dissertation will be a tribute to those who participated in this research.

3. Organization of the findings and analysis

Analyzing each process is quite challenging, and putting them into words is even more so. Each step is linked to the next, but not necessarily in a linear fashion. An action that happens at a certain point in time can affect something that will happen next or much later in the process. An actor who plays a small role early in the process can become more important as it evolves. Consequently, my account of the various situations tends to reflect this complexity. For that reason, I ask the reader to forgive what will, from time to time, seem a very non-linear development. An actor might at some point be very briefly introduced for the purpose of an argument and then be introduced in greater detail later. On such occasions, clear references will be given to the original description and context, that the reader may consult as needed.

The way I conceptualized and analyzed the wish process follows Gronroos's (2004, 2007) relationship framework. His framework pertains to the relationship between a producer and a consumer and holds that the exchange or transfer of "product" from the producer to the consumer is part of a global relationship between the two entities. This approach conceptualizes a relationship as being composed of various interactions over time. It has various components that, when added up, create the story of the relationship[24] (Holmlund, 1996). Indeed, each relationship will contain acts, episodes, and sequences. The relationship between the components is expressed in the following figure.

Figure 2.1: Gronroos's relationship framework[25]
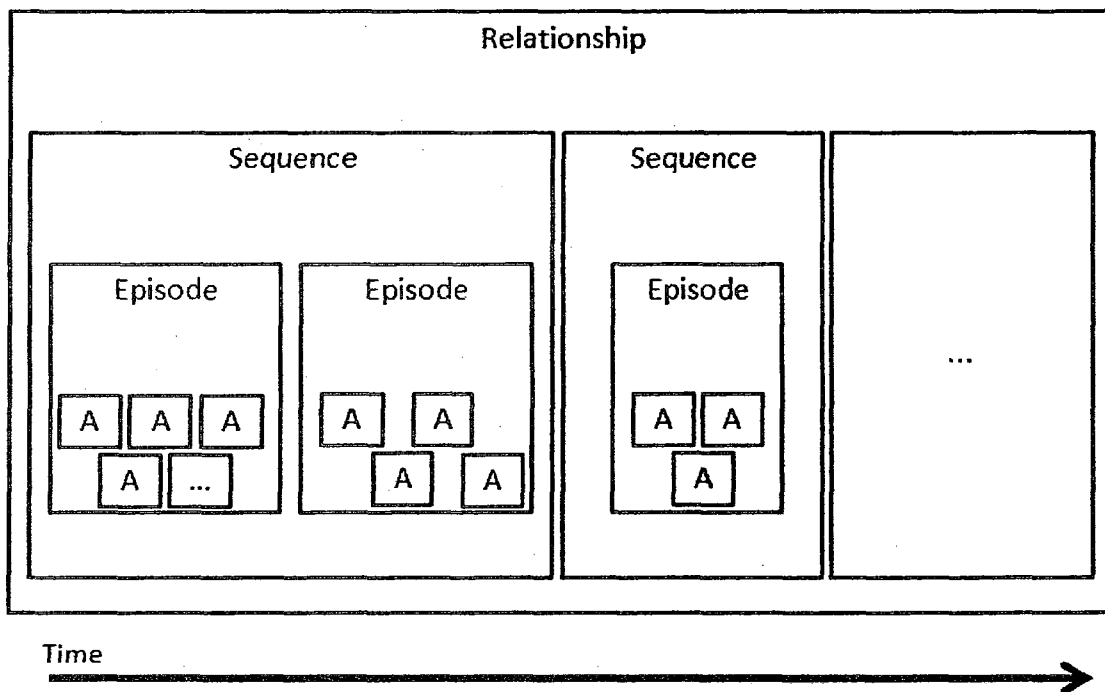
An *act* is the smallest unit of analysis and consists of a single action in a specific encounter between two actors (e.g. a phone call, confirmation of a hotel reservation, an email, etc.). An *episode* consists of a specific encounter, such as a negotiation, a shipment

of goods, or a dinner during a stay at a hotel, which is made up of a series of acts. For instance, a shipment episode could include acts such as placing an order by phone, assembling and packaging, making a complaint, and sending and paying an invoice. A *sequence* comprises interrelated episodes. It is normally defined in terms of a specific time or otherwise defined period, like a fiscal year, a campaign, or a project. Finally, a *relationship* is the most aggregate level and represents the accumulation of several sequences involving specific entities. In other words, it is the accumulation of sequences composed of various episodes, which are themselves composed of a multiplicity of acts.

My concept of relationships is based on a loose interpretation of this model. For instance, I do not consider a relationship to be restricted to two partners, as Gronroos implies. I would not limit it to the associations between the charity and its beneficiaries (as a company offering a product or service to a customer would do). Rather, like Latour, I include any other actor that plays a significant role. Gronroos's framework is nevertheless helpful to understand the overall wish phenomenon from a process angle, and it lends structure to the analysis of actions.

My view of the relationships described here takes the wish as the point of departure of any individual interaction between two actors. A relationship can in fact be described here as the story of the development of a wish. This is illustrated in the following figure.

In order to build the story line of the following sections of my dissertation, I have organized the main findings and analyses into three chapters, each of which represents one of the three sequences of the wish granting process: Chapter 3 will focus on the

processes leading up to the wish granting (i.e. how the wish is constructed from the first contact between the CWF and the family to its approval and final planning); Chapter 4 will look at the materialization of the wish and will closely follow the fulfillment of one particular Disney wish with additional examples described in Appendix 2; Chapter 5 will will delve into the "afterlife" of the wish – how the life after the wish is contemplated, and what happens after its fulfillment. To do this, I chose a rather specific angle and have proposed to explore the notion of hope as it relates to the wish, as well as its link with the perceived potential outcomes of the wish.

Figure 2.2: The wish story

Wish story		
Wish-granting process sequence (Chapter 3)	Wish-fulfillment sequence (Chapter 4)	After-life sequence (Chapter 5)

Time ——————————————————————➤
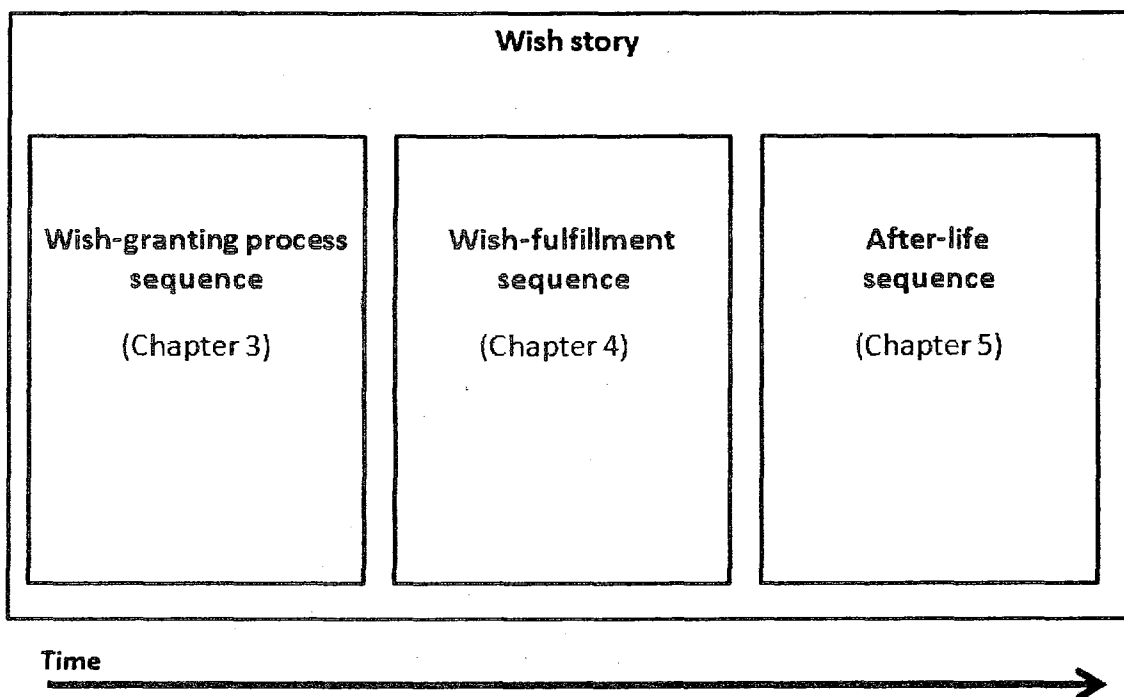
Each sequence of the relationship is defined by a series of episodes, which in turn are comprised of numerous acts. For instance, as we will see in Chapter 3, the wish granting sequence will include episodes, such as the verification of the eligibility of the child. This episode will be composed of various acts: the child's medical background submitted to a

CWF representative, preliminary verification of the child's background, discussions between the CWF representative and the physician or between two physicians to assess the severity and eligibility of the illness, and so on. Data was analyzed following Arnould and Price's (1993) recommendations. Participant and non-participant observation, informal and formal interviews, and consultation of documents and visuals formed the basis of a systematic analysis of behaviours and discourse at an *emic* level in order to gain an experiential understanding of the actors and the process. "Disjunctures" (gaps between discourse and practice, and discrepancies observed through various data collection methods and between informants) were examined to develop an *etic* understanding of the wish granting phenomenon. Gronroos' (2004, 2007) relationship framework was also used to organize, categorize, and analyze the flow of information in order to account for the process-based nature of the phenomenon. Each actor's action, verbal report, or other communication was coded whenever such acts were deemed a relevant part of episodes belonging to specific sequences. NVivo 8 was used to create the codes and manage the large amount of information generated during the fieldwork.

When reading Chapter 3, the reader will notice that for obvious reasons of conciseness, I chose not to base my account on acts, but rather on episodes, while providing a synthesized account of their constituent acts. In Chapter 4, I will also dissect episodes, this time based on wish destinations (e.g. going to Disney), or time (e.g. the first day, the last day), simply for purposes of flow. Chapter 5 will analyze the process from a different perspective and look at how hope is related to the wish, the illness and to potential outcomes. Finally, the conclusions will take a broader perspective and reflect on the whole process, that is the relationship between the sequences.

Now that I have defined the methodological and analytical framework of this research, it is time to delve into the reality of wish granting by first taking a look at the process involved in constructing wishes. The reader is also invited to read the Appendix 1 to learn more about the context of the CWF.

Chapter 3

Wishes in progress:

An Actor-Network Description of the Construction of Wishes

"It all begins with a simple wish. Once a child is referred to us and the case has been medically approved, the child is asked to make the most important decision. In the realm of possibilities, what would bring them the greatest happiness?

For many children, making that decision and answering that question can be the most exciting part of the process. They can choose literally any wish imaginable as long as it won't jeopardize their health or safety.

Whatever the wish, Children's Wish is committed to using its talents, time and energy to ensure each and every wish child realizes their dream." (Annual Report 2007-2008, p. 4)

Choosing a wish is an exciting adventure, and mobilizing people and resources to help make that wish come true is truly fascinating. But how exactly does this process work? The Children's Wish Foundation ensures us that it is "committed to using its talents, time and energy to ensure each and every wish child realizes their dream." What kind of dream? Children's creativity is solicited in order to discover, within "the realm of possibilities, what would bring them the greatest happiness." What is this realm of possibilities? The CWF tells us that the children can choose "literally any wish imaginable as long as it won't jeopardize their health or safety." The previous excerpt

from the CWF's annual report, though quite vague in regards to children's wishes, is greatly inspiring and most intriguing. In the following chapter, I will pay close attention to this first sequence of the relationship between the CWF and families: What are the major steps and mechanisms involved? Who are the main actors solicited throughout the process? What needs to be done behind the scenes in order to make the wish come true? I will then reflect on the complexity of the process and show that the conceptualization of the relationship between consumers and society will need to be changed when considering the process-based and global nature of motivation phenomena.

1. The process in a nutshell...

After almost three years of constant and not-so-constant fieldwork, this is my final attempt to provide an overview of my observations concerning the wish-granting process at the Children's Wish Foundation. Before starting, it's worth mentioning just how complex this task has proven to be. I have gone through a lengthy and multiple-perspective process in my attempt to arrive at a comprehensive understanding of this phenomenon. Yet even today, I cannot purport that my reading is exhaustive, for each wish is unique, and has a life of its own. Hence, I do not intend to claim that I have been successful in addressing reality fully, in a monolithic perspective. I would say, rather, that I have only partially grasped the multiple facets comprising the many realities surrounding the world of the wish. My greatest wish is to be respectful to this complexity and to invite readers to delve with me into this fascinating realm.

After a careful reading of my notes, discussions with my informants, and reflection on my fieldwork experience, I came up with a visual depiction of the process, a

depiction that I later discussed with one of my informants, Wendy, who I will introduce shortly. This representation serves as the basic blueprint for wish granting at the CWF (see Figure 3.1) and I will explore it in detail in the following pages.

This process is not the depiction of *one particular wish*. Instead, it is the result of an accumulation of evidence derived from a variety of wish stories, my objective being to highlight the overarching commonality of the granting practices. I chose to present the process chronologically, from the diagnosis of the illness to the after-life of the wish. Even though this time-ordered model may sometimes impose a certain simplification or bending of reality, it offers a birds-eye view of the evolution of most wishes and an appreciation of the joint efforts required of the actors involved at the different stages of the process. Moreover, it allows for a telling of the tales the way they are told at the CWF, where each wish has its own story. In addition, this order is reflected in the relationship between the CWF and most of the wish families: a family approaches the Foundation and then eventually fades away...Each dream, each story, has a beginning and an end.

Figure 3.1: Wish-granting process

Figure 3.1: Wish-granting process
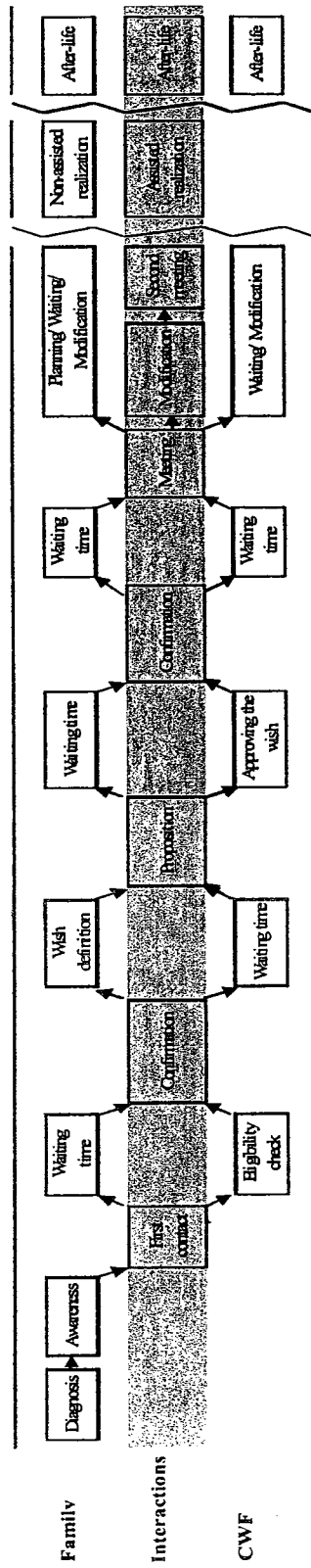
In order to take into account the role of the actors, I divided the process into three parts. The first and third (above and below the grey area) represent, respectively, the perspective of the family and that of the CWF. The grey zone in the middle represents the direct interactions between the CWF and the families. In a nutshell, the process can be described as follows: First, the child is diagnosed with the illness. After a certain time, the family becomes aware of the existence of the CWF and initiates a first contact (interaction). After contacting the Foundation, the family waits while the CWF performs the eligibility check. Once the eligibility of the child is approved, the CWF contacts the family (interaction) to tell them the news. After this call, the family must define the content of the wish in detail. During this time, the CWF is in waiting mode. After a while, the family contacts the CWF again to communicate their proposal for a wish. The CWF then analyzes the proposal so that, during the confirmation call (interaction), they can either approve it, or ask for modifications if necessary. Then, after a certain waiting period, the two parties meet to discuss the final elements of the wish. After this meeting, the only thing left to do in some cases is to wait until the wish is realized, while in others it is necessary to meet again to modify the wish before it can come true. Depending on the nature of the wish, it can either be realized privately within the family or it can be realized with the assistance of the CWF. After realization of the child's dream, some families fade into oblivion and are never seen again by the organization, while others maintain strong ties to the organization and participate in various events.

This chapter will cover every step of the process, from the diagnosis to the meetings. This segment of the process lays the groundwork for the realization of the wish and

involves many fragmented activities, each of which will be summarized here. Following the description of the process, I will present a series of observations.

2. The wish-granting process

2.1. Diagnosis

Before first contact is ever made with the CWF, the family goes through a series of events, the first being the diagnosis of the illness. Elisabeth, a retired social worker who worked for more than 20 years in the oncology department of a children's hospital, summarizes[26] the experiences of the families she accompanied during those years:

> *What often happens is that the family comes to the hospital because a kid has the flu and fever. Then comes the diagnosis: the effect is like a bomb. The fathers often keep everything inside. The mothers cry. Denial. Frustration. Blame. The family is under shock. The family is shocked by the fragility of life. The family is confronted by this reality. It is not the time to talk about the CWF.*

> *We live in a society in which we don't talk about death. It is a taboo. The doctor talks about the survival rate (1%, 5%, 10%). Unfortunately, the family focuses on the 1%. They don't consider the opportunity to prepare themselves to face death. It's hard even for the youngest kids. They see their parents' fear. Older kids also have a difficult time. They are just starting to "enter into life." They see their dreams collapsing.*

> *The diagnosis is given in front of the parents and children. The parents don't have time to adapt to the illness. The treatments start right away. The child receives*

shots and is afraid. The family is thrown into a major upheaval. One parent may

quit his/her job. Siblings are pushed to the side. One parent is at home, the other

at the hospital. There is no more time for the couple.

After a while, the situation improves. Then comes remission. But parents live with

the "immediacy of death." Fear and hope. Nothing in between.

Then comes the relapse. The parents lose faith in medicine. The hospital offers a

new chemotherapy or an experimental treatment. Sometimes it works, most often

it doesn't.

Children suffer a lot. Nausea, ulcers, major constipation. The parents feel

powerless. (Field notes, May 27, 2006)

As emphasized by Elisabeth, this period is deeply troubling for the families. The illness

appears as a sudden, unexpected threat. It provokes a major crisis in the household,

causing extreme emotions and placing a critical strain on family dynamics.[27] During this

early stage, the Children's Wish Foundation is not, for the families, an important element.

Indeed, it can take weeks, months, or even years before it becomes something the

families actually consider, and before the CWF enters their life. Fortunately, the scenario

described by Elisabeth does not always end tragically; while many families will indeed

suffer a long and excruciating fight against the illness (sometimes ending with the death

of the child), others will experience *somewhat* happier endings.[28]

The CWF deals with numerous families facing a variety of illnesses, and so illness

is a daily topic of conversation within the walls of the Foundation. To give the reader an

idea of the kinds of diseases that affect the children, the following table shows the 10

most frequently reported illnesses per year since 2004. As this table shows, leukemia, cystic fibrosis, and brain tumours are the three most frequent illnesses among the children who benefit from the CWF's services.

Table 3.1: Most frequently reported childhood diseases since 2004[29]

Illness	2004-2005	2005-2006	2006-2007	2007-2008
Acute lymphoblastic leukemia	145	155	145	145
Cystic fibrosis	76	70	75	65
Brain tumour	65	80	60	62
Congenital heart disease	44	55	40	12
Renal failure	41	55	40	40
Hodgkin's lymphoma	39	50	55	10
Ewing's sarcoma	27	30	20	-
Acute myelocytic leukemia	25	-	28	25
Neuroblastoma	25	20	20	20
Wilm's tumour	22			

Duchesne's muscular dystrophy	-	35	-	30
Rhabdomyosacroma	-	20	-	-
Osteogenic sarcoma	-	-	28	-

2.2. Awareness and first contact

There are many different paths leading families of sick children to the CWF. Some families simply never hear about the Foundation, or they hear about it too late (i.e. when the child is too old or after s/he passes away). This unfortunate situation is commonly discussed by employees at the CWF, which consistently claims that, while approximately 4,000 children are diagnosed with a life-threatening disease every year in Canada, only 1,000 will eventually receive a wish.[30]

For the "more fortunate" ones, first contact is generally made via a phone call to Wendy. Wendy is a *wish coordinator* at the CWF. She is a central figure at the Foundation. Her work consists of coordinating the granting of all wishes falling under her provincial jurisdiction. In addition, as we will see throughout this chapter, she is involved in most steps of the wish-granting process.

During an audio-taped discussion we had together, she commented on a typical first interaction between the Foundation and the families:

When we get a call about a child, most often he or she has been referred by someone from the hospital, be it a nurse, doctor, social worker... sometimes it can be other children or families who've either received a wish or are about to have theirs granted. They say, "Call them! Call them so he can get his dream too!" So that's when they usually call us. As I said before, they tend to be a little timid at first, not too sure how or if we can help. For one thing, they worry that they're taking advantage of the Foundation by asking, and secondly – and I find this particularly troubling – they start asking themselves whether their child is in the terminal phase. "My child isn't terminally ill, is he? Did the [doctor] forget to tell me something? Is my child terminally ill and someone neglected to tell me?"

(Wendy, interview transcript, July 2008)

I heard this story – told by Wendy and other people – many times throughout my stay at the Foundation. Wendy's observations highlight the fact that before contacting the CWF, families first hear about the CWF in one way or another, and that this mere awareness is sometimes enough to trigger immediate and sudden distress regarding the condition of the sick child. Indeed, in many cases, the first reaction of the parents when discovering that their child could qualify for a wish is to think that he or she has reached the terminal phase and that the medical staff are now implicitly proposing to realize a *final wish*. This common misconception regarding the CWF is prevalent among the general population and seems to originate from a lack of information. Actually, the CWF does not focus solely on terminally ill children, but considers any child living with a life-threatening illness (see section 2.3). Due to this confusion, the medical experts – and even Wendy –

often feel the need to comfort the families and reaffirm the non-terminal – albeit threatening – condition of the child when they mention the possibility of granting a wish.

Wendy also points out that word of mouth and social networking are very important elements in explaining how the families come to know of the existence of the CWF. In fact, families spend a significant amount of time at the hospital during the treatment phase. It becomes the gravitational centre that dictates the rhythm of their lives over a certain period of time.[31] In some instances, the sick child spends weeks without leaving the health care facility. In other cases, the family makes frequent visits to the doctor, receives treatments, runs tests, etc. As a result, the sick child inevitably spends time with other sick children while the adults get acquainted with other parents facing the same situation. In this context, the hospital becomes an important *place of socialization*. Most families I met spontaneously mentioned other children or parents who they met in the hospital context. Parents sometimes also refer to "hospital friends" to distinguish children met at the hospital from friends who are not related to the illness. In this context, wish stories are frequently shared among the children. Often, it doesn't take long for a newly admitted family to hear about wishes granted by the CWF. Some families even told me that the first encounter they had with other families was through the telling of a wish: wishes are told, photos are shown, and corporate promotional materials (brochures, websites, DVDs, etc.) are passed around. As a result, a wish can become "contagious" and can spread easily throughout a medical department. As such, it is not surprising, for instance, to hear Wendy mention that French Polynesia became "trendy" among families after one child (Simon, who we will meet later) went there a few years ago. Also, the *Disney Vacation Planning DVD* is one of the more popular promotional materials to get

passed around in hospitals. I met several families who mentioned being exposed to the Disney wish through this medium (one of them, Bobby, will be introduced later in this chapter and is also presented in Appendix 2).[32]

Wendy also calls attention to the role played by doctors, nurses, social workers, psychiatrists, and psychologists. These practitioners represent a second significant source of awareness of the CWF. Medical experts familiar with the CWF become privileged informants and representatives by spreading the word to the families. For this reason, the Foundation keeps in contact with them by means of "courtesy calls," information sessions, and partnerships (sometimes even donations) across the different departments of hospitals, with the aim of maintaining and enhancing long-term relationships in order to ensure constant referrals from medical professionals.

Thanks to these two main socialization agents, some families become aware of the CWF very rapidly, while others can take years to realize (or be told) that their child is eligible to receive a wish. For instance, the medical staff in the cystic fibrosis department often wait until the children reach nine or ten years of age, or even older, before introducing the CWF to their families. They argue that, since the child's life expectancy is longer than before (and longer than for other diseases), it is better for the child to wait until he or she is a little older in order to fully appreciate his or her wish.[33]

In any event, families interested in or curious about the CWF will eventually initiate first contact, either by calling Wendy directly or by sending an information request to the national office (by email, for example), which redirects the message to the wish coordinator. At that point, Wendy opens a file under the name of the child and takes

note of basic information, such as the age of the child and a precise description of the medical condition. During this call, she also enquires about the wish. According to her, approximately 90% of all the children already know what kind of wish they want to realize before contacting the CWF. This information will be used to verify the eligibility of the child (see next section).

In cases where the families have no prior idea of what the wish will be, Wendy suggests that they undertake an exercise in creative thinking, or, as Wendy tells them: *"Now it's time to dream!"* She will recommend that they browse the Internet, look for travel destinations, or other ideas. She will recommend, if they are interested in a trip, that they get travel brochures and meet travel agents for more suggestions. She will ask the parents to talk to their child in order to help him or her express his or her deepest wishes. The conversation will then end, and the family will be invited to contact the CWF later, when a final decision has been reached.

Finally, it is worth mentioning that not all families are interested in the CWF. According to Wendy, wealthy families and public personalities are less likely to request a wish from the CWF. She claims that the main reason for this is their autonomy and financial ability to afford the wish. Public personalities are apparently also reluctant to approach the Foundation for fear of abusing and damaging their public image.[34]

2.3. Eligibility check

After contacting the CWF, there is a period of uncertainty, as the family doesn't know yet whether or not the child will qualify for a wish. While the family waits, the CWF starts

evaluating the eligibility of the child. Three criteria serve as a guideline for defining eligibility:[35] age, citizenship, and illness.

First, the child must be at least three years old to realize his or her wish. According to the CWF, the purpose of this rule is to make sure the child can express the wish by him or herself. Also, the child must be under 18 years of age at the time the request is received by the CWF. However, the wish can be granted after reaching adulthood, if not possible otherwise. Second, the child must be a Canadian citizen or legal permanent resident of the country (i.e., authorized to live and/or work in Canada without any time limit on his or her stay). Third, he or she must be diagnosed with an illness which is categorized as a "high-risk, life-threatening condition" by the CWF.

While the first two criteria are straightforward and easy to verify, the third one creates uncertainty, and may in some cases require in-depth investigation and external expertise. In order to facilitate the analysis of medical eligibility, the CWF, in collaboration with medical doctors, created a list dividing illnesses into two main groups: A and B. The *A-List* consists of "those diagnoses having such a poor prognosis that the mere assurance of the diagnosis would meet the Foundation's intent."[36] For example, the following illnesses are considered a part of this category: the main forms of leukemia, AIDS, renal or cardiac failure, and all organ transplants excluding eyes. Each of these illnesses automatically meets the CWF's conditions. The A-List contains around 40 illnesses or categories of illnesses. The *B-List*, on the other hand, consists of "those diagnoses which need to be considered on a case-by-case basis to ascertain whether the condition meets the Foundation's criteria."[37] They include non-Hodgkin's lymphoma, congenital heart diseases, and Friedreich's ataxia. This list also contains around 40

illnesses or categories of illnesses. Under this list, some illnesses automatically require a justification letter from the child's physician in order to be considered for eligibility. Some illnesses that would require such a letter are: juvenile rheumatoid arthritis, lupus erythematosus, muscular dystrophy, severe Crohn's disease, and spinal muscular atrophy. Illnesses not on the official list are also evaluated on an individual basis. Serious illnesses considered non-life threatening, such as mental handicaps, do not qualify unless they are combined with another condition that is deemed life-threatening. Overall, the extent to which a child will automatically qualify to be granted a wish varies depending on the type and severity of the illness. The CWF Medical Advisory Committee (MAC)[38] is responsible for examining cases and making decisions regarding the eligibility of each *non-automatic* case. In addition, the lists evolve over time, depending, for instance, on medical progress (some illnesses were considered high-risk in the past but are not anymore). Consequently, the CWF from time to time revises the Medical Criteria List based on the advice of the MAC. For instance, since May 2008, all forms of cancers are now part of the *A-List* (intestinal cancer, which was previously included on the B-List, is now considered on the same level as leukemia).[39]

One of Wendy's tasks is to pre-screen the families based on the medical criteria. Here is how she explains this aspect of her work:

> *Pretty often, I would say, I'll open a file on a child because I sense that the parent*
>
> *has no clue about his or her child's condition. It's astounding to see that some*
>
> *parents do not understand their child's medical condition at all. So what I do is I*
>
> *open a file and I ask them to ask their doctor to send me something in writing that*
>
> *describes the illness. When I receive the letter, I forward it to the Foundation's*

medical team, who will evaluate it, decide if it's a yes or no. Even if the child's

illness isn't on our list, it's rare that I say no right off the bat. Usually, I'll ask

parents, "Do you consider your child to have a high-risk illness? Is it life-

threatening?" Usually they know the answer to this and they'll say no. (Interview

with Wendy, July 2008)

The previous quote shows that the child's medical situation is sometimes unclear to the

parents when they contact the CWF, and that they cannot always assess the gravity of

their child's disease. In order to deal with such situations, Wendy asks the family to have

the doctor forward the medical information to her. Interestingly, she also mentions that

she seldom automatically says no to a family, unless the parents can clearly tell her that

their child is not at risk.

Once the child's eligibility is assessed, the wish must be approved by the doctor. At

this point, the wish might still be vague, but a general description is sent to the doctor for

approval. In many cases, when the wish is simple and does not involve any sort of

physical challenge (e.g. the acquisition of a computer), acceptance is almost automatic. In

other cases, such as travel wishes, for example, the child's condition is assessed more

thoroughly in order to determine whether he or she is sufficiently physically fit for the

wish (for example, when taking a plane, the change in cabin pressure could be harmful,

depending on the child's condition), whether he or she requires medical assistance (like a

nurse) or equipment (breathing machine, etc.), whether he or she can be away from

hospital for an extended period of time (up to seven days), etc. For example, one child

wanted to spend time alone with her family at a resort away from her hometown (and

from the hospital), but was forced by her doctor to stay in the city because she needed

daily treatment at the hospital.[40] In other cases, wishes for certain objects may also require extensive analysis and eventually be refused by physicians. For instance, 12-year-old Emily's wish[41] for a spa was declined because her doctor claimed that high temperatures could be hazardous to the health of a child with cystic fibrosis. She then refocused the wish on a regular swimming pool.

2.4.   Confirmation

When the final verdict is made available, Wendy communicates with the family to relay the decision. This stage is very emotional. The news often triggers cries of joy. The following brief excerpt from my observation notes reveals the feelings of one mother after hearing the good news and emphasizes that families often mention that the confirmation of the child's eligibility is the first "good news" they have received in a while.

> *When the doctor told the mother that the CWF could grant (daughter's name's) wish, she didn't believe it at first. The mother said that being a winner (i.e. winning prizes) is something that usually happens to others.* (Field notes, April 25, 2006)

During this call, Wendy also assigns the family what she calls the *wish mission*. The wish mission is when the family has to define the composition of the wish in precise detail. Wendy requires them to come up with a detailed list of all the elements the child would like to be included in his or her wish. She often tells the children, *"The wish does not belong to me. It belongs to you. All I can do is guide you, but I won't tell you what your dream will be and how it will be granted. You will tell me how it will happen."*[42] She also

recommends that they cram as much as they can think of onto their wish list. She says, *"Make your list as big as possible. However, there is a possibility that you will have to negotiate and decide what you want to keep in it."*[43] The list will vary based on the type of wish. For instance, a travel wish list could include the exact location of the wish, the activities the trip will entail, the persons who will travel with the child, and the precise moment of the trip and of each activity. A process of incubation and negotiation is frequently needed when defining the wish list.

At this stage, the timeline of the wish is an important part of the discussion, because some children will not be able to realize their wish before a certain period. For example, children with cancer frequently start a chemotherapy protocol immediately after the diagnosis of the illness. This treatment phase can last up to two years, depending on the specificity of the treatment. For these kids, realizing a wish can be premature at this point, due to the difficulties imposed by their treatment. Thus, in most cases, the families wait until the end, or close to the end, of treatment to realize the wish. The main reason given by families, doctors, and Wendy for postponing wish fulfillment is for the child to have a chance to appreciate the wish even more. In addition to the treatment period, the family must take into consideration other time constraints such as school and work schedules. Also, in the case of international travel wishes, the dates can also be chosen to avoid bad weather periods such as the monsoon season.

2.5. Wish definition

2.5.1. Maria's reflection

After the confirmation call, the child and his or her family will take time together to deliberate in order to develop a wish. The following excerpt from my field notes presents the case of Maria, whom I met with Wendy at the children's hospital during her weekly medical visit. This description comes right after she told us her wish was to swim with dolphins in Cuba:

> *Wendy told her: "It's your dream. You have to dream." Wendy brought some travel brochures to help the family choose a destination. She brought magazines from Air Transat. She also encouraged the family to find other travel magazines (offered at no cost in travel agencies).*
>
> *The mother and the aunt don't seem to appreciate the choice of Cuba. They think it is too constraining to impose a country at the very beginning, without looking at other possibilities. Wendy agrees with that. Twice during the meeting, the mother, Wendy, and the aunt tried to convince her to look at other destinations.*
>
> *For the girl, however, it seems comforting to go to a place that has been experienced by someone she knows. She doesn't seem comfortable with the unknown and unfamiliar. At any rate, they all agree that the girl should open her mind to other possibilities.*
>
> *Maria started to look at the brochures and to discover various possibilities in terms of resorts and potential activities. At the very beginning, the only thing that*

mattered to her was to swim with dolphins. However, she gradually came to

realize that there were other activities that could be very interesting for her.

An important aspect in her mind was that her little brother had to enjoy the trip.

According to her mother: "Maria is a person who always puts others first." She

also says that Maria has a very humanistic side.

At the beginning, the child was extremely focused. She only wanted to swim with

the dolphins. She even said that swimming with the dolphins was the only thing

she had not accomplished in her life so far. Her mother seemed annoyed by this

statement. In order to strengthen her argument, the girl said that her father had

helped her fulfil all of her dreams so far and that there was nothing more to

dream about (except for swimming with the dolphins).

However, as she flipped through the magazines, she progressively came to refine

her dream. She discovered various destinations and saw many different hotels,

types of scenery, and activities. At the end of the meeting, she formed the

following set of criteria for her wish: 1) going to a small place (small hotel, not a

big resort); 2) swimming with the dolphins; 3) going to a place where there's a

water park; 4) going to a place where there are toys and games for her brother,

and 5) going to a place where she can sail (catamaran).

Also, in the end, she said that it could be in another country than Cuba (because

she realized that there are a lot of potentially interesting destinations in other

countries). (Field notes, April 25, 2006)

Maria is 13 years old and was diagnosed with leukemia in December, 2005. She wanted to swim with dolphins in Cuba because her aunt Janice had already gone there to do that years ago. Her case stresses the importance of negotiation and shows the role played by the actors who are closely involved in helping define the wish. Maria's mother and aunt – with the support of Wendy – disapproved of her hasty decision and wanted her to take more time to deliberate. On the other hand, the girl seemed pretty comfortable with the idea of following in her aunt's footsteps. Although the girl's project was decided before meeting Wendy, she eventually started rethinking the idea. During their conversation, Wendy presented the girl with some promotional material. Then, while browsing through the material, Maria gradually began to have second thoughts and started refining her idea for the wish. Indeed, she went from a simple idea (going to Cuba to swim with dolphins) to progressively developing more sophisticated criteria that in the end led her to include five specific decisional conditions.

The influence of others in the defining of the wish varies from one family to the other. For instance, Bobby,[44] a 9-year-old boy with a severe physical handicap and mental development retardation, wanted to go to Disney World in Florida. When I asked why the family chose this destination, the mother and Bobby's 11-year-old brother both said that Bobby had watched the *Disney Vacation Planning DVD* almost every day with great attention, and it just seemed a logical choice to everyone. In this case, contrary to Maria's case, little deliberation and negotiation were necessary to reach a *final version* of the wish.

2.5.2. Simon's deliberation

Other cases, however, require a longer, more complex process. In this regard, the case of Simon is very insightful. Simon was 13 when he was diagnosed with a rare muscular tumour. He and his parents learned about the CWF at the hospital: *"Have you chosen your wish yet?"* was a frequent question heard when they would gather in the teenager's "playroom" in the oncology department. Specifically, an older teenage girl talked about the CWF: *"Ask for whatever you want, you can go all out. Personally, I asked for something, but I could have received more."* Simon then said to his mother: *"I'm eligible, so we can fill in the forms and we'll have plenty of time to choose a wish."* To help guide him in the process of choosing a wish, his parents defined *what a wish should be*:

> *If you're going to pick a wish, the important thing is that it be something big, not something you could buy yourself. Like, a home theatre isn't a wish; we have a TV at home, we have cable. A wish is something inaccessible, you know? Like you would have to work to be able to afford it. Take a computer, for example. We already have one at home, we don't need a second one that would be just for you. We can share the one we have. A wish is something that's beyond your reach. So using that as your starting point, draw up the dream you want, and that'll be fine.*
> (Interview with Simon's parents, September 2008)

They also insisted on avoiding purchasing something they already had at home, such as a second computer or a sound system. Then he started looking for ideas. The first idea he came up with was snowboarding equipment. His parents insisted this was something he could eventually get by his own means. At that time, he was passionately reading the

Harry Potter novels and eventually proposed that he could spend a summer at J.K. Rowling's mansion to learn English and visit the set of the movie. They sent a letter to Wendy to explain the wish. Wendy's first reaction was to comment on the duration of the trip. According to Anna, the mother, she said: *"To spend a summer there, forget about it. Trips cannot last longer than 10 days."* Then she told them she would see what she could do. At the time, Simon was in chemotherapy. One day, Wendy called and said there was an opportunity to go onto the set and meet the actors. A group of around 30 people (unrelated to the CWF) would soon be undertaking such a trip. Wendy was not enthusiastic about this idea and let the family decide. As she once mentioned to them: *"The wishes that involve artists are the wishes that I enjoy the least because they often lead to disappointment."* After deliberation, Simon finally said: *"It doesn't matter, we'll do something else."* Later, he came up with the idea of a photo safari. Anna said that this choice was probably influenced by the fact that he had been very attached to the imaginary world of Mowgli in *The Jungle Book* when he was younger. In the meantime, he also started to be interested in Japan. The idea emerged when he was participating in an excursion to Alaska with other children with cancer. His instructor was a martial arts teacher and had received a samurai sword for his fiftieth birthday. During the trip, he talked to Simon about martial arts and Japan and taught him some karate moves. Simon's new idea was to go to Japan and travel the path of the samurai. His mother warned him that everything would be in English (at that time, they did not know that they were eligible to be assisted by an interpreter). He consequently abandoned the idea. Time was passing and, in the spring of 2005, he finally settled on his wish: he decided to go to Bora-Bora. He made the decision after watching the movie *Triple X* (xXx). The 2002

movie directed by Rob Cohen starred the muscular action movie hero Vin Diesel. After saving a large city from a weapon of mass destruction, Vin Diesel retires peacefully with his new girlfriend in Bora-Bora. Although the scene lasts less than a minute, it had a strong impact on Simon. After seeing the movie, he decided his wish would be to visit the islands and stay in an overwater bungalow (like Vin Diesel). His mother then started to do research on the Internet[45] to figure out what they could do there. *"Are we just going to sun-bathe?"* she asked him. Her involvement in the process created friction in the family. *"It's my dream,"* Simon complained to Anna. His mother described how she responded: *"I know that very well Simon, but you have to elaborate on it. Are we going to spend the week at the same place? What are we going to do? Then go on the Internet and search for information: Where do you want to go? What do you want to do? See their culture?"* He finally decided that he wanted to do an underwater photo safari. He also added that he wanted to go into the ocean to see the great whites (sharks) and take pictures of them from a cage. His parents told him the CWF would never accept this idea because it was too dangerous.

At that point, the wish was to go to the French Polynesian islands of Bora-Bora, to stay in an overwater bungalow, and to attend a typical local Polynesian spectacle so as to be exposed to the local culture. He also asked for an underwater photo camera, but that element was considered a "second wish" by the CWF and was denied. In the meantime, his parents also started planning the things they would like to do and see. As Anna reasoned, *"Since we are going there, since we are travelling that far, there are things we would also like to see."* They mainly wanted to visit a pearl factory and a vanilla plantation. They then produced a final version of the wish involving all of these elements:

the arrival at Bora-Bora, the move to a second island, a catamaran cruise (for Anna, while Simon and his father were doing underwater photography), a visit to a third island to see the vanilla plantation and the pearl factory, and the end of the trip in an overwater bungalow.

Overall, the whole wish-definition process, including incubation and negotiation, took around one year. This case encapsulates many of the aspects of the wish process that were introduced earlier: the role of the hospital social network in the development of awareness about the CWF, the interaction between the wish coordinator (Wendy) and the family, and the relationship between the ill child and his or her parents during the process of incubation and negotiation leading to the definition of the wish.

This case demonstrates that, in addition to the child, other actors, such as parents, are likely to have their own implicit expectations or ideas about what the wish should be. These expectations or ideas are likely to be taken into account by the child in the decisional process leading to the definition of the wish. The case of Simon shows that his parents played an important role early in the process by setting rules and boundaries regarding what they considered to be an "appropriate wish" (i.e. something that cannot be easily fulfilled by one's own means). They also pushed him to be more involved in specifying the details of the wish. They also imposed certain limits by claiming that the "shark element" would be deemed too dangerous by the Foundation. They even took the opportunity to "throw in" some ideas related to their own interests. However, despite their controlling tendencies, they encouraged Simon's creative initiatives all along. The family also regularly followed up with Wendy, who also played a significant role in the process. In the case of J.K. Rowling, for instance, we saw that Wendy rejected the first

proposal (spending a month at Rowling's mansion) and came up with a compromise solution. She also displayed mixed feelings and communicated her concerns about the celebrity wish, which led Simon's ideas to evolve, eventually crystallizing into the idea of a journey to Bora-Bora.

2.6. Approving the wish

Each year, approximately 1,000 wishes are officially granted by the CWF across Canada. But before being granted, each wish has to go through an approval process. Once the wish is officially defined by the family, a proposal is sent to the wish coordinator. A series of criteria will then be analyzed before the wish can finally be accepted by the national wish-granting coordinator at CWF headquarters in Ajax, Ontario. These criteria are listed in the CWF procedures manual and will be outlined briefly here.[46] They can be summarized under four main themes: the *focus on the beneficiary,* the *appropriateness of the wish,* the case of *international travel wishes,* and the case of *celebrities.*

2.6.1. Focus on the beneficiary

The first set of criteria is directly aimed at focussing on and protecting the sick child. According to the manual, the wish is approved based on what is deemed appropriate for the individual child, taking into consideration his or her age, his or her abilities, and the limitations imposed by the illness. As we saw before, the doctor's approval is a key element. The doctor has to confirm that the child's condition won't be aggravated or put at risk.

When the child is not considered at risk, other considerations are evaluated to make sure he or she remains the main beneficiary. First, if the wish includes (benefits)

other people in addition to the sick child, as it does in most cases of travel wishes, the legitimacy of each participant will be analyzed. According to the manual, immediate family (parents/step-parents, brothers, sisters, stepbrothers, stepsisters, half-brothers, half-sisters) *living at the same address as the wish child* will be included under the spending budget of the CWF. In other words, a sibling who lives on his own will normally have to pay to participate in the wish. Uncles, aunts, grandparents, friends, and cousins are also usually excluded, except in extraordinary circumstances. Bobby (the 9-year-old I briefly introduced earlier) is one such exception. He lives on a daily basis with his mother and older brother. Since his parents are divorced, they could not both accompany him on the trip. His grandmother (maternal side) is close to the family and very important in the eyes of Bobby. For these reasons, she was allowed to go along with them and was included in the CWF spending budget.

Second, the wish has to be considered "the child's wish, and [cannot be] perceived to be for the benefit of other persons,"[47] which places at the forefront the *prevention of false wishes.* Indeed, according to the CWF, one key aspect of wish definition is that it must originate with the sick child. As the procedures manual states: *"No effort should be spared to establish that the request is truly the wish of the child, and not the result of influences from self-interested parties."*[48]

Preventing false wishes is one of the most complex tasks of CWF representatives and is a significant source of concern for them. During my stay at the Foundation, I frequently heard Wendy and volunteers talking about this aspect of their work. They stressed the importance of avoiding excessive influence on the part of the parents when defining the wish. This point is so central that it became an important part of the 2006 CWF annual

volunteers meeting.[49] On many occasions during that day, the volunteers shared various stories involving "ambiguous cases" in which the origin of the wish was uncertain and in which the parents were suspected of having had an undesirably heavy influence on the decision. For instance, one volunteer mentioned the case of a 4-year-old boy who wanted a VTT or a boat. The volunteer strongly doubted the wish was coming from the child. Another explained that one family was asking for a computer for the sick child. The problem for this volunteer was that the family wanted to install the computer in the playroom, not in the sick child's room, which meant, he implied, that the wish was *for the whole family and not only for the sick child*. Wendy also mentioned a related case in which a child who was asking for a computer was definitely too young to know what a computer was. The following excerpt from my field notes relates an even more extreme case divulged by a third volunteer during this meeting:

> *Volunteer: "A child was supposed to go to Disney, but the dream was cancelled by the doctor due to the child's terminal condition. She (the mother) came to me to ask for the cheque back. The mother told me: 'I thought you would leave me the money so that I could make the trip after his death'."*
>
> *The audience: That is disgusting!* (Field notes, May 27, 2006)

In this case, the volunteers unanimously condemned the mother's reaction, her seeming desire to take advantage of her son's misfortune. The testimony of the third volunteer, although also condemned by the audience, gave rise to a series of alternative interpretations. Elisabeth, the social worker I introduced earlier, who was invited as a guest speaker at the event, proposed a different reading of the mother's reaction: "*Maybe*

she wanted to do it in the memory of her child." This reflection had a strong impact on the audience, whose members became quiet and pensive.

Another volunteer highlighted a different but related story that is briefly summarized in my field notes:

> *Volunteer: A 17-year-old boy wanted to go to Hawaii. (Name of the volunteer) did not believe him. The boy told (name of the volunteer): "My parents have made a lot of sacrifices for me. It is the gift I want to offer them."* (Field notes, May 27, 2006)

The two examples above reveal that the analysis of a wish's source can be understood from different perspectives, and that the intention of the parents cannot automatically be interpreted as *self-interested*. They also show that the assessment of the origin of the wish is complex, and that the origin must be interpreted in the context of the relationship between the child and his or her family.

Finally, there are some rare cases that require a reconsideration of the role of the parents in the origin of the wish. Indeed, due to their condition, some children, such as those living with severe Down syndrome, have no way to express what kind of wish they want. In those instances, the wish coordinator or the volunteers have no choice but to *rely entirely* on the parents to identify what the wish should be. Here is an excerpt of a conversation Wendy had with another employee:

> *(Employee). It's amazing how you have to be so in-tune and attentive to the kids, because you don't know whether for this child, Cinderella really is what he wants.*

(Wendy). It's true, because he's not the one who expressed the wish, but who'd

know better than a parent what his dream would be. For sure, if the mom had told

me that he wanted a motorboat—you know, I'd start to wonder—but a 16-year-

old boy who wants to meet Cinderella, that's pretty unusual. She could have said

he wanted a home theater and I would have believed it, because at a certain point,

I think you also have to trust parents. It's not often that this kind of situation

comes up, but when it does, I think you have to trust parents. (Interview with

Wendy, July 2008)

This case concerns a family who contacted Wendy and told her that their 16-year-old son Jim wanted to meet Cinderella at Disney World. This boy suffers from a severe illness that impairs the development of his communication abilities. As mentioned during the conversation, there was no way for the CWF to verify whether the boy's wish really was to meet Cinderella. However, as Wendy explains, the wish was "too unorthodox" to be something concocted by other interested parties. Also, for Wendy, trust is the key element. As she said, she also would have believed the parents even if the child had wanted a home theatre.

2.6.2. Appropriateness of the wish

The second set of criteria is more concerned with the constitution of the wish itself. The first element here is the safety of the wish. Once the child's condition is deemed appropriate for the realization of a specific wish, the CWF must also ascertain whether the wish itself could potentially be harmful to the child's life or health. For this reason, the CWF does not accept any wish requests that involve firearms or related equipment,

nor does it consider items such as motorized vehicles, trampolines, skateboards, or bicycle ramps, which are deemed a "threat to the welfare of the child."[50]

Second, the manual stipulates that the wish must be "themed" and remain under "one wish category." The Foundation groups the wishes into categories that should, to a certain extent, be mutually exclusive. The wish coordinator is responsible for making such judgments. For example, Simon's request for an underwater camera was denied because Wendy classified the wish as the combination of "two themes" or two "wish categories," the main wish being to go to Bora-Bora (travel wish) and the second being to own an underwater camera (item wish).

Third, the cost of a wish must normally not exceed a *ceiling price,* unless justified. In order to determine the ceiling prices, each wish granted by the CWF is reported, and its final cost compiled, in a database to be analyzed. Thanks to this database, it is possible to affirm, for instance, that the average cost of a wish on a national basis last year was around $9,000 and is now closer to $10,000 (at the time of writing). In addition, the manual documents the average cost of each type of wish in detail. For instance, "big-screen TV" wishes are expected to cost no more than approximately $6,000, personal computers and laptops $5,000, swimming pools $9,800, camping trailers $15,000,[51] shopping wishes between $1,500 and $5,000, depending on the child's age,[52] and so on.

Wendy is expected to respect the ceiling prices as much as possible when approving the wishes. According to her, this task is usually easy since the children's requests are very often *conservative* (her own word) and rarely exceed the ceiling price.

Fourth, requests for medical equipment are not considered a wish and are not eligible unless they are deemed necessary for the realization of a specific wish. For instance, the CWF would pay for oxygen during a trip to Disney World if a child needed respiratory assistance. Medical attendants (e.g. nurses and caregivers) are also included in the wish spending budget if considered necessary. This decision is based mainly on the physician's declaration concerning the child's condition. Also, requests to finance trips for medical treatment are not considered wishes and are therefore declined.

Fifth, wishes that require major construction or renovation, or that will demonstrably increase the value of a property, are not eligible. However, room redecoration (e.g. bedroom, playroom) is acceptable to the CWF.

Sixth, in the case of travel wishes, the CWF must confirm that the destination is available at the time the family wants to make the trip. Due to seasonal factors, some popular destinations must be booked in advance to ensure the availability of flights and hotel rooms. For instance, families who want to reside in Give Kids the World[53] (GKTW) during their trip to Disney World in Florida must normally reserve around six months in advance. Any wish that requires a flight is processed through Kane Travel, the official and *exclusive* travel agency of the CWF, based in St-John, New Brunswick.

In addition to these six general criteria that are used to determine the appropriateness of the wish, other, more specific criteria apply when considering wishes individually. In fact, each wish is subject to its own set of regulations, which are reported in the CWF procedures manual. A non-exhaustive list of wishes detailed in the manual includes entertainment centres, flat-screen TVs, computers, swimming pools, shopping

excursions, bedroom redecoration, pets, outdoor playhouses, fishing and hunting experiences, hot tubs, sports equipment, and tickets for professional sporting teams. For each wish, the requirements include elements that are accepted and excluded, as well as the average "ceiling price." For instance, the description of the "entertainment centre" wish stipulates that the following items may be included:[54]

- Television (up to 34")

- DVD player and/or VCR

- CD Player

- MP3 player

- A reasonable set of speakers

- One gaming system (i.e. Play Station 3, Nintendo Wii, X-Box 360, or other similar system)

- All hardware and cabling required for operation of the system

- Entertainment unit to house components of the system

- One year of cable or digital cable service

- $500-$1,000 worth of games, movies and music (games, movies and music may be purchased from the supplier, or a cheque or bank draft may be issued to the wish family to purchase them on their own, or a store gift certificate may be purchased and provided to the wish family)

The manual also notes that the average cost of this wish is approximately $6,000 and warns that "care should be taken to ensure that such wishes do not exceed this cost (unless special circumstances exist to warrant a greater cost)."

Special destinations for travel wishes, such as Disney World and Disneyland, a Disney Cruise, Hawaii, Australia, the Bahamas, and Europe are also reported. The "swimming with dolphins" wish is a good example of a travel wish for which the manual provides detailed instruction. The manual specifies that a "swimming with dolphins wish" includes:[55]

- Transportation (air or ground) for all family members from their home to the wish destination

- 7 nights of accommodation at a hotel or resort

- A rental vehicle (car, minivan, full-size van, or wheelchair van) or other transportation options (shuttles or taxis)

- One or more dolphin swim encounters (depending on the destination)

- Spending money (amount depending on the number of participants)

Although the CWF does not impose any one destination for the dolphin encounters, the manual highlights the three most popular locations: Florida, Hawaii, and the Bahamas. For each of these destinations, it also proposes a series of options. For instance, Florida has four options (Discovery Cove "Trainer for a Day" Program, Dolphin Plus, Dolphin Research Centre, and Island Dolphin Care), with detailed information for each program. For example, a family going to Discovery Cove could stay at the Star Island Hotel ("or

similar") and receive a one-week pass to either Sea World or Busch Gardens (in Tampa). No additional attractions are included.

2.6.3. The case of international travel wishes

For international travel wishes, additional criteria need to be analyzed. A first element that is verified by the wish coordinator is whether any traveller involved in the wish will have a potential problem entering the country of destination. Three conditions must be met. First, the families have to indicate whether any of the travellers have a criminal record. Depending on the gravity of the offence, the CWF can sometimes obtain special one-week waivers from U.S. customs[56] (called a *Waiver of Excludability with United States Customs & Border Protection*). Also, certain complex wishes require gathering together family members living in different countries in a specific geographical area. Such cases sometimes involve people living in countries that are denied access by the chosen country of gathering. For instance, Wendy told me the story of a Congolese immigrant child who wanted to bring his family to Canada. Despite the fact that the family was quite wealthy, the Canadian government did not grant them a visa, which led the child to choose another wish.

Second, the participants also have to indicate whether anyone suffers from a disease that could potentially cause them to be denied entry into the country of destination. In this regard, the procedures manual cites the specific case of HIV/AIDS and stipulates that "the Public Health Agency of Canada strongly recommends that persons living with HIV/AIDS consult with a travel medical professional and with their personal physician well in advance of departure, to ensure that all necessary precautions

for travel are taken."[57] For instance, in countries such as the U.S.A., waivers for short-period travel are sometimes granted to HIV-positive travellers. In such cases, the CWF works with the families to try to obtain the visas. However, if visas cannot be acquired, "the affected family member(s) will not be permitted to travel, or the wish family will be required to select a travel destination where no restriction exists."[58]

A final aspect related to customs involves situations where the child is travelling without one or both of his or her parents or legal guardians. In these cases, the travelling family must carry the appropriate documentation proving that the child has the permission of the absent legal parent or guardian to travel.[59]

Another important element concerns the safety of travel destinations. According to the manual, trips "involving areas of the world in crisis" can be declined. More specifically, any wish concerning a country that has a warning posted by the Canadian Department of Foreign Affairs and International Trade (CDFAIT) is not authorized by the CWF. For instance, any requests to visit Afghanistan, Albania, Algeria, Bangladesh, Azerbaijan, Kinshasa and Brazzaville (Congo), East Timor, Iraq, Iran, Haiti, Moldova, Myanmar, Peru, the Philippines, and Rwanda are declined by the CWF.[60] The MAC is also sometimes consulted to help evaluate the potential harmfulness of a wish when needed.

Finally, once the above-mentioned conditions are met, the CWF must confirm that the travellers are eligible for insurance coverage, by obtaining approval from the Blue Cross insurance company. Blue Cross is a major partner of the CWF and its exclusive provider of insurance. According to the official documentation, the agreement "provides

all wish families with [*donated*] medical insurance which waives the 'pre-existing' illness clause for the wish child and covers the rest of the wish family for medical emergencies during the execution of the wish."[61] If needed, it also covers medical attendants and translators for free. The main condition regards the destination of the travellers. Destinations falling under the "Main Zone" are automatically accepted. This zone includes the U.S., the Caribbean, Mexico, Central America, and various European countries (e.g.: Austria, Belgium, Denmark, Finland, France, Germany, Greece, Ireland, Italy, United Kingdom, etc.). Countries falling outside of the "Main Zone" have to be approved based on a case-by-case analysis.[62] In addition, the insurance coverage does not exceed 8 days. Therefore, a wish requiring more than 8 days outside of Canada will not be eligible for insurance and will be rejected by the CWF.

2.6.4. The case of celebrities

In the case of celebrity wishes, special care is also necessary in order to make the wish possible. Depending on the scope of the request, various actors are likely to be involved in the approval of the wish. The meeting of a local celebrity will require that the wish coordinator contact the celebrity or his or her agent in order to verify his or her availability and openness to the project. A wish involving an international celebrity, on the other hand, will require the assistance of the National Celebrity Wish Coordinator. This person is responsible for developing networks with celebrities all around the world and for maintaining these relations in order to facilitate the process. These wishes are the ones over which the CWF has the least control because final approval is subject to the celebrity's acceptance to participate in the wish. Even when they agree to be part of a wish, celebrities may set rules regarding the duration and conditions of the meeting. In

some cases, the celebrity will provide free tickets to attend a show and allow only a few minutes for autographs, while others will spend an entire afternoon with the child. In addition to conditional acceptance, the CWF also has to deal with the celebrity's time constraints. Due to their busy schedules, it is nearly impossible to meet some celebrities in the short term. For instance, a child hoping to meet Céline Dion can expect to wait more than a year. For this reason, the Foundation states that such wishes are "not advisable for children in [a] palliative stage or emergency situation." [63]

In addition, some celebrities are only accessible through other wish-granting agencies with which they have exclusivity contracts. For wishes involving Bill Gates, for instance, the CWF must submit a request to the *Make a Wish Foundation*, an American charity also devoted to granting wishes to critically ill children. Make a Wish is then free to accept the request or not. In addition to requiring that the family sign the Make a Wish legal forms, a Bill Gates wish presents the following scenario: the child is invited along with other sick children to Microsoft headquarters in Seattle, where each child is allowed to spend 20 minutes alone with Bill Gates, accompanied by one parent. No cameras are allowed (Gates has his own photographer). During this period, the child is permitted to bring along a list of 20 questions that must be pre-approved by the Make a Wish Foundation. After the meeting, the group takes part in a guided tour of the company and is invited to have lunch together with Mr. Gates.

2.7. Meetings

Once the wish is officially accepted, Wendy contacts the family to tell them the news. At this point, the wish is precisely circumscribed, and the details of its realization are

described. It is possible to say exactly how and when the wish will be granted, as well as who will be involved in its realization. In many cases, the family and a CWF representative will then agree upon a date and meet for the first time. Depending on where the family resides, Wendy will either take care of the wish herself or assign a volunteer to take charge of the process. Over the years, the CWF has developed a network of volunteers working in provinces across the country. Some of them devote their time and energy to fundraising activities, while others develop close contact with the families and become responsible for supervising the granting of wishes located in their area.

This meeting is an important step in the wish-granting process. At this point, the CWF representative (either Wendy or a volunteer) will often be seeing the family for the first time. This meeting is often very emotional. After many conversations on the phone involving the disclosure of intimate information regarding the child's condition, the parents' feelings, and other such matters, this meeting generally starts off with warm hugs and kisses and slowly evolves toward the three main topics: legal issues, gift-giving, and the prevention of false wishes.

2.7.1. Discussion of legal issues

During the meeting, important legal issues are introduced and discussed with the family. In order to make the wish come true, a number of forms must be signed by the family members, including[64] the physician's statement form, the information release form, the publicity authorization form, and the liability release forms. The physician's statement and information release forms concern principally the release of medical information to

allow the doctor to disclose private details to the CWF throughout the process in order to facilitate the granting of the wish. For instance, it authorizes the doctor to disclose to the CWF the child's condition and to detail any medical assistance that may be needed to fulfil the wish. The publicity form concerns the family's agreement to participate directly or indirectly in the promotional activities of the CWF (e.g. publishing a picture of the family, publishing the wish story of the family on the CWF website, or asking a family member to participate in a TV interview.) Families are free to decide whether they want their story to be publicized. Finally, of all the documents, the liability waiver is probably the most important. Essentially, it includes the following information:

> *By my signature below, and in consideration of the wish, I hereby release and forever discharge the Foundation from any liability in connection with the execution and fulfillment of the wish. The terms "execution" and "fulfillment" shall include, but not be limited to, any acts of commission or omission by the Foundation in connection with its involvement and assistance in making arrangements for and participation in the execution of the wish, including transportation, accommodation, food, medical problems both physical and/or emotional, entertainment, the taking of any photographs and other similar activities.*

> *With respect to the effect of the wish on me, I acknowledge that I have received the approval of Dr. _____ MD for me to participate in the wish, and am relying upon his/her advice and acknowledge that the Foundation has not given any advice or counsel in this regard.[65]* (Excerpt from the Liability Release – Adult wish child)

This form basically releases the Foundation from *any responsibility* that could arise during the delivery of the wish. As stated in the document:

> *As evidenced by my signature below, and in consideration of the monies expended to enable me to accompany the wish child, I hereby release and forever discharge the Foundation from any liability in connection with the execution and fulfillment of the wish. The terms "execution" and "fulfillment" shall include, but not be limited to, any acts of commission or omission of the Foundation in connection with its involvement and assistance in making arrangements for the participation in the execution of the wish, including the transportation, accommodation, food, medical problems, both physical and/or emotional, entertainment, the taking of any photographs, and other similar activities.* (Excerpt from the Liability Release–Parent/Legal guardian of wish child)

Every actor participating in the wish (wish child, siblings, parents, translator, etc.) must sign the form, or be represented by an adult if under 18. The reason provided to the families by Wendy or the volunteers to justify this form is that, in order to carry out its mission, the CWF needs to be protected from lawsuits. To paraphrase Wendy's explanation of the form to parents: "*We have made a lot of promises to kids like yours across the country and it would be terrible to break those promises due to legal actions.*" In addition, by signing the form, the parties also agree to the Blue Cross conditions regarding the duration of the trip outside Canada, which stipulate that the traveller will "assume complete financial responsibility for any medical expenses incurred outside of the 8-day period specified by the Children's Wish Foundation of Canada."

The CWF representative often proposes that families consult a lawyer before signing the documents. Paraphrasing Wendy again: *"This is a legal document, I recommend that you read it thoroughly and get legal advice if you have any doubts or questions."* Based on my observations and discussions with CWF representatives, however, in almost every case the families comply without hesitation. Once in a while, a few additional questions are asked, but no major issues are raised.

2.7.2. Gift-giving

In most cases, this meeting is an occasion for the CWF representative to give the child a set of objects as a treat in preparation for his or her wish. The CWF call these objects "wish paraphernalia." They are standard gifts provided to all the wish children across Canada. The list includes[66] a black backpack with the CWF logo, an autograph book, a CWF cap, a CWF t-shirt (in white or medium blue), a CWF pin, Roary (a stuffed animal), and the Birnbaum book. The CWF mascot "Roary," a big, smiling lion dressed in the CWF t-shirt, is given only to the sick child and not to his or her siblings. In the case of families with more than one child, another stuffed animal is provided to the siblings so they don't feel left out. The Birnbaum book is a short story about "Roary."

Although standardized across Canada, which items the family receives depends on the type of wish granted. For instance, the CWF pin is an item mainly relevant for the Disney wishes. It allows the employees at Disney theme park sites to identify CWF families and to provide them with "extra care" (e.g. skipping the waiting lines to enjoy the attractions more rapidly).

These items are ritually presented to the children as surprise gifts and usually trigger very positive emotions. From the encounters I witnessed, the strongest reactions are provoked when Wendy or a volunteer takes Roary out of the backpack and gives it to the child (they normally hide the items in the backpack, and take them out one at a time). Everyone, from the 3 year-olds to the 17-year-olds, seem touched by the fluffy stuffed lion wearing the CWF t-shirt. In the picture below, we can see Roary in the arms of a wish child, along with the winner of the Laura Cole Volunteer of the Year Award.[67]

In the case of travel wishes, the first meeting is also often the occasion for giving to the family the flight tickets and official schedule. In the cases I witnessed, this moment was also usually framed as a surprise gift. Indeed, on many occasions, Wendy kept the confirmation of the tickets secret until the meeting in order to surprise the family. They then go through the itinerary line by line, and provide complementary information documents (for instance, confirmation of car and hotel reservations, tickets for special events during the trip, or information on border crossings.) The objective is to make sure that all necessary details are transmitted to the family.

2.7.3. Preventing false wishes

The first encounter with the family is another opportunity to assess the source of the wish.[68] By talking to and observing the family members, Wendy and the volunteers can get a clearer idea of the family dynamics in order to assess the potential influence of others on the definition of the wish. To evaluate the situation, some of the volunteers have developed certain techniques. For example, one volunteer mentioned that when he first meets the child, he starts by asking him or her a direct question about the wish. According to this volunteer, the idea is to analyze the genuine reaction of the child. He would ask: *"So! You want to go to the zoo?"* and wait to see the child's reaction. An answer to the effect of, *"No, my parents want to go. What I want is..."* would immediately set off an alarm, and lead him to question the parents. All in all, this intimate moment with the family helps the volunteers to confirm the origin of the wish and make sure the focus is on the beneficiary.

2.8.   The next step...

On some occasions, the CWF representative will meet the family for a second time. Although the second meeting used to be common practice, it has become rarer today. When I was conducting my research, the families were still often unsure of the precise definition of the wish at the time of the first meeting. This meeting was often organized to help motivate the child and put him or her on the *wish mission*. Nowadays, in order to deal more efficiently with the increasing number of wishes granted, Wendy insists on having a final version of the wish before the first meeting. However, this is not always the case (as we saw with Maria). Also, depending on the situation, some or all of the gifts

(wish paraphernalia) may not have been provided during the first meeting. Indeed, when the wish is not yet decided by the first meeting, Wendy or the volunteer will sometimes wait until a final decision is made to give the items. This also often happens for wishes involving travel (e.g. Disney wishes). In such cases, the CWF representative often waits until the electronic tickets are available and printed to give the paraphernalia to the family. Finally, it sometimes happens that items that were on back order at the time of the first meeting (e.g.: if the Foundation runs out of t-shirts) are given during the second meeting.

Normally, after the meeting(s), the Foundation and the families are all set to go, and the only thing left to do is wait for the wish to be realized. At this point, all the information and the items necessary for the granting of the wish have been exchanged and both parties are ready for the fantastic journey to come... unless, of course, the illness decides otherwise and casts a shadow over the plans. In fact, another element that can force the CWF and the families to meet a second time is the unpredictable course of the illness. During my fieldwork at the CWF, I witnessed cases where the wish had to be dramatically modified due to the deterioration of the child's condition. What was envisioned as a memorable journey to Disney World sometimes becomes a three-day stay in a local hotel if the condition of the child suddenly worsens and requires frequent visits to the hospital. Many things can happen between the moment the wish is finalized and the moment it is realized. Each wish is, in this sense, special, and its course can be hard to predict...

3. An actor-network view of the process

When considering wishes from a process-based angle, their powerful social signature becomes evident. A wish is a social entity. As with any social phenomenon, a diverse array of actors influences it and is affected by it. We will now reflect on the social construction of wishes.

3.1. Mapping out the actors

Figure 3.2 illustrates the relationships among the actors as they unfold during the wish granting process. The figure combines the major steps identified in the previous section of this chapter (see also Figure 3.1) as well as the key potential actors involved at each step of the process.[69] This actor-network mapping shows the complexity of the social network that lies behind the construction of a wish. We can identify seven distinct groups of actors potentially involved in the building of a wish:

- Family (close and extended) and friends
- CWF actors (local wish coordinator, national wish coordinator, other employees, volunteers)
- Medical agents (child's medical team and the CWF-MAC)
- Other wish families
- The marketplace (travel agency, travel brochures, celebrities and their agents, lawyers, the Blue Cross, the media, corporate websites, etc.)
- Other wish-granting organizations
- Customs and airport security agents

For the sake of simplicity of presentation, I will classify the actors according to three main themes: charity-based actors, community, and marketplace. These actors have different roles and levels of importance in the wish-granting process, and they are summarized in the figure below.

Figure 3.2: Actors involved in the wish granting process

Family actions

CWF-Family interactions

CWF actions

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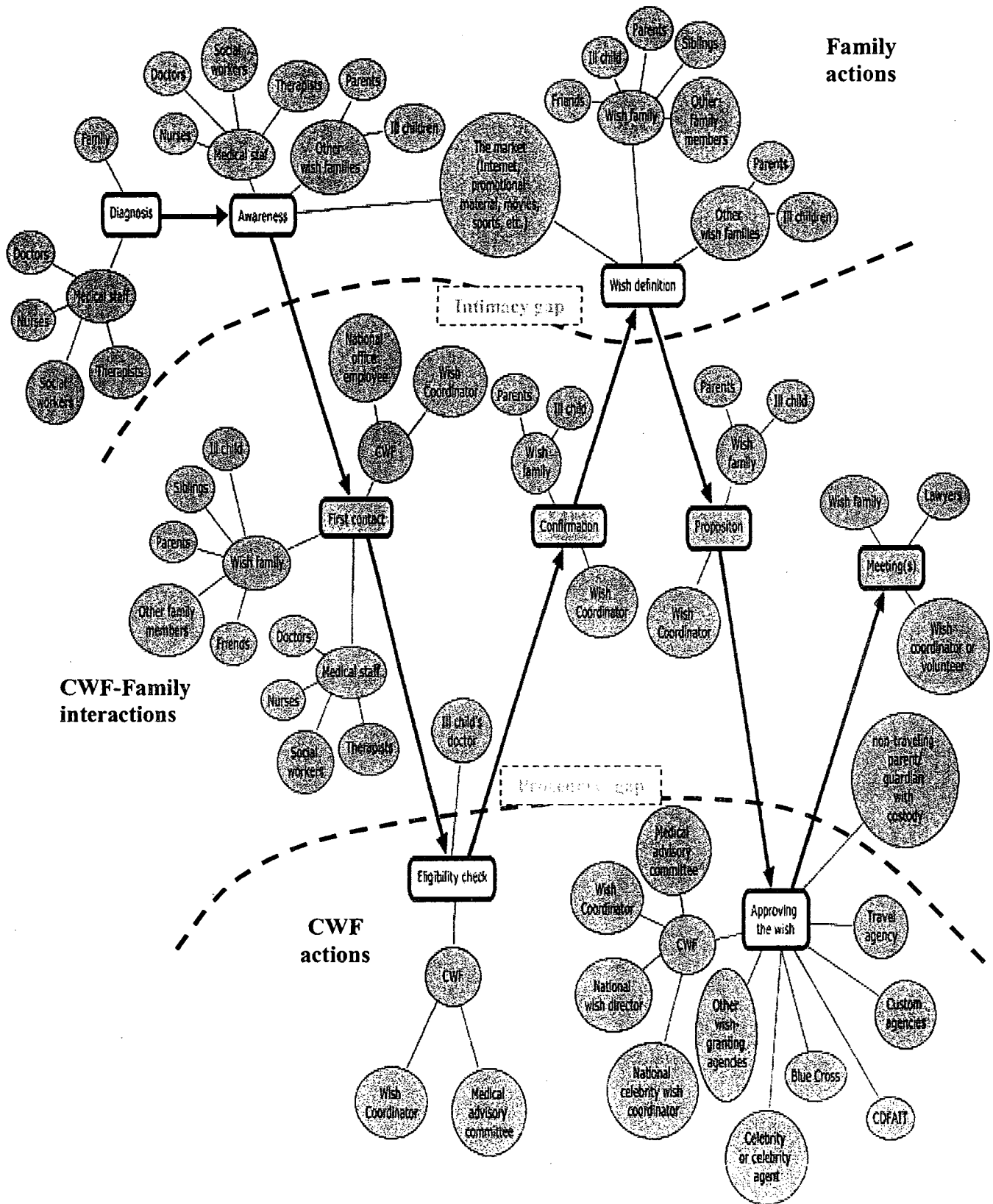
3.1.1. Charity-based actors

The wish families and the wish coordinator are by far and away the most central actors. Families are the initiating force, manifested by their contacting of the CWF: The child – with the support and guidance of his or her family – comes up with a wish, which becomes the substance of the starting point of the relationship. The CWF, represented by the wish coordinator, creates the possibility of the wish coming to fruition. By combining the logistics, expertise, and money necessary to deliver the wish, the CWF fosters its realization. The families and the wish coordinator work hand in hand until the final moments of the meeting – and sometimes up to the wish fulfilment itself – to define a wish that will at once meet the sick child's aspirations and satisfy the CWF's requirements.

Other wish families might also play a part at different points in time. They can help raise awareness about the CWF by talking to prospective wish families in the hospital and can serve as sources of inspiration in the definition of the wish. For instance, Simon's family heard about the CWF through hospital companions. In addition, Simon was influenced by another wish child who suggested he "go all out" when defining his dream.[70]

Finally, other wish-granting organizations can sometimes play a significant role in the process. As we saw, the Make-a-Wish Foundation is at times directly involved in the approval of specific celebrity wishes. Furthermore, Give Kids the World plays a significant part in the granting of Disney wishes. Given that roughly 25% of all wishes granted by the CWF are Disney World wishes, Give Kids the World becomes a key actor

in the granting of wishes. GKTW mainly comes into play when the tickets are purchased. Every purchase of theme park tickets is processed through this Floridian charity, which is mandated by the major parks (the Disney Corporation, Universal Studios, and Sea World) to manage the relationship with wish families. They are also involved in the reservation of villas, when families like Sonya's (as we will see in Chapter 4) choose this type of resort as their lodging.

3.1.2. Community

A number of actors from the community may also be involved in a wish. First, the medical community is deeply entrenched in the process. It represents the only group of actors who may be solicited in all three segments of the process (family actions, CWF-family interactions, and CWF actions). They are mainly called upon for their expertise and for their potential to help raise awareness about CWF. More specifically, the doctors (whether it be the child's physician or members of the CWF Medical Advisory Committee) have a very important voice in the process, for they are the ones who ultimately decide whether a child is eligible and whether a specific wish is suitable. As such, they also affect the course of a wish and its definition. As we saw with Emily, due to her doctor's specifications, the spa wish had to be redefined as a swimming pool.

Finally, government actors can play a major role in the granting of specific wishes. For instance, customs and other government agencies (Canadian or other) are involved in cases of international travel wishes. Their cooperation can be crucial in the granting of such wishes, for they alone may allow the travellers to enter the country of destination. As we saw previously, the CDFAIT plays an important role by ranking

countries based on the risk they represent. This ranking becomes a reference used in the approval of international wishes as well as in the attempt to secure insurance for families through the Blue Cross.

3.1.3. Marketplace

During the wish granting process, the marketplace operates at two levels. First, early on in the process, it stimulates the definition of the wish. Families receive marketplace information from what they hear and see at the hospital or in the media (e.g. promotional brochures, Internet, TV, etc.). For instance, Bobby's wish was taken directly from a Disney promotional DVD, while Maria's consultation of travel brochures led her to refine the criteria used to define her wish. The marketplace comes into play again later in the process, when the wish needs to be fine-tuned (i.e. after the child is deemed eligible and the preliminary wish concept is approved). At this point, precise planning of the wish fulfillment schedule and order of attractions (when applicable), the activities to enjoy, the places to visit, and so forth, are taking place. Generally speaking, the marketplace plays a "passive" role in this process. Companies and salespersons do not directly solicit business from the families except through normal channels (TV, radio, etc.). The wish families, rather, explore the marketplace themselves (while looking for an idea). Alternatively, families are exposed to the marketplace by word of mouth through socializing that occurs between wish families or with outside friends.

3.1.4. Complexity of wish granting and actor deployment

Although they have been discussed separately, it is important to note that the actors may all be interconnected. Depending on the wish, the marketplace, the charities, and the

community can be in constant interaction with one another. For instance, international travel requires the collaboration of all three groups. In such cases, each actor's action or decision is likely to affect those of the other actors in the wish. For example, once a country is declared a risk by the CDFAIT, chances are that the Blue Cross will not insure the family (for reasons of the destination falling outside of the "Main Zone"), or customs might not grant its citizens access to Canada, which will lead the CWF to reject the wish request as is.

The number of potential interconnections among actors directly affects the complexity of the wish. A wish's complexity can be reasonably well assessed along three non-exclusive dimensions: the type of wish, its duration, and its location. The following figure represents the link between the complexity of the granting process and the three dimensions.

Figure 3.3: Complexity of deployment during wish granting process
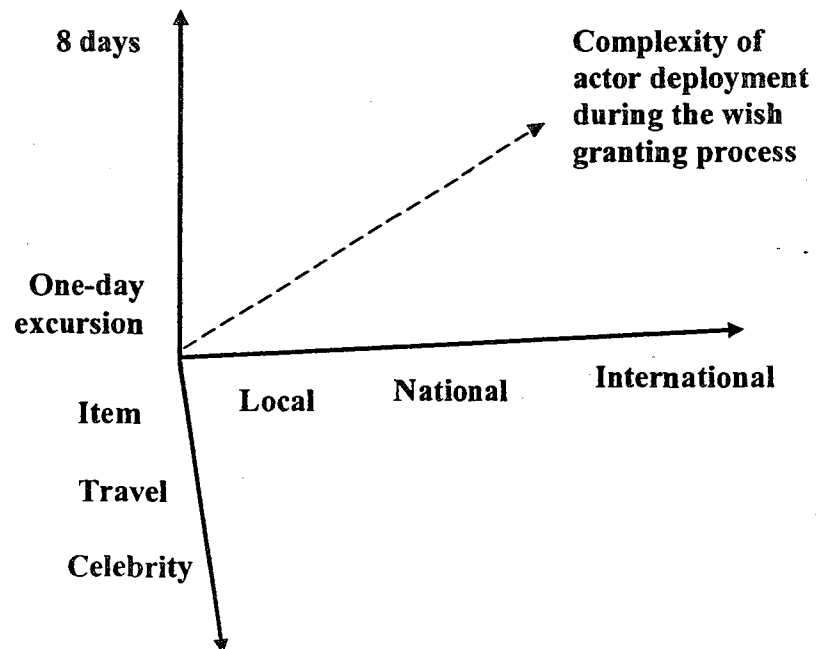
First, let us examine the dimension of the *type of wish*. As we saw above, three types of wishes can be granted according to the CWF's categorizations: item, celebrity, and travel wishes. As a general rule, item wishes are less complex than travel or celebrity wishes. Scheduling a shopping excursion to Toys "R" Us is usually much simpler and results in a more limited exposure to actors than a travel wish. In the former, only the family, a CWF representative, and a store employee or manager are likely to be involved. A travel wish, however, by its very nature, will likely necessitate the mobilization of a vast array of actors, from the airline company, to the travel agency, and other various actors at the destination. A celebrity wish can potentially deploy an even larger number of actors and be even more technically difficult to grant, considering that one becomes dependent on the celebrity's agent, their receptivity, and their availability, among other things. That being said, this categorization scheme is rather simplistic and does not give a full picture of the composition and complexity of certain wishes. For instance, meeting Tobey Maguire (star of the Spiderman movies) in California will be regarded as a celebrity wish by the CWF although it obviously entails a travel component. As such, the processing of such a wish will involve careful planning of hotel rooms and plane tickets as well as a verification of family members' compliance with United States customs regulations.

The second dimension consists of the *location* of the wish. Generally speaking, the further the wish, the more complex the deployment of actors to grant it. In other words, the planning of a local wish normally involves a more limited range of actors than an interprovincial wish (which might require additional transportation, lodging, and dining). Similarly, an international wish will deploy even more actors.

The third dimension is *duration*. Simply put, on average, the lengthier the wish, the more complex the deployment of actors involved in its preparation. These three dimensions are clearly interrelated, if not correlated. A travel wish has a greater chance of being held in far-off locations and of lasting longer than an item wish, and by extension, of having an overall greater complexity of actor deployment.

3.1.5. Illness as an actor

So far, I have highlighted the importance of people's actions and described their interrelationships with regards to the wish granting process. A closer look at this phenomenon reveals, however, that people are not the only players involved. In a Latourian sense, the illness itself can also be considered an actor. Indeed, as we saw in Chapter 2, Latour's conception of an actor is not limited to humans. It encompasses any thing, be it an object or person, that makes a difference in a state of affairs. By its mere manifestation and diagnosis, illness can be considered an actor, insofar as it mobilizes and affects a multiplicity of other actors.

If families are seen as the usual initiating force behind the wish granting process, the illness can be seen as the initiator of the deployment of actors. In fact, the illness colours the entire process. In my experience, the illness can impact six sources of uncertainties associated with the wish granting process: the timing of entry in the process, the eligibility, the speed of processing, the wish definition and approval, the temporal gap between granting and fulfillment, and the stability of the entire process. First, it directly affects the timing of entry in the process. Cases of cystic fibrosis are an apt example. Due to the slowly degenerative yet life-threatening nature of the disease, the moment a family

contacts the CWF might be postponed until later in the child's life. On the other hand, children diagnosed with cancer will normally be put in touch with the CWF earlier in their illness. Second, illness can affect the likelihood of eligibility. In fact, as we've seen, the illness is one of three criteria that determine the eligibility of a child. In particular, the type and severity of illness are taken into consideration. A-List illnesses are automatically accepted, whereas B-List illnesses require deliberation and possibly further negotiation between the various actors. Third, the severity and course of the illness will affect the speed of wish processing. A terminal illness will take precedence over a non-terminal illness in terms of the order in which they are processed. Furthermore, as logic would dictate, a wish whose realization is held off for two years after its approval (e.g. until after the end of a particular chemotherapy protocol) will be treated as less urgent (especially when the child responds well to the treatment). Fourth, the illness also affects the gap between the processing and the fulfillment of the wish. Each illness is unique in terms of its severity and treatment. For instance, cancer can be treated with various chemotherapy protocols, lasting varying periods of time. In most cases, where the health of the child allows, the families will wait until the end of the treatment before fulfilling the wish. In this scenario, from the moment the process is initiated, a wish can take up to two years to be fulfilled. In some unfortunate cases, relapses will further delay the fulfillment, which might take place three, four or even five years later. A fifth impact of the disease concerns the limits it imposes on the definition of a wish. In some cases that we've seen, illness impairs the child's capacity to communicate, which greatly limits his or her ability to provide input into the definition of the wish, causing everyone to rely on the parents' knowledge of their child's desires. Certain other illnesses can force doctors

to restrict the type of wish granted. For instance, Emily's initial wish for a spa had to be slightly modified into a swimming pool to accommodate the nature of her illness. Generally speaking, the severity and specificity of the illness can limit options concerning the three wish dimensions I identified. It can, for example, oblige a child to focus on a local wish in order to be able to continue to receive vital treatments. The severity might also restrict the duration of the wish, as in Danny's case (see section 2.3.2.2 of Chapter 5). Finally, the illness can destabilize the entire process by altering its course in unpredictable ways. For example, a Disney wish originally planned to materialize in two years can end up being altered into something smaller scale and sooner, if the child's condition worsens drastically.

In sum, the powerful influence exerted by the illness over the wish granting process is incontrovertible. Its involvement at various levels makes it an actor that cannot be overlooked in the study of wish granting. Yet illness can also have a positive influence on the wish process. On the one hand, it can be the wish's worst enemy by creating ambiguity, destabilizing order, compressing the time horizon, and so on. On the other hand, it may be an ally which facilitates the wish by making it easier to approve and process. No one can predict its manifestation, but either way, its presence in the process should not go unnoticed.

3.2. Actors' awareness of the process

Due to each actor's varying degrees of participation, the level of awareness and understanding one has over the process greatly depends on the actor and his or her involvement, and on the compartmentalization of specific actions. When analyzing the

knowledge of actors, two main knowledge gaps can be identified, namely, the intimacy gap and the procedural gap.

3.2.1. Intimacy gap

Wendy, as the wish coordinator, has a global understanding of the process from the moment of the first call to the realization of the wish. Nonetheless, her understanding of the process is still partially incomplete. Indeed, although she supervises the entire process, Wendy is, for the most part, unaware of the top segment of the figure (entitled *family actions* in Figure 3.2). She will never be fully aware of what happens between the moment the doctor diagnoses the illness and the moment the family contacts her. The family can only reconstruct this intimate period of their lives through story telling. In addition, she will gain only a limited understanding of what takes place within the family as they attempt to define the wish. During this phase, the families' work is mainly introspective. Finally, many wishes end up being defined internally by the family. Most item, travel, and celebrity wishes are constructed this way (Simon and Maria are such examples). This first separation between the CWF and the family, defined as the *intimacy gap*, is represented by a dotted curved line in the upper part of the diagram.

Other actors, although involved in the procedural aspects of the wish, have a limited understanding of the families' stories. For instance, the CWF Medical Advisory Committee will potentially get involved only during the eligibility check and wish approval (in the case of a child with a B-List illness and/or with a wish requiring a medical opinion.) Their knowledge of the family history is restricted to the medical implications of the wish. In addition, the national wish director normally receives a final

description of the wish without necessarily being aware of the steps that led to that final version (depending on whether the wish is complex, unusual, common, etc.). Similarly, marketplace actors involved in the process will not necessarily develop an in-depth understanding of the families' situation. For instance, the Blue Cross and the travel agency only become involved later in the process and receive little information about the family, except for the child's illness (in the case of Blue Cross) and the destination and duration of the wish (in the case of Kane Travel).

3.2.2. Procedural gap

The wish families are closely involved in most of the steps leading to the granting of the wish. Nonetheless, despite their central importance, the families gain only a partial grasp of the overall process. For one thing, their initial perception of the CWF's mission and procedures is sometimes misinformed (i.e. they often believe that the mission of the CWF is to grant wishes to *terminally ill* children). Second, they also have a very limited understanding of the evaluation of the eligibility of the child and the approval of the wish. Once the family allows the doctor to release the medical information on the child, the decisions are in the hands of others. The situation is similar during the approval of the wish. Often, the family is not fully – if at all – informed regarding any communication with the insurance company (unless a problem arises, such as wanting to visit a country outside of the "main zone") or the travel agency, which is done solely by Wendy. Most other aspects of this step are not controlled by the family (e.g. the planning and negotiation of the conditions regarding the meeting of a celebrity, the necessary communication with other wish-granting agencies, etc). In fact, despite the quite complex nature of the wish approval process (as we saw earlier), there is actually very little

discussion with the families. For instance, the ceiling prices are normally kept private and the elements to be included in or excluded from each specific wish, in accordance with the procedures manual, are not explicitly explained to the families. This second separation between the CWF and the family is defined in the figure as the *procedural gap*.

This gap also reveals that families are often unaware of the myriad of actors involved in the daily activities of the CWF that enable their wish to come true (see Chapter 2 for more details). They rarely meet the volunteers who participate in the fundraising events or who work closely with other families. They are also often unaware of the work of the other CWF employees, who manage the relationship between the Foundation and the volunteers, and who oversee the hundreds of fundraising activities organized annually by the CWF, individuals, and private companies. They also don't know which companies or individuals donate and/or organize fundraisers, unless they visit the CWF website or accept an invitation to participate in a fundraising event (such as a fundraiser golf tournament).

These two gaps are, to a certain extent, unavoidable. A barrier will always exist between the CWF and its beneficiaries. This separation, furthermore, is sometimes necessary for the benefit of both parties. Some families prefer to keep a high degree of privacy and communicate as little as possible with the CWF. Interactions in such cases are generally brief and straight to the point. Wendy respects their wishes, which generally means limiting communication with families strictly to an as-needed basis. It can also mean deliberately ending contact with families after the wish has been fulfilled. The decision to keep in touch with families is in fact an ongoing debate at the CWF, and

many conversations with Wendy and other employees revolve around whether the CWF should keep track of families who "vanish" after the wish. In other respects, the procedural gap is seen by Wendy as a necessity. As long as the wish child's eligibility has not yet been confirmed, Wendy exercises great caution in her interactions with the family in order to avoid giving false hope (as we will see in Chapter 5).

3.3. A highly emotional process

Previous research has shown the devastating impact of illness on families. Communication is complexified (Glaser and Strauss 1965), families' lives are disrupted, many couples break up, and healthy siblings are often left aside (Bluebond-Langer and 1996).[71] As my informant Elisabeth observed, early in the process, the wish is far from a priority for these families. Progressively, though, families will evolve through the experience. Some of them, at least, will obtain positive results from the initial treatments, and eventually the situation will improve. Hence, families go through ongoing, emotionally intense phases. For them, the journey is frightful, strange, and almost surreal, to the extent that they suddenly have to deal with the life-threatening illness of a child, while at the same time having the possibility to realize a wish, which has the potential to brighten the darkest of moments (see chapter 5).

3.3.1. *Gaps and emotions*

As they go through the process, the families are not always aware of every step, and they can experience a certain separation, or estrangement, from the Foundation, which can trigger strong feelings. As I observed earlier, when the doctor or the nurse first exposes the family to the CWF, the family can experience intense negative emotions. By

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misinterpreting the mission of the CWF as being a charity devoted to helping only *terminally ill* children, the parents often form falsely tragic impressions about the condition of their child. This impression needs to be corrected through a discussion with the doctor and/or the wish coordinator. Also, *the procedural gap*, caused by an estrangement from the eligibility and approval phases, can sometimes lead to insecurity and anxiety for the family awaiting the results of the decision. Hence, this compartmentalization of the steps is likely to cause conflicting and sometimes contradictory experiences for the family: while the children and the parents are full of hope and expectations regarding the wish, they are at the same time likely to experience intense moments of anxiety before the final version of the wish is approved.

CWF employees and volunteers also experience intense emotions throughout the process. First, the CWF actors must develop a capacity to evaluate the legitimacy of a wish. The estrangement from the family during the early phases of the process and during the family's defining of the wish (intimacy gap) can explain the CWF's strong emphasis on preventing the false wish. Although not every wish is considered problematic from this angle, the mere possibility of the existence of a false wish creates anxiety and concern for the wish coordinator and the volunteers interacting with the families. In addition, the evolving nature of illness puts the CWF representative in a constant state of alert when contacting a family. Indeed, one never knows what the family is going through at the moment of a call or a visit (it could be joy, but it could also be extreme sadness and despair).

Negative-valence emotions, such as sadness, anxiety, and distress, are not the only ones families experience in the process. Indeed, imagining the wish, planning it, and

foreseeing its fulfilment can also be incredible sources of joy, excitement, and hope. Families may perform what Belk, Ger, and Askegaard (2003) call self-seduction. As these authors propose, rather than being mere passive receivers of the marketplace, consumers actively seek ways to feed their passion for consumption by browsing magazines, watching TV, window shopping, and so on (p. 341). Wish families could be said to engage in similar types of behaviours by discussing the wish at the dining room table, counting down the days on the calendar, and browsing wish-related websites, among other things. By engaging in these positive anticipatory behaviours, families make the wish even more appealing.

These observations are consistent with the research on motivation, which suggests that emotions have a prospective orientation. Appraisal theories have been used to explain the relationship between emotions and goals or desires. Specifically, emotions originate in the appraisal of planned or unplanned events that concern one's well-being (Bagozzi, Gopinath, and Nyer, 1999). Roseman (1991), for instance, proposes that the type of appraisal of a given situation will give rise to specific emotions. In other words, situations controlled by external circumstances, by others, or by the self will lead to different respective emotional reactions. One important aspect of appraisal is the relevance of the goal to one's life (Lazarus, 1991). This is highly consistent with what the family and the CWF actors experience. The absence of information, the externalization of agency, and the waiting periods are appraised, and the outcomes foreseen dictate the kinds of emotions they experience.

3.3.2. The emotional labour of wish granting

From the organizational perspective, the process is emotionally loaded. Although the CWF and the family only sporadically interact, each interaction is critical and must be handled with the utmost professionalism. From a marketing perspective, these interactions correspond to *service encounters* (Czepiel, Solomon, and Surprenant, 1985): the first contact, the confirmation call, the reception of the official proposal, and the meeting(s) represent *moments of truth*, where the CWF representative has to interact with members of (or with the entire) family in order to deliver the service. For the CWF representative, these few moments of interaction require considerable social skills and empathy. They also necessitate a significant control of emotions, or *emotional labour*, which requires that they be able to induce or suppress their own feelings in order to project appropriate emotions (Hochschild, 1983). In fact, the CWF actors' work involves a composite of contradictory *emotional interactions*: dealing, on the one hand, with a large number of families facing the eventuality of death, and, on the other hand, with the grandeur of a wish. Consequently, they must deal on a daily basis with a *floating reality* that requires, from one phone call or meeting to the next, a shift from a state of deep empathy, as one mother expresses her emotional distress, to a state of cheerfulness and joy, as another fantasizes about the wish of her child. Ultimately, in a single day, someone like Wendy could be offering her condolences at a funeral in the morning, and participating in a shopping excursion wish at the local electronic store with another family later that afternoon. All in all, the CWF's strong focus on the families requires Wendy and the volunteers to balance and contain their private emotions in order to put the families first. Although an integral part of her work, to be emotionally on par with

families can be a difficult and exhausting exercise. Wendy's comments are insightful in this regard. The next excerpt is from an observation she made following a phone conversation with a family:

> *They don't realize that listening to their stories ... if every parent called, that's all we'd ever do. As nice as it is that they share their stories, at a certain point, I find it ... and you have to be an active listener [by saying things like], "Ah! Yes! Oh no!" It's important you do that because to them, it's unique, and their wish the only one that exists. And [this approach applies] from the moment of their first call, when they're all embarrassed to tell us that someone at Ste-Justine's or the Montreal Children's Hospital recommended they call, that they might be eligible for a wish... to their last call, which is quite euphoric. You have to maintain that same level of enthusiasm, because they're all equally important – whether it's for Alexandra, Samuel, or Gabriel, whoever – it's crucial that the enthusiasm you display with respect to any particular wish – whether it's a trip like that one to Italy or one to Disney, which are a dime a dozen – is perceived [as genuine by the family] so they feel like their wish is as unique as any ... It's not easy. It takes talent, that's for sure! (laughter).* (Interview with Wendy, July 2008)

This quote exemplifies the challenge of being emotionally involved at all times, from the first call to the realization of the wish. Every time a family calls, she has to display positive feelings and perform active listening. As she mentioned to me on various occasions (paraphrasing), *"Whatever your mood of the day, these families experience extreme situations and need to be supported."* This echoes my own personal experience of meeting Sonya's family. Here are the notes I took after my first encounter with them:

It was a long drive back home. I was really tired when I finally arrived (it was

close to midnight). This whole experience was great, but really exhausting. One of

the most energy-draining aspects is that I have a big responsibility: that of

creating a wonderful experience for the family. I really had to be in a positive

mood while I was there, otherwise I could potentially compromise their mood...

They are so excited about this adventure that I have to deliver something fabulous

to them. There is no room for mistakes... (Personal notes, October 19, 2006)

This forced positive emotional display, this *burden of positivity*, can become extremely

exhausting, particularly when one is not in the mood, when one experiences *emotional*

dissonance (Van Dijk and Brown, 2006), a mismatch between felt and displayed

emotions (Rafaeli and Sutton, 1987). Furthermore, this performance applies not only to

one family, but to everyone the CWF calls or meets. In fact, even if Wendy answers 20

different calls in a day, she has to display this enthusiastic, cheerful attitude for each one.

Even after hearing five families consecutively talking about their unique trip to Disney,

she has to act as if it is as new to her as it is to them.

Hochschild's conceptualization of the "managed heart," which opened the way to

new fields of research in marketing, human resources, organizational behaviour, and

health care services, builds on the premise that the appropriate emotions displayed by the

employee are part of a broader script defining the way employees should interact with

customers. The script is part of the drama metaphor (Grove and Fisk, 1983) which has

been employed widely since the early 80s in order to define the serviscape (see for

example Lovelock, 1996). This metaphor suggests, for instance, that employees, like

actors, should follow scripts crafted by marketing strategists ("writers" or "directors") in

order to enhance their performance and increase customer satisfaction, by providing an appropriate theatrical performance (Baron, Harris, and Harris, 2001). We are in the era of the experience economy, in which every encounter between an organization and its service recipients becomes the stage of potentially memorable and transformative events (Pine and Gilmore 1999). This logic, which was developed for for-profit organizations, can also apply to charities such as the CWF. A wish must be a memorable event, and all interactions between CWF representatives and the families should aim for this ideal. Ultimately, the CWF produces wishes and must manage, to the extent possible, the families' experiences. Interestingly, however, Wendy's attitude is not the result of the internalization of a script designed by corporate thinkers. Indeed, the CWF has no formal way of training their wish coordinators (emotionally speaking), nor does the procedures manual contain explicit mention of how a wish coordinator or a volunteer ought to interact with families.[72] Instead, Wendy's reflection on emotional labour is the result of experience and a personal reflective understanding of the CWF's mission. Her strong sense of moral obligation towards the families (putting the families first) led her to develop the *self-managed code of emotional conduct* described above.

Although the management of emotions is a significant part of the direct interactions between the CWF staff and the families, this aspect of the work is not necessarily experienced as a burden. Indeed, to the CWF representative, being in contact with wish families is more often than not very gratifying. Bringing a potentially memorable and pleasurable event to the lives of others can be highly rewarding and ego-boosting. Consider Debbie's reflection on the symbolic nature of her volunteer work:

If you want to feel appreciated in life, walk to Ste-Justine's with a Foundation t-shirt on your back. It's something else. They follow you and wonder aloud who's going to get their wish that day. "Will it be my turn?" (Interview with Debbie, May 2009)

3.4. A highly regulated process

A final element to consider that has been implicit in my writing so far is the highly regulated nature of the wish process. In order to be processed, the wish must comply with an extensive set of regulations stemming from the work of many of the actors previously identified. First, the CWF, as an institution specialized in the granting of wishes, has developed an impressive volume of procedures to facilitate the flow of the process. For instance, there are regulations about acceptable referral sources (e.g. family and medical staff) as well as rules defining the eligibility of children (age, citizenship, and type of illness). The CWF has also developed guidelines for approving wishes (e.g. a focus on the beneficiary, the decline of certain wishes deemed too dangerous, the ceiling price, and the format of wishes). Second, families can add their own rules to the framework. Simon's family is a good example, in that the parents imposed a certain definition of what a wish *should* be: something otherwise out of one's reach. Maria also developed a set of criteria to define her wish. Families further tend to regulate the process by applying a self-censorship policy. As Wendy mentioned, families rarely exceed the ceiling price in their requests, even though this figure is never disclosed. Children rarely have extravagant wishes, but rather tend towards the conservative. Third, the medical community exerts a regulating influence on the process. At a primary level, they are responsible for defining what constitutes a life-threatening illness and, by extension,

which illnesses to include on the A- and B-Lists. The development of new cures, incidentally, will further affect the eligibility of a child (e.g. some previously life-threatening diseases are no longer considered as such). Medical experts also have their say in judging the appropriateness of a wish and determining whether a destination or a means of transportation is deemed safe for a child. Fourth, government actors come into the mix with their own set of regulations. Their influence is felt at two levels related to international travel. First and foremost, they list a set of eligibility criteria for gaining access to particular countries. Factors such as a traveller's criminal record, country of origin (citizens of certain countries might not be granted access everywhere), or health condition (travellers with specific illnesses may be denied entry into some countries) are assessed systematically. There are also certain rules surrounding custody arrangements for children of divorced parents, and this requires additional paperwork. At a second level, government actors affect the process indirectly by rating the risk of a given country. As we've seen, the Canadian Department of Foreign Affairs and International Trade (CDFAIT) plays such a role by examining the situation of countries around the world and issuing warnings about those deemed dangerous for travel. Finally, marketplace actors impose their own norms and regulations. For the most part, they are responsible for establishing the *four Ps* of the products and experiences the families are to consume. Item and travel wishes are developed and promoted in a specific way, and offered at a set price, in a set place, and at a specific point in time. As such, the marketplace delineates what families can wish for and receive. Furthermore, the wish packages developed by the CWF are subject to this offering: a Disney wish must include "3-day hopper passes" because that's what Disney principally offers to its customers. An

"entertainment centre" wish – in terms of the types of gaming systems or TV sets that can be given to children – is constrained by what is available on the market at that particular point in time. Similarly, the quality of the products or experiences is dependent on the companies' offer. The CWF can try to influence this aspect from time to time (as we will see in the next chapter), but ultimately, it's the companies that have the final say. Another way the marketplace exerts a direct impact on the wish is through regulations regarding travel insurance. The Blue Cross imposes a variety of rules, including those regarding the duration of the trip (maximum 8 days), the country of destination (must be in the "main zone"), and the extent of coverage (only the wish child receives the pre-existing condition clause waiver).

4. Discussion: From panoptic to oligoptic analysis of consumer phenomena

In this chapter, I have attempted to outline the network associated with the granting of wishes at the CWF. I identified what I believe to be the main actors involved in its success. Due to the compartmentalization of the actors' actions, their deployment is episodic and their weight varies throughout the process, depending on the type of wish and illness involved. The wish granting process can therefore be seen almost as organic; and like all living organisms, it adapts to each situation encountered. It is no coincidence that the process proposed in Figure 3.2 is represented in the shape of a molecule. In this living process, an analysis of the actors' knowledge unequivocally points to the conclusion that no actor *ever* has a complete view or understanding of the entire process. In fact, a wish – whose fulfillment both the CWF and the families see as an intensely significant goal – is constructed without being completely understood by any one

individual. The process is controlled and regulated by various individuals and groups having various stakes in it. Even the CWF, which is ultimately responsible for the overall management of the process, can't grasp it fully: things happen behind the scenes, in the privacy of the families. This absence of an overarching source of control has its effect on both the process and its actors: families are anxious to know whether the child will be eligible and the wish approved, and the CWF actors resent their inability to know for certain whether the wish is what the ill child actually wants. The marketplace actors are perhaps the least concerned by this situation, as to a certain extent they perform their duty just as they would with any other consumer (i.e. by making an item available, scheduling a flight, booking a hotel reservation, etc.).

This lack of a central source of control reinforces the importance of looking at motivation phenomena, such as desires, goals, and wishes, from a process-based angle when considering their actualization. As I mentioned in Chapter 1, too often, studies devoted to these topics focus simply on a uni-dimensional cross-sectional account of these phenomena. Belk, Ger, and Askeegard (2003) formed the conclusions of their work on desire from the single perspective of consumer interviews. D'Astous and Deschenes (2005) analyzed the phenomenon of consumer dreams from one-shot interviews and a survey. Even Bagozzi and Dholakia (1999), when presenting their "process" of goal setting and goal striving, based their reflections on survey accounts of projections about future goals (e.g. intentions to regulate body weight) (Bagozzi and Edwards, 2000). This approach does not capture the actual sequence of events. Furthermore, these studies not only put the consumer at the centre of the analysis, but also consider him to be the only actor involved in his desires, goals, or dreams. The consumer is conceptualized as the

ultimate bearer of his fate. He is alone in the guilt he experiences when succumbing to his desires (Belk, Ger, and Askeegard, 2003). He is also alone when trying to set and achieve his goals (Bagozzi and Dholakia, 1999). These studies conceive the consumer as an isolated actor.

This approach echoes a panoptic consumer perspective. The panopticon, a prison[73] cleverly designed in the late 18th century by Jeremy Bentham, was conceived in such a way that the prisoners could be seen from anywhere in the prison without knowing they were being seen. This idea fed into the paranoia of prisoners (never knowing when they were being watched) as well as the megalomania of the observer (being able to observe anyone at any time). Michel Foucault (1975) applied the metaphor of the panopticon to modern-day society's tendency to discipline its subjects through schools, military institutions, hospitals, and so on, which constantly observe and record information about their respective disciplines. Under the constant pressure to conform to rules and norms, individuals internalize the rules of compliance and become self-regulating obedient bodies. The panopticon image has been used to describe today's consumer condition. Places of consumption, like casinos, shopping malls, and retail stores, develop techniques to observe consumer behaviour and offer them a world that has been rationally designed to create consumers en masse (Holt, 2002; Ritzer, 2005). Kozinets, Sherry, Storm, Duhacheck, Nuttavuthist, and Deberry-Spence (2004) applied the analogy to the ESPN Zone and argued that the architectural structure of the company is "designed especially to enable the consumers' desire to be observed" (p. 670). Even technology is seen as a way to reveal society's disciplinary tendencies: "Technology is

linked to work, work is associated with goal pursuit and fulfillment through 'society's approval thing' (Kozinets, 2008:865).

The study of motivation, to a certain extent, is consistent with this vision of the consumer and sees him as an agent trying to negotiate and regulate his desires, goals, and dreams. Taking a "micropolitics of power" perspective (Foucault, 1975), it conceives the consumer as his own observer, his own jail-keeper, who is ultimately responsible for the fact of his desire, the consequences of his desires, and the potential to fulfill his desires. The consumer is theorized as being responsible for the implementation of a goal stream that is consistent with his "perceived control," "attitudes," "anticipated emotions," and "internalization of subjective norms" (Perugini and Bagozzi, 2001). Irvine's (2006) argumentation is about how to better regulate one's desires. He proposes that by knowing the structure and functioning of our desires, we might be able to better control them. The consumer is also held accountable for the negotiation of tensions between morally acceptable and individually-felt desires (Belk, Ger, and Askeegard, 2003). Certain studies have found that one's capacity to regulate his weight is based on one's appraisal of means (Baggozzi and Edwards, 2000; Fischer, Otnes, and Tuncay, 2007).

On the other hand, a study of the wish granting process exposes the importance of taking a global perspective of the phenomenon. It reveals that, while striving to meet the end goal, certain factors, or sources of uncertainty, are external to the desiring subject. Indeed, the eligibility of the child, the approval of the wish, the delay between its granting and its fulfillment, and so on, are all elements that are to a certain extent beyond the family's control. The CWF in fact becomes the primary agent in attaining the wish. However, when considering the full range and deployment of actors, one must admit that

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even the CWF cannot fully control these factors. As we have seen, the illness is also an agent in the process that creates instability, as do the actors in the marketplace who impose their own agenda and rules on the process.

As Latour (2005) would argue figuratively, the *panopticon* would have to be replaced in this context by an *oligopticon*. In fact, in the wish process described here, no paranoia of the observed or omniscience of the observer exists. The family cannot be considered the singular agent of the potential success or failure of the wish, nor as the ultimate observer and regulator of its actions. The panoptic perspective indeed would put too much emphasis on self-regulation and obedience. Similarly, the CWF cannot be considered the ultimate controlling agency that overlooks the process and imposes its long-reach view on others. One could even say that the absence of a complete overview of the process can create a reversal of the expected effect on the actors (like a reversal of the effect of the prison on the observer). In some cases, the observer himself (e.g. the wish coordinator overseeing the process or the volunteer interacting with a family) tends to develop a certain degree of paranoia that the wish might be appropriated by parties other than the child that are beyond their scope of vision during the various steps of the process. On the flipside, the absence of full control could lead some families to take advantage of the situation which, in turn, reinforces the observer's paranoia.

Although interesting, this perspective does not capture the essence of the wish granting process. It focuses too much on self-regulation and paranoia. An oligoptic view of consumers would suggest a more moderate and more suitable approach. It would propose that no one oversees everything, "but what they see, they see... well" (Latour, 2005:181). Each actor involved in the process does indeed have a fully formed

understanding of and control over what is within his or her purview. And in some cases, this information does not even imply information about the wish families. During the process, the travel agency books hotel rooms and seats on a plane as they would for any other customer, regardless of the child (unless some specificities of the illness require special attention, like travelling with a nurse, needing oxygen during the flight, needing a stretcher, and so on.) Globally, the physicians, customs agents, volunteers, travel agencies, airline companies, wish coordinators, family members, and so on, all fulfill their tasks with due diligence based on the information they are able to receive or find about the wish, the families, and each other (e.g. the interconnection between the CWF, the Blue Cross, and CDFAIT). It is through this multi-perspective deployment of human and other actors that a wish can ultimately reach the moment of its fulfillment. We will now depart from the process to observe a wish in its fulfilment.

Chapter 4

When the dream comes true: Naturalistic insights into the

fulfillment of a wish

This chapter will centre on the second sequence of the relationship between the CWF and the families. It will present the detailed case of a wish fulfillment and follow the actors involved in its materialization. I will present a detailed account of the experience using a narrative perspective (Langley, 1999), in order to expose the naturalistic side of the experience. The intended goal of this idiosyncratic approach is to provide a vicarious experience of the richness and complexity of a wish setting (Lincoln and Guba, 1985: 359). The reader can also refer to Appendix 2, which includes descriptions of three other wish fulfillments that I will use from time to time to illustrate certain ideas. Due to its popularity at the CWF, I chose to describe a Disney wish. Disney wishes are a *passage obligé* in the exploration of wish fulfillment. As outlined in table 2.1 in Appendix 1, Disney-related wishes (Disney World, Disney Cruise, and Disneyland) are the most popular type of wish, representing more than 30% of the total number of wishes granted annually.[74] This comes as no surprise, considering the prominent place that Disney has held over the past century with its vast offering of animation movies, children's and educational products, artwork and collectibles, theme parks, resorts, and so on. Disney has become a symbol of family values and childhood and holds an almost sacred place in the heart of North Americans (Wasko, 2001).

The description will be followed by an analysis of the wish. I will identify my main findings regarding this wish that are also common to other wishes I witnessed or heard about. I will then dissect this very specific consumer experience and apply it to the relevant literature. Finally, I will reflect on the tensions between the CWF and the marketplace as they emerged from the particularities of this experience.

1. A princess's tale: A photo-ethnographic account of Sonya's trip to Disney

Sonya's family was the second family I accompanied to Disney World.[75] It was to be this family's first trip by plane. Sonya, a seven-year-old girl, suffered a ruptured brain aneurysm which haemorrhaged and put her in a coma for months before – against all odds – she regained consciousness with her cerebral functions almost perfectly intact.[76] Subsequent to Sonya's condition, Kathrin, her 27-year-old mother, went through a separation from the father.[77] In addition, she was forced to leave a good job and go on welfare in order to take care of her daughter. A few months before we met, Kathrin was finally able to return to work as a butcher in a grocery store. Linda, Sonya's grandmother, was an integral part of the family and therefore planned to accompany them.

1.1. A disastrous first experience with wish granting

With the help of a nurse, Sonya first made a request to go to Disney World through Starlight Children's Foundation Canada.[78] This foundation offered them a three-day travel package. In early September, 2006, however, Starlight cancelled the trip because they were unable to obtain airplane tickets. They told the family that it would only be possible to reschedule the trip for November of the following year (2007). Kathrin

decided to call Wendy, who immediately shared the story with the Foundation. "A heartbreaking story" were the words Wendy used to describe the situation.

When we met again recently, Kathrin summarized the impact that the cancellation had had on the family in the following reflection:

We just about dropped dead. Because it was cancelled ... gosh... two weeks before

we were supposed to leave. For Sonya and all, it was a shock... For me it was

mostly frustration, because you can't play with a child's emotions like that by

saying, "Yes, we will grant you your wish," and then turn around and say no, no,

no. (Interview with the family, March 2009)

To this day – almost three years after the event – she still carries resentment towards the Starlight Foundation and its handling of the situation:

...Can you believe I still receive mail from them every two months? Invitations,

happenings, like those organized by the CWF. I receive more invitations from

them than from the CWF. That's nervy: you don't withdraw a wish from a child

and then send the family invitations... it's a little irritating. I don't think I'll ever

attend one of their events! (Interview with the family, March 2009)

After being contacted by the family, Wendy processed the wish right away and got it approved in the days that followed. Sonya's family would stay at the Give Kids the World (GKTW) Resort.[79]

In the meantime, on someone's advice, Kathrin contacted a local TV station concerning her experience. Shortly thereafter, she received a call from Starlight, offering

her new tickets. She refused their offer because, as she said, she felt she could no longer trust them.

1.2. Preparations for the trip

This trip to Disney was cause for some anxiety, and not only because of the novelty of flying. Indeed, despite the doctor's assertion that Sonya was sufficiently medically stable to fly on a plane, her mother couldn't shake the fear that the flight might cause other damage, such as problems related to a pressure change in the cabin. Consequently, two months before the trip, she started reporting problems sleeping.

We arranged to meet on October 19th. At this first meeting, I wanted to introduce myself to the family, describe my role as a researcher and accompanier, and try to establish a rapport with the child. A connection with the children is crucial from an ethical as well as organizational point of view. First of all, from an ethical perspective, I needed to establish a relation of trust and comfort with the child since I was going to "impose" my presence upon the intimate sphere of her family for an entire week. The family therefore needed an opportunity to see if they liked me and then to judge whether they wanted me to join them on this great adventure. Secondly, their acceptance of me was crucial from an organizational perspective. The fulfillment of wishes tacitly implies that the people from the CWF involved in the realization of the wish will contribute in a positive manner to the construction of the wish (as I observed in the previous chapter). Hence, Sonya needed to feel a positive connection with me before we travelled together.[80]

Kathrin chose a spaghetti restaurant near her house. I brought the wish paraphernalia along with me and arrived 45 minutes late due to traffic. The following notes describe our first moments together:

When I arrived, Kathrin saw me through the window and smiled. I entered the restaurant and went directly to them. When Sonya saw me, she became really shy. She lowered her head and did not respond to my "Hello". Kathrin got up and hugged and kissed me. Sonya went to hide between her mother's legs. Then I offered her a candy flower bouquet. To my great pleasure, she smiled instantly and became very happy!

Kathrin said they also had something for me. She gave me a bouquet of three pinkish-red roses, each rose representing one family member (Sonya, Kathrin, and the grandmother). They chose pinkish-red because pink is Sonya's favourite colour. After that, Kathrin told me they had another present for me. They gave me a pretty pink bag with two ceramic angels attached to it. The angels were in a prayer position with their hands together and fingers pointing towards the sky. The bag contained a card and an angel made out of clay that can light up when plugged in. Kathrin explained to me that Sonya was also in a prayer position when she lay in a coma. She asked me to deliver a similar present to Wendy.

Kathrin told me that the angels had a special significance for Sonya. When she was in a coma, Sonya saw many angels dressed in blue. According to Kathrin, Sonya's real dream is not to go to Disney, but to fly high in the sky in the hope of seeing her angels. Kathrin can hardly believe her. However, she said that if, after

the flight, her daughter says she did not see the angels, then she will start

believing that Sonya really did see angels during her coma, the rationale being

that if Sonya does not see the angels in the sky, it would mean that she really saw

something that cannot be seen anymore. (Field notes, October 19, 2006)

We then had dinner and talked about the Foundation and Sonya. The mother brought her photo album and showed me dozens of pictures she had taken of her daughter during her coma and afterwards. When describing that troubled period, she kept emphasizing her daughter's eyes. She said that they were empty, as if covered with some sort of blurry filter.

We also talked about the planning of the trip. Since they had never travelled before, it was important for them that the trip be trouble-free. They counted on me to make it a smooth experience:

At some point in the conversation, Kathrin said that she didn't want to put

pressure on me, but that none of them had ever travelled before. So, she wants me

to take care of virtually everything. She said that since I have some previous

experience with Disney World, she wants me to decide which sites to visit. I told

her I can make suggestions, but that it is not my job to decide for her. In any

event, it does not seem to matter to her, as long as it is trouble-free. (Field notes,

October 19, 2006)

Later, when we left the restaurant, she reflected on her impression of me:

She admitted she observed me a lot when the she and the grandmother went

outside for a cigarette. She said she is usually very protective of her daughter. For

instance, she never lets anyone except Sonya's grandmother babysit. Yet she said

that she had great confidence in me. She said that she sees a genuine caring in my

eyes when I talk to her daughter and that she would trust me to babysit. (Field

notes, October 19, 2006)

I then returned home, exhausted by the intense experience.

Days went by and, in the meantime, Wendy worked on the logistics. On October

31st, we received the money for our trip from the national office. I would get US$325 for

my personal expenses (including the purchase of my theme park tickets) while the family

would get US$675 for theirs. Their theme park tickets would be provided by Give Kids

the World.

A few days before the trip, Kathrin told me she couldn't sleep at all, and the

grandmother was experiencing intestinal problems. She added that, during a Halloween

party, she had won $200 for the best costume – money she would use for the trip. We

also finalized the time for the limousine to pick them up. Kathrin told me she had not yet

told the rest of the family about the limo in order to make it a surprise on the departure

day. Weeks before, she had told them there would be another surprise and had given

them some vague clues every week to see if they could guess what it was.[81] During this

waiting time, the family was officially counting down the days remaining before their big

departure; they had a calendar at home on which they would mark the days, and Kathrin

was counting down the days on her MSN page.

1.3. Sonya's wish come true

Finally, on November 24th, Sonya's wish came true. At around 1:45 p.m., the limousine picked them up at home. They let Sonya enter first. She said, "All this for me?" She was dressed in a pink princess costume. They arrived at their hotel fairly late, because the chauffer got lost on the way. When they finally arrived at the hotel and saw their room, Sonya exclaimed, "A princess room!" There was a gift waiting for them, a travel bag that can hold a camera.[82] We then settled down in our respective rooms and got ready for dinner. Before going to the hotel restaurant, Kathrin offered us a small flashing pin depicting Disney characters. She said it was just one of the many surprises of the trip.

At the restaurant, Sonya was still dressed in her princess outfit. The waiter, who asked what we were celebrating, was told Sonya's entire story: her illness, the details of the surgery, and now their trip to Disney. The waiter shared that his son had had brain cancer a few years ago and was now 22 and in remission. On several occasions, he came back to talk to us about illness, surgery, and death. At the end of the dinner, he offered Sonya a piece of cake, on the house.

We then went to the indoor swimming pool and met a nurse who worked at the hospital where Sonya had been treated. Kathrin retold her daughter's story.[83] Afterwards, we spent a very relaxing time in the pool. Later, we returned to our rooms for the night.

The next morning the family got up at 4 a.m. and was already in the lobby by the time I got up. The mother told me then that they had forgotten their video camera in the limousine. There was nothing we could do at that point, and we decided that we would

wait until after the trip to call the company.[84] We took the 6 a.m. shuttle to the airport. On the way, with intense interest, they watched the airplanes taking off.

At the Air Canada desk, we quickly checked the luggage and smoothly passed through customs. We proceeded to security. The grandmother had forgotten to remove a lighter from her purse, and because of this item, the agents decided to search her hand bag. Although everything was fine – except for the lighter, which got confiscated – the grandmother felt shaken by the experience. We then went for breakfast and headed to our gate. While waiting to board, the family looked at the airplane through the window and took pictures of it. When we boarded, we met another wish family, who were also going to Disney World. The flight was uneventful; the sky was blue and everything went perfectly. Kathrin told me she couldn't believe she was on a plane. The whole family was very emotional during the flight, especially at the moment of landing. Before exiting the plane, we got to visit the cockpit and speak to the captain.

1.4.   Give Kids the World Village

At the airport, a retired man in his late 60s holding a sign with Sonya's name on it was waiting for us. This man was one of GKTW's thousands of volunteers. His work consists

of greeting the families at the airport and leading them to the Hertz shuttle van. In doing so, he meets more than 400 families a year.

After picking up our rental car, we found our way to the Village and arrived at around 3 p.m.

The Village is composed of hundreds of small houses hosting close to 6,000 families per year. Like any real village, it has its own mayor, except this one is a six-foot-tall rabbit named Clayton. The design of the entire village is child-centred: All the houses and administrative buildings are painted in playful colours, and the many recreational buildings are all decorated with giant animals and plants, like red and white mushrooms. In addition, there are two swimming pools and lots of activities that vary from day to day. From top left to bottom right, the following pictures show Amberville, (a playhouse containing a ping-pong table, a miniature train, and various other toys and games including an outdoor mini-golf course), the movie theatre, the reception office, the Gingerbread House (cafeteria), one of the swimming pools, and a carousel.
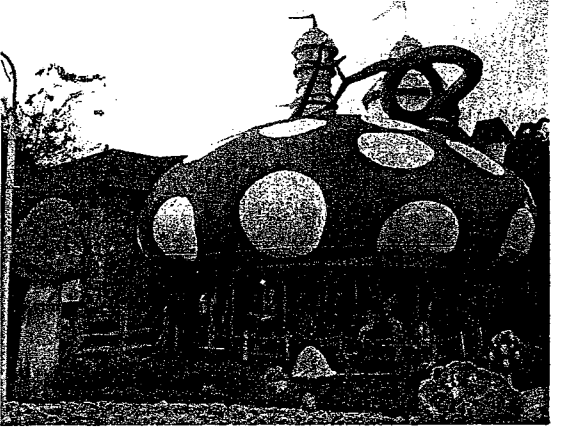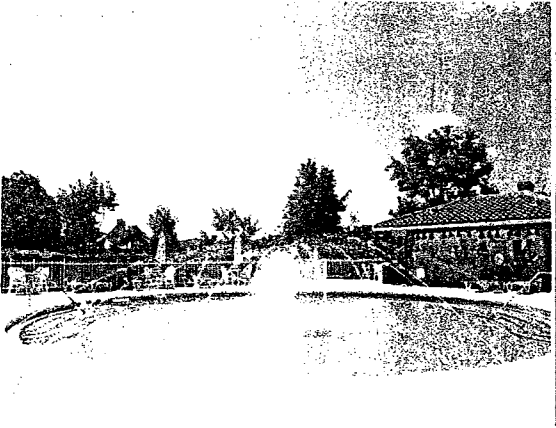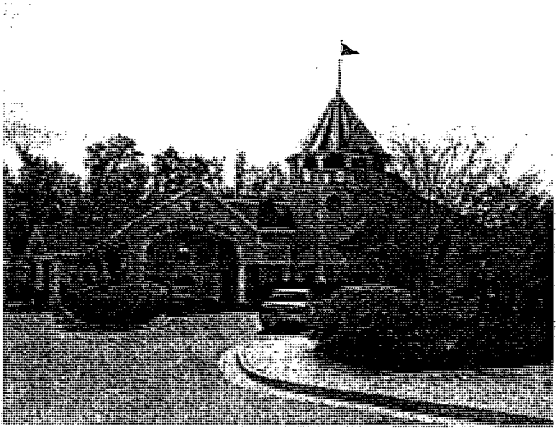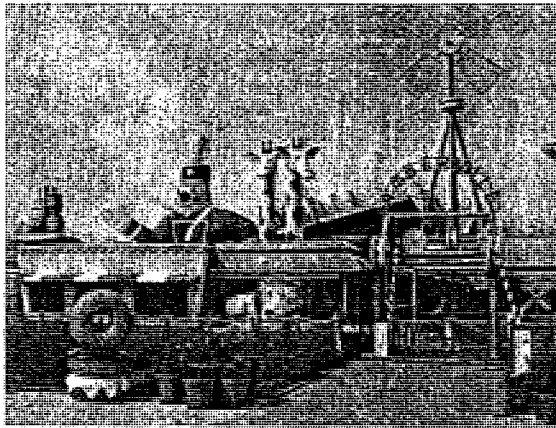
In the Gingerbread House, the walls are covered with antique dolls and miniature cars, and the tables are child-size, which amusingly makes us old ones uncomfortable while we eat. Everything on the site is free, from the food at the cafeteria (which serves full meals morning and night), to the banana splits we got from the ice cream parlour, to the pizza

we ordered through delivery late at night. There was even a video camera available for free rental (including the mini DVs), which was a great relief to Kathrin.

For the duration of our visit, we stayed in a cozy pink house, or *villa*, as the houses are called at the Village. Adjacent to the driveway, there was a mailbox with Sonya's family's name written on it. Our villa had two bedrooms (the master bedroom and a two-bed children's room), a large bathroom adjacent to the children's room fully equipped to accommodate children in wheelchairs, plus a smaller bathroom close to the master bedroom. The house also contained a kitchen and an adjoining living room that was designed with an open concept. The following pictures show the exterior of the house and the children's bedroom.

Upon our arrival, we noticed a welcome gift on the table and some documentation about the day's activities.
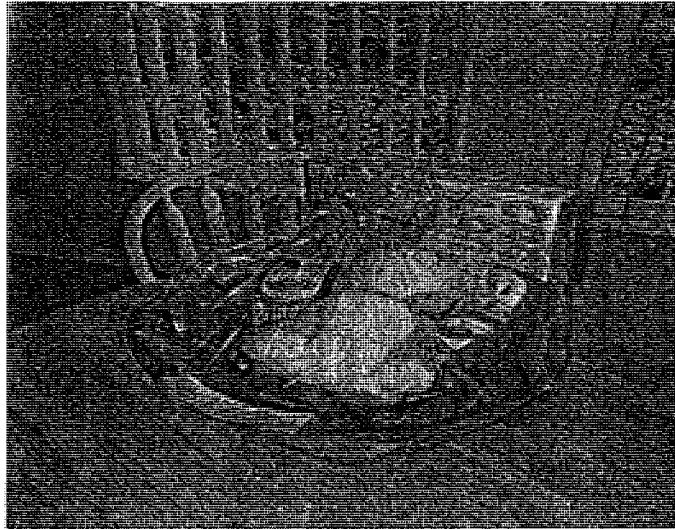
We spent the rest of the day walking and playing around in the Village. At night, we ordered pizza and went to bed exhausted at around 10 o'clock.

1.5. First days in the theme parks

The next morning, we had breakfast at the Gingerbread House and took pictures with Mayor Clayton.

Then we went to Magic Kingdom. We took the ferry to reach the island. The picture below shows the family waiting at the ferry gate.

We took many pictures with the Disney characters around the theme park.
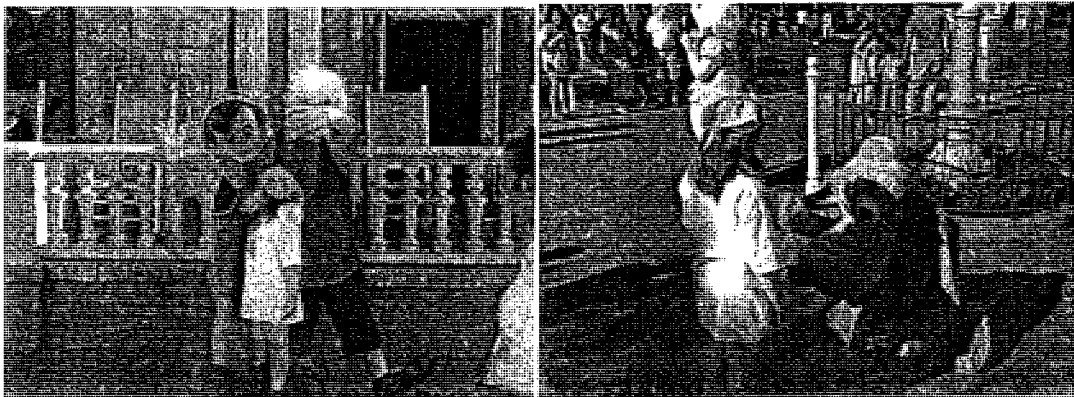
Sonya was particularly drawn to the variety of princess dresses we could see through the windows of the souvenir boutiques. We spent time going from window to window, taking pictures.

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During the day, the especially hot weather affected Sonya. We had to take frequent pauses to cool down and rest, otherwise, according to her mother, she would have eventually grown exhausted and "zoned out." [85] On several occasions, she complained about the heat and mentioned she wanted to go back to the Village to swim. The following picture shows a heat-affected Sonya disinterested in the main show at the Cinderella Castle.

Meal time was a welcome reprieve and gave Sonya some more energy to continue.

In the afternoon, Kathrin decided to rent a stroller so her daughter could better enjoy her time at Magic Kingdom. We went to the customer service desk and were directed to the stroller and wheelchair facility. To our surprise, the stroller was offered for free when we showed our CWF pin. The stroller significantly improved the experience. Afterwards, Sonya was quieter and more patient, and she had a lot more fun. Later, when reflecting on the day, Kathrin admitted she preferred the afternoon to the morning because her daughter seemed to enjoy it more. "Her eyes had more of a sparkle," she would say.

We walked around and saw some performances, like the country bears show, which the family greatly enjoyed.
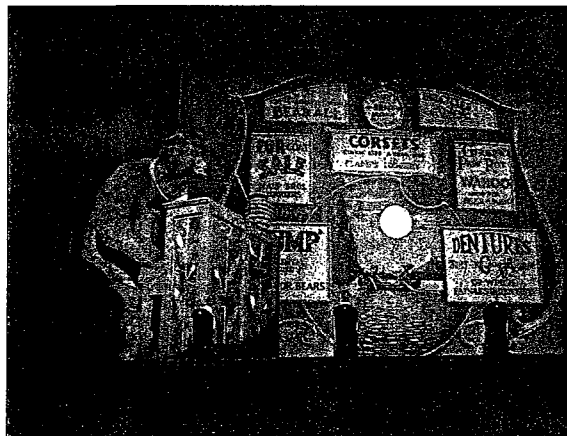
Later we took the train to Mickey's Toontown Fair, where we took pictures with Mickey, Mini, Pluto, and Goofy. The characters were located in different areas of a circular room, and we had to meet them individually. After meeting them one by one, however, the employee in charge asked the characters to gather together for a group picture with Sonya and her mother, something they don't normally allow in the photo sessions...

We then went to the princesses' room to take more pictures. Here again, the princesses (Cinderella, Sleeping Beauty, and Snow White) joined the family for a memorable group photo.

After the photo session, we slowly made our way back to the entrance. It was getting darker and the theme park was becoming progressively more illuminated.

While passing by the Castle, we noticed that the show we had seen in the morning was playing once more. We decided to stop and watch it again. It was just past 5:30 p.m., and the temperature was cooling down. This time, Sonya was completely captivated by the show, and she even danced. Afterwards, we drove back home and spent the night at the Village.

The next day, the family decided to spend the day at the Village to enjoy some quiet time. Early in the morning, while heading to the Gingerbread House, we noticed that an equestrian centre, which had been put together earlier in the morning, was offering free horse rides to the children. We decided to go right after breakfast. Sonya put on a helmet and waited for her turn. She then mounted the horse accompanied by two volunteers.

After the ride, they gave her a cowboy hat and a certificate attesting that she was now a member of Clayton's Saddle Club.
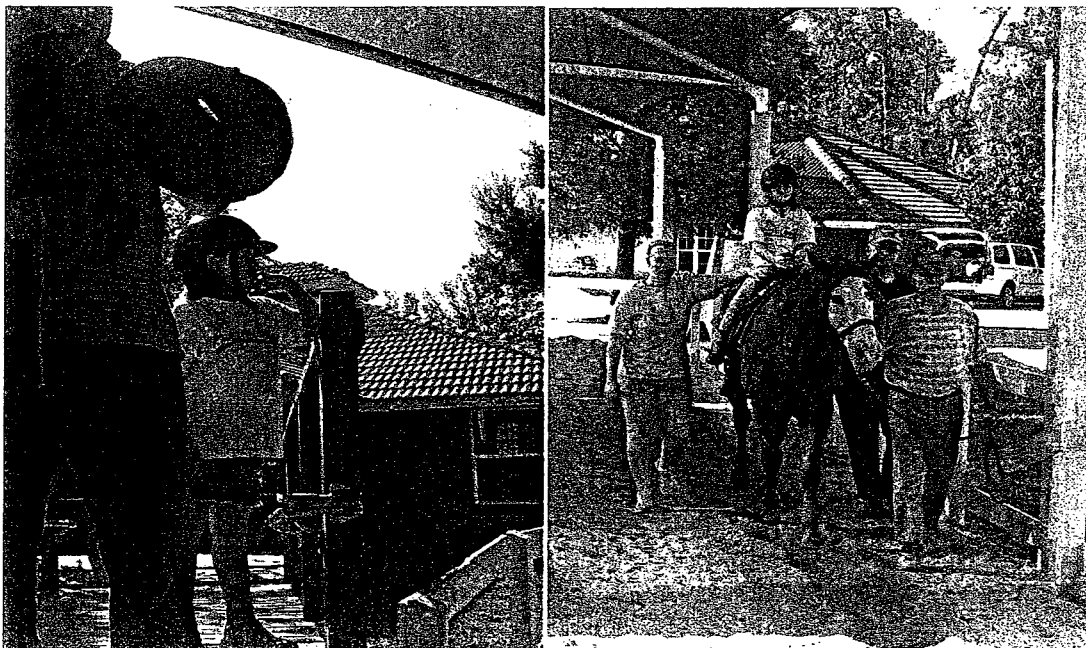
Afterwards, we went to the swimming pool. We noticed the weather was starting to change: early in the morning the temperature had been chilly and the sky filled with menacing clouds, but after breakfast it warmed up and the sky cleared. We stayed one hour at the pool, until the sky darkened again and it started to rain. After a cigarette break,[86] we hopped in the car and headed to the nearest Wal-Mart to buy some souvenirs. The store is located less than five minutes from the Village on the main road leading to Disney World. We spent almost two hours there browsing and shopping. Kathrin bought a Disney sweater, sandals, and a Strawberry Shortcake watch as a surprise for her daughter. Kathrin was really impressed by the store and mentioned she wanted to come back again.

Meanwhile, at the villa, volunteers were busy decorating the house with Christmas garlands, as it was Christmas Day at the Village. In the Christmas spirit,

Kathrin decided to make it a surprise for her daughter and didn't tell her about it in advance. When we came back, Sonya was astonished by the changes to the house. Kathrin told her that Santa Claus's elves had come to decorate the place. She then placed the watch she had bought at Wal-Mart in the Christmas stocking.

We spent the rest of the morning and afternoon at the Village and decided to go back to the Magic Kingdom to see the night shows we had missed the day before, as well as visit the Little Mermaid. For the occasion, Sonya dressed up as a pink princess.

This time, we decided to take the train rather than the ferry to the island. Arriving on site, we realized that the park would be closing at 7 p.m. that day due to a special Christmas party event. The party was not included in the regular fare and would have cost an extra $40 per person, which was out of our price range. So we decided to quickly visit some other attractions before closing time and ended up in the Little Mermaid's cave for a photo and autograph session.

It was getting dark and we slowly made our way back to the train.
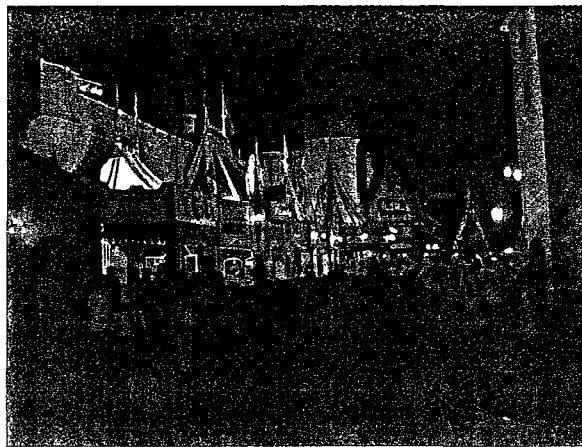
Just as we were exiting the park, it started "snowing." Artificial snowflakes were falling from the cloudless sky at +30 degrees Celsius. Even though we knew it wasn't real (the snowflakes were made of some sort of synthetic foam), this change in weather simply dazzled us...

Back at the train area, we avoided what we estimated to be a one-hour waiting line by talking to an employee and showing him our CWF credentials. Although this was not meant to be part of the benefits associated with either the special guest pass or the CWF pin, the employee let us take the resort residents line, which took us directly to the train

boarding zone. On our way back to the villa, we stopped at an all-you-can-eat restaurant that Susan considered to be "clean and very good." There, Sonya told me she was thinking of her father, her cat, and her friends. She asked her mother when she would see them. Back at the villa, she asked whether she could call her father. Indeed, Sonya wondered about her relatives on several occasions during the trip. She even reported missing a duck she used to feed back home but that got run over by a car.[87]

Back at the villa, Kathrin at one point took Sonya on her lap and told her, "Remember, this is just a trip and afterwards we have to return back to normal life at home." Later that night, after Sonya went to bed, Kathrin and I discussed the schedule for the rest of the week:

- Tuesday: Sea World.

- Wednesday: Animal Kingdom until 5 p.m., followed by Magic Kingdom in the evening.

- Thursday: Universal Studios until 5 p.m., followed by Christmas party at GKTW from 6 to 9 p.m. Tuck-in with Mayor Clayton at 10 p.m.

- Friday: Melbourne Beach until 3 p.m., Medieval Times restaurant at 6 p.m.

1.6.   Sea World

The next day, we headed to Sea World early in the morning. We arrived there at 10:30 a.m., and after looking around for a short while, we took a photo with Shamu, the Sea World mascot. For the occasion, Sonya was dressed as a blue princess.
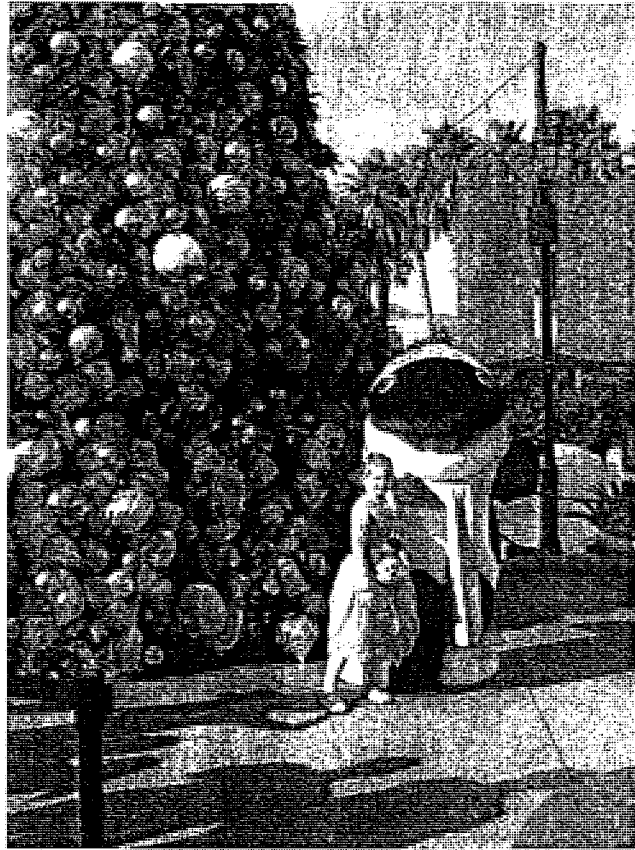
Right after Shamu, we decided to go and get a stroller. Once again, the employee lent it to us for free. While working our way through the park, we stopped by the turtle and the stingray exhibits and then went to see three back-to-back shows (the dolphins, the killer whales, and the circus). After the shows, we took pictures with the acrobats. The following photos were taken after the dolphin show and the circus performance.

We stopped for lunch at 1:30 p.m., and then, after Sonya mentioned many times that she wanted to touch the dolphins, we went to Dolphin Cove. We spent approximately one hour at the Cove, bending over the edge and trying unsuccessfully to reach the dolphins. Kathrin was disappointed that the employees wouldn't help us until feeding time, which wasn't for another three hours. We decided to walk around the park and watch some street performances; we shopped in various souvenir boutiques and took in the pink flamingos.
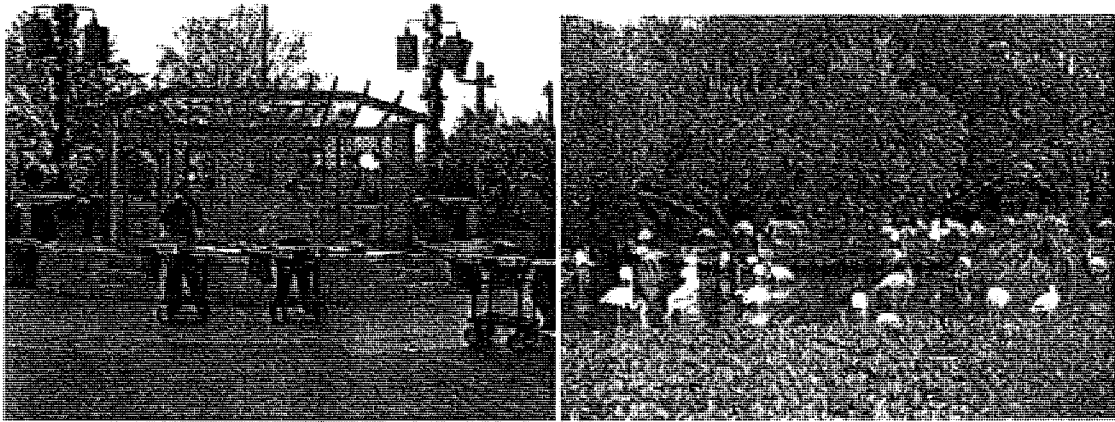
We then slowly made our way back to Dolphin Cove and waited another hour before the feeding show started. With the help of the employee, everyone was finally able to touch and feed the dolphins.
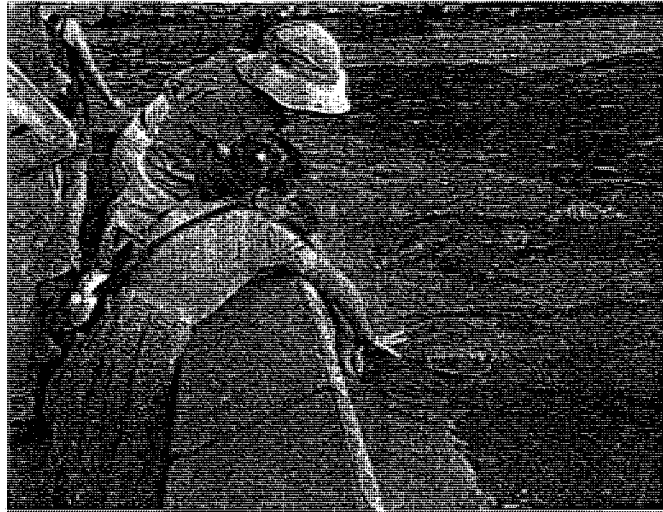
After that, the weather changed, and dark clouds started covering the sky. We decided to make our way toward the exit. On our way, we stopped at an artist's booth to get a portrait of Sonya made.

It was growing darker, and the Christmas tree where we had stood in the morning with Shamu was being lit up. We took one last look and returned to the villa.
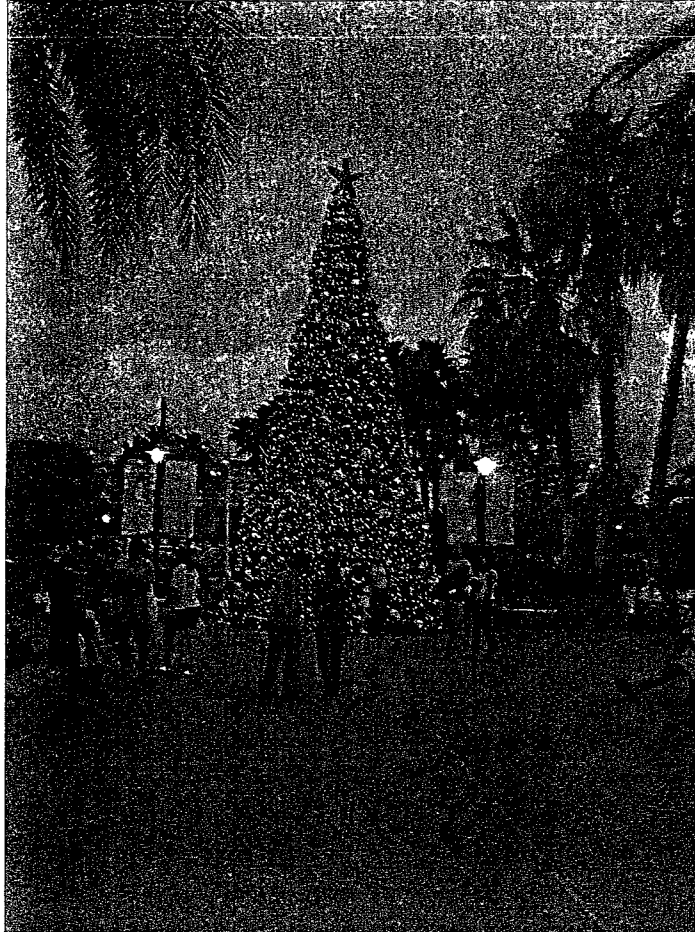
On several occasions during the day, Sonya mentioned that she wanted to move to Florida and live here forever. Kathrin and her mother also joked, saying that they wanted to stay an extra week. Overall, Kathrin said she was less tired that day, or at least, she was not experiencing the same kind of fatigue. She felt Sea World had a different energy than Disney World. People were in less of a hurry, and the decor was more relaxing.

1.7. The following days

The next day, we went to the Animal Kingdom. Here again, we took many photos with Disney characters, walked around the park, attended various shows, and watched the closing parade. We then returned to the Magic Kingdom to see the late night shows. I

waited at a spot in Cinderella square while the family went shopping. Linda had promised to get Sonya a particular toy cell phone. They returned an hour later at 7 p.m. As we waited for the show to start, we met a Christian family from Mississippi (husband, wife, a daughter Sonya's age, and a younger son). After explaining Sonya's condition, the lady asked whether she could add Kathrin's daughter to her prayer list. Sonya played for a while with the daughter of the Mississippi family. We came back late after the shows and found that the toilet was clogged at the villa. I called Reception, and they sent the concierge. A few moments later, a nice African-American man arrived and fixed the toilet. We learned that he was a retired kick-boxer who had fought in Canada.

The next morning, after breakfast, we set sail for Melbourne Beach located a one hour's drive from Orlando on the east coast of Florida. When we arrived, Linda shed tears of joy. She shared that she had just realized one of her dreams. The weather was perfect: light clouds were covering the sky, and a nice and strong ocean breeze was cooling us down. We spent five hours on the beach collecting sea shells, resting, and playing volleyball. Although they spent time in the shallow water, nobody went swimming because we had found some dried up jellyfish on the sand, and we were all afraid of them. All in all, the family was delighted by the awe-inspiring experience.
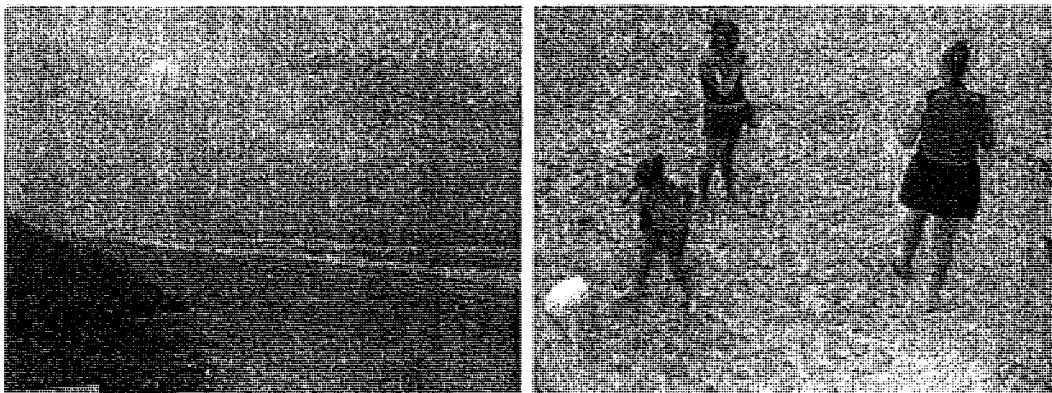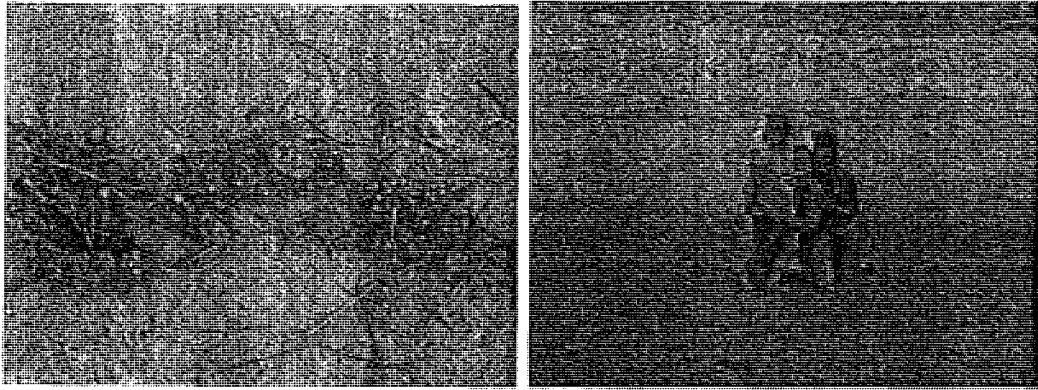
We also met a group of surfers. After explaining her daughter's condition to one of them, Kathrin enquired about the pain that jellyfish can inflict. The surfer told us she had been stung many times but added that it's a pain you get used to. And once you get accustomed to it, she said, you don't fear them anymore and can fully enjoy the surfing.

When we came back that night, we met another CWF wish family while walking in the Village. The mother approached us. They were also spending the week at the GKTW Village and had arrived one day after us. Their 13-year-old son had stopped walking, growing, and talking due to a lack of a special enzyme, and he also had a serious heart condition. They had taken their first day off because the travel had been too exhausting for their son. After mentioning that we had gone to see the ocean, they said they too had planned to go but had changed their minds:

> *They wanted to go to the beach and put their son's feet in the water, but then they thought he would not remember it and that it would be more for them than for him. That's why they decided to stick to the theme parks instead.* (Field notes, November 30, 2006)

During this short conversation, they also mentioned that they had received financial support from their community, who had raised $150 for their trip. Kathrin revealed that the same had happened to her. The people in her town had secretly raised $835 and given her the money the day before they left. This family told us they were also going to go to the Medieval Times restaurant the next day, so we decided to go together.

That night, the Village was throwing a big Christmas party. Decorations were set everywhere, and cheerful holiday music could be heard in the recreational area of the Village.
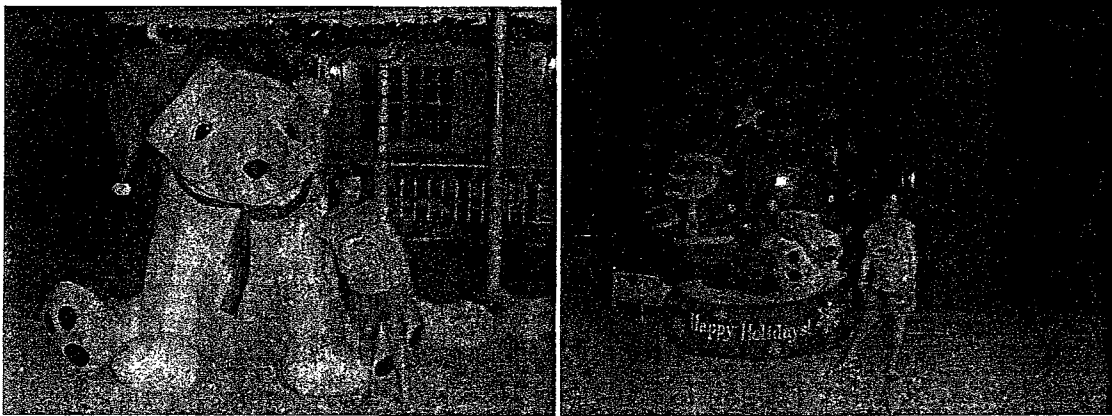
After playing around and making some Christmas cookies, we headed to the Village's Magic Castle to meet Santa Claus.

The castle was crowded with people who had come from all over the country through the help of various charities, such as *Make a Wish*, *A Special Wish*, and *Wishing Star*. We waited in line and finally met Santa and his wife. We took some pictures, and Sonya was invited to choose a present from a pile of donated gifts. When we left the castle, snow was falling from the sky just as it had two nights before at the Magic Kingdom. Children were dancing and revelling in the experience.

We then returned to the villa, and at 9:30 p.m., Mayor Clayton's wife arrived to tuck
Sonya in. She played with Sonya for a while and then put her to bed.
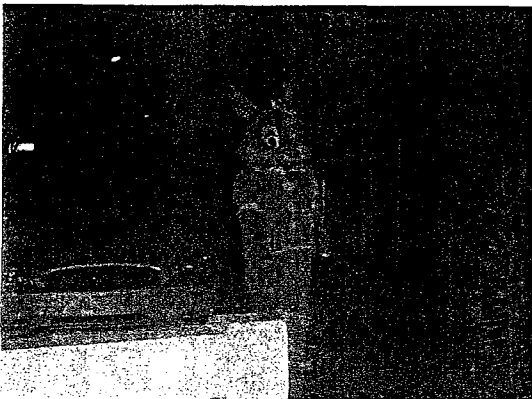
After Sonya fell asleep, we spent time on the balcony and chatted. Kathrin talked about
her relationship with her daughter since she had come out of the coma:

> *The mother told me her relationship with her daughter changed since the illness.*
>
> *Now each moment spent together is more intense. Before, it was "simply her*
>
> *daughter" and she did not realize all the progress she had made.* (Field notes,
>
> November 30, 2006)

1.8. The last day

The next morning, we were welcomed at the Village by Barney and his friends and by Jimmy Neutron – an excellent prelude to a day to be spent at Universal Studios.

The day at Universal was similar to the ones spent in the other parks: we walked around, saw some shows, and took pictures with Universal characters (Barney again, Dora, and Woody Woodpecker). We enjoyed lunch at Mel's Drive-in, a classical 50s' diner, and took pictures with Marilyn Monroe.

We then headed back to the villa to get ready for the final event of the week, the Medieval Times restaurant. This restaurant offers the experience of an 11th century-themed four-course feast, served by waiters dressed in period costumes, and accompanied by an authentic medieval tournament. The family got dressed up for the occasion, and Sonya decided to dress as a princess once again. Upon arrival, we were invited to wear paper crowns. We then walked around and took pictures of the scenery and some workers in character.
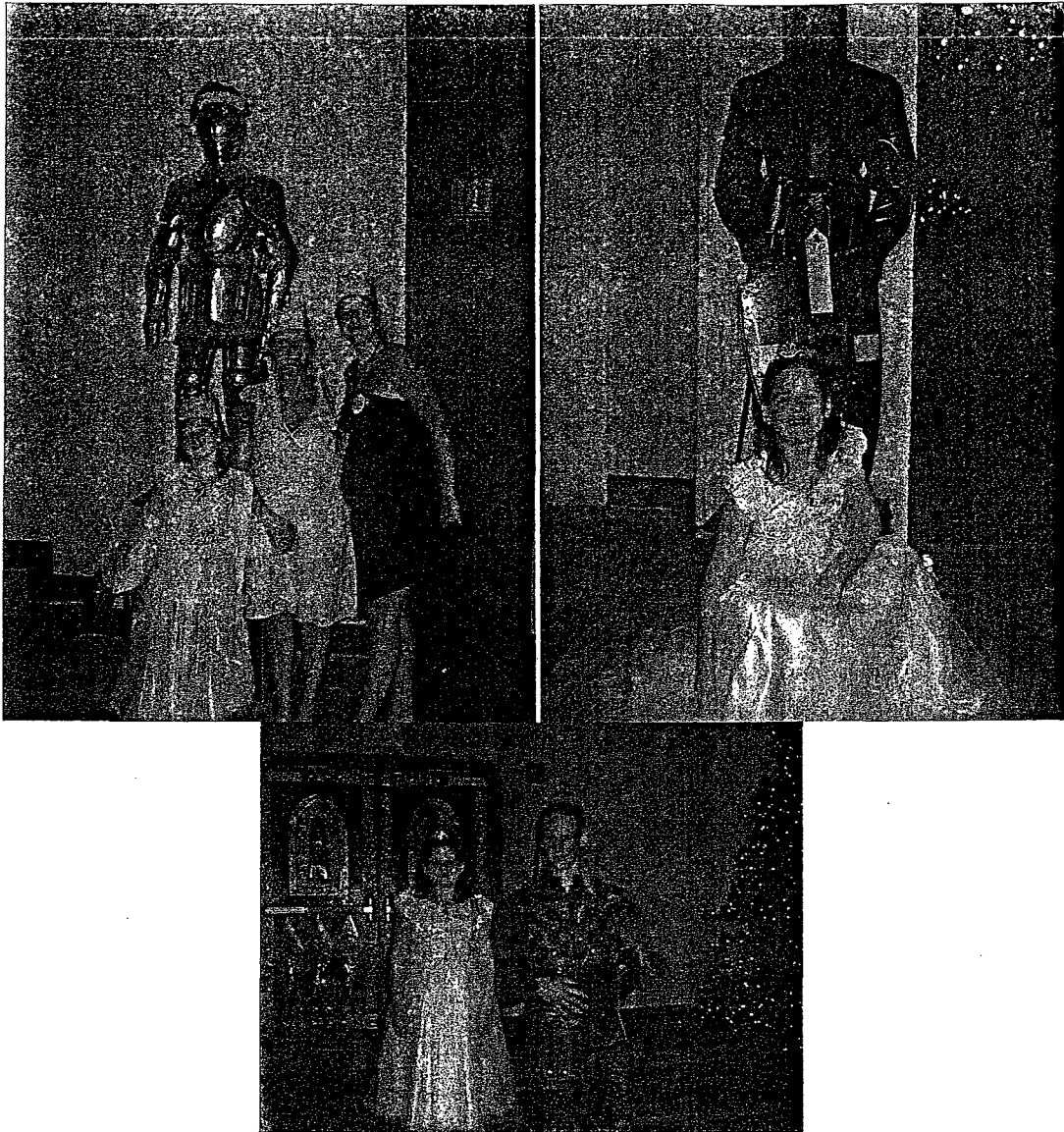
We were then invited to enter the dining area, a large rectangular auditorium with an open area in the centre covered with sand.

The show started, and the food was served in the traditional style: with no utensils except for a spoon for the soup. The show involved dozens of actors; some were simple flag bearers while others were skilled at horseback riding and ground combat. Each section of the auditorium was painted in a different colour, each representing one of the teams of the competing knights. Our champion was the "black and gold knight." In order to be declared winner of the tournament, the knights had to compete against each other in various competitions on horseback and on the ground, reaching targets while riding a horse, jousting, ground combat, and so on. As the perfect ending to a memorable week, our knight won the competition and even threw a flower at our table.
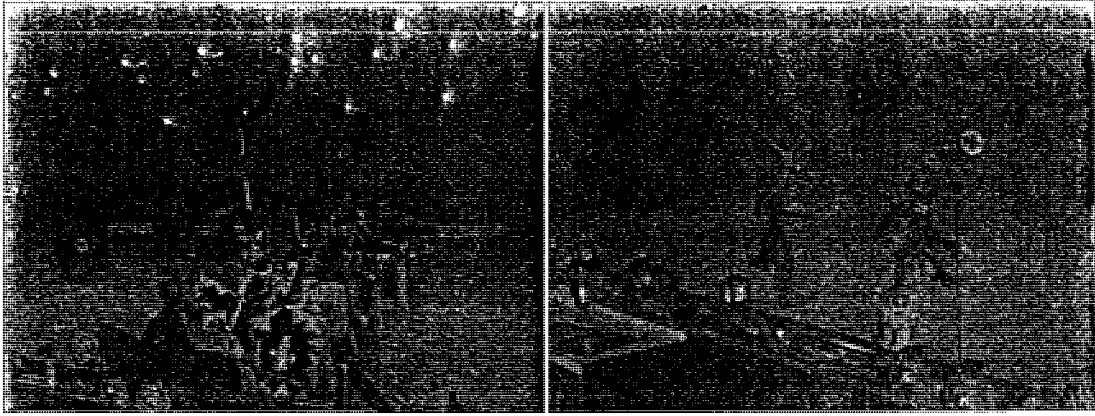
Before leaving, we got a picture with the victorious champion.

The next day, we left the Village in the morning, and by 1 p.m. we were in the sky, flying back home. Time to get back to normal life...
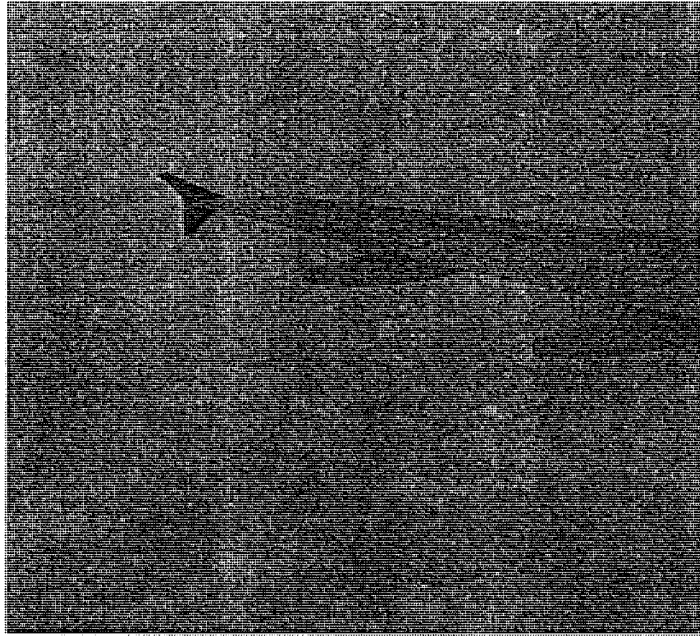
2. Observations regarding the wish fulfillment

The week spent at Disney World in Orlando was filled with a great diversity of encounters, experiences, and emotions. I have tried to provide a "down-to-earth" visual and textual description of Sonya's wish, to offer a double perspective to the reader. Words can't always capture the essence of a situation. This description represents the wish as I observed it – partly distant; partly involved – as it unfolded in front of me. Its representation is at best partial but presents an honest attempt on my part to account for the experience.

In the course of my fieldwork, I was fortunate enough to witness the realization of several wishes. However, to summarize these phenomena is very challenging, because so many events occur during the fulfillment of a wish, and each one is so different. I would even go so far as to say that when it comes to wish fulfillment, the exception is most often the rule. To paraphrase Wendy, there are as many ways of fulfilling wishes as there

are families. One fascinating aspect of wishes is indeed that two initially similar sounding wishes, planned in a similar way, can – and will – be experienced in two very different ways. The two Disney wishes described in this dissertation, Sonya's and Bobby's (Appendix 2), are two such perfect examples: in both cases, the families spent a week at Disney World in Florida; both were single-parent families; in both cases, the grandmother took part in the journey; it was also the first time for both these families to experience long-distance travel. However, the stories reveal two completely different wish experiences. For one, the mobilization of the actors within the network unfolded differently in the two cases. For instance, the respective choice of lodging created two very different scenarios. The Give Kids the World Village is entirely geared to wish families by its very design, decorations, and services offered. Sonya's family genuinely enjoyed every aspect of the Village, from the pizza that can be ordered late at night, to the swimming pool, to the horse rides. The Village in itself constituted an experience, almost overshadowing that of the theme parks. In Kathrin's own words "Give Kids the World could constitute a wish in itself." The Star Island Hotel experienced by Bobby's family, on the other hand, made for a very different experience. Aside from the swimming pool and the spacious rooms, the facility did not attract much of the family's attention, which remained entirely devoted to the theme parks.

Family dynamics also affect the way the families experience their wish. In Bobby's case, the mother had to spend a great deal of energy to contain the boys. Bobby's older brother Jeff needed constant attention from his mother. Although, on the one hand, Jeff was very protective of his younger brother, he was also constantly teasing and provoking him. The wheelchair also became the focus of unending conflict. At the

end of each day, the mother came back home completely drained. No such thing happened with Sonya's wish, whose family experienced a calmer – yet no less exhausting – trip. Other small details made the wishes divergent, from the people incidentally encountered (like the other wish family in Sonya's case) to the stores and restaurants visited (Wal-Mart, Medieval Times, etc.). In short, two separate and distinct wishes gradually emerged from these two a priori identical events.

In the following section, I will highlight three elements of Sonya's wish that can be derived from the experience and that more or less pervade other wishes granted by the CWF.

2.1. Emotional and physical exhaustion

The pace of a one-week trip to Disney is gruelling: You arrive fatigued from travelling, you wake up early the next morning, you spend long hours on your feet, walking almost all day long in hot weather, you return home, you get a little bit of rest, you rise early again the next morning, and you start the routine all over again. Sonya's family experienced this fatigue and talked openly about it. This trip was their first long-distance vacation as well as their first time flying. The novelty of this life experience roused some anxiety well before the trip began. Kathrin described her level of stress before departure:

> *The morning of the flight, we woke up early, because from where our room was in*
>
> *the hotel, we could hear and see the planes taking off. So like it or not, you're like*
>
> *a kid again. My mother and I were beside ourselves. We couldn't sleep, we were*
>
> *so stressed – would everything go as planned? But it didn't, and thank God we*
>
> *had Jonathan with us, eh Sonya? Because personally, I would have been*

completely lost at the airport, and THAT I found stressful! It's a part of the trip

you have to go through, but I didn't like it. I was very glad when we finally got to

sit down for breakfast before leaving. (Follow-up interview, March 2009)

The evening and morning of the flight were especially stressful for the family. Kathrin and her mother did not sleep well. The episode with the lighter added to their anxiety. Breakfast time was longed for and welcomed, because it signalled the end of all stressful airport procedures, since the restaurants were located in the boarding area. Once at Disney, getting a stroller was deemed a necessity in order to help Sonya get through the day. We observed that Sonya's mood and general condition dramatically improved after getting the stroller, which in turn enhanced everyone else's experience of the theme parks. The experience was so exhausting that we found we even needed a "day off" at GKTW after the first day at Magic Kingdom. Not every moment of the trip was considered exhausting, though. According to Kathrin, the experience at Sea World was very different, in that its ambiance (i.e. "people were less in a hurry" and "the decor is more relaxing") did not bring about exhaustion as Magic Kingdom did. Finally, the day spent at Melbourne Beach gave the family a chance to relax.

Fatigue seems to be a common experience of families in the Disney wishes. The scenario described above is fairly similar to the other trips in which I participated. In all cases, we rose early, walked all day, and went to bed relatively late. Bobby's case was even more extreme. We took no breaks from the theme parks all week, and spent most of our days and evenings there. We often returned to the hotel after 10 p.m., went to bed past 11 o'clock, and got up at around six the next morning to eat and get ready to arrive to the site early. "There is too much to see!" and "We don't have enough time to see

everything!" were thoughts commonly expressed by families faced with the vastness of Disney World's, Universal Studios', and Sea World's offerings. In a follow-up interview, Linda and Kathrin reflected on this aspect of the trip:

Linda: Disney was wonderful and all, but they were long days... it was like too jam-packed. You just don't have enough time...

Kathrin: It would have been better to stay two weeks to see everything in detail. It just means we'll have to go back—with a child who's fully recovered.

Linda: Maybe, but it's a lot to pack into a small amount of time. It makes for long, long days, plus you want her to come back with as many memories as possible, so I felt we were rushing through. It was a little too much, it was like she didn't see all that she was supposed to have seen — you know what I mean? But it's not like she complained about it! (Follow-up interview, March 2009)

Wendy and I also discussed this generalized daunting aspect of the Disney wishes. In the following passage, Wendy expresses how impressed she is by families' endurance.

Wendy: It's so intense. Personally, I don't know how they do it. We were there one week, and I just don't get it. I can't figure it out. It's true that it's not like going to any amusement park here; it's not the same thing. But it's hard to grasp that you're going to do six days of theme parks.

J: Yeah, the forced break is a must. I'm in shape and I'm pretty young, but at one point I felt like I couldn't keep up. But, at the same time it's their trip... so you go to bed at a quarter to 11, and you get up at five, because the kids are already up.

So, the parents have dark circles under their eyes, and the kids, by 10:30 in the morning, are already tired and cranky.

W: Those families who do six days at the parks, plus the flight... it's no wonder they don't call us as soon as they get back to tell us how fun their trip was. It takes some time to unwind from all that. (Conversation with Wendy, October 2008)

Obviously, not every wish is exhausting. Many wishes last less than a week or don't involve a flight. Item wishes, like Emily's swimming pool wish (Appendix 2) for example, do not tend to be experienced this way. On the other hand, regardless of whether one travels or not, aspects of the wish can still be draining. Lindsay's (Appendix 2) wish is a good example. Although they arrived one day before the show, and had time to rest, the evening turned out to be wearying. It was a long time before they were allowed to speak to the singer. The time spent stuck in the crowd after the meeting also added to the length of the day. We ended up leaving the place around midnight. It was a long evening for everyone.

2.2. A memorable experience

A wish like Sonya's provides a great source of joyful and memorable experiences. Everything the family experiences can evoke discoveries and stir emotions that are likely to create lasting memories. Theme parks like Disney are themselves veritable worlds of wonder. They gear themselves toward families and carefully engineer their environments so as to enchant the lives of visitors (Ritzer, 2005). They create lasting impressions by means of their large scale, their special use of space and time, their cleanliness and

sophistication, their preponderance of cues that foster positive feelings, and their stimulation of the senses (Pine and Guilmore, 1999).

Indeed, the various shows, the meetings with characters, the atmosphere, and the attractions all combined to inspire awe and enchantment. The photographs presented throughout my description, though a pale rendering of the magnificence of the place, offer an idea of its grandness: bright colours, music, dancing, live animals, princesses, high-tech visual presentations, larger-than-life characters, and so on. These elements all contributed to the dazzling experience. Fatigue aside, the ever-present smiles in the photos are representative of the family's spirits throughout the wish fulfillment. Other elements contributed to the fantastic nature of this journey. Give Kids the World Village played a major role in the creation of the experience. Its theme park-inspired architectural design and philosophy speaks directly to children's fantasy worlds: the presence of Disney characters, a movie theatre, games, brightly coloured buildings, child-size equipment and furniture, free ice cream and pizza, and so forth. The VIP treatment offered by the limousine service further made Sonya feel important, just like a princess. A final factor that added to the marvel of the wish fulfillment was the fact that the family was embarking on its first flight, and got to visit the cockpit.

Even more memorably, the wish itself enabled the fulfillment of a second dream. Specifically, it allowed Linda to see the ocean for the first time. This dream had a particular significance for her. At the end of the follow-up interview, she shared her feelings with me about the importance of realizing one's dreams, and the appreciation she feels for what her late mother told her before she died.

I didn't understand, when my mother was dying, she was telling me she wanted to take a train trip. Then she died and she never got her train ride. But I didn't understand why she kept saying, "Don't waste any time. Live your life, do what you have to do." At the time, I didn't really get why she was saying this, but now I understand. I saw my mom tell me, "I'm going to die and I'm not going to get my train ride." It's sad, you know? And then there's [Sonya], she's only six and this happens to her. You know? She was six, not sixty. It's like wake up, time is running out! It really made me more aware. It's not that I didn't already know it, my mom had already told me this. It's just that it hadn't sunk in before, so... we don't have 50 lives to live, we only get one. If you want to take a trip in a train, then go for it. Don't wait to be retired. It was a wonderful experience, a truly wonderful experience. I'd do it again any time! (Follow-up interview, March 2009)

My observations, as well as discussions with informants, have shown me that the vast majority of families experience wonderful and memorable wish fulfillment events. The children and their families usually experience the wish as a joyful time. Just like Sonya, for instance, Bobby could frequently be seen, throughout the trip, snapping his fingers, shouting gleefully (his way of expressing excitement), and laughing with sheer delight. I saw his mother and grandmother looking at him and smiling and laughing along with him. I witnessed Emily full of smiles for the entire duration of her swimming pool shopping excursion. And these are just a sample of the memories that stand out. I also came across other families, during CWF activities or times they came to the CWF office to describe their wish, who reported equally high degrees of joy.

2.3. Full of surprises

An important element in the organization of this memorable event is unpredictability or surprise. In addition to generating intense emotions, surprise can make an event much more memorable. Pine and Guilmore (1999) explain this using the example of flight experiences: "The most memorable flight experiences, for example, have nothing to do with the expectations of normal – good or bad – airline service but with the events that occur outside the domain of expectations" (p. 96).

Sonya's wish fulfillment experience abounds with surprises and unexpected events, which – for better or worse – inevitably made the event more memorable. To begin with, the tragic cancellation of the Starlight wish had a strong negative impact on the family. They felt highly distressed over the possibility of Sonya's wish being revoked. To this day, Kathrin continues to have bitter feelings about the charity's invitations and solicitations for donations. However, the CWF managed to turn this dramatic situation around and transform it into a joyfully memorable event. Sonya received various unexpected gifts throughout the trip, including the camera bag at the hotel and one gift per day at GKTW. Sonya's mother became an agent of surprise herself by spontaneously offering presents, such as the flashing pins and the watch. At times, she deliberately withheld information from her daughter, to increase the shock effect. For instance, she didn't tell her that a limousine would drive them to the hotel, nor that the villa would be decorated for "Christmas Day." A third element of surprise occurred every time someone unexpected encountered the family in unpredictable ways. The episode in the limousine got things off to an interesting start:

Then at one point, the limo got lost. The driver didn't know where he was.

[Sonya] said, "I feel like we're going around in circles." "No, no," I told Sonya,

she must have had a little too much champagne, it was her head that was

spinning. So the chauffeur came to see us. He was Italian and he said, "I'm lost,

ladies. Don't worry, I'm honest enough to tell you that we're lost." But we

already knew we'd been turning in circles. Is the driver stalling us on purpose? Is

there something special we're supposed to be noticing outside? And then when we

arrived at the hotel, we were welcomed ... and Sonya went wild over her dress!

And then we were so excited about our trip that we forgot the camera in the limo

[...] (Follow-up interview, March 2009)

Another unexpected event involved the waiter we met at the hotel's restaurant the night before the flight, who by chance had a son who'd been seriously ill. This spurred interesting conversations, and Sonya ended up getting treated to a free piece of cake. We also incidentally encountered two wish families during the journey. A connection was made with the second of these families, and they accompanied us to Medieval Times. A volunteer from GKTW, furthermore, surprised everyone by greeting us at the airport. All these people, encountered by coincidence, added to the magic of the wish experience.

As detailed as Wendy's plans had been, there was still room in the trip for a number of unexpected activities and situations. For instance, no one had predicted that Sonya would be riding a horse at GKTW. The Medieval Times dinner and the visit to Melbourne Beach also occurred to us only once we arrived in Florida. Other elements, such as the visit to Wal-Mart, became possible only due to the convenience of the store's location. Finally, the weather added an element of uncertainty, as it changed dramatically,

every day, from one hour to the next. We sometimes had to adjust the schedule accordingly (e.g. we left Sea World somewhat early because the sky was becoming ominously dark).

The other wishes I witnessed or heard about all contained elements of surprise. For example, we did not expect that Bobby would be traumatized by the Lilo and Stitch show, affecting the course of events (see Appendix 2). The entire family was also fascinated by the many lizards seen running everywhere on the hotel grounds. A Greek family who went to the 2006 World Cup in Germany serendipitously met another Greek family who invited them to dinner at their home, which led to a memorable evening. Lindsay's boyfriend (see Appendix 2) surprised her by showing up at the concert after driving thousands of kilometres. It was also impossible to envision how the meeting with the singer would be orchestrated in Lindsay's wish: we didn't know when or how it would happen, or how long it would last. Less elaborate wishes, even item purchases, can be embedded with surprises. Emily and her mother (see Appendix 2), for instance, did not expect the whole store to be decorated with balloons and CWF banners, nor did they expect to be welcomed with chips and refreshments. They didn't expect Debbie to bring Harley Davidson clothes either.

In Chapter 3, I proposed that a procedural gap manifests at specific steps along the wish granting process. During the wish fulfillment sequence, the element of surprise signals another important gap, namely the *script gap*. A script is defined as "a coherent sequence of events expected by the individual, involving him either as a participant or as an observer" (Abelson, 1976:33). A script gap suggests that the participants (in this case, the family members) have no prior experience-based knowledge about the upcoming

course of events, nor of their exact role within the scenario (Salomon, Surprenant, Czepiel, and Gutman, 1985). Indeed, for the vast majority of families,[88] the granting of a wish is a once-in-a-lifetime experience, and previous landmarks or memories regarding wishes are limited if not completely absent.[89] Most of them have had no prior experience with a wish-granting organization and therefore have no basis for internalized expectations about the story line. In addition, like Sonya's family, a number of others had never experienced international travel, celebrity encounters, or the purchase of particular specialty items like a luxury guitar, a trailer, a swimming pool, and so on. As such, it is natural that they would experience unexpected events through the unfolding of their wish.

2.4.   A multiplicity of actors

Similar to the process sequence described in the previous chapter, the wish fulfillment sequence can be extensively enmeshed with a web of actors. In fact, the wishes described throughout this dissertation highlight the variety of roles played by, and the varying degrees of involvement of, the different actors concerned with wish delivery. Sonya's wish fulfillment is an apt example of how the social network can be deployed to its fullest extent to enable the wish to come true. Figure 4.1 summarizes the various actors (or groups of actors) who took part in granting her wish. Their order of appearance roughly follows the timing of their initial involvement with the fulfillment.[90]

Figure 4.1: Chronological appearance of actors involved in the fulfillment of
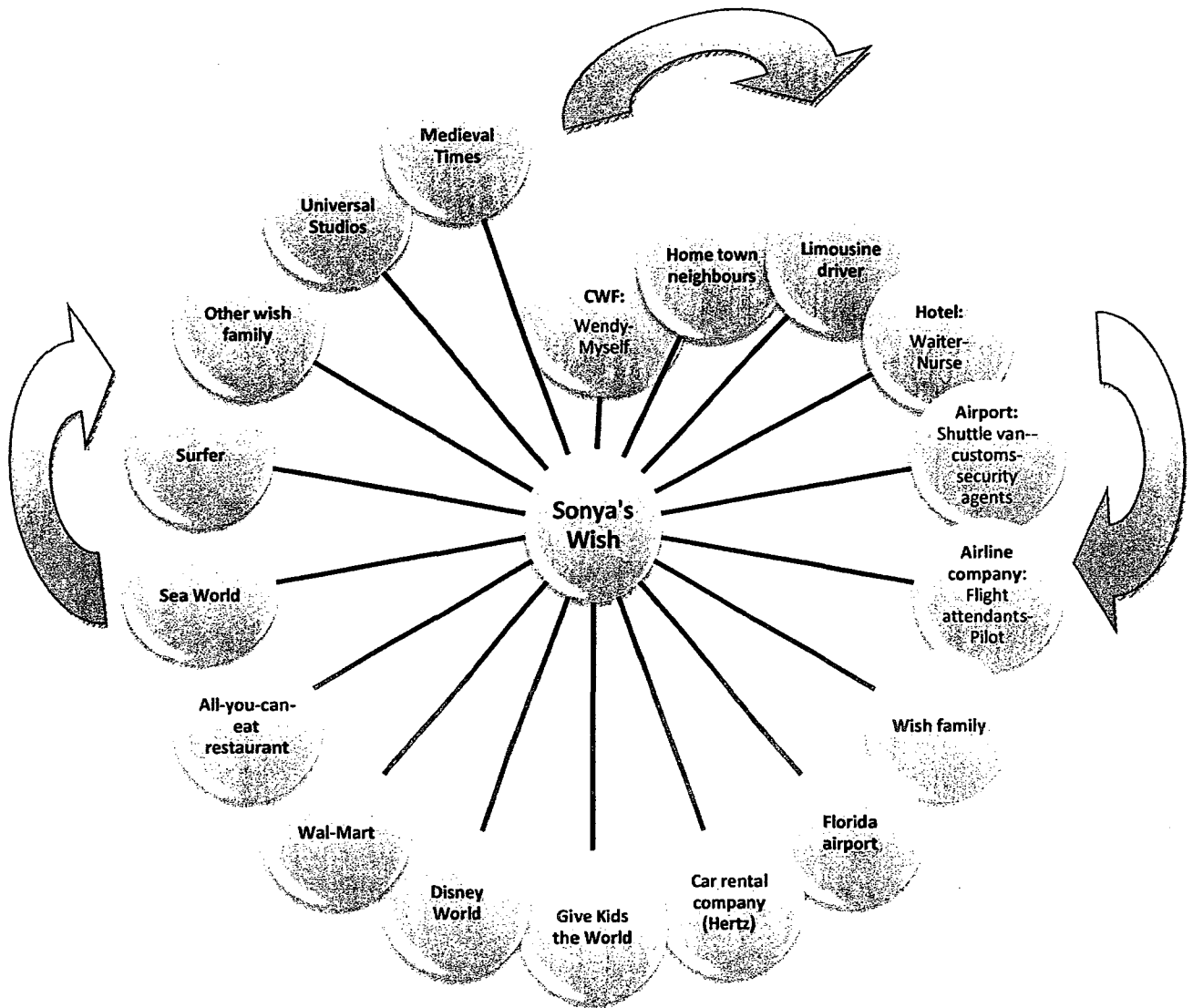
Sonya's wish

In this figure, we can see that the three groups identified in chapter 3, namely the marketplace, the community, and the wish-based actors, are again involved in the construction of the wish.

2.4.1. The marketplace

Sonya's wish offers a great example of the prevalence of the marketplace in the fulfillment sequence. The marketplace's presence can indeed be felt everywhere. In fact, broadly speaking, the majority of the individuals or organizations involved in her wish are tied to the market, insofar as they offered a product or service in exchange for money (either paid for by the family or the CWF). If it were not for them, the wish simply could not have been a reality. The marketplace takes various forms and fulfills a number of functions. Some marketplace players are necessary for the wish to come true even if they do not occupy a central place. They are necessary from a logistics perspective. In Sonya's case, the hotel, Air Canada, Hertz rental car in Florida, and the limousine company all played this facilitative role. Indeed, the limousine clearly enabled the wish by providing a means of transportation between her home and the hotel at the beginning and end of the trip. In addition, the family needed a two nights' stay in a hotel in order to make their early morning departure and return trip feasible. Finally, the wish would not have been possible without air transportation, nor would it have been easy to get around Orlando and the surrounding area without a car.

The marketplace does not only play a logistical function, but can also be associated with the core definition of a particular wish. In Sonya's case, going to Disney was the essence of her wish. Every aspect of the theme park was associated with a product or service that promotes consumption: meeting princesses and other Disney characters, attending performances, eating in themed restaurants, purchasing souvenirs, seeing the attractions, and so on. In other words, for Sonya and her family, Disney was the wish,[91] and by extension, the marketplace *was* the wish. It should be noted that

Universal studios and Sea World also figured prominently in her wish and the family's later appreciation for the trip. As those other two parks were part of the original wish definition, which consisted of spending a week in central Florida to visit three theme parks (Disney, Universal Studios, and Sea World), they too *were* the wish. However, for efficiency of communication, this wish is normally referred to as the "Disney wish" in the wish-granting policies manual, as well as by Wendy, other employees, and the families.

Finally, some encounters or activities derived from the marketplace, while not planned in advance as part of the definition of the wish, end up occupying an important place in the wish fulfillment experience. For instance, although one could not have foreseen it as part of the wish, Wal-Mart played a significant role in Sonya's fulfillment trip. Indeed, unexpectedly, this retail giant became a memorable attraction. The family enjoyed visiting it and were amazed by its size. Wal-Mart also became an important provider of souvenirs and surprise gifts that the family brought back to the villa and their home. A major factor leading to its role in the wish adventure was its convenient location. The store is easily accessible en route between the theme parks and GKTW. In the same vein, the Medieval Times restaurant played an important, yet unexpected, role in the wish. It was only after looking at the GKTW brochures that we considered going to the restaurant. The restaurant's medieval experience added notable colour and flavour to the journey. The family greatly enjoyed the performance with the horses and actors. They also liked the abundant food served in the traditional fashion. Furthermore, the show provided an opportunity to get to know another wish family. Finally, the all-you-can-eat

restaurant also turned out to be memorable for the family, who revelled in the variety and abundance of the food offered.

The marketplace is not the only actor involved in wish fulfillment, of course. Although non-marketplace actors (i.e. charity- or community-based) do not occupy as central a role in the wish fulfillment as they do in the wish process sequence (see Chapter 3), they are often nonetheless active in the wish fulfillment.

2.4.2. Charity-based actors

Three charity-based actors were involved in the fulfillment of Sonya's wish: the CWF, other wish families, and GKTW. Sonya's case highlights the fact that, in addition to being the orchestrator of the process sequence, the Children's Wish Foundation is sometimes also involved in the fulfillment of the wish. In her case, it was by means of a volunteer (myself) who accompanied the family to Orlando. In such a scenario, the volunteer acts as an active facilitator of the wish and assists the family throughout the experience: getting through the airport and customs, driving around Orlando, liaising with the various theme park employees on behalf of the family, acting as a translator or interpreter when a family's English is limited (as can be the case with some families from Quebec), and in many other ways. In addition to facilitating the wish, the volunteer complements it by developing a cheerful and upbeat rapport with the children and their parents. Debbie's participation in wish granting illustrates another example of the important role the CWF can play during the fulfillment. In Emily's case, she accompanied the family during the shopping trip and took care of the administrative and financial matters. This allowed the family to focus mainly on the activity of shopping.

The CWF also sometimes sends an employee to take part directly in the fulfillment. In most cases, Wendy is the one designated to participate in shopping excursions with families. In such cases, Wendy not only adds to the positive spirit of the experience, but also supervises the entire activity to make sure that budgets are respected and that the child's voice is heard when there are doubts as to whether other actors, such as family members, may appropriate the wish or interfere with its realization. Other rare cases like Lindsay's may require the presence of a CWF employee to ensure the smooth delivery of the wish and to protect the family as well as the wish provider (see Appendix 2).

Other wish families may, occasionally and usually unexpectedly, enter into the realization of a child's wish. Sonya's family accidentally ran into two other families during their trip. The first they encountered on the plane, and they met the other family at Give Kids the World. The latter family ended up accompanying us to the Medieval Times restaurant, where we spent an enjoyable evening together. To this day,[92] Sonya's mother Kathrin talks about these coincidental encounters. In this sense, wish families can grow to complement one another's wishes.

Finally, aside from the CWF, Give Kids the World is an important charity often involved in wishes. During the fulfillment of Sonya's wish, it played two roles. First, it offered an inexpensive alternative to the regular hotels and provided highly comfortable lodging tailored to the needs of ill children. It also became the main intermediary between the CWF, the family, and the theme parks by communicating useful information and tips regarding the theme parks and providing the much needed Guest Assistance Pass and tickets. As such, in this case as in others, GKTW takes on a facilitative role in the

fulfillment of wishes. Second, it plays a complementary role in the experience with its larger-than-life facilities, activities, characters, and fun.

2.4.3. Community actors

Three main community actors were involved: the extended family, the customs agent, and a local Florida resident (the surfer). Normally, extended family and friends may or may not be involved in the process, depending on the context of the family and the desires of the sick child. A shopping excursion might, for instance, involve the child and the parents alone, while a trip may also include grandparents, cousins, and friends. In Sonya's case (as well as Bobby's), the grandmother was an integral member of the family, and a wish without these women would hardly have been the same.[93]

Customs agents play an important role in the wish. For wishes involving international travel, the border crossing is an unavoidable step. Agents facilitate wishes by authorizing families to enter a country. However, as we saw with Sonya, they may also actively complement the wish by becoming a memorable part of the whole experience. Families like Sonya's, who are new to travelling, often report that the customs procedures stand out for them as a significant part of the experience. In addition, unexpected events surrounding customs and security can add a layer of anxiety. Sonya's grandmother Linda, having left a cigarette lighter in her purse, had to be searched, which created a stressful moment. In fact, it's still fresh in their memories almost three years after the trip.[94] Finally, other people from the community may participate indirectly in the wish. The Melbourne Beach surfer, for one, was added to Sonya's wish experience when she kindly spoke to us about surfing and her experience with jellyfish, and took pictures with us.

3. Discussion

My detailed description of Sonya's family experience is an attempt to delve into the materialization of wishes. This description (as well as the others offered in Appendix 2) proposes to put the consumer back into the wish, *literally speaking*. Too often, as I mentioned in Chapter 1, the study of desires, goals and dreams has relied heavily on discourse, either through self-reported surveys or interviews, of past or anticipated aspirations, like studies of Belk, Ger and Askeegard (2003), Fournier and Guiry (1993) and d'Astous and Deschenes (2005), the work of Bagozzi and his colleagues, and so forth. In this chapter, I sought to seize the opportunity to introduce the wish, not as it is explained or described by informants, but as it was experienced. I highlighted four findings regarding Sonya's wish: the emotionally and physically exhausting nature of the wish, its potentially memorable and surprising qualities, and the depth of the deployment of actors involved in the wish. I will now take a step back and offer an analysis of the wish by reflecting on its qualities as a consumer experience. To do so, I will compare it mainly to Arnould and Price's (1993) analysis of the river rafting experience.

3.1. The wish as an extraordinary experience

When reflecting on the experience as it was lived in the context of Sonya, it is possible to argue that the materialization of a wish is best described as an extraordinary experience. Following Arnould and Price (1993) and their conceptualization of the experience of river rafting, Sonya's wish can indeed be considered extraordinary. An extraordinary experience, as the authors put it, "is triggered by unusual events and is characterized by high levels of emotional intensity and experience" (p. 25). Indeed, Sonya's wish is not merely an enjoyable moment or hedonic consumer event (Holbrook and Hirschman,

1982). As I illustrated, it builds on various highly enjoyable developments. In addition, her wish is highly intense and absorbing – another main element of extraordinary experiences according to the authors – as it stems from a multitude of highly focused elements new to the family: taking a plane, going to the US and crossing the border, visiting theme parks, experiencing hot weather, going to the sea, etc. Finally, the novelty of the wish experience for the family suggests an extraordinary dimension. As Arnould and Price (1993) argue, the highly novel character of an experience will make it extraordinary if it is anticipated only with vague expectations. Due to its novel and dynamic character, the extraordinary experience emerges as unpredictable, and is therefore likely to be attached to vague expectations. As mentioned in the findings, the experience of Sonya's wish exemplifies this novel, emergent, and unpredictable aspect of the extraordinary experience.

3.1.1. Components of the extraordinary wish

An extraordinary experience stems from the global narrative of events and actions (Arnould and Price, 1993). Based on the description of the wish and the preliminary findings, we can see that the extraordinary character of Sonya's wish is embodied by three overarching themes: the intensive involvement of the body, the particularities of space, and the engagement of people.

Intensive involvement of the body. Experiencing is defined as "the act of living through and observation of events" (Hoch, 2002:448). It is therefore not just something to be witnessed. It is experienced in the flesh. For instance, Sherry (1998) showed that tactile and proprioceptive engagement allows the building of the experience of the Nike Town

brand. Joy and Sherry (2003) go further and show that the body deeply mediates the relationship between the consumer and the experience on conscious, phenomenological, and unconscious levels. Here, the experience was felt through the body through intense emotion and fatigue.

First, the powerful impact of the wish materialized in the form of highly intense emotions. This emotional aspect of the wish was reflected in the body *before* and *during* the wish fulfillment. During their preparations, the anxiety of the unknown associated with the trip (taking a first flight, passing through customs) and the fear of aggravating Sonya's condition contributed to a sleep disorder, which appeared long before the trip and progressively disappeared in Florida. Overall, the extreme physical character of the experience was definitely out of the ordinary for them and helped define the specificity of the wish. Also reflected in the body during the wish was the emotional aspect. Smiles, laughter, expressions of wonder and curiosity, and dancing were omnipresent throughout. I, myself, still remember experiencing muscular fatigue after smiling for too long a period.

Second, a week at Disney requires a large amount of energy and becomes potentially exhausting, like many other travel wishes. Wishes like Sonya's demand high levels of energy from the moment of departure until the moment of return. It is not just a matter of exhaustion, though. It is experienced in the body; it permeates it. Physical exhaustion is experienced in space, as miles and miles have to be walked in order to witness what every site has to offer. It is also experienced in time and exposure to the constant heat of the Florida weather. Days start early and end late under the burning sun. The evolution of Sonya's condition through the week revealed the importance of the

bodily experience of the wish. In the first days of the week, after long walks and constant exposure to the sun, she just couldn't handle it. At some point, she *could no longer experience the extraordinary*. As her bodily expressions suggested, she appreciated the time spent in the air-conditioned restaurant even more than spectacles like the one at the Disney castle. Throughout the week, the family learned to deal with physical exhaustion. A major change in the situation was achieved after getting the stroller. Sonya's energy was renewed and her ability to take lengthy walks increased. They also realized the necessity to take "time off" during the stay (staying at GKTW and going to the beach). All in all, this intense emotional and physical fatigue experienced through the body contributed to the specificity of this extraordinary experience.

Particularities of space. The experience was also fashioned by the particularities of the places we visited. Pine and Guilmore (1999) argue that this aspect of space is the most critical component of the experience and has to be carefully planned by the marketers to offer a combination of engaging realms of experience. For instance, Kozinets, Sherry, Storm, Duhachek, Nuttavuthist, and Deberry-Spence (2004) provide an example of setting and its impact on the consumer when exploring the ESPN zone. They conclude that the manifestation of the audience, the shining spotlights, and the multiple elevated stages contribute to the selling of the superstar athlete and celebrity fantasies. In the wish we explored, many elements of space contributed to the extraordinary nature of the wish. For one, a cockpit is an unusual site of attraction for lay consumers, and being able to visit the cockpit and talk to the captain was a very special event. Also, GKTW's unusual architecture and its adaptation to the scale of children's bodies created a sense of fascination. The family had not been expecting to sit on a child-size chair at a child-size

table while eating at a Gingerbread House. Furthermore, Disney and other theme parks' extravagant buildings, colors, and spectacles (Ritzer, 2005) contributed greatly to the experience. For instance, to see snow falling from a cloudless sky during a burning hot day was exceptional. The possibility to touch and feed dolphins also left a powerful impression on the family. Finally, the vision of the sea was spectacular for the first-time viewers.

The specificity of the experience came not only from buildings and sites, but also from the means of transportation unusually used by the family to go from one place to the other: plane, train, limousine, and ferryboat. "All this for me?" was the expression used by Sonya to express her surprise when seeing the limousine for the first time. With transportation comes the experience of distance. We had to walk and drive long distances. The sea was an hour away from Orlando and forced us to explore unknown places. Distance was also experienced in terms of how far we were from home during the experience. The family kept in mind throughout the trip how far they were from home, and they brought with them to Florida memories of loved ones and homesickness. (At night, whenever time permitted, Kathrin called her new boyfriend and Sonya spoke to her father and stepsister). Being far away, in spectacular places, therefore participated in the creation of the extraordinary character of the experience.

Engagement of people. Finally, people actively played a critical role in the development of this extraordinary wish. Primarily, the family "accommodated" the wish on many occasions. As Hoch (2002) rightfully suggests, we often tend to forget that consumers are flexible in accommodating their experiences. In fact, Sonya's family did not make a case when they learned that the Disney site was closing early due to a special event. In

addition, they consented to walk long hours and go to bed late and exhausted. They did it despite the fact that they would have to do it again the next day. They also consented to be away from home, friends, and loved ones. They did it despite the fact that Sonya was a "sick child" (although she recovered from the disease.)[95] Globally, these little accommodations, when added up together, allowed the wish to be what it became. Without accepting these conditions, the family would hardly have allowed the wish to become a grandiose experience. They decided to *open up to the extraordinary* and consented to experience things as they unfolded. On many occasions, the family also took charge of the wish. They made decisions (for example to go to the beach or to go to Medieval Times). They were not afraid to try things and seize opportunities.

In addition, in the construction of the extraordinary, various people helped to add the element of surprise. Various actors appeared and disappeared at particular moments in unplanned ways and contributed to the event. They also gave unexpected gifts (like the waiter at the hotel who gave Sonya a piece of cake, or Kathrin who bought her presents on diverse occasions). Finally, another extraordinary element embodied in the people who participated is the fact that the wish became a means to fulfill another wish. Sonya's grandmother Linda, thanks to her granddaughter, was able to see the ocean for the first time. The fulfillment of this wish added a special dimension to the whole experience. It permitted Linda to create a connection with her late mother and to reflect on the importance of fulfilling one's dreams – knowing one's finitude. Hence, the various people engaged in the wish contributed to its extraordinary nature.

3.1.2. Comparing River Magic and Sonya's Disney wish

These narrative components of Sonya's wish share both similarities and differences with the ones identified in the river rafting case. First, similarly to Arnould and Price (1993), they highlight the importance of people in the creation of extraordinariness. According to Arnould and Price, extraordinariness reveals itself in a communion of actors, described by the authors as "feelings of linkage, of belonging, of group devotion, to a transcendental goal" (p.34). In Sonya's case, the communion was not as central to the experience. In fact, aside from the family, most of the actors were involved in a sporadic manner, with multiple disconnected goals (as various actors are involved in different episodes of the wish.) Furthermore, the family's capacity to accommodate the wish is central to the experience. Wish families are significantly distinct from the consumers involved in the river rafting case in that they have to deal not with imaginary or anticipated potential bodily threats, but with real illnesses and medical complications.

Second, also in the same way as in river magic, the experience of the wish involves a relationship wish space. What contributed to the rafting experience was the canyons' fascinating beauty and "limiting" design: its divine character, the "narrowness" and "solitude of the canyons," limited by the lack of noise from the city and by the surrounding walls. The experience of the lieu followed the "time of the river": they got up with the sun and went to bed by nightfall. No watch was allowed, except for the guides. The space in Sonya's case, contrarily, was experienced in a highly engineered setting. It took its specificity from its extravagance and its greater-than-nature aesthetic feel. Also, it seems to have been experienced as vaster and more diversified – as we had to travel long distances both in and to various sites, and by various means of

transportation. Also, contrary to the river rafting experience, time was set by strict around-the-clock planning, to maximize site coverage and to ensure we would be at the right place at the right time.

The river rafting experience involves a sense of personal growth and renewal of self through skill acquisition (learning a language, mastering boating navigation techniques) made necessary by the dangers and obstacles to overcome. The bodily transformation is hence encapsulated in these sorts of transformations. In the wish case, we saw that the experience is also highly embodied and that it also entails elements of transformation (for instance, Linda developing the understanding of the existential concern formulated by her mother). The notion of potential transformation will be further explored in Chapter 5.

Based on this comparison, we can conclude that extraordinary experiences can happen in distinct settings, as summarized in the comparative table below. In that regard, it is also interesting to note that to Arnould and Price (1993), extreme sport and the divine wild define an experience as extraordinary. Indeed, in clarifying the definition of the extraordinary, they mainly compared river rafting to rock climbing and sky diving. Similarly, Celsi, Rose, and Leigh (1993) found that consumers experience the wild and the extreme as a way to create the extraordinary by reinforcing a dramatic worldview in their existence. Contrary to this implicit association, my research suggests that the experience of the extraordinary is not limited to extreme sport situations. Sonya and her family experienced a consumption of the extraordinary in the "comfortable" zone offered by theme parks and associated urban consumption places (Ritzer, 2005). It follows the study by Kozinets, Sherry, Storm, Duhachek, Nuttavuthist, and Deberry-Spence (2004),

who shows that exceptional experiences can also happen in the commercial context of retail stores.

Also of importance in the creation of the extraordinary, is the divine wild. The communion with nature was possible through reverent feelings towards its greatness. The guide participated in creating this divine narrative by emphasizing the fact that "you have to believe in something in a place like this." Similarly, O'Guinn and Belk (1989) noted that the religious aspect of Heritage Village was necessary in the creation of the extraordinary shopping experience. The religious is then contaminated by the secular sphere of consumption (Belk, Wallendorf, and Sherry, 1989). In the context of my research, the religious aspect is not part of the extraordinary. Finally, the guide notably played an important role in the creation of the rafting experience by "inviting the production of community" and "reinforcing the production of teamwork" (p. 34). In the case of Sonya's wish, there is no formal guide. However, Wendy played an upstream role in the process. Once on the wish fulfillment adventure, the family was "set loose" to live the experience.

Table 4.1: Comparison between "River Magic" and Sonya's Disney wish

River magic experience	Sonya's Disney wish experience
Natural setting	Engineered urban setting
Divine nature	Greater-than-nature engineered settings
Wilderness experienced as limiting and narrow	Urbanity experienced as vast and diversified
Following nature's time	Following rigorous time management
Guided communal-goal group	Family-centered, surrounded by sporadic goal-diversified actors
Embodied experience through acquisition of skills	Embodied experience through emotional and physical intensity
Transformation	Transformation
Formal guide participating in the experience	Informal. Played un upstream role in the construction of the experience

It is also interesting to note that Arnould and Price's (1993) definition of the extraordinary is even more restrictive when considering their argument regarding the notion of expectation. As mentioned earlier, extraordinary events are highly specific and are hence expected to lead to the creation of vague expectations –an idea also in line with the experience of Sonya's wish. This idea leads Arnould and Price (1993) to reject the usual theory of expectation based on the disconfirmation paradigm. This paradigm proposes that expected and actual situations are compared when assessing the experience: "purchase and usage reveal actual performance levels which are thought to be compared

to expectation levels using a better-than, worse-than heuristic" (Oliver, Rust, and Varki, 1997:315). High levels of joy and other emotions are triggered by *positive disconfirmation*, which happens when "low probability desirable events occur or high probability undesirable events do not" (Oliver, Rust, and Varki, 1997:315). Indeed, the novel and unpredictable aspect of an extraordinary experience forces us to challenge this approach: no one really knows what to expect from such a novel situation. No one really knows what to expect from river rafting before doing it for the first time. Disconfirmation then has no relevance. In their attempt to further the criticism of disconfirmation theory, they distinguish extraordinary experiences from other types of experiences through the culturally-embedded premise that "well known" consumer situations do not pertain to the realm of the extraordinary. In order to show an example of a non-extraordinary experience, they apply this reasoning to Disney and say, "Disney World packages history, fantasy, and the future into conventional plots, portraying idealized American cultural values" (p. 27). Disney customers would have the cultural references needed to build expectations which would diminish the extraordinary aspect of the experience. Based on that culturally-embedded premise, then, in theory, Sonya's wish would not include the extraordinary. When we apply their argument to Sonya's case literally, we are forced to acknowledge that each aspect of her wish is "culturally well-known" – from a Western perspective, at least: being a tourist, flying, going to theme parks, dining in restaurants, sleeping in hotels, going to the sea, etc.

Based on the experience of Sonya's wish (as well as others such as Bobby's), this limited conceptualization of the extraordinary experience is simplistic. In fact, Sonya's trip proves that this culturally-embedded condition is not sufficient in defining the

extraordinary experience. In Sonya's case, the novelty resided not in the absence of culturally-shaped expectations (of which there were many) but in *a generalized absence of individual script about the wish* (as I mentioned in Section 2.3). As Latour would argue, culture here is an "actant": it does not play an active role in the creation (or should we say in the hindrance) of the novelty and of the extraordinary. The family had seen planes before (and watched movies featuring planes), had visited tourist places before (and therefore experienced the idea of being a tourist), had seen Disney movies and seen the theme parks from the Disney brochures, and had discussed theme parks with friends. More generally speaking, many families like Sonya's discuss their wishes with other families, as I showed in Chapter 3 (wishes can be contagious).

In sum, the experience of Sonya's wish – which echoes the experience of many Disney wishes – forces one to revisit Arnould and Price's (1993) somewhat restrictive definition of an extraordinary experience. The elements that make anything an extraordinary experience are not limited by socially and culturally predetermined conceptions. On the contrary, I showed one can experience the extraordinary in his own culture. As the experience of the wish has shown, if it is experienced through the intense use of the body, spectacular dimensions of space, and a strong engagement with people, it may reveal its extraordinary dimension regardless of the cultural setting in which it unfolds.

So far we have observed the process leading to the creation of a wish and the experience of its fulfillment. It is now time to look at the final sequence and try to understand its impact on the family.

Chapter 5

A taste of the 'wish afterlife' through the experience of hope

The following chapter explores the third and final phase of the wish sequence: its afterlife. More precisely, I propose to look at the evocative power of the wish and the influence that even its mere contemplation can have on the course of a family's life. I argue that when facing childhood illness, contemplation of the wish can trigger the development and preservation of hope. Hope is a recent concept in consumer research, introduced by Deborah MacInnis and the late Gustavo de Mello. This chapter explores the relationship between hope, the wish, and the illness in the lives of the wish families. It introduces three types of hope that families commonly experience: hope for the wished item or experience, hope for outcomes, and hope for a personal or life transformation. It will show the way that these three levels of hope manifest themselves and the strategies families use to evoke them. This chapter further builds on de Mello and MacInnis's (2005) preliminary exploration of the three facets of hope – having hope, being hopeful, and hoping – and demonstrates how exploring the three facets can help shed light on the evolution of hope, from hoping the wish will be granted and fulfilled to hoping on a deeper, more existential level. My reflections are rounded out by findings from the literature on hope and illness, mainly from the fields of psychology and medicine.

1. Hope in the context of wish granting

In the context of illness and healing, hope in Western culture is central. It is deeply enmeshed with the practice of medicine. Nowadays,[96] doctors give much importance to

instilling hope into their patients through positive prognoses and the disclosure of medical procedures, to help facilitate the clinical relationship and the illness experience (Delvecchio Good, Good, Schaffer, and Lind, 1990). Hope is also ever-present in the advertising and fundraising events of major illness-related charities, such as the American Cancer Society and the Breast Cancer Society, lending support to the "search for a cure" (Patterson, 1987; King, 2006). At the root of giving charity and obtaining government funding, this phenomenon can be referred to as the *political economy of hope*:

> *"The funding of cancer research both depends on and promotes a vision of cancer as curable. Thus, research and treatment institutions, together with patterns of availability and promotion of particular anti-cancer therapies, the search for treatments and cures by patients and their families, and norms of disclosure are linked in what we have chosen to call 'the political economy of hope.'"* (Delvecchio Good et al., 1990:60)

Hope plays a central role when dealing with illness and when raising money to cure diseases. Along these lines, hope is omnipresent in the reality of the CWF. Every day, employees like Wendy and volunteers like Debbie spend time with families planning and fulfilling wishes. In both my interactions with the families, and my observations of the interactions (verbal and written) of the CWF representatives with the families, it struck me that hope was not present merely in relation to the illness, but in relation to everything, permeating the entire process. A wish offers hope and consequently reverberates into deeper issues than the illness or even the wish itself. It can change the course, temporarily at least, of the downward spiral described in chapter 1. A wish can potentially reintroduce continuity into the family system by providing a future-oriented

common goal, into which they may invest their psychic energy. Introducing a wish into one's life can inspire or reinforce hope in life itself. As Dr. Dany Charest, paediatric neurosurgeon, points out:

> *"From the moment we start with treatment, there has to be hope, there has to be a goal. And I think that Children's Wish provides [families] with these hopes and something to look forward to."* (Excerpt from *Can Hope Heal?*)

We will explore this idea first by identifying the types of hope that families commonly experience.

2. Types of hope

Consistent with MacInnis and Chun (2006), families interacting with the CWF expressed three types of hope: hope for the wish item or experience, hope for outcomes, and hope for personal or life transformation. These findings emerged through my observations of the participants and my readings of the many letters sent to the CWF. They will be elaborated in the following pages.

2.1. Hope for the wish item/experience

Hope for the wish item or experience is a by-product, per se, of the wish granting process sequence. It arises in relation to specific uncertainties inherent in the process. It can be manifested at two points in time. The first occurs with the question of the eligibility of the child. Before eligibility is confirmed, families are kept in a waiting period during which they hope that it will be granted. The source of uncertainty lies with the three eligibility criteria. As we saw in chapter 3, although the first two criteria (age and

citizenship) are relatively easy to assess, the child's condition sometimes requires further investigation, putting the family in a hopeful waiting mode until the assessment of eligibility is provided.

The second instance of hope relates to the approval of the wish. Some wishes, like going to Disney, are common and therefore easy to approve by the CWF, while other less common ones, like travelling to Japan, meeting a celebrity, or cycling around the face of a volcano, require more thorough evaluation. Other family-related issues, such as travelling with a specific disease, or trying to bring relatives from a sensitive country into Canada, also create uncertainty in the approval outcome, and require hope both in the process and the competence of the CWF employees.

Sonya's case is an apt illustration of the tension and hope inherent in the granting process. At the beginning, their horrible experience with Starlight, whereby their wish was put to an end just weeks before the trip was to take place, was heart-breaking for the family. Kathrin's contact with Wendy offered a second chance to keep the wish alive, thereby restoring balance in the family. Sonya's case, however, was uncertain due to the progression of her illness; it had, thankfully, been growing less life-threatening over time, as she recovered from the coma, but this had the side effect of potentially diminishing her chances to go to Disney World. Kathrin recalls the phone conversation she had with Wendy:

> *"She said, 'One thing's for sure, I can't leave you like this... but you know,*
>
> *usually we prioritize cases where [chances of survival are critical], like leukemia;*
>
> *the serious cases.' She said, 'In my opinion, your child's case is serious enough.'*
>
> *But she didn't have Sonya's complete medical file [...] Wendy did everything she*

could and we were able to leave for Florida – to Walt Disney." (Interview with

Sonya's family, March 2009)

Clearly, at the beginning, the outcome of the process was uncertain, although Wendy

seemed somehow optimistic. Kathrin's reminiscence shows that Wendy, like other CWF

employees and volunteers, keep the notion of hope in mind at all times when interacting

with families throughout the wish granting process. When unsure of a child's eligibility,

for instance, Wendy normally prefers to use a neutral tone with families to avoid

instilling false hope. She usually waits until the final decision has been made before

conveying anything about the verdict, unless she can be sure that the child's medical

condition will make them eligible (e.g. A-list illnesses examined in chapter 3) and that

the wish will pose no threat to the health of the child.

2.2. Hope for outcomes

Even after the wish is approved, families continue to nurture hope, but now the target of

hope shifts to the potential outcomes and consequences of the wish. Hope for outcomes

are twofold: wish-related outcomes and illness-related outcomes..

2.2.1. Wish-related outcomes

Wish-related hope stems from contemplation of the fulfilment of the wish itself. It can be

experienced at two levels. First, families may hope that positive wish-congruent

outcomes will be experienced during the realization of the wish. Families hope for quality

family time and genuine enjoyment of the event. This is, in essence, what motivated

Maria (chapter 3) in the definition of her wish; she hoped that the wish would be a

positive experience for her hyperactive younger brother, which led her to significantly

modify her wish from a Cuba trip to a Disney Cruise. Bobby's brother Jeff (Appendix 2) also expressed hope for positive outcomes on many occasions prior to departure, such as when he asked enthusiastically, "We're gonna have fun, hey?" or when he stated simply, "We're gonna have a very nice weekend."

The mere suggestion of the wish and its potential positive outcomes can carry an emotional charge. One family sent, along with the documents Wendy required to finalize the approval of the wish (medical information), a letter. In the letter, Laura's mother briefly describes her daughter's feelings since the process began. The impending granting of the wish was filling her with excitement and anticipation:

Hello,

As promised, I am enclosing the papers completed by Laura's doctor. I'll wait for your phone call to know the next steps.

Laura has been beside herself with excitement since I told her about this wish (after you and I talked). She's on cloud nine. This wish has given her a burst of energy and boosted her morale, which has encouraged her to persevere with her treatments. And it has come just when she needed it most. She said to me, "I have CF [cystic fibrosis]. It's not fun, but at least I can eat all the fattening salty foods I want, and I'm going to go on an awesome trip."She sees this wish as a reward, and it's given her a lot of motivation.

I am extremely grateful for the time you have invested in my child's happiness. I look forward to hearing from you soon.

Sincerely, Jenny (Laura's mother) (Wish letter from a family, November 2008)

The following excerpt shows how anticipation of the wish builds as the realization of the wish approaches. It consists of diary entries made by the sister of a wish child, which she later sent in a scrapbook to the CWF after the wish had been fulfilled.

September 17

4:42 p.m. Only 10 days left until we leave. We're all so excited, especially Gabriel. We've started to talk about what we're going to bring.

5:08 p.m. Gabriel is super excited when we talk about leaving! He especially wants to see the famous Eiffel Tower...

September 20

9:00 p.m. In exactly one week, we will be at the airport! Cool!

September 23

12:03 p.m. We've finally started packing. I don't want to be too "last minute!" We'll only take what we really need to France. We're leaving in 4 days!... It's getting closer... Vive la France!

September 27

4:38 p.m. We're in the car and headed straight for the airport. We're all thrilled! It's also very stressful... Gabriel is very, very excited. He wants to see the planes, and he wants to find a figurine of the Eiffel Tower when we're in France...more later!

5:32 p.m. We're at the airport now. Already my brother and I are in awe. Gabriel can't believe he's going to be in Paris, it's like a dream... I feel the exact same way!

5:27 p.m. We're waiting for the plane. We just got went through security, and luckily nobody set off any buzzers... we were all a bit scared! The waiting room is really beautiful and comfortable. Gabriel had a lot of fun eating and browsing in the souvenir shops... We still have about another 2 hours to wait...but we're already enjoying the trip! It's just the beginning!

8:24 p.m. Our plane is ready. We're getting more and more excited. Sam can't wait to board the plane. We're listening closely for the boarding announcement.

9:16 p.m. We got to board the plane first and now we're waiting for everyone else to take their seats.

9:41 p.m. The plane just took off and we're slowly climbing. Gabriel was so excited, he was shaking! Personally, I feel a bit dizzy... only 5 530 km to go! Just before we left, Sam said, "Oh my God, I'm going crazy, and we haven't even left yet. We're not even in Paris yet!" (Excerpt from a scrapbook sent to the CWF)

These notes show how the exhilaration can mount prior to the wish, and culminate at the moment of its fulfillment. In her dairy, the sister took detailed notes of the countdown to their departure. The closer they got to the wish, and the more concrete their visualization of the wish became, the more palpable the excitement became in her writing. The time spent at the airport waiting for their flight was exhilarating for them. The moments before

takeoff were almost overwhelming. The children were buzzing with excitement over the positive experience to come.

Families will sometimes more specifically hope that *negative wish-congruent outcomes* will be avoided. Some families fear that their child's condition may be aggravated by the wish, for example by the travelling. Although a physician thoroughly assesses the child's condition before the wish is approved, (as we saw in chapter 3), parents may still have apprehensions. Kathrin's case exemplifies this idea. Long before departing for Disney, she was anxious about the upcoming flight, due to her fear that it might aggravate Sonya's condition, and this caused her persistent sleep difficulties.

Avoidance of negative outcomes that are unrelated to the illness can also become a source of hope. In another case I witnessed, the mother withheld information about a criminal record that she had received as a result of a youthful indiscretion.[97] A week before departure, she contacted me in a state of panic to explain the situation; she was afraid the wish would be ruined by her past behaviour, should the customs agent decide to block her entry to the destination country. After verifying with the relevant authorities, we learned that she had received a pardon and assured her that everything would be fine.

She acknowledged being terrified about the moment of passing through customs. She hoped desperately that they wouldn't stop her. After passing through the customs gate, the mother admitted to me that she had not slept for the past three days. I was also emotionally affected by this border crossing. The note I took in relation to this event is revealing about the experience of hope: "I desperately hope that everything will go right! If it turns into a nightmare, I will feel personally responsible."[98] "Everything is going to

be alright" is a statement infused with hope and commonly expressed by informants when reflecting on an upcoming wish fulfillment. In fact, Bobby's mother Mary expressed these very words after confessing that was scared about many aspects of the Disney trip: she was new to flying, and was worrying about the luggage check-in and the border crossing. "Everything is gonna be alright" became a way for her to express her hope for an uneventful journey. This common statement represents more than mere optimism. As we saw before, optimism is an attitude that everything will turn out for the best. The informants' use of this expression is more than a philosophical attitude. They acknowledge the reality of their situation and resent – still acknowledging – that things could go wrong. In addition, "Everything is going to be all right" is here injected with intense emotions (as the quote from my diary suggests). This reveals another difference between hope and optimism, the latter being conceptualized as "in important respects similar to hope, but without the corresponding emotional connotation" (Averill, Katlin, and Chon, 1990: 95).

2.2.2. Illness-related outcomes

Although there is no consensus on the medical effects of hope,[99] an implicit discourse surrounding the potential healing power of the mind is prevalent in society. Scientists openly discuss the power of mind over body and over the brain.[100] And the market is increasingly inundated with (scientific or not so scientific) self-help books devoted to aiding people cure their illnesses through the power of mind and visualization. Three such books, *Body Symbolism: The Fascinating Study of Mind-Body Communication, with Suggestions to Enhance our Body's Healing Ability* (Ribicki, 2007), *Healing With the Mind's Eye: How to Use Guided Imagery and Visions to Heal Body, Mind and Spirit*

(Samuels, 2003), and *Psychobiology of Mind Body Healing* (Rossi, 1993), are but a few of the many available. We can observe this theme in two hope-based beliefs in the context of the CWF: the wish as a cure and the wish as making a difference.

2.2.2.1. *Wish as a cure or as making a difference*

Hope and goals are represented in pop culture as motivational forces in the healing process.[101] Movies sometimes capture the essence of this belief. A great example can be found in the movie *The Blue Butterfly* (2004), directed by Lea Pool and starring William Hurt, Pascale Buissières, and Marc Donato. The movie is inspired by the true story of David Maranger (called Pete in the movie and played by Donato), who, after being diagnosed with a terminal stage brain tumour, realizes his wish (with the CWF) in 1988 to catch a blue morpho in a tropical rain forest of South America. Brilliantly filmed, it concludes with the boy's healing, as, during the trip, the tumour miraculously[102] disappears. This notion of the power of hope, which reinforces the belief that wishes can contribute to a dramatic change in one's health, is internalized by the CWF in its daily operations. *The Blue Butterfly* is an inspiring tale for the CWF and its employees; a poster of the movie decorates the lobby of its offices. The idea of the "ultimate potential" of the wish is never far from the minds of the employees or the volunteers. When probed, they will promptly recite a case of miraculous wish-related healing, or relate how a wish could have made a difference in the life of a child, had it been granted on time. I took the following notes during a weekly meeting at the CWF. They concern the premature death of a child who hadn't been able to receive his wish due to an administrative pitfall.[103] The notes highlight Wendy's implicit perception that the wish could have saved the child's life:

Wendy told us sad news today. A boy died last Sunday without having had his wish granted. She is very sad about it. She said: "These are the worst cases." She said that it was all due to an administrative problem.

(...) The boy's dream was to have new furniture in his bedroom.

(...) Wendy added that if the boy had had the chance to sleep in his new bedroom on Saturday night, perhaps he would have had a reason to continue the fight...

(Field notes September 19, 2006)

The idea promoted by the movie, of the wish-as-a-cure, however, is not a belief necessarily shared by all CWF employees. In fact, this "ultimate potential" is never explicitly stated, nor is it present in any public communications. Wendy, for instance, would never have expressed her view that the wish could somehow have saved the child outside the walls of the CWF. This notion, rather, is kept at the CWF as an unwritten belief. As a volunteer said upon meeting potential donors, "*We cannot measure the effect [the wish] has on the efficiency of the drugs...*"

A more middle-ground version of the belief tends to permeate CWF's organizational culture and corporate communications, which is that the wish *can make some difference*. Often, the employees refer amongst themselves to the various potential benefits of wishes and the ways in which they can help children through their treatment, such as, for example, by re-introducing some childhood normalcy into their highly alienated life. This version approximates the opinion of the medical community. A CWF promotional video, *Can Hope Heal?*, illustrates this idea through words expressed by Dr. Charest:

It certainly has a positive effect on the kid's psychology and the family's psychology. But I also strongly believe that it has an impact on the results that we have, because it provides them with an incentive to heal. (Excerpt from Can Hope Heal?)

This more muted version is passed on to families who eventually develop hope that the wish can assist in the healing process. For example, a mother reflects on her daughter's wish to meet TV's famous Chef Michael Smith and the role hope played in the fight for her daughter's life:

"The most important part of the wish was the anticipation and also the hope that gave her something to strive for. 'One more unit of blood and you're one step closer to your wish.' And it gave her hope." (Excerpt from A Recipe for Hope)

The mother's words reflect the role the wish played in motivating the child to persist in the treatment. Each transfusion became a way of marking time until the moment of wish fulfillment. This objective measure helped keep the child focused on a goal and gave her the will to get through her treatments. In other words, her hope empowered her to prevail through her difficulties. Doctors, nurses, and therapists understand the importance of the wish for the families in this regard, and use it accordingly. "You are one poke closer to your dream," or "One more unit of blood and you're one step closer to your wish," are expressions frequently used to motivate children. This instrumentalization of the wish has been reported in many conversations with parents and CWF employees as well as in discussions with health specialists. Wendy elaborates on this strategy for uplifting children's spirits:

As Wendy says, ultimately, the wish is a tool that people can use to help the kid. For instance, you can comfort a child who is about to receive a shot by saying 'Have you thought of your dream recently? What do you think you might wish for?' (Field notes May 27, 2006)

In a special case I once heard, the family received the wished item (a go-cart) just before the child entered the hospital for his organ transplant. After the surgery, desperate for a way to encourage his son through the difficult recovery, the father decided to bring the go-cart onto the street outside the hospital where his son could see it through the window. In this case, the father placed his hope in the power of the longed-for go-cart, which became a material manifestation of his hope.

2.2.3. How wishes can help

The hope that the wish can help the ill child indeed has proven founded. Many families claimed afterwards that the wish played a distinct motivational role in the fight against adversity. Kathrin, for instance, reported that the wish helped Sonya through her physical rehabilitation process. The wish can also play a key role in motivating children to persist with their repetitive treatments in cases of long-term degenerative illnesses, like cystic fibrosis. For instance, a mother informed the CWF that since receiving his computer, her son was better able to cope with his daily respiratory therapy, as he could undergo the treatments while in front of the computer. The following thank-you letter illustrates this point:

Thank you Wendy and thank you to the Children's Wish Foundation for making our son John's wish come true. The joy and happiness you've brought him are

indescribable. Every hour of every day, he's enjoying his computer, desk and chair! Soon he's going to visit Ubisoft, which will undoubtedly be the "icing on the cake" of this wonderful wish. The respiratory therapy treatments are a lot less challenging, because he does them in front of his computer!

Again, thanks a million! (mother's name) (father's name), (sister's name) and John. (Thank-you note, February 2009)

The impact of the wish on a child's condition can potentially be remarkable. In a thank-you letter sent to the CWF, a mother describes, through her child's eyes, the improvement in her condition. Here is an excerpt from this letter:

Hello,

My name is Sarah. I'm four and a half. When I was born, I didn't have any muscle tone or reflexes. What's more, I couldn't breathe on my own. One day, when I was eight and a half months old, I felt I'd had enough. I was too tired, and the doctors and my parents decided to let me go. Just before, my mom said to me, "If you keep fighting, I promise you that one day we'll go to Disney. You're too young to know what this is, but believe me, you'd love it." I decided to fight, just to see what it was!

(...)

The magic of Disney is real. There were fairies that made waiting lines disappear right before my eyes. They gave me tons of gifts, even though it wasn't my birthday, and I got so much attention they even got me talking! Imagine, I had

only spoken 10 words before I left home, and a week later I had spoken more than

seventy! Plus, since I got back, I've continued to get better. Today, against all

odds, I can walk, climb, I've started biking, and I can swim with my head under

water. The only thing stopping me is what people tell me I can't do…and that only

makes me want to ignore them!

As you can see, hope gives you wings!

(…) (Excerpt from a thank-you letter)

This letter again shows the importance of wishes in motivating the child to endure through the treatments. Although it is hard to know whether the child was able to grasp the notion of Disney, her mother seemed to believe that the gesture of giving her daughter a wish to fight for helped her persevere. She believed in the power of hope. She believed that it gave her daughter the strength to carry on when everyone around her was about to give up. This letter also shows us how the wish can be associated with a child's progress or an improvement in their condition.[104]

The motivational *power of a wish*[105] can be felt even more profoundly. A volunteer I met during the CWF Volunteers Day told me the story of a child whose life had been "saved by the wish":

After the group meeting Henry came to talk to me. He told me the story of a boy

whose simple wish was for his computer to be upgraded (i.e. not even to have a

new computer). Two years later, Henry ran into the boy's sister. She told him that

the CWF had saved her brother's life. In fact, he had given up on his treatment a

few weeks before the wish was granted. The doctors' prognosis was very bleak,

giving him only a few months to live. Upon his wish being granted, however, the

child decided to resume the treatments. He is now in remission. (Field notes May

27, 2006)

A simple computer upgrade was a sufficiently large dose of motivation to help the boy

persist. In the darkest of hours, when the child's mood is desperately low and all hopes

have vanished, the thought of a wish can change everything[106] by re-introducing the

hopeful thinking needed to persist and overcome adversity. The wish can create

momentum and help fight the inertia that illness, despair, and hopelessness can cause.

2.3. Hope for transformation

While envisioning their wish, families can picture themselves in a transformed reality,

safe and far away from the illness. Families approach the hoped-for transformation in two

different ways: one is to picture an escape, and the other is to capture the transformed

reality for the creation of future memories.

2.3.1. Framing the imagined escape

Families mainly engage in imagining an escape as a way to relieve themselves of the

prolonged struggles being experienced in the here and now. The difficult moments spent

at the hospital have concentrated families' attention on the dreadfulness of the disease. It

becomes hard for them to avoid being constantly reminded of the illness: "Where can we

go? How can we escape? It's everywhere" (Bluebond-Langer, 1996:163). For this reason,

families try to find ways of escaping by performing various activities (ibid). Some

families view the wish as an opportunity to escape their current reality. Indeed, the wish

can become a means of evading the present, momentarily at least, and redirecting

attention towards something or someplace else in order to bring the possibility of a better life into their current reality. In other words, the wish becomes a springboard for imagining a transformed life of health and happiness together.

2.3.1.1.   Strategies for framing the imagined escape

Families use one of two main strategies in their quest for a transformative escape; they imagine their escape either by picturing themselves fleeing the here and now, or by evoking images of the lost childhood.

Fleeing the now. A family's hope for transformation is manifested in an imagined escape from the current state of the illness. In some cases, all they long for is a short reprieve. Wendy once told us the story of Jake, a boy who wanted to spend his dream vacation at a ski resort not far from the city. The wish could not be granted in its original form, because the doctors thought the boy would be too far from the hospital, and he needed regular treatments. They ended up instead reserving two rooms in the presidential suite of a luxury hotel and arranging for a limousine to drive him to and from the hospital for his daily blood transfusions. The child wanted, for a few days, to live a life of luxury with his family. Wendy mentioned that "he just wants to get out of the hospital, that's all he wants." For this child, the wish represented a temporary escape from the hospital.

CWF employees also aspire to provide this escapist aspect of the wish for the families. For example, at first, before starting to send families to the Give Kids the World Village on a regular basis, Wendy had been preoccupied with apprehensions. Because the village welcomes only families with sick children, those sent by the CWF may have felt that they hadn't fully gotten away from the medical environment, thereby hindering their

ability to put the illness out of their minds. Her impression progressively vanished, though, as I, along with various families, reported how positive the GKTW experience had been. Wendy decided, therefore, that GKTW did in fact serve as an effective escape.

Escaping the medical context and the reality of the illness is often cited by families as a secondary effect of the wish fulfillment. Many thank-you letters specifically mention this impact of the wish. Below is an excerpt from a mother's letter that highlights this facet of the wish:

> *You can't imagine how happy Melissa was this week. The permanent smile on her face, the sparkle in her eyes, and her wholehearted laughs alone were worth more than anything. Over eight days, I discovered another side to Melissa. I uncovered a six-year-old child who felt free to play, run, and climb without a thought for tomorrow, of treatments, or of the needles she'd soon get. At night, as she was going to bed, it wasn't, "Mommy, are we going to the hospital tomorrow?" but rather, "Are we still going to be here tomorrow?"*

This letter shows how the mother experienced an actual transformation during the wish, as she discovered another side to her daughter. She points out how happy her child had suddenly become. She also emphasizes that the wish helped her daughter to forget about her illness. This escape fostered her daughter's transformation by keeping thoughts of the illness at bay.

Families not only hope for temporary transformations. In other instances, they may seek a permanent escape from their suffering. Indeed, some families seek a symbolic closure to the wish, whereby, as one family expressed in a letter, the escape "represents

hopefully the closing chapter of this very tiring time." One such case is of a family I once visited with Debbie. The following notes were taken after the meeting. They describe part of a conversation that took place at a meeting around the dining table.

Everyone introduced themselves.

Jenny finally arrived with her little puppy in her hands. She is a beautiful 12-year-old girl with a loving smile. Her hair is still growing back from chemotherapy.

Debbie started talking about her high school work. For a number of minutes, she talked about Jenny's upcoming exams. Debbie said that the French exam would be really interesting.

The father was the first to speak next. He said that this trip is really symbolic. It marks the end of a long year of treatment and the beginning of a new life. He was emotional.

The mother and father also mentioned that Jenny had spent the entire previous summer in the hospital. (Field notes, May 21, 2006)

The father's emotional display shows us that the hope the wish represented for this family was one of a transformation through symbolic closure, an end to the forever being trapped in the now of the illness, so that they may become open to what comes next.

Closure may actually be experienced during the fulfillment of a wish, as I witnessed personally with Sonya's mother Kathrin. One evening at the villa, Kathrin told me that the wish was allowing her relationship with Sonya to evolve into something new.

It had enabled her to see her daughter as a healthy girl, who could now handle challenging situations like taking airplanes:

> *Late that evening, the mother told me this trip would help her move on. She said*
>
> *that often she does not sleep well at night. Sonya is on her mind a lot. She said*
>
> *that now that she's seen her take a plane, she will worry less for her.* (Field notes,
>
> November 27, 2006)

This example illustrates how a transformation unfolded during the fulfillment of the wish. Being away from home created a perspective from which the mother could confirm that her daughter's illness was at its end, and that the daughter was on the road to becoming healthy again. The daughter's transformation into a healthy child was facilitated by the symbolic experience of closure provided by the wish. In addition, the daughter's transformation reverberated onto the mother. Indeed, by witnessing her daughter's increasing capacity to prevail, she began to move from a state of constant vigilance to one of relative relaxation, where she could eventually sleep better at night.[107]

Views of childhood. In their hope for transformation, families frequently express culturally constructed associations with or images of a "normal childhood." For instance, in a letter, a mother describes an aspect of childhood that the wish helped to bring back into her daughter's life:

> *On behalf of our daughter and our family, we would like to express our profound*
>
> *gratitude and thanks to the CWF and yourselves for contributing to the*
>
> *realization of a cherished dream of Kasey's.*

As you know, because of the chemotherapy treatments she received to eliminate her tumour – a neuroblastoma diagnosed last February – she was not allowed to go to any public pools.

This unexpected gift allowed her to fully experience the great joy that children her age have in swimming in a pool in a controlled environment, under her family's supervision.

It's so difficult for parents to learn that their child has a serious illness. The medical procedures and post-operative examinations are always filled with stress and uncertainty.

A little attention, a smile, and some comforting words go a long way in these circumstances.

We would like to take this opportunity to once again thank the Children's Wish Foundation, its directors, and yourselves for the exceptional attention you paid to our daughter and our family.

We hope that your organization may continue to do the outstanding work it does for children in difficulty.

Our warmest regards (Letter from a wish family, October 2007)

Due to the chemotherapy, the child couldn't go to a public swimming pool, something the mother considered to be part of any normal childhood. By the CWF giving this girl her own swimming pool, she could, at least in part, live what was deemed to be a "normal childhood."

The previously cited letter from Melissa's mother is another telling example. This letter displays socially constructed Western[108] ideas of childhood: innocence, playing, running, jumping around, smiling, laughing, and so on. In her letter, the mother emphasizes her daughter's age as a way to drive home the notion that these are things she *should* be doing, were she not affected by the illness. Normalcy of childhood becomes for her a reference point against which she can judge and project a different life for her daughter.

Images of childhood are not only expressed by the families in cultural terms. Families may also hope to escape from the now by evoking memories of the life they had with their child before it was taken away by illness. In so doing, they revert to the past and make reference to lost images, cherished memories, and a reality that should not have been interrupted, but should have continued into the present and future. In a letter, one father stated, "As a parent, when your child gets sick, you want to do everything in your power to make his stay a little better. You want to see that smile again, you want to see that spark. We lost that for long time." For parents, losing this precious childhood can be devastating (as discussed earlier in this chapter). For this father, the word *again* takes on a critical level of importance by evoking glorious images of a past that could and may be relived in a wish. The father hopes for a transformation from the wish that will bring elements of his child's lost childhood back into the present.

As a matter of fact, families often witness the return of this past during the wish itself, an experience they often share in their letters, as in the case of the following note. Here, a parent writes about the hope she had for her son, Cameron, which she saw materialize during the wish fulfillment:

We watched Cameron's eyes light up with joy for the first time since he was

diagnosed with cancer. I did a lot of crying on the trip because Cameron was so

HAPPY, EXCITED, FULL OF ENERGY,[109] and was being a normal four-year-

old again. That in itself was my wish for him.[110]

Finally, closely tied to this image of life with their child, and their child's experiences of a normal childhood, is an image of the family reunited. As mentioned before, so many families are kept apart during this tragic time. The wish can intervene by providing a momentary respite, an escape from the now of illness to a now filled with joy, cheer, and togetherness, elements of an earlier life. On many occasions, the families remarked on the joy of spending time together as they used to: parents seeing their children play around again, or healthy siblings having the chance to bond with their sick brother or sister.

2.3.1.2.   A progressive transformation

A transformation does not necessarily happen overnight. Sometimes it can be a much more gradual process. The following excerpt illustrates this point. It comes from a thank-you letter sent by the mother and sibling of an ill child:

Mother: From the day Shelby realized she had a chance to go to Paris, her will to

fight was renewed. She threw herself into the preparations for her trip. She had a

mission, a purpose. It was a miracle.

(...)

Our wish was to see Shelby happy, to spend time together, away from doctors and

fear. In Paris, our fear was replaced by excitement, exploration, and love. Really,

I have never been that interested in Paris. Now, I appreciate the beauty and history that is Paris, because Paris is a part of Shelby.

(...)

Sibling: This organization stepped in when everything seemed darkest. They asked Shelby what she wanted more than everything else in the world. My sister, who had not been able to hold a paintbrush in weeks, wished to go to Paris to see all of the masters' great art.

It was like seeing Shelby coming alive again. Slowly, surely, she started to get better, to escape from the darkness that had seemed to smother her. She began to make plans again, and to dream. Shelby had received what no doctor could prescribe - hope.

My family was whisked off to Paris after my older brother's high school graduation. Our family enjoyed being together for some uninterrupted fun time, which was definitively what the doctor had ordered. We saw the works of Van Gogh, Monet, Renoir, and other famous painters. Shelby's eyes lit up at each new sight, taking pictures of everything so she could draw them when we got home. My sister, who earlier could not hold a paintbrush, wanted to draw everything in Paris.

On that trip, we thought more about the Eiffel Tower and how much we missed real Coke than we did about Shelby's illness. Best of all, instead of pushing me away some more, Shelby seemed to remember that I was her special friend, and

we became as close as we had ever been. It was like Shelby's relapse had never happened.

We returned home and Shelby made up more dreams and ideas. Instead of thinking about how sick she was, she dreamed about everything from college to her desire to be in a food fight.

(...) (Excerpt of a letter in *The Power of Hope* (Spizman, 2006:42-44))

This quote is an interesting example of how a family conceives of transformation in an ill child. The mother and the sister express their hope for a transformation in terms of Shelby being happy and the family being together. Their description illustrates again the ways an escape from the present reality can help a family attain a life transformation, as well as the ripple effects brought on by this escape: seeing Shelby happy and spending time together brought back memories of a previously happy and normal childhood, while being away from doctors and fear prompted their desire to live beyond the here and now. Earlier, a relapse of her illness, juvenile dermatomyositis (JDM), had caused her condition to deteriorate, and she had lost the ability to hold up her harms or grab things like her beloved paintbrush. She had been losing hope, and her family hadn't known how to lift her up again. Then, apparently, the introduction of the wish began to transform her. The letter shows how she gradually emerged after the start of her involvement in the wish granting process. Contemplating the wish made her come "alive again" and willed her to fight the disease. She started making plans for the future again. The wish was the catalyst of this process, and its contemplation gave her hope. The wish ultimately initiated a transformation that led her to start envisioning a future, one which included her.

2.3.2. Capturing the transformation

For most, if not all, of the families, the last months or years had been emotionally, psychologically, and socially scarring: seeing the child endure painful treatments, spending long hours at the hospital, experiencing the family being torn apart as one partner takes care of the healthy siblings at home and the other stays at the hospital. When imagining themselves in the future, looking back on this dark chapter, they would rather see lighter and more joyful memories than the ones currently being constructed. They would rather remember themselves differently: a child who's healthier and happier, away from the illness and hospital, and surrounded by relatives. Families seek ways to capture images and memories of the transformation they hope for. The wish offers them this opportunity. In fact, before embarking on the adventure, some families develop hope that the wish will help create positive memories into which they can project a different reality of themselves.

Preserving positive memories is so important that it can become the focus of attention for one or more family members. For instance, when asked during a follow-up interview what she liked about the performances, Kathrin mentioned that she was not paying too much attention to them, as she was focused on capturing her daughter's smile and happiness on tape:

> *(...) the thing that struck me most was to see Sonya happy, the expression in her eyes. Because personally, I was behind the camera, so I was more caught up with her facial expressions as such than the shows. I only have a vague memory of the*

performances, because I was filming and was more concerned with making a nice

video for Sonya. (Interview Sonya's family, March 14, 2009)

In this excerpt, Kathrin expresses her heart-felt desire to create memories depicting a happy and smiling daughter.

For some families, remembering the event can be challenging, and as such, causes some anxiety. In another Disney wish I witnessed, the mother was worried about her capacity to remember the experience. For this wish, Martin, a 10-year-old boy in remission from leukemia, was travelling with his mother, father, and younger sister. The night before our return home, she and her husband briefly reflected on the events of the past week and their ability to remember them:

> *The mother told me she was wondering whether she would remember everything.*
>
> *She added that she realizes that she was already starting to forget what had*
>
> *happened at Magic Kingdom (first day of the trip). The father said that he*
>
> *remembers most of the events, but he does not necessarily remember where they*
>
> *happened exactly. For instance, he thought the Beatle 53 show was in Animal*
>
> *Kingdom (while it was at Universal Studios). He said that the movies and photos*
>
> *would help a lot.* (Field notes, March 3, 2007)

These parents are concerned about their ability to retain accurate memories of the experience. They mention that the videos and photos will help them in this respect. In fact, in their hope to capture and preserve these precious moments, families often mention the use of the following strategies.

2.3.2.1.   Strategies for memory creation

Remembering is important for families, and thus finding the right way to remember is critical. Three such strategies were identified in the course of my fieldwork: creating memories through photographs and videos, choosing the appropriate time of wish fulfillment, and choosing the appropriate wish.

Creating memories through visuals. Being able to preserve memories through videos and photos can be crucial, as we saw for Martin's family. Families often report taking hundreds of pictures and hours of video footage during the fulfillment of the wish. The wishes I witnessed all led to a substantial number of pictures. For instance, Kathrin filmed more than 17 hours of footage. Martin's family also documented a large amount of visual memories: 5 full mini DVs, representing many hours of video footage, and more than 600 photos. During their trip, an unfortunate event further evidenced the importance of memory creation. One night, the family decided to go to the Medieval Times restaurant (like Sonya). After the show, the employees cleaned the tables. As we were leaving, the father realized that he had left one of his memory cards on the table, and that the card had been taken away by an employee. The father was beside himself. We rushed to the kitchen and explained the particulars of our situation. Our waiter came and showed us the garbage section, which was a huge room full of large metal containers. He told us that the chances of finding the card were very limited. He did, however, kindly offer to try to retrieve it. I can still clearly remember him putting on big rubber gloves, jumping in the containers, and literally sifting through piles of waste. After an unfruitful search, we gave up and left the restaurant. The father was finally able to console himself by telling himself it was his small memory card and that luckily the one with 600 pictures was still

safe. Although it is no longer a big deal to the family,[111] at the time this loss felt very significant.

Choosing the appropriate time. The extent to which the child will be able to recall the wish in the future is often a factor in memory creation. This concern is more likely an issue when the child is younger, since early memories tend to diminish or vanish with age. For instance, during the follow-up interview, Emily reflected on the impact of age on memory and proposed that the child should wait as long as possible before fulfilling his or her wish:

> *It's been two years and already I've forgotten all that we went through. For me at seven years old, it's all a blur, so it might be better to wait a bit.* (Interview with Emily's family, May 18 2009)

Parents are concerned about their child's ability to retain memories and sometimes prefer to wait before contacting the CWF. It is for this reason also, as we saw in chapter 3, that the medical staff will wait as long as possible before introducing the CWF to families in cases of chronic illnesses. Waiting can indeed be appropriate in the case of degenerative chronic illnesses. However, in fast-striking, non chronic diseases, like cancer, time works against families. In these scenarios, the illness to a certain extent dictates the timing of wish fulfillment. It can force families to embark on a wish when the child is as young as three years of age. In these cases, photos and videos will be instrumental for the family to share memories of the wish when the child grows older.

Choosing the appropriate wish. This desire to commit experiences to memory can also impact the process sequence. It can lead one to design a wish with a maximum potential

for being remembered. To do so, one may opt to fulfill a wish that will leave tangible traces rather than just stored memories. This is one of the reasons that Emily ended up choosing a swimming pool. The following excerpt reveals how Emily and her mother emphasized this aspect while Emily was considering this item instead of a vacation:

> *Mother: Emily also talked about wanting to go to Hawaii, it was... no? You don't remember? Anyways, I said "Yes, Hawaii would certainly be wonderful, but what will we have to show for it? You know? The memory of this challenge, or the memory of I'd say the positive or happier moments of this illness."*

> *Emily: Well, I don't know but I remember people were asking me why I didn't take a trip instead, because we already had a pool, but it was really far, and it was always freezing because the trees kept it in the shade. It was small and old and everything, that's why I wanted a pool because I'm always cold, so I decided I wanted a water-heater, and I wanted it to be bigger and more beautiful. Then people were still asking me why I didn't want to go on a trip instead, and I remember I told them, "Well, I won't have any memory of it, you know? Sure, I'll remember some things, but I won't have anything concrete that I can... apart from photos or presents." I really wanted something that would be there forever.*
> (Interview with Emily and her mother, May 18, 2009)

2.3.2.2.   Preserving memories

This hope proves to be justified. The creation of these positive memories can help manage meaning for families and recreate order through storytelling (Wong, 2006). CWF employees constantly encounter the importance of storytelling. Many times during my

fieldwork, families showed up at the office to share their happy wish stories and brought pictures with them to give to Wendy. Other times they sent thank-you notes with descriptions of the wish and pictures with explanatory details. Some families even created scrapbooks that they either sent or showed during their visit. After showing us these letters and photos, Wendy would carefully place them in binders that could be consulted in the office lobby – keeping these fresh memories close by and readily accessible.

The wish can indeed provide priceless memories for families. My informants unanimously reported that the wish created positive lasting images and stories that are still, from time to time, shared and retold. The following letter shows the important place memories hold in the life of the family after the fulfilment of the wish.

Dear Wendy,

I just wanted to take a moment to write to you and to thank you and the Children's Wish Foundation. Words cannot describe how much we loved and appreciated our trip to Disney.

Although it was of course Tracy's wish to start, it soon grew to be a family dream. Afterwards, I asked myself what parents wouldn't have this kind of dream for their family. I'm so happy to have had this chance, and I owe it all to you.

Vanessa and James were thrilled about their trip. They got to go to Walt Disney, but at the same time, they were realizing Tracy's dream. I don't think one day went by where they didn't thank Tracy for being able to share these wonderful moments with her. For her part, despite the fatigue and a few minor health issues,

Tracy was deeply affected by all she experienced. You should see her facial expression as she looks at her photos now. It's like she's relived her trip fifty times since we came back! Scrapbooking activities will definitely be on the agenda this winter. She brought back pamphlets from all of the activities and parks, and we must have at least 375 photos. We've enclosed a few of them to show you.

Tracy came back completely in awe of her trip, as did Vanessa and James. In fact, so much so that we're still living the magic of Disney through all the films. It's Vanessa's birthday this weekend, and you can be sure, it's going to be a "Princess Party."

For me it was a magical time experienced with my family. It was also a very touching experience to be able to share a vacation with my three children and to see them rejoice every day.

Once again, thank you Children's Wish! (Letter sent to the CWF, December 2006)

The wish fostered the creation of lasting memories for the whole family. Taking pictures proved to be a way to capture the transformation: the photos taken during the trip helped Tracy to emotionally re-experience the journey again and again. The magic of Disney has permeated their lives and continues to bring them happiness even after their return home.

The wish memories, furthermore, can extend over very long periods. One example is the case of a mother who, 20 years after the granting of her eight-year-old son's wish,

sent a thank-you email to the Foundation. After all this time, she still retains precious memories of the wish. The opening of her letter reads as follows:

Dear Madam,

It was by chance that I ended up visiting your website today, and it has compelled me to share a very special memory with you. It doesn't matter where this message ends up, because this wish, which was realized almost 20 years ago now... will forever remain wonderful and very fresh in my mind. (Letter sent to the Foundation in September 2007)

The memories of the wish can prove critical for families, especially for those dealing with the impending death of their child. Although they cannot erase the past, the wish provides them with uplifting images, events, emotions, and scenarios that offer something different and positive about the final days of their child's life. The following letter captures the impact of the wish and those final memories in the life of Matt's family:

In June 2006, we learned that Matt had leukemia. As parents, we felt completely powerless. To see his future compromised and feel his sadness, his suffering and his fears was at times unbearable.

Matt's life took a drastic turn. For two years, his daily life consisted of trips to the hospital, needles and all sorts of restrictions that brought down his morale. Accompanying our young son in this battle turned our lives upside down. The fact that someone recognized how much he deserved this dream was a tremendous source of comfort to us. Suddenly we had something to occupy our thoughts other than the illness.

Knowing he'd be celebrating his fourth birthday by meeting his heroes gave him a boost of energy and hope. Shrek, Buzz Lightyear and the rest of them had all helped him get through his illness. I will never forget the many hours we spent lying on his hospital bed, watching or reading the Disney classics. I like to believe that when he closed his eyes, Peter Pan would lead him on all sorts of crazy adventures so that he could forget his suffering for a few hours.

When we were there, from the first contact with his heroes, his smile and the sparkle in his eyes instantly reappeared. We saw the laughing, energetic and spontaneous child that we knew Matt to be. The whole family experienced this trip as a moment of lightness.

This experience will always be a treasure of immeasurable value, one which we will keep tucked away in our hearts. Matt laughed, played and had fun like the young boy he was. He never got to celebrate his fourth birthday. The trip had to be moved earlier. He left us shortly after our return.

So what did this trip mean to Matt? Simply an immense pleasure. We will treasure this memory within us forever. It was the only trip the five of us took together.

This wish took on a highly significant meaning for this family. Because of the wish, the family had something with which to build positive memories of Matt in his final days. These memories were of a different Matt – a happy, smiling, and energetic Matt meeting his heroes at Disney World. These are memories that could be kept after his passing. The father's description again highlights the importance of escaping from the illness reality to create joyful memories. Fleeing the context of the illness uplifted him. It was while being

away from that context that Matt became enthusiastic and energetic. In addition, the description of Matt's transformation is imbued with images of his lost childhood. Laughter, playfulness, and fun were aspects of Matt as he used to be, which, in his later life as a sick child, were rekindled.

A similar situation was revealed to me during a conversation with Wendy. This was the story of Danny, a child who had been granted just a three-day trip to Disney, due to the severity of his condition. He died on the second day of the trip in his hotel room. The following excerpt reveals the impact of the wish:

> *Wendy: For me, it was very intense, but for the family, the memory they have is of something beautiful. To them, it was far from being catastrophic, what happened there. They were able to spend a full day at Disney in an amusement park where they saw a child – little (name of the child) – who was happy and smiling, at least as much you could expect a child in his state to be able to do. When he returned to the condo, he collapsed and woke up briefly to say his final farewells to his family. And for them... and what the nurse later told me, was that the headboard of the bed where he lay was a rainbow, and it was like he departed on that rainbow, it was so touching. As for the family, they hold happy memories of that moment, well quote unquote happy, but they are cherished memories.*

> *From time to time, the family sends me e-mails and it's funny because the mother – maybe once a year since this happened – she tells me, "I don't know if you remember us, but don't worry, I remember you, you'll be etched in my memory for life." And that's why to them, it's a memory and an important one at that. They*

relive it. At the same time every year, the mother sends me an e-mail to recall that event, and that's fine because it must do her some good. To me, it just makes me think, 'Ah yes, it was at this time of year that it happened...'

Interviewer: I imagine that to them, to have been able to share their son's death in Florida, as opposed to the hospital, must have meant the world to them.

Wendy: I think that day was absolutely incredible. To see [name] who, despite his extremely weakened state, was laughing, smiling and very present... even if the time they spent there was so short, it was an intensely lived moment. I'm sure that it wouldn't have been like that if they'd been at the hospital. And the way it ended, that day, it was really unique. Each time I remember that rainbow, it was like...it was meant to be that way. It couldn't have been more beautiful. There would have been no rainbow at the hospital, that's for sure. So the entire event was symbolic, but that day in particular, from start to finish, was very, very special. There was not a single insignificant moment in that day, and that's what stays with me. It's a memory that will never leave me, never. (Interview with Wendy, May 7, 2009)

As tragic as the death of a child amidst the fulfillment of his wish may sound, the event provided powerful emotions and images that have been crystallized in the memories of the family members who took part in the wish. In fact, this wish created the kind of pleasant and meaningful memory that most families hope for.

3. Discussion

Hope is an emotion inseparably linked to illness. In order to help a person prevail, hope must be instilled, nurtured, and maintained. In the context of wish fulfillment, hope can

be seen as a normal emotion, insofar as it is expected to be experienced in some form by most families. In this context, the fulfillment of a wish can play an important role for families with ill children. By redirecting families' psychic energy towards the future, the wish helps initiate and maintain the hope mechanism. It becomes possible to dream and hope again. It recreates a certain order, or continuity, in their otherwise disrupted lives.

3.1. Anatomy of hope in the context of ill children's wish fulfillment

In the previous section, we saw that in the context of wish fulfillment, hope is experienced as an anticipatory emotion that can manifest itself in various forms. In the process of exploring the concept, I incidentally uncovered a framework whereby each type of hope has its own specific antecedent and focus of attention. These elements are summarized in the upper part of the figure below. The bottom part of the figure also presents the materialization of hope.

Figure 5.1: Anatomy of hope: Antecedents, focus, and materialization

Origin ⇩	Procedural gap	Script gap	The power of a wish	The reality of the now
Focus ⇩	Child eligibility Wish approval	Positive and negative wish consequences	Illness	Framing the imagined escape Capturing the transformation
Hope level	Hope for wish item /experience	Hope for wish-related outcomes	Hope for illness-related outcomes	Hope for transformation

Materialization of hope

Product/experience ⇨ Outcomes ⇨ Transformation

Time

3.1.1. A typology of hope

Hope can be found at three levels: hope for the wish item/experience, hope for the outcomes, and hope for a transformation. Hope for the wish item/experience is a by-product of the wish granting process. During these times, families are hopeful that the wish will be accepted and granted to the child. Hope for outcomes concerns the direct positive ramifications of the wish itself and its potential impact on the illness. Finally, families can also nurture hope for a transformation. Families picture themselves in a better place, where they would be happier, healthier, together, and away from the medical context and the illness.

Moreover, the three types of hope are not mutually exclusive and can be experienced simultaneously. In Sonya's case, for instance, in addition to hoping that the wish would be accepted, her mother Kathrin hoped that the flight would not worsen her daughter's condition (hope for outcomes) and also expressed hope for a transformation as she was capturing her daughter's excitement through 17 hours of video of Sonya's smile and excitement.

3.1.2. Origin of hope and focus of attention

As mentioned above, hope arises in relation to specific goal uncertainties. As Snyder (1994) puts it, "The goals involving hope fall somewhere between an impossibility and a sure thing" (p. 6). As we've observed, a severe illness with an ambiguous prognosis creates significant uncertainties in the lives of families with respect to changes brought on by the disease, the duration of the fight, the chances of survival, and so on. Families nurture hope to manage these insecurities. Throughout this thesis, I have highlighted

different uncertainties inherent to the wish itself that become the ignition of hope. Each uncertainty-born hope is further associated with a specific focus of attention. Indeed, in their nurturance of hope, families direct their attention to specific aspects of a process, to elements or to strategies.

First, the procedural gap leads to the development of hope in the wish item or experience. This type of hope is inherent to the process. As we saw in chapter 3, many aspects of this process are not disclosed to families. As such, their difficulty in assessing the likelihood of the desired outcomes of their child's eligibility and wish approval becomes potential sources of the development of hope. Kathrin's case, for example, provided fertile ground for nurturing hope, since her daughter's condition did not fall into the A-List illness category, and her health had improved such that it could have made her case less of a priority.

Hope in the outcomes originates mainly from two sources of uncertainty. The first is what was called in Chapter 4 the script gap, which is explained by the fact that most families have had no prior experience with a wish-granting organization or have never experienced international travel, celebrity encounters, or the purchase of particular specialty items. The focus of attention of hope in these cases may be on the outcomes of the wish itself. On the one hand, families may hope for positive outcomes, such as quality family time, joy, and excitement. The impending fulfillment of the wish can lead to intensifying emotions in the anticipation of what is to come, as we saw in Gabriel's case. On the other hand, families' hopes may be focused on the avoidance of negative outcomes. Kathrin provided such an example by hoping her daughter's condition would

not deteriorate due to the flight. As for illness-related outcomes, on the other hand, families may nurture hope that the wish will help in the healing process.

The second uncertainty is rooted in the wish's potential power to positively influence, in one way or another, the improvement of the child's condition. A socially-laden discourse concerning the positive power of a wish permeates the medical community, self-help books, and CWF employees' own philosophy. This belief is passed on to families who nurture hope that the wish might somehow help their child overcome the illness. The medical community attempts to maximize the healing power of the wish by integrating this belief into the relations they develop with families. Families may also strategically use the motivational power of a wish to positively influence illness-related outcomes. The go-cart wish is an apt such example.

Finally, the third level or hope, for transformation, stems mainly from the families' state of a disrupted life. Here again, two kinds of focus were identified. First, through an imagined escape, families can envision themselves (permanently or not) away from hospital and illness. Being away from the medical context could, in such imaginings, lead to a different and better life situation. Jake's desire to "be away from the hospital" is an example of such hope in an escape. In addition, views of childhood, in terms of how their child *should* be or how they *used to* be, are invoked and further characterize the imagined escape. These imagined escapes offer a model to which the families can project the hoped-for transformation. The second focus is on capturing the transformation through the creation of memories. When imagining themselves in the future, looking back on this dark chapter, families would rather see lighter and more joyful memories than the ones currently being constructed. Memory creation can be a

powerful mechanism used by families to capture the transformed child. Taking photos and videos is a frequent way used to preserve images of the happy child. Whenever possible, choosing the right wish and the right timing of the wish – as in Emily's case – can help optimize these memories.

3.1.3. Materialization of hope

As the CWF stated in its annual report, "It all begins with a simple wish." Once a wish is granted, its fulfillment can take on proportions far greater than the wish itself. Indeed, as seen throughout this chapter, a wish can have spectacular consequences. These consequences are parallel to the levels of hope. John's case exemplifies the materialization of hope for outcomes. In her letter, his mother wrote that ever since the computer wish had been fulfilled, he had been enjoying it every day (wish-related outcome). In addition, it enabled him to face his daily respiratory therapy much more easily (illness-related outcome). Families generally report wonderful experiences during the fulfillment of their wish. The many photos and thank-you letters sent to the CWF, the wishes I myself witnessed, and the conversations I had with my informants, all point to this conclusion.[112] Many families also reported illness-related consequences. As in John's case, motivation to pursue treatment is the most frequently reported consequence. There can, however, be even greater ramifications. A wish can go as far as re-instilling hope in a child who had lost the will to fight (as in the story told by Henry the volunteer). The wish may also spur a child's development, as in the case of Sarah, who went from speaking 10 words to speaking more than 70, or as in the case I witnessed with Bobby.

In addition to the aforementioned outcomes, a transformation may emerge during or after the wish. It can happen symbolically through closure, as when Kathrin expressed that over the course of the trip, her daughter was becoming – in her eyes – a healthy child. It can also restore the lost ideals of childhood, as when Melissa's mother noted that she had uncovered a side of her daughter that was smiling and laughing, running and climbing, everywhere throughout the trip. Perhaps Shelby's case illustrates the most noticeable transformation. She began to change from the moment she was involved in the wish granting process. Her will to fight was renewed; she regained hope and began to make plans and have dreams again. During the trip, her family rarely mentioned the illness, as they were distracted and amazed by the beauty of Paris. Shelby became close to her sister again and regained the desire to paint. The transformations did not stop there, however, as she continued to dream and make plans after her wish had been fulfilled. This case shows how one can emerge from darkness because of a wish. Mostly, it shows that a transformation does not necessarily occur overnight, but may evolve slowly once initiated. Groopman (2005) calls this mechanism the *domino effect of hope*. As he puts it, "Hope can be imagined as a domino effect, a chain reaction, each increment making the next increase feasible" (p. 120). In this sense, contemplation of the wish was the first push of the domino, creating a momentum and redirecting her attention so that, step by step, the future seemed for Shelby to be once again possible.

Finally, these outcomes suggest alignment in a causal relationship. The granting of the wish is the first step in the creation of wondrous experiences associated with its fulfillment and the beginning of the motivation to fight. These positive experiences are subsequently involved in more transformations of one form or another. Naturally, one

could hardly re-experience the joy and playfulness associated with childhood if the experience of the wish fulfillment is not itself positive, or if one is unable to put the reality of the illness aside, at least temporarily. Implicit in this relationship between the types of hope and their materialization in the wish is also the idea of temporality, or a time factor. For instance, Shelby's transformation was described as occurring over a protracted period of time. Sonya's transformation, as witnessed by her mother, also occurred progressively during the trip.

3.2. Three facets of hope in the context of ill children's wishes

As we saw in Chapter 1, de Mello and MacInnis conceptualize hope in three facets: having hope, being hopeful, and hoping (de Mello and MacInnis, 2005). *Having hope* is to enjoy the feeling that a goal-congruent outcome is possible. *Being hopeful* is to assign a probability value to the occurrence of such outcome. Finally, *hoping* is to yearn for an outcome believed to be possible, and the degree of hoping is a factor of the extent to which the goal is valued. These facets apply directly to the contexts of the wishes we have described. For instance, in terms of wish item/experience-related hope, a family could *have hope* that the child will be eligible for a wish and *hope* for the wish to come true. They may *be* more or less *hopeful,* depending on their view of the likelihood of their child's health status improving and their wish being approved by the CWF. In terms of outcome-related hope, a family could *have hope* that the wish will be a great adventure and *hope* for this to materialize, and *be* more or less *hopeful* that positive outcomes will occur and negative ones will be avoided, depending on their respective likelihoods. In addition to elucidating the concept of hope, the three facets can be used to further conceptualize the abstraction shift that takes place from one type of wish to another. As

we have seen, families have hope not only for the wish. A wish's reach can indeed extend far beyond its mere fulfillment. Wishes come to take on a highly symbolic, future-oriented meaning, and hope is at the centre of this meaning projection. In fact, in addition to having hope *for* the wish, families can have hope *in* the wish, in its capacity to make a difference in their lives. The abstraction of hope can be conceptualized following the three facets: to *have hope* in the wish would translate into *being hopeful* in the cure and *to hope* for a better life. The conceptual shift from *having hope*, to *being hopeful* and *hoping* is illustrated in the following figure. It builds on Gronroos's (2007, 2004) conceptualization of the relationships that we introduced in Chapter 2. It suggests that the illness and the wish are highly enmeshed and represent important sequences in the current period of a family's biography.

Figure 5.2: Relationship between hope, illness, and the wish in a family's life
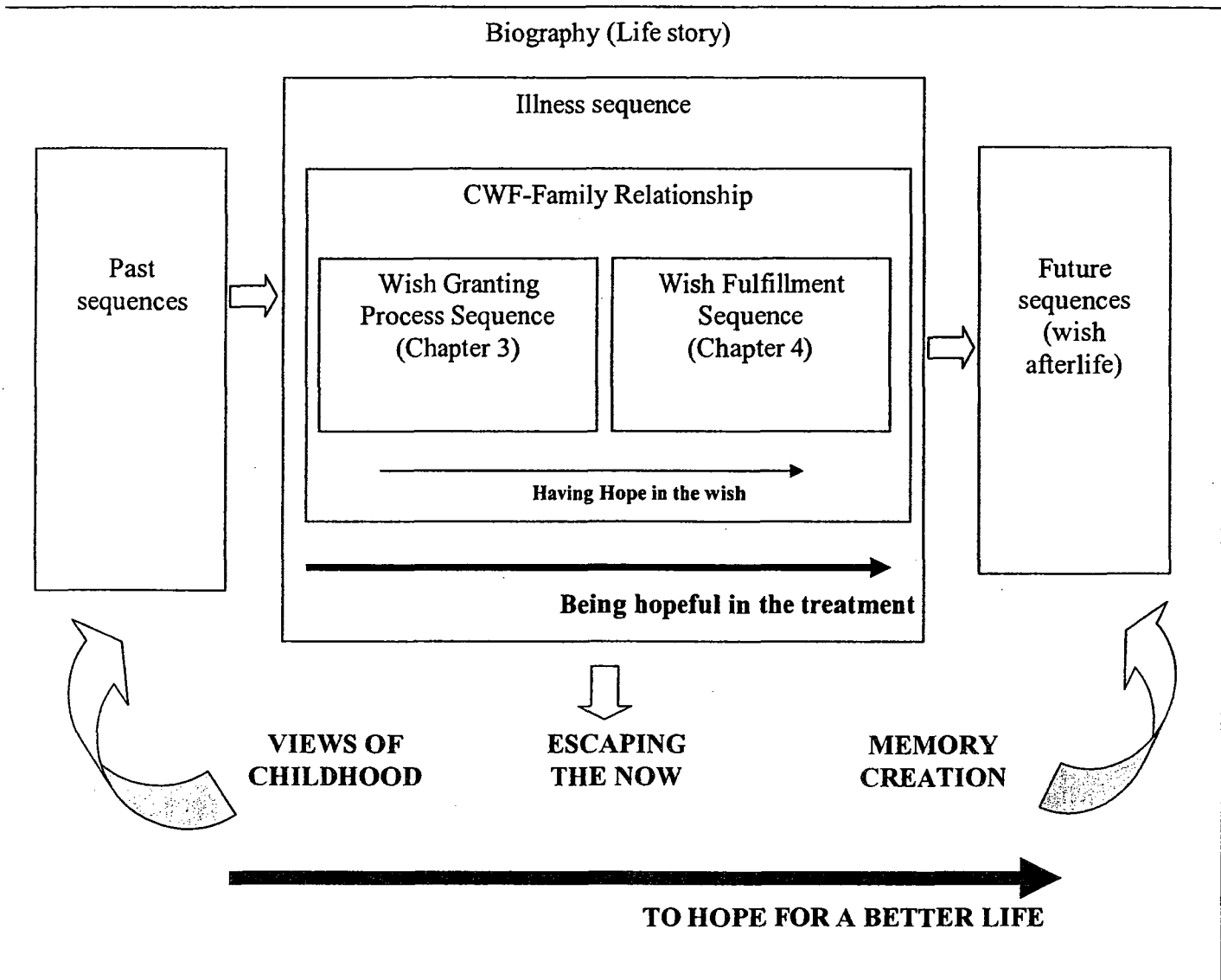
3.2.1. Abstraction shift 1: From having hope to being hopeful

The first shift is associated with the possibility that the wish may assist in the child's healing. In other words, *having hope* in the wish can lead to *being hopeful* about the prognosis of the illness. As we observed, some families indeed believe in the power of the wish, and hope that it can affect the healing process; they believe that keeping the

idea of the wish alive will help the child stay positive, focused, and motivated to fight, which could ultimately lead to a positive prognosis or improved condition. Hanging on to the wish becomes a metaphor for hanging on to life.

3.2.2. *Abstraction shift 2: From having hope to hoping*

The second shift further extends the reach of the wish, in that *having hope* in the wish can give rise to *hope* for a better life. For families who are in despair, hoping in the wish can reintroduce a forward-looking perspective into their lives and images of a better life. Without hope, there is no possibility to envision a better life, nor is there a reason to fight for one's life. Without hope, we become captive to our immediate environment (Reading, 2004). Without hope, "images of death, nothingness or emptiness" are all that seem to appear in the daily narratives of critically ill patients (Becker, 1997: 177). Consequently, losing hope in the face of such a threat can be highly detrimental to one's life (Groopman, 2005). [113] In order to get through tough times and excruciating treatments, it is important to retain hope in something better, something greater.

Even in cases of terminal illness, hope is critical up to the very end. In a groundbreaking study on the experience of dying, Elisabeth Kübler-Ross (1969) delineated five stages through which the terminally ill are likely to pass: denial, anger, bargaining, depression, and acceptance. She emphasized that, though many emotions come and go through these stages, hope is one that almost always persists. Even when getting close to the end of their lives and beginning to accept their fate, her informants held out hope, hope in a miracle, or hope that a breakthrough treatment will become available. It is hope that sustained them. Hope can enable a forward-looking perspective, despite the gravity

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of the situation. As Groopman adds, "Even when there is no longer hope for the body, there is always hope for the soul" (2005:xiii).

My fieldwork revealed that a wish can play the function of keeping or reactivating this much-needed hope.

> *This is for a future. This has helped me a lot. It's made me feel like I can still do whatever I want.* (Wish child reflecting on his wish in a promotional video)

This short quote exemplifies the importance of the wish in sustaining hope that, beyond the illness, there is still something on the horizon, something beyond the here-and-now imposed by the illness. In other words, thinking of the wish redirects one's psychic energy back towards the future. It fosters *hope* for a future.

> *You too have the right to realize your dreams. You have the right to cling to and realize things and then say, 'See? I can do things. I can achieve things and it's not over.' You have the right to dream of tomorrow, of the future, to just dream... I think that's what it's all about and to say 'I'm going to live to 95, you know.' You have the right to say that too.* (Interview with Emily and her mother, May 18, 2009)

As we can see from this second quote, Emily's mother Rose stresses to her daughter the importance of allowing herself to envision and hope for a future. By reintroducing a forward-looking perspective into her daughter's life, the wish granted by the CWF enabled Emily to do precisely that.

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3.2.3. *Imagined escape and memory creation as displaced meanings*

Contemplating the eventuality of a wish fulfillment and nurturing hope in a –transformed – better life constitutes a forward-looking perspective. Hope in a better life can be conceptualized as a *displaced meaning*, since the value is "removed from the daily life and relocated in a distant cultural domain" (McCracken, 1988:104). Meanings may be displaced across space and time as a way of reconciling the gap between the real (now) and the ideal (the better life) (McCracken, 1988). My fieldwork revealed that this "better life ideal" can exist in different spatial-temporal domains. They can be rooted in the future, in the past, or anywhere other than the here and now. This displacement occurs through the two mechanisms discussed earlier: creation of memory and imagined escape.

Creation of memory, like hope for a better life, represents a displacement of meaning towards the future. The memory-to-be is imagined to be created through the upcoming wish and is preserved thereafter. According to McCracken, the future is "unconstrained by historical record or demonstrable fact" and "has no limitation but the imagination that contemplates it" (McCracken, 1988:107). The unspecified and open-ended nature of memory creation thus holds appeal for families of sick children. Having hope in the wish is therefore critical to being able to hope to create such memories: in order to generate these memories, a family must first hope to experience the positive aspects of the wish while avoiding the negative ones.

Imagined escape, on the other hand, is potentially anchored in two displacements. The first is directed toward the past and seeks to bring back what "used to be": a life without hospitals and pain, a normal childhood, a family together. This displaced

meaning towards the past can be very reassuring, as the reliving of a remembered reality in the present can give hope for the same reality in the future. As McCracken (1988) puts it, the past reassuringly abounds with documentation and evidence. Hence, these re-enacted moments potentially offer solace and allow one to aspire to a better life, by bringing back mementos of a life already experienced. Moreover, Becker (1997) states:

> *Markers of continuity emerge from life experience and the layers of meaning*
> *people attach to their lives over time. Indications, no matter how limited, of the*
> *ability to return to activities engaged in before the onset of the disability are*
> *cause for hope. (p. 151)*

The second displacement is more targeted at getting away from the "visceral" experience of the now. Some families indeed wish to simply flee the present and forget about the illness for a while, or forever if possible. Their expressions of childhood as it *should* be are a manifestation of this desire to deny the present reality and replace it with a societally-based image of what their child could be.

3.3. Concomitant emotions

Aside from the research cited above, scientists have largely disregarded hope in the study of emotions, because of its elusive nature[114] (Cornelius, 1996). The present study shows the importance of the concept of hope in regards to fulfillment of the wishes of ill children. Furthermore, it reveals the array of emotions associated with hope. In fact, although hope has been the focus of this chapter, other related emotions have also been described. We highlighted the presence of negative emotions. The diagnosis and subsequent fight against the illness bring along with them many intense emotions, such as

fright, anxiety, and anger[115] (Lazarus, 1999), as these emotions are generated by the expectation of highly unpleasant events and existential threats (Lazarus, 1991; Reading, 2004). We also saw that the wish itself was accompanied by negative emotions. For instance, Kathrin's case showed the disastrous emotional impact an unfulfilled wish can have on a family. She also reported, as many other families have, the feelings of anxiety about the unknown that surround the wish fulfillment. Negative emotions can also arise from the hope to avoid negative outcomes, such as a deterioration of the child's condition, or a refusal to allow passage at customs. Sleep disturbances could be caused by these negative emotions. The desire to create memories can also bring its share of negatively-toned emotions, as in the case of Martin's family.

Positive emotions were, of course, also reported and were mainly associated with the anticipation of the wish, as in Laura's case. Gabriel's sister's diary illustrates the importance of anticipation and the tendency for emotions to intensify as the wish fulfillment approaches. The fulfillment of the wish can also unleash highly positive emotions, as with John, to whom the computer wish brought happiness, or with Melissa, who was full of smiles, laughter, and excitement for eight days. The positive emotions can endure beyond the wish, as in the case of Tracy who constantly relived the positive emotions she felt during the trip by looking at the pictures they had taken.

These observations are in line with the work of Averill, Catlin, and Chon (1990), Lazarus (1999), and MacInnis and Chun (2006), and confirm that hope is an emotion often accompanied by other emotions. As Cornelius (1996) points out, hope is associated with situations of uncertain outcomes, which may lead one to "experience hope in situations involving the whole gamut of common as well as uncommon emotions, from

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joy and love to resentment, sadness, and anxiety" (p. 207). In the context of the illness, wish families experience hope in conjunction with various emotions. In order to fully grasp the importance of hope, its link to other emotions must be acknowledged. The exploration of hope leads to the discovery of an entire range of emotions – both positive and negative – experienced by families in the course of their involvement with the CWF.

3.4.   The marketplace, hope, and the evocative power of everydayness

Hope is a powerful motivating force that shapes our vision of life and subsequent behaviours. Future-oriented behaviours such as building a house, planting a garden, or going to school, are infused with hope (Reading, 2004). The marketplace capitalizes on this emotion and delivers products that can ultimately alter one's imagination of future events. If used strategically by corporations, hope has the potential to influence behaviours, attitude formation, and product choices and satisfaction. Such communication strategies suggest the prospect of turning the impossible into the possible by selling the promise of innovation, personal growth, and anticipatory benefits, or by enhancing yearning by encouraging fantasy, a comparison of actual self with an ideal self, and an association of products or activities with higher-order goals (MacInnis and de Mello, 2005). My fieldwork revealed that due to its centrality during wish fulfillment (as we saw in Chapter 4), the marketplace, and the products available through it, play an important role in the fostering of hope. As illustrated throughout this chapter, providing an opportunity to go to Disney, or Paris, or to own a special guitar, can indeed be the trigger that spawns hope. In this relation between the families and the marketplace, however, the CWF is a mediator of hope. It facilitates the possibility of wish fulfillment. Indeed, the families alone would mostly not have been able to mobilize the necessary

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elements of the marketplace to create the fulfillment of the wish. The CWF is also very careful in its utilization of hope, in order to avoid instilling false hope.

A wish is culturally associated with the grandiose, the fantastic, and the far reaches of the imagination. Statements like "Make a wish" or "May all your wishes come true" evoke a fantastical discourse in which everything seems possible, even the craziest of ideas. In a consumer world where everything must live up to the expectation of being an outstanding, transcendent experience (Pine and Guilmore 1999), places like Disney fuel the childhood imaginary with ideas of dreams and re-enchant the world through the carefully crafted spectacular (Ritzer 2005). Consequently, the marketplace is viewed as an inexhaustible source of fantasy, myth, and the imaginary.[116] With the cooperation of the marketplace, the wishes granted by the CWF aim to fulfill the grandiose ideas of children, ideas shared by their siblings and parents.

Despite the imagined nature of families' hopes, their hopes for a better life do not seem to be built on an imaginary promise. In fact, in their attempt to escape, families don't appear to take refuge in the imaginary realm of the wish, but rather in the aspects of the experience that are familiar to them, aspects of the world they knew and lived *before* the illness. They hope for a successful treatment, for the possibility of gathering positive memories in and for the future, for an escape from their current reality, and for a chance to relive images from a lost childhood. That better life is not a fantastic, imaginary one shaped by consumer objects or experiences.

Although an important discourse in consumer research is anchored in a postmodern philosophy which celebrates the emancipated, spectacular, simulating, and

performed aspects of our lives (Firat and Venkatesh, 1995), what makes these families hope is built on the evocative power of everydayness, an everydayness of which they were robbed and for which they yearn. The ordinary objects, activities, places, and moments that are normally taken for granted in the usual course of life (Csikszentmihalyi and Rocheberg-Halton, 1981; McCracken 1988; Miller 1998; Coupland, 2005) constitute for them a central meaning and purpose in the rebuilding of a better life.

This observation echoes a theoretical discourse which postulates that hope is grounded in realism and acknowledges obstacles and pitfalls along life's path (Groopman, 2005:xiv). Hope is not delusional. As Lazarus (1999) points out, hope is regarded as "an affective blend which, depending on how we understand what is happening, includes both positive and negative judgments" (p. 655) In order for hope to exist, there must be something in one's representation of the world – which is formed from past and present experiences – that makes the desired goal seem plausible (Reading, 2004). In their exploration of hope, Averill, Catlin, and Chon (1990) also came to this conclusion and stated that hope must follow "prudential rules." As they put it, "One of the most consistent findings to emerge from the data thus far is an emphasis on realism." (p. 33). Hope is therefore conceptually different from fantasy, in that "[i]t involves imaginative expectations that are constrained by what we believe may plausibly happen" (Reading, 2004:176).

3.4.1. Escaping

Consumer researchers have been interested in the notion of escape for many years. They have explored consumers' imagination by evoking an imaginary world (Martin, 2004).

They have reflected on the possibility of consumers escaping the market (Kozinets, 2002). They have also demonstrated that the market can be manifested as a way to escape from other forms of exchange, like the gift economy (Marcoux, 2009). My fieldwork revealed that the marketplace can become a *veritable escape destination* for families facing childhood disease. Imagining as well as consuming the wishes (like going to Disney, acquiring a specific item, or meeting a celebrity) can procure a transformational escape from the now of the illness, and provide the possibility of capturing such moments in memory.

A common thread in all of these examples is that escaping is a fundamental, "inescapably" human tendency. The drive to escape is a force of nature. Some hold that it is manifested in the creation of culture itself, insofar as culture can be viewed as a form of flight from nature, from our animal state, and from the fear of loneliness and singularity (Tuan, 1998). The context described here – of families with severely ill children – highlights another, perhaps less abstract, but no less human quest or need to escape. It shows that an escape can be performed mentally through a displacement of meaning, hope being the driving force behind this displacement. As McCracken (1988:109) puts it, "Astute displacement of meaning through hope can make astoundingly unhappy situations more tolerable." Indeed, displacements into the future (through memory creation) and into the past or away from the here and now (through an imagined escape) have the power to procure a measure of relief from the current situation by contemplating a better reality. Hope is perhaps the strongest of all escapes, and nothing may be more valuable than its recovery after an episode of hopelessness and

despair. In her book *Healing Spaces*, Esther Sternberg beautifully captures this sudden

return of hope and escape from darkness:

> *There is a turning point in the course of healing when you go from the dark side*
>
> *to the light, when your interest in the world revives and when despair gives way to*
>
> *hope. As you lie in bed, you suddenly notice the dappled sunlight on the blinds*
>
> *and no longer turn your head and shield your eyes. You become aware of bird*
>
> *songs outside the window and the soothing whir of the ventilation system down*
>
> *the hall. You no longer dread the effort needed to get up, but take your cautious*
>
> *steps, like a child, to explore the newfound space around you. The smell of food*
>
> *does not bring on waves of nausea or revulsion, but triggers hunger and a desire*
>
> *to eat. The bed sheets feel cool and soothing – their touch no longer sends shivers*
>
> *throughout you, like chalk-squeak on a blackboard. Instead of shrinking from*
>
> *others, you welcome the chit-chat of the nurse who enters the room.* (Sternberg,
>
> 2009, p. 1)

Conclusions

Negotiating the tensions of a highly commercialized charity context

1. Summary of the ideas

In this dissertation we delved into the fascinating complexity of the charitable granting of ill children's wishes. Through an ethnographic exploration of the social life of wishes, I furthered the understanding of motivation research regarding the notion of the wish. Indeed, my reflections on the phenomenon suggest the need for a major shift in exploration of wishes or aspirations to one that encompasses the following perspectives: the wish as an evolving, more socially-embedded phenomenon; not limited to the study of average healthy consumers; and more inclusive of the body and the imaginary. By looking at the phenomenon simultaneously from the perspectives of the charity, the beneficiaries and the marketplace, this dissertation aimed to provide a more comprehensive picture of the wish phenomenon than what currently exists in the literature on the charity marketing sector.

In the exploration of the wish, I looked at the phenomenon from three very different perspectives: In Chapter 3, I proposed to explore the *process* of wish granting as it is carried out to make wishes possible. I identified five major steps in this process: eligibility check, confirmation, wish definition, wish approval, and meetings. These steps contain actions of varying complexity and involve a vast array of actors, from charities

(not only the CWF), marketplace and the community. I proposed that the process is highly emotional for some of the actors, and furthermore, that it is highly regulated. I also explored the complexity of the wish with regards to the deployment of the actors and concluded that the three dimensions of the wish (its duration, location, and nature) contributed to explaining of the deployment of actors (the greater the complexity, the greater the deployment). I also observed that the awareness of actors varied significantly across the process. I concluded that this analysis of the process forces one to reconsider the generally accepted idea of the panopticon when conceptualizing the consumer facing his desires, goals, and dreams. I argued that the wish cannot be seen as the sole burden of the dreamer and that the dreamer cannot be considered to be the singular regulator of his desires. I proposed instead that the oligopticon prespective, as advanced by Latour (2005), should be taken in order to account for the feasibility of the wish, and moreover, the fact that no single actor is entirely responsible for it; not even the family or the CWF.

Chapter 4 looked at the wish fulfillment form a naturalistic perspective. We followed Sonya, her mother, and her grandmother through the entire week they spent at Disney and described the experience as it unfolded. I then highlighted important elements of the wish that are, in one way or another, common to other wishes: the fact that the wish was emotionally and physically draining; that it had the potential to become a memorable event; that it was full of surprises; and that it involved a multiplicity of actors. In the discussion, I proposed the idea of the wish as an extraordinary experience and compared it mostly to Arnould and Price's (1993) ethnographic analysis of the white river rafting experience. I identified three main narrative components that qualified the wish as extraordinary: the intense use of the body, the particularities of space, and the

engagement of people. When contrasting the two experiences, I concluded that the authors' vision of the extraordinary was limited by the tacit belief that it is derived from the divine, the wild, and extreme sports. In Sonya's case, the extraordinary surfaced in a vastly different setting; one that is highly commercialized and engineered and that contains all the comforts of civilization. I also argued that, contrary to Arnould and Price (1993), highly culturally-embedded events like taking a plane, going to the restaurant, or sleeping in a hotel can also contribute to create an extraordinary experience. As Latour would conclude, I proposed that culture would in this case be an actant (and not an actor) in the sense that highly culturally familiar settings do not necessarily diminish the extraordinary aspect of an experience.

Chapter 5 looked at the afterlife of the wish, and specifically how this is anticipated and showed how hope is intimately linked with the wish. Consistent with MacInnis and Chun (2006), three types of hope were identified: hope in the wish item/experience, hope in the outcomes and hope in a transformation. Each type of hope was shown to be associated with a particular trigger element: the procedural gap (hope for wish item or experience), the script gap (hope for wish-related outcomes), the power of a wish (hope for illness-related outcomes), and the reality of the now (hope for transformation). Each type of hope was also seen to be associated with a specific focus of attention: the child's eligibility and wish approval was linked to hope for wish item or experience; the anticipation of positive and negative wish consequences were related to hope for wish-related outcomes; the illness was of course associated with hope for illness-related outcomes; and imagining an escape and capturing the transformation was directly linked to hope for transformation. I demonstrated that these hopes are not just

purely mental activities, and that they can materialize into real consequences. I also illustrated the shift between the levels of hope using the three facets of hope introduced by de Mello and MacInnis (2005). I argued that *having hope* for the wish can lead to *being hopeful* about the prognosis of the illness and *to hope* for a better life.

2. What is the Wish Factory?

In a general sense, these findings and analyses answer the research questions identified in the introduction of this dissertation. To summarize them, I will begin by addressing the general question that drove my entire research: how can we conceptualize and understand the phenomenon of ill children's wish granting and its impact on the relationships among the various actors, as they are deployed throughout the process?

2.1. A definition of the Wish Factory

I believe that the easiest way to answer this question is to propose a definition of the Wish Factory. In light of this research, I therefore define it as follows:

> *A process that pools finances, people, expertise, and consumer goods and services*
>
> *in a globally-regulated – yet not entirely controlled – manner, leading to the*
>
> *creation of extraordinary events that are likely to make a significant difference in*
>
> *the life of a family facing a childhood illness.*

A process. The Wish Factory develops a wish through many steps. It is first designed and approved following at times several rounds of negotiations and is occasionally postponed until the time of its fulfillment. Its materialization is also something that unfolds differentially, at times only for the brief duration of a shopping excursion, at others for

periods as long as eight days of travel, and in still other cases, lasting many years (as in the case of a wish for a swimming pool).

Pooling. In the construction of a wish, the Wish Factory accumulates, aggregates, links, separates, and sometimes reunites the actors involved in it.

Finances. In order to be able to grant and fulfill wishes, the Wish Factory's actors from the marketplace develop relationships and work together towards accomplishing their complementary goals to create value.

People. In order to construct and fulfill wishes, the Wish Factory invites and involves a vast array of people at different points in time. The roles and power relations among actors will vary based on the time and nature of their involvement. For instance, doctors play a highly important role at the beginning of the process but become far less active (to completely inactive) as the wish evolves and is fulfilled. The actors communicate with each other to an extent dependent on their entry in the process and on the roles they play.

Expertise. The Wish Factory will employ various people who have extensive specialized expertise that is critical to the success of the endeavour. Physicians have highly technical knowledge concerning the disease. Wish coordinators like Wendy have a tremendous understanding of the complexity of the process and on how to involve other experts (doctors, customs agents, insurance brokers, celebrity agents, etc.).

Consumer goods and services. Each wish is by its very nature highly embedded in the marketplace and takes from the market what it can offer in terms of items, travels, and celebrities. The wish's extraordinary nature and hope-generating capacities are thus, at least in part, derived from the marketplace.

Globally-regulated, yet not entirely controlled. In order to process wishes, the Wish Factory must comply with an extensive set of regulations stemming from the work of many of the actors. For instance, the CWF has developed an impressive volume of procedures to facilitate the flow of the process. Families also perform regulation when setting the boundaries of the wish's definition. The medical community regulates by defining which illnesses are deemed life-threatening. Although highly regulated, the Wish Factory has no means of being completely overseen by any single actor or group of actors. Like in the oligopticon, each actor has a partial view and understanding based on what he can grasp of the process. Despite this partial perspective, the actor is able to execute adequately because the information he possesses is sufficient to perform his duty.

Extraordinary events. The Wish Factory creates extraordinary events insofar as being highly enjoyable, unique, all-consuming and unpredictable. The wish further derives its extraordinary character from the integration of narrative components, such as the intense use of the body, the uniqueness of places and the engagement of people. It is through the materialization of the wish that the extraordinary nature reveals itself.

Makes a significant difference. The Wish Factory grants and fulfills wishes of seriously ill children. As such, it evolves primarily in the context of illness. The wish is felt as an experience that can have deep existential impacts on the families. Such impacts can be experienced at two levels. First and foremost, the wish is a highly anticipated event that can re-ignite a state of hopefulness in a situation where hope was dwindling. Hope in the wish is infections and has the power to extend its reaches far beyond the wish itself. It can also have a highly emotional impact on other actors, such as the wish coordinator or the volunteers.

In light of the above definition, we are forced to conclude that the Wish Factory is not the Children's Wish Foundation. Rather, the CWF is one of its agents, just as the marketplace, the doctors, the insurance brokers, and others are. They all work together in the creation of the event. As I suggested, the Wish Factory is the sum of all efforts, all actors, and all perspectives that contribute to the development and fulfillment of the wish and of its ramifications.

2.2. Negotiating the tension between the extraordinary and the plain commercial: The experience of the families

In light of all this, the wish is not just the end result; it is also part of the process. It is something that is created, fulfilled, and experienced. Interestingly, the idea of the experience of the wish can pose a theoretical problem. At an individual level the wish may perhaps be experienced by families as extraordinary, or perhaps as a highly important goal to fulfill – as it would most likely be seen by the CWF representatives. However, it can also be seen as something far less extraordinary, far less unique. To some of the actors involved in segments of its life, it may be nothing more than a mere commercial transaction. For example, there is no "wish element" in the mind of the waiter who serves a wish family who decides to treat themselves and eat at a fast-food restaurant after a memorable day spent together in a theme park. To the family, insofar as this dining experience represents something they used to do together before the coming of the disease, it might be extraordinary, or in the very least, it might add to the extraordinary aspect of the wish. One must therefore acknowledge that the process is polysemic. It allows multiple voices and multiple meanings – which are sometimes even

contradictory – to operate at the same time towards the creation of the wish. This is perhaps the truly extraordinary characteristic of the wish.

How is this possible? A first explanation involves the partially connected nature of the relationship between the actors. The CWF's dealings with doctors to determine, in medical terms, the eligibility of a child has nothing to do with the highly hope-charged experience of the child and his family during this moment. Here the exchange occurs beneath the procedural gap (see Figure 3.2 in Chapter 3). In the same vein, a family might be ecstatic to spend time discussing the wish, defining it, searching the Web for ideas, while the CWF employees are busy discussing fundraising tactics. The exchange between the family members occurs above the intimacy gap (see Figure 3.2).

The rationale of the partial involvement does not explain the situation of the waiter and the family in the fast-food restaurant, however. Thinking in terms of sacred and profane (Belk, Wallendorf, and Sherry, 1989) would not help here either, because one could say that under this scenario, in that very moment, *both* the sacred and the profane are at play: the family is experiencing the grandness of the wish, while the employee flips burgers and thinks of his next paycheck (dramatization).

This fictitious example reflects the overall tension that exists in most wishes, in that although they are highly unique and special, they are nonetheless embedded in the marketplace and take their source in multiple consumer products and/or experiences, as shown in Figure C.1 below, which is borrowed from the image of Janus.[117] One can look back at Sonya's wish in Chapter 4 and identify all of the exposures to marketplace actors during its fulfillment.[118]

Figure C.1: The tension in the wish[119]

> *The wish is an extraordinary experience.*

> *The wish is highly embedded in the marketplace.*
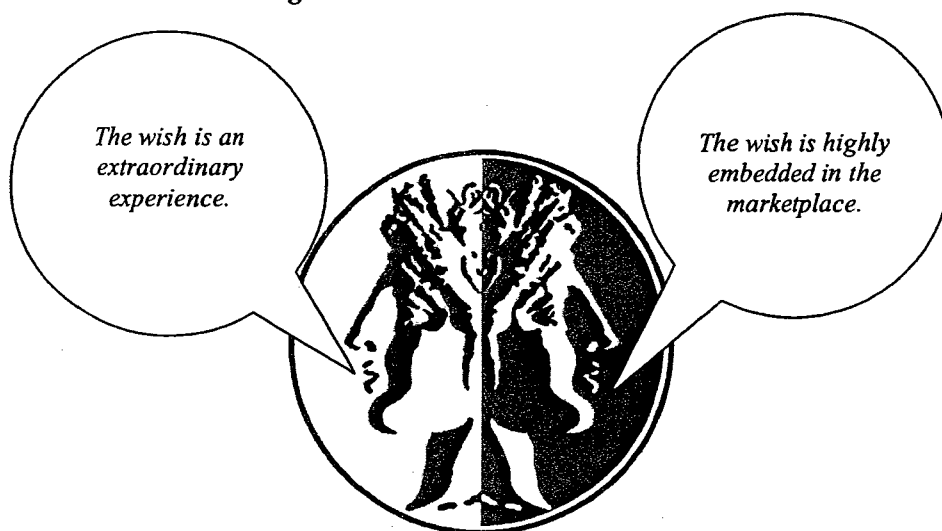
This tension between the extraordinary and the plain commercial – and the fact that it can be successfully incorporated into the wish during encounters between families and the marketplace – is an expression of the regimes of value expressed in every *commodity situation* (Appadurai, 1986). Before explaining what a regime of value is, I will first define a commodity situation. A commodity situation looks for the *commodity candidacy* of a social thing, that is, the context under which a thing can move in and out of the commodity state (Kopytoff, 1986). A commodity is simply defined here as a "thing that has a use value that can be exchanged in a discrete transaction for a counterpart" (Kopytoff, 1986: 68). One should note, however, that I do not intend at all to convey a wish as a commodity. It is not my intention here to put the wish "on trial." In fact, following Appadurai, the interest does not reside in determining whether a thing is a commodity or not, but rather in examining the *commodity situation,* which considers the social life of any "thing" as a process and the condition under which its exchange or consumption occur. Consequently, the interest resides in the fact that the wish, or part of

it, depending on the context, can at some point be transacted in the marketplace, as exemplified by the fast-food scenario.

Bearing this definition of a commodity situation in mind, allow me to now show how the regimes of value become meaningful by explaining how the tension between the extraordinary and the highly mundane can be resolved. A regime of value, in Appadurai's (1986:15) view, implies that "not every act of commodity exchange presupposes a complete cultural sharing of assumptions." Appadurai primarily uses the notion of regime of value to explain that transactions between individuals from highly different cultural backgrounds can occur when they both focus on the shared standard value associated with the exchange.

This explains why the family can experience the extraordinary in face of another actor who does not see any element of wish in the transaction. It simply shows that in such a scenario, the values of the transaction do not revolve around the wish, but rather the element of the transaction. The two actors are thus free to experience the wish their separate, incongruent ways without generating any conflict.

Figure C.2: Resolving tension at the family level

The wish that is created is highly unique.

Many transactions occurring during the wish experience are occurring at the level of commodity.
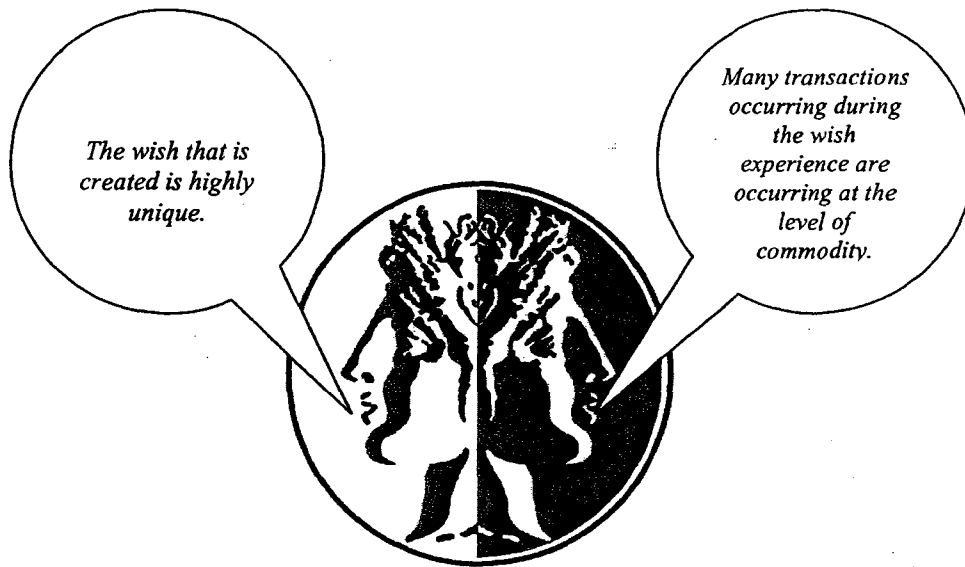
In that sense, the idea of the sacred and the profane (Belk, Wallenforf and Sherry, 1989) could apply here as well. The regime of value here would function as an unconscious protection mechanism to avoid contamination of the sacred by the profane. In other words, by focusing on the shared standard value during the transaction, the family is simply momentarily "bracketing" the wish to better reincorporate it later.

2.3. Negotiating the tension between the extraordinary and the plain commercial: The experiences of the CWF and the marketplace

Does this tension apply solely at the level of the family? Is the tension also "experienced" at other levels? In other words, do the two opposing forces occur throughout the process? A tentative answer is yes. I will show how it can reverberate at the level of the two other main groups of actors involved in the relationship: the CWF and the marketplace.

First, interestingly, this tension between the unique and the plain commercial in the wish operates at the level of the Foundation. As mentioned earlier, the CWF

representatives, when dealing with families, try to make every wish exceptional. Their efforts go towards the singularization of the wish, for each wish *should* be extraordinary. This can imply, for instance, emotional labour (as we saw in Chapter 3). But it also often implies an attempt to involve the marketplace actors in the fulfillment of the wish. In fact, as we saw in Chapter 3, although the marketplace plays an integral role in the fulfilment of wishes, the individual actors within that marketplace possess varying (and often limited) degrees of knowledge about the fulfillment of the wish in which they participate. Furthermore, their level of involvement also varies greatly. Airline companies are an interesting example in this regard. The two major carriers normally involved in the transportation of families are Air Canada and Air Transat. Air Transat (see Appendix 1) is actively involved in the delivery of the experience. It also possesses specific knowledge about each situation and instructs front line employees to identify wish families upon boarding and give them special attention. Air Transat's employees, then, are actively involved in the wish. Air Canada's involvement, on the other hand, is somewhat removed. Wish families are considered regular passengers and receive no preferential treatment from employees. The family itself has to take a proactive stance in order to receive something. For example, as I described in Bobby's wish, in order to visit the cockpit, I had to go to the boarding desk, inform the employee that a wish child would be boarding, and ask if "something special" could be done for him. The company would not have known about the family or have done anything special otherwise. Furthermore, playing an important role in a wish does not necessarily mean the market provider will develop an in-depth understanding of the situation. The theme parks offer an interesting example of this realty. Although they can be as important as *being* the

wish, Disney, Universal, and SeaWorld have limited information about the wish families. They mainly know the number of people in a family's party and their names so they can produce the Guest Assistance Card. This is a special card that indicates to theme park employees that the bearer needs special care. Its benefits generally entail having their employees escort families directly to the attractions through the exit gates or employee entrances, or being allowed to pass into the fast track line (see Bobby's wish in Appendix 2 for a photo of the pass). This preferential treatment enhances families' experience by allowing them to circumvent long waiting lines under the scorching Florida sun. Families also benefit from "special favours" during character meeting sessions.[120] This special care, though appearing to be personalized, is merely a learned script performed by employees as part of their customer care policy. In that regard, and consistent with what I explained previously, when dealing with a wish at a transaction level, the marketplace actor tends not to consider or be aware of the extraordinary aspect of it. This is illustrated in the first Janus face of each actor in the following figure:

Figure C.3: Tension at the *micro* level for CWF and marketplace
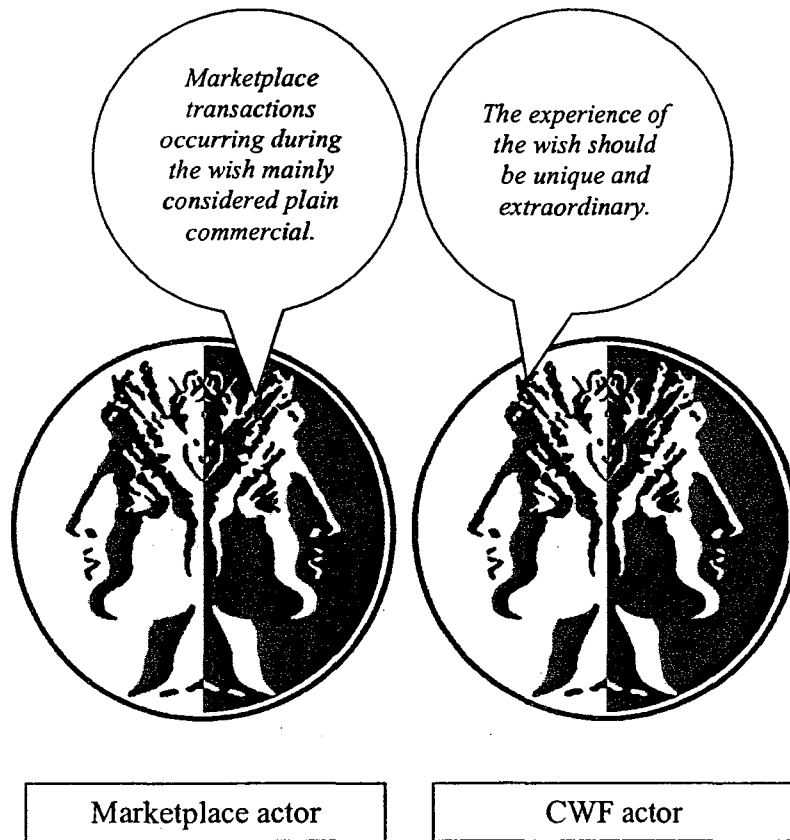
Then, interestingly, when we *step back* and take a more macro perspective, that is, when we consider the CWF operations as a whole, we notice a different position. As I mentioned before, the CWF processes a vast number of wishes in its daily operations. A person like Wendy can supervise the granting of more than 300 wishes in one year. In Canada, a total of 15,114[121] wishes have been granted since the creation of the Foundation, which represents a large deployment of effort and money. Currently, the CWF orchestrates the fulfillment of more than 1,000 wishes annually. "One wish is granted every meal of the day," as they say. Consequently, from a practical standpoint, the foundation is forced to "manage like a business" (see Appendix 1). Globally speaking, they have a tendency to view wishes from a cost-based production perspective

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and to try to find ways to decrease their operational costs as much as possible. They try to "standardize" or formulate wishes in such a way as to make them more efficient to handle and process. As we saw in Chapter 3, the procedures manual is the ultimate representation of this institutional bias. It abounds with rules and detailed descriptions of what a wish should contain. Offering wish "packages" (like the swimming with dolphins wish that I described in Chapter 3) can help garner deals with marketplace partners (and possibly save money), accelerate wish processing, facilitate the planning of the wish schedule and its ensuing details, make expenditures and budgets more predictable, and so on. It is indeed easier to process a dozen similar Disney wishes consisting of three days at Disney, two at Universal Studios, and one at Sea world, a rental car, and a stay at GKTW (or Star Island) than develop a dozen entirely customized trips. This construction of similar wishes can ultimately help Wendy and her colleagues supervise the granting of more than 300 wishes annually. Just as would be the case with any for-profit business, CWF's overall performance is assessed, monitored, and communicated to the major stakeholders (Boards of Directors, corporate sponsors, individual donators).

A macro look at the marketplace also reveals something fascinating. As we have seen throughout this dissertation, it is partly due to the variety of actors, as well as their roles in the fulfillment of the wish, that the creation of the extraordinary aspect of the wish can happen. It is indeed through the many evolving and unexpected encounters with those actors that a wish takes on its social life and extraordinariness. The marketplace is an integral part of this construction of the extraordinary, when considering that from a global perspective, each marketplace actor progressively fits in the overall network of a

wish, which contributes to creating its unique, extraordinary life. This completes the

second Janus face of the marketplace and the CWF.

Figure C.4: Tension at the *macro* level for CWF and marketplace
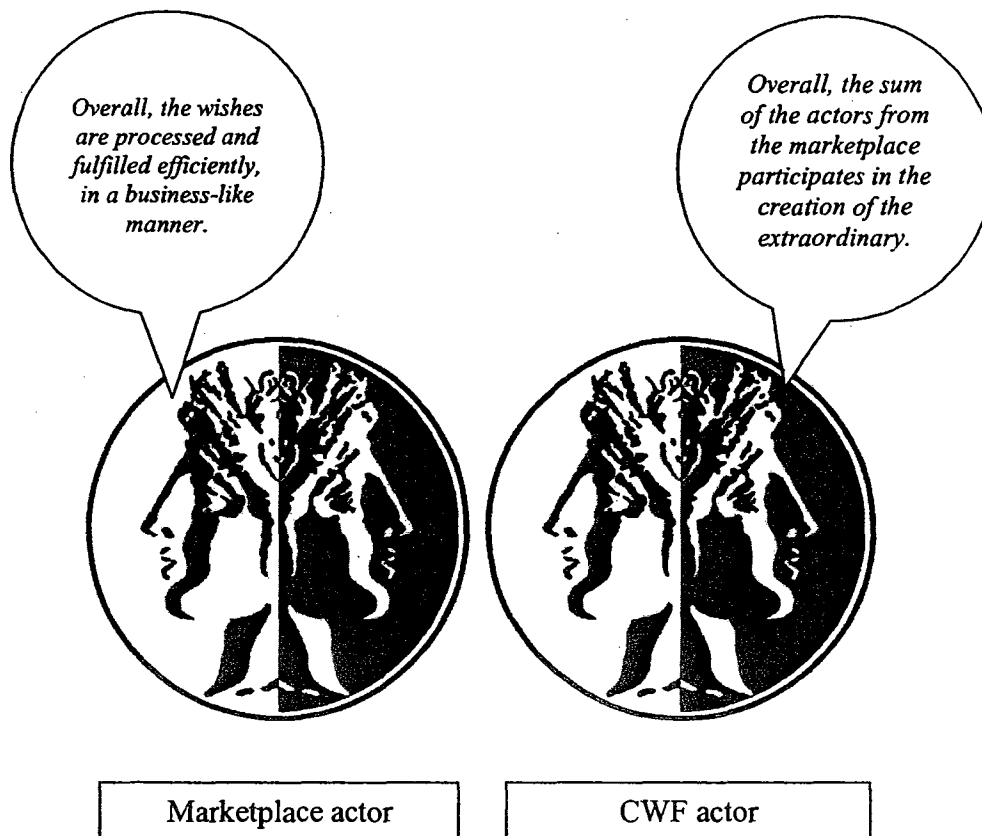
The extraordinary aspect of a wish truly resides in its capacity to integrate all of these

opposing forces into one single wish (and in so doing, combine the many regimes of

value). In that sense, we are seeing a picture of the marketplace that opposes, to a certain

extent, this overall discourse about how its engineering contributes to the re-enchantment

of everyday life (Ritzer, 2005). I have shown that it is not only through the magnificent or

spectacular that the effect occurs, as is often emphasized by consumer researchers

(O'Guinn and Belk, 1989; Sherry, 1998; Kozinets, Sherry, Storm, Duhacheck,

Nuttavuthisit, and Deberry-Spence, 2004, etc.). It also happens, as we saw in Chapter 5, through the *power of everydayness*.

3. Concluding remarks

This discussion has led us far from the current debate in the field of motivation research. This is to be expected. When considering a goal, a desire, or a dream from the single perspective of the individual, any such tension disappears. Moreover, when performing any form of reification of the notion, that is, when considering the aspiration as a separate entity from the desiring subject, one can hardly consider these questions since the aspiration cannot be negotiated: it exists as it is. The perspective I chose, one that follows Latour (2005) and Appadurai (1986), forces one to consider the aspiration as a process. As I mentioned before, I considered the wish *as a process*. I was not interested in a retrospective or prospective perspective. I was interested in examining the wish *in the making*. This perspective forces one to consider mechanisms that pertain more to the social than to the psychological. From this standpoint, we can show that the ramifications of the wish can vary wildly depending on the perspective of the actor involved in its fulfillment. We can show that although the illness is central in the creation of the wish as well as to the perspective of the family, it can be irrelevant somewhere or for someone else in the process.

The notion of regimes of value provides an interesting way of explaining why the extraordinary nature of the wish prevails despite the plain commercial context of some (or many) of the transactions occurring throughout its fulfillment. At a more abstract level, it also helps explain why highly religious (O'Guinn and Belk, 1989) divine nature

settings (Arnould and Price, 1993), or in an extreme sport (Celsi, Rose and Leigh, 1993) are not prerequisites of an extraordinary experience. When considering the process as Latour would do, all of these things become possible.

I do not intend to suggest that a psychological perspective is irrelevant or unsuitable in the study of consumer phenomena. I am merely stating that a different perspective on concepts can lead to asking different research questions (such as the ones I formulated in Chapter 1).

I also pushed the analysis further and attempted to fill a gap in the charity literature. First, my entire thesis is focused on the beneficiaries. I showed how they interact with the marketplace and the charity, how they participate in the construction of their wish. I also showed that they have power in the definition of their wish (they have the final say), and that, most of all, the child is the focus of this element of power (which creates a certain anxiety among the CWF troops). I further showed that their power is limited by the other actors involved. Although I did not propose a systematic analysis of the beneficiary, its place has been well acknowledged and highlighted whenever necessary and possible. I proposed an examination of the phenomenon from a process perspective, not from an individual one. This directly fills a gap in the literature and showed that considering the Wish Factory as a process allows one to freely explore the intricate links between the charity, the beneficiary, and the marketplace.

I can finally state what the Wish Factory really is. It is *the cause*. It is the reason why all of these actors are deployed; some of them are directly and actively involved in creating something grand, while others are indirectly and vaguely concerned. Therefore,

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to study the intricate relationships between the charity, the marketplace and the beneficiaries, one should take the cause as a point of departure and analyze it as a process — not from a strict *Cause-Related Marketing* point of view (which reifies the case), but from the perspective of viewing the cause as it is negotiated and received by the actors, and as it evolves.

Limitations

Obviously ethnography has its limitations. Van Maanen (1988) identifies specific caveats. First, it is experientially driven, and hence, relies heavily on what the ethnographer can witness. I might not have had access to every cultural scene. Also, building alliances with some informants may have precluded rapport with others. Second, ethnography is politically mediated; the "power of one group to represent another is always involved" (p.4-5). I tried to access all groups and to hear all voices, but some of them have perhaps been downplayed in the process. Third, ethnography is shaped by a tradition and a discipline. I recognize that my understanding of the fieldwork is affected by the assumptions, theories, frameworks and paradigms of the academic institution in which they have been trained. Fourth, ethnography is about rhetorical choices. The choice of narratives, personal expressions, metaphors and textual organization belongs to the ethnographers as writers; they are accountable for their style. In my attempt to represent the complexity of the phenomenon, perhaps other examples or terms could have been used.

My research in itself also contains limitations. It does not cover the negative side of the wish in great detail. For instance, what happens when a wish is not approved or when a child's condition is rejected? How is this situation negotiated by the actors? What is the impact on the family? How do families deal with dissatisfaction concerning their wishes? How can they or do they communicate their dissatisfaction to the CWF – their generous gift-giver? Moreover, there are people who disagree with the mere notion of a wish (mainly doctors). Why is this so? What can we learn from this dissident voice? This limitation in fact reveals that my view has clearly been biased by the "dominant group."

It also reveals that my understanding of the causes and consequences of the wish are perhaps still partial, that my understanding of the network is still incomplete. I also did not explore the illness to its fullest extent. Its manifestation and reality are deeply intertwined with many wish families and affect the process in kind. That being said, I believe the approach that I used to explore and experience this phenomenon, although imperfect, contributed to its better understanding.

End notes

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[1] I don't mean that religion no longer exists in modern societies. Even if many thinkers talk of "a modernity" that has erased, secularized the world, and disenchanted life through science and rationalization, it is false to believe that it has vanished completely. We also cannot restrict our understanding of religion to the contexts of televangelism (O'Guinn and Belk, 1989) or of "religiosity," as in brand consumption (Muniz and Schau, 2005).

[2] As of yet, no African countries are served by this organization.

[3] Source: http://www.childrenswish.ca/index_2007.php/en/national/page/150. As of August 4, 2009.

[4] According to Glaser and Strauss: "to generate theory… we suggest as the best approach an initial, systematic discovery of the theory from the data of social research. Then one can be relatively sure that the theory will fit the work. And since categories are discovered by examination of the data, laymen involved in the area to which the theory applies will usually be able to understand it, while sociologists who work in other areas will recognize an understandable theory linked with the data of a given area." (p.2-3)

[5] Source: d'Astous and Deschenes (2005: 5)

[6] Darwinian and Jamesian psychologists technically do not consider hope to be an emotion (Cornelius 1996). For instance Ekman (1984) does not include hope in his list of basic emotions (anger, disgust, fear, happiness, sadness, surprise) because it is not

associated with distinct facial expressions, and Izard (1977) sees hope as an element of the basic emotion of interest.

[7] I concur with cognitive and social constructivist psychologists and consider hope to be an emotion. As Lazarus (1999) would put it, from an appraisal theory perspective, an emotion arises from presumed goals, which forces us to consider hope as an emotion: "Hope is a response to goal outcomes, and as such, it should be treated as an emotion" (p. 663).

[8] Generally speaking, to Koreans, hope was perceived as relatively stable, whereas Americans conceptualized it more as a transitory state. Koreans described hope episodes that were longer in duration and more within their control than Americans. According to the authors, Confucianism puts less of an emphasis on transcendental power than on the cultivation of one's humanity, which places hope in a much more peripheral role for Koreans. These findings could explain why in another study (Boucher, 1980) Koreans did not spontaneously list hope as an emotion, as the Americans had.

[9] The ACR 2005 Presidential Address was entirely focused on the necessity of adopting the *transformative research paradigm*, doing more socially relevant research in the field of consumer research. Moreover, during this conference, many special sessions were organized around topics of transformative research such as child obesity, consumer vulnerability, public health issues, etc.

[10] Fournier and Guiry (1993), d'Astous and Deschenes (2005), Dholakia and Bagozzi (2002), Bagozzi and Edwards (2000), Bagozzi and Dabholkar (2000), Perugini and Bagozzi (2001), Sirin, Diemer, Jackson, Gonsalves, and Angela Howell (2004), and

Anderson, Bechhofer, McCrone, Jamieson, Li, and Stewart (2005) are good examples of prospective motivation research.

[11] Belk, Ger and Askegaard's (2003) study reveals such insights.

[12] Defined as any group that affects or that can be affected by the organization's actions and objectives (Freeman, 1984).

[13] Inspired from Daw's (2006) writing.

[14] Daw (2006) identifies various ways of communicating values through the marketplace: cause-supported product purchase, facilitated giving, licensed products, issue promotion, cause promotional events, and public service cause marketing.

[15] Andreason, Goodstein, and Wilson (2005) identify nine main differences affecting the transfer of marketing knowledge to the non-profit community. For instance, an extremely small marketing budget, the promotion of behaviours actively opposed by target audiences, an absence of direct retribution in return for the service provided, the critical importance of volunteers, a focus on the mission rather than on competitiveness, a higher risk aversion caused by extensive public scrutiny, etc.

[16] Analyses of performance also tend to support that claim. See, for instance, Duque-Zuluaga and Schneider (2008) and Shoham, Ruvio, Vigoda-Gadot and Schwabsky (2006) for a summary of past research on the link between marketing orientation and NPO performance.

[17] However some studies have explored the three domains together, for instance Brown and Lankford (1992), García-Mainar and Marcuello (2007) and Handy and Katz (2008).

[18] I am not implying that beneficiaries are all vulnerable. Nor am I taking a paternalist-moralist perspective by saying that all vulnerable people *must* be protected from the marketplace. I do not subscribe to the "dumb consumer model" (Calfee and Ringold, 1992) which sees consumers as passive actors succumbing to marketers' strategies. I do believe, however, that some beneficiaries may be vulnerable and may need support from charities. Generally speaking, one must avoid early categorizing of individuals and groups as being vulnerable, since the vulnerability might only represent one's imposed perception of others. There can be a difference between perceived and actual vulnerability (Smith and Cooper-Martin, 1997).

[19] SROI involves an attempt to calculate the real impact (i.e. social change) of an economic investment in a cause (Brest and Harvey, 2008).

[20] In order to make sense, order, and structure, and use the information, objects, and social interactions in our lives, we need to deploy a certain amount psychic energy. Psychic energy is defined as intention that "directs the attention through which information is selected and processed in consciousness" (Csikszentmihalyi and Rocheberg-Halton, 1981:4). Csikszentmihalyi and Rocheberg-Halton propose that this energy is vital to the development of humans at all stage of their lives: It is used for instance to focus on moving and playing with objects like toys in order to develop self awareness in early infancy (*creation of self*), to self-reflect on control of impulses and emotions during adolescence (*differentiation of self*), and to focus on others in order to

develop into a fully socially participating adult (*integration of self*). Broadly speaking, this attention is intention-driven or goal-directed in that it serves a specific purpose. The adequate use and cultivation of this energy through intention formation and goal striving is constitutive of the development and maintenance of the self and the deployment of personhood. Indeed, by cultivating goals, individuals become persons (Csikszentmihalyi and Rocheberg-Halton, 1981).

[21] I must say that this conception is partial and does not define the notion of parenthood in its entirety. Other mechanisms anchored in the present also define parents' roles. Miller (1998), for instance, showed that women's apparently mundane act of provisioning for families (a present-focused activity) can in fact reveal a deep display of love and care for the partner and the children.

[22] Mutual pretence is a complex form of social interaction in which all parties are aware of the prognosis of the illness but tacitly agree to act otherwise by pursuing culturally and socially expected roles.

[23] Latour argues that epistemological reflexivity does not ultimately lead to "truer texts," contrary to what radical reflexivity proposes. In fact, for him, the writing in fieldwork remains in all cases a fiction, whether it be accompanied with reflexive accounts or not.

[24] Which can be considered from the perspective of customer relationship management (Gronroos, 2007).

[25] Inspired from Holmlund (1996:96) and Gronroos (2007:132)

[26] During a presentation she made at the annual meeting of CWF volunteers.

[27] In fact, there have been some stories of families that have undergone multiple consecutive traumas. In one case, the mother won two successive battles with cancer. She was diagnosed with a third cancer shortly before her son was diagnosed with a brain tumor.

[28] For instance, one of the children I accompanied to Disney World was officially in remission only two months after starting chemotherapy treatments and has been doing well since then. Also, although the exact number has not been calculated, a certain proportion of the children associated with the CWF also encounter happy endings.

[29] Source: CWF annual reports from 2004 to 2008.

[30] The numbers are taken from a private study sponsored by the CWF. The CWF uses this statistic to reinforce its corporate mission, to motivate employees and volunteers, and to enhance its value in the eyes of donors.

[31] See, for instance, the wonderful ethnography of hospitalized children living with leukemia by Myra BlueBond-Langer (1978).

[32] Also see Appendix 1 for a description of his wish.

[33] Based on a conversation with medical experts during a CWF information meeting held in a children's hospital on February 1, 2007.

[34] This information is hard to confirm with official numbers, since the CWF does not keep any records on the social status of the families. However, based on my observations,

I would believe this observation to be quite accurate, but it is difficult to make a strong and objective case in support of her analysis.

[35] Source: The Children's Wish Foundation of Canada's wish-granting policies and processes. Section 3: Establishing wish child eligibility.

[36] Source: The Children's Wish Foundation of Canada's wish-granting policies and processes, Appendix A1 (updated in August 2007).

[37] Idem.

[38] The MAC is composed of six medical doctors from across the country (Quebec, Ontario, Manitoba, Saskatchewan, and British Colombia). Source: The Children's Wish Foundation of Canada's wish-granting policies and processes, Appendix A2.

[39] Source: Medical Eligibility Criteria, May 2008.

[40] The wish settled on was a week's stay in a five-star hotel in the downtown area.

[41] Emily's wish is presented in Appendix 2.

[42] Excerpt from an interview with Wendy in October 2008.

[43] Excerpt from an interview with Wendy in October 2008.

[44] Bobby's wish is presented in greater detail in Appendix 2.

[45] During the whole process, the child never really did any of the Internet research. He left this job to his mother.

[46] Information taken mainly from The Children's Wish Foundation of Canada's wish-granting policies, sections 7, 8 and 9.

[47] Source: The Children's Wish Foundation of Canada's wish-granting policies (p. 25).

[48] Source: The Children's Wish Foundation of Canada's wish-granting policies and processes. Section 4: Establishing the wish request.

[49] Once a year, CWF volunteers and employees meet in a hotel to discuss current issues.

[50] Source: The Children's Wish Foundation of Canada's wish-granting policies and processes (p. 26).

[51] In the case of campers, the manual explains that families can be expected to personally cover any cost in excess of the $15,000 paid by the CWF.

[52] In cases where travel is required to fulfill the shopping wish, travel costs should not exceed $3,500 to $4,000.

[53] Give Kids the World is a charity that offers children with life-threatening illnesses vacations in Orlando, Fl.

[54] Source: The Children's Wish Foundation of Canada's wish-granting policies and processes (p. 32).

[55] Source: The Children's Wish Foundation of Canada's wish-granting policies and processes (p. 96-99).

[56] Source: The Children's Wish Foundation of Canada's wish-granting policies and processes (p. 59).

[57] Source: The Children's Wish Foundation of Canada's wish-granting policies and processes (p. 65).

[58] Ibid.

[59] Ibid., p. 62.

[60] Based on Foreign Affairs and International Trade Canada Travel Reports and Warnings (http://www.voyage.gc.ca/dest/ctry/reportpage-en.asp) as of September 24, 2008.

[61] Ibid, p. 48.

[62] Source: The Children's Wish Foundation of Canada's wish-granting policies and processes: National Blue Cross program for the Children's Wish Foundation of Canada (Appendix G).

[63] Source: The Children's Wish Foundation of Canada's wish-granting policies and processes (p. 99).

[64] Source: The Children's Wish Foundation of Canada's wish-granting policies and processes (updated on August 2007).

[65] Source: The Children's Wish Foundation of Canada's wish-granting policies and processes. Appendix E11a.

[66] Source: The Children's Wish Foundation of Canada's wish-granting policies and processes.

[67] Source:

http://www.childrenswish.ca/index_2007.php/en/stories/feature/story/699/chap/0/cat/5. Consulted on November 25, 2008.

[68] On rare occasions, it happens that the wish is not finalized during the first meeting. In these cases, the source of the wish will be assessed during the second meeting or during the wish-fulfillment moment.

[69] In order to make it easier to read, I have only included the main steps of the process (excluding waiting periods).

[70] It is also interesting to note that French Polynesia wishes became popular after Simon's wish, an indication that wishes are communicated and trends initiated through social contagion.

[71] See Chapter 5 for a detailed description of the potential impact of illness on the life a family.

[72] This explains the presence of a social worker during the Volunteers Day gathering, as no one at the CWF is properly trained to deal with the emotional reality of ill children and death.

[73] The prison was never built despite Bentham's many efforts.

[74] The Foundation grants approximately 1000 wishes a year.

[75] The first family I accompanied was Bobby's. Their journey is described in detail in the appendix.

[76] Although a recent follow-up conversation (February 24, 2009) revealed that her condition seems to be deteriorating and that she will need to consult a neurologist for further examination.

[77] However, when I met them, the father was starting to be more involved in his daughter's life again.

[78] Starlight is an international foundation dedicated to "brighten[ing] up the lives of seriously ill children and their families through a variety of in-hospital and outpatient programs and services" (source: http://www.starlightcanada.ca/page.asp?intNodeID=4337 consulted on October 24, 2008). This foundation accomplishes its mission through six major components, including wish granting.

[79] GKTW is a non-profit organization located in Orlando, Florida, that allows children with life-threatening diseases and their families from around the world to enjoy an inexpensive stay in Orlando while visiting the theme parks (e.g., Disney World, Universal Studios, etc.). It offers a village atmosphere specially designed to cater to the needs and wants of young children (www.gktw.org).

[80] After the meeting, Wendy contacted the family and asked their impression of me. Once the mother confirmed that the family welcomed my presence, we finalized the procedure.

[81] Afterwards, Wendy told me the provision of a limousine had been an exception. Families are normally responsible for arranging their own transport from their home to the airport.

[82] The hotel offered this gift to Sonya after I told them her story at check-in.

[83] As far as I could observe, Kathrin never hesitated to share the details of her daughter's condition and surgery to anyone who inquired about her daughter.

[84] I was told in a follow-up conversation that they were able to retrieve the camera after the trip.

[85] Due to her condition, when Sonya is tired, especially at night, she loses concentration and focus.

[86] Throughout our journey, Kathrin and her mother frequently had to stop for cigarette breaks.

[87] In response to that, Kathrin said that perhaps the duck was now living here in Orlando since this place was like paradise.

[88] Very rarely, some families receive more than one wish. This scenario occurs when more than one child is living with a life-threatening disease (as can sometimes be the case with hereditary illnesses).

[89] Depending on the extent of their exposure to other families realizing wishes.

[90] In the interests of simplicity, certain actors, like the GKTW for example, appear only once. In this case, GKTW appears after the encounter with the car rental company, even though it was a predominant player throughout the fulfillment.

[91] Disney's recent "Year of a Million Dreams" promotion suggests that the company itself conceptualizes its offer in the same sense.

[92] As of May 2009.

[93] Although she was not prominently mentioned in the description of the wish.

[94] See also the example in Chapter 5 of a mother who was terrified that customs would block her entry to the USA due to a juvenile criminal record.

[95] For many other families, the situation is much more critical, and the whole experience of the wish must take into account the reality of the illness. For instance, Bobby's case revealed that extra attention had to be taken not to embark on rides that could have hazardous effects on his heart.

[96] This has not always been the case. Dealing with the emotional realm of illnesses was until recently considered outside the scope of medical training. For instance, Groopman (2005) reflects on how he, and in parallel the medical field, came to consider hope as a means to facilitate healing and treatment only after many years of practice and disastrous interactions with patients diagnosed with cancer.

[97] She was arrested for shoplifting as a young adult.

[98] Field notes, August 4, 2006.

[99] For instance, Delvecchio Good et al. (1990) revealed that while around 30% of the physicians interviewed believe that a positive attitude can affect the outcome of cancer, the agreement varies according to specialty (57% of surgeons agreed vs. 21% of radiation specialists).

[100] This issue, which until recently was highly controversial, has become a part of experts' discussions, for instance concerning the neuro-plasticity of the brain and the suggestive power of the conscious mind over the body (see for instance Begley 2007, Martin 1998, Schwartz and Begley 2003).

[101] See for example the non-scientific resource *Beliefs: Pathways to Health and Well-being* (Dilts, Hallbom, and Smith, 1990). Scientists, however, also contribute to the discussion. Neurological theories have begun to emerge as to how hope can impact one's response mechanism to pain. It is held that hope can have a blocking effect on pain "by releasing the brain's endorphins and enkephalins, thereby mimicking the effects of morphine" (Groopman, 2005:171).

[102] No explanation for the healing was found by doctors, and the case remains to this day a miracle of modern medicine. David is now in his late 20s and travels around the world to give talks on his life and passion for butterflies.

[103] This policy was later corrected to prevent the situation from happening again.

[104] Similarly, a tremendous improvement in Bobby's language proficiency was noted during our stay in Disney (see Appendix 2).

[105] "The power of a wish" is an expression used to convey the potentially transformative power of wishes. The Make a Wish Foundation uses this term in their promotional communications. A book sold to raise funds for the Make a Wish Foundation has also used this expression (Spizman, 2006).

[106] Wendy also reported being told during a meeting with a wish child that the child had expressed a desire to end her life only a few days before meeting with her. Wendy told her, "Don't forget that if you get through this, you'll get to swim with the dolphins."

[107] During follow-ups, she observed that her sleep was becoming better as each week passed.

[108] I do not assume that these images necessarily prevail across cultures, but they are present in the West. In other societies, images of work or family assistance can be more dominant than free child play and innocence. As Lancy (2008) observes, "While we hamstring our children to keep them from the labor force, fearing their loss of innocence, and studiousness, the norm elsewhere is to open the pathway to adulthood. We will find that as soon as children can "help out" and make an economic contribution, they do so eagerly, without coercion, and with minimal guidance." (p.234)

[109] In capital letters in the text.

[110] Spizman (2005:19)

[111] Interestingly, when I met the family for a follow-up interview, the father had no memory of this.

[112] See discussion in chapter 4 regarding the absence of "bad wishes."

[113] It can go as far as affecting people's recovery efforts (Becker, 1997).

[114] This is not to say that it is disregarded as an emotion. As I mentioned in Chapter 1, a group of cognitive and social constructivist psychologists are including it in their investigation of emotions. Hope has largely been neglected rather because scientists tend to avoid studying it due to its complex nature.

[115] For purposes of clarification, the emotions described here are in accordance with Lazarus's (1991) appraisal theory of emotions. Fright arises "when facing an immediate, concrete, and overwhelming danger." Anxiety is caused by "facing uncertain, existential threat." Anger is "a demeaning offense against me and mine." Happiness is experienced when "making progress toward the realization of a goal." Sadness is the result of "having experienced an irrevocable loss." Love results in "desiring or participating in affection, usually, but not necessarily reciprocated." Source: Lazarus (1991), Table 3.4, p. 122.

[116] Various consumer research studies validate this function of the marketplace: Kozinets (2001), Holbrook and Hirschman (1982), Martin (2004), Thompson (2004), Thompson and Tian (2008), and Belk and Costa (1998).

[117] I borrow this metaphor from the work of Latour (1987) who also uses Janus in order to represent the two opposite views of scientific facts.

[118] I do not intend to convey that every exchange between a family and the marketplace is defined in terms of this tension. In Sonya's case, for instance, the hotel waiter who ended up talking with the family about his own experience with childhood illness and offering a

free slice of cake would not pertain to this tension. This situation would perhaps be better defined by the idea of co-construction of meanings between producers and consumers (Kozinets, Sherry, Storm, Duhachek, Nuttavuthist, and Deberry-Spence, 2004). In fact, in this situation, a hermeneutic game (Gadamer, 2004) is performed during which each actor participates in understanding each other and in the creation of highly meaningful exchange. This would also be how Arnould and Price's (1993) *communitas* is experienced by the rafters.

[119] Image of Janus taken from: http://www.houseabsolute.com/presentations/sql-is-not-relational/slide1c.html#end.

[120] See Sonya's wish (as well as Bobby's wish in Appendix 2) for more details.

[121] Source: www.childrenswish.ca As of August 8, 2009.

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Appendix 1

A foot in the field: Description of the Wish Factory

The Children's Wish Foundation of Canada is a charitable organization "dedicated to working within the community to fulfill heart-felt wishes for children diagnosed with a high-risk, life-threatening illness"[i]. Founded in 1983, the national foundation was able to realize about 20 dreams per year at that time[ii]. Over the next 20 years, branches were established in every province (see Figure A.1). Five years ago, they were orchestrating the realization of more than 800 dreams per year. At the time this dissertation was submitted, the CWF was granting approximately 1,000 wishes Canada-wide per year and granted its 15,000th wish in the summer of 2009.

Dreams include requests for a variety of goods (computer, home theatre, playground, pet, etc.), for travel experiences (going to Disney World, to Holland, to the Black Beauty Ranch in Texas, etc.) and for meetings with celebrities (Kelly Clarkson, the Olsen twin sisters, professional golfer Mike Weir, etc.).

Figure A.1: CWF chapters across Canada[iii]
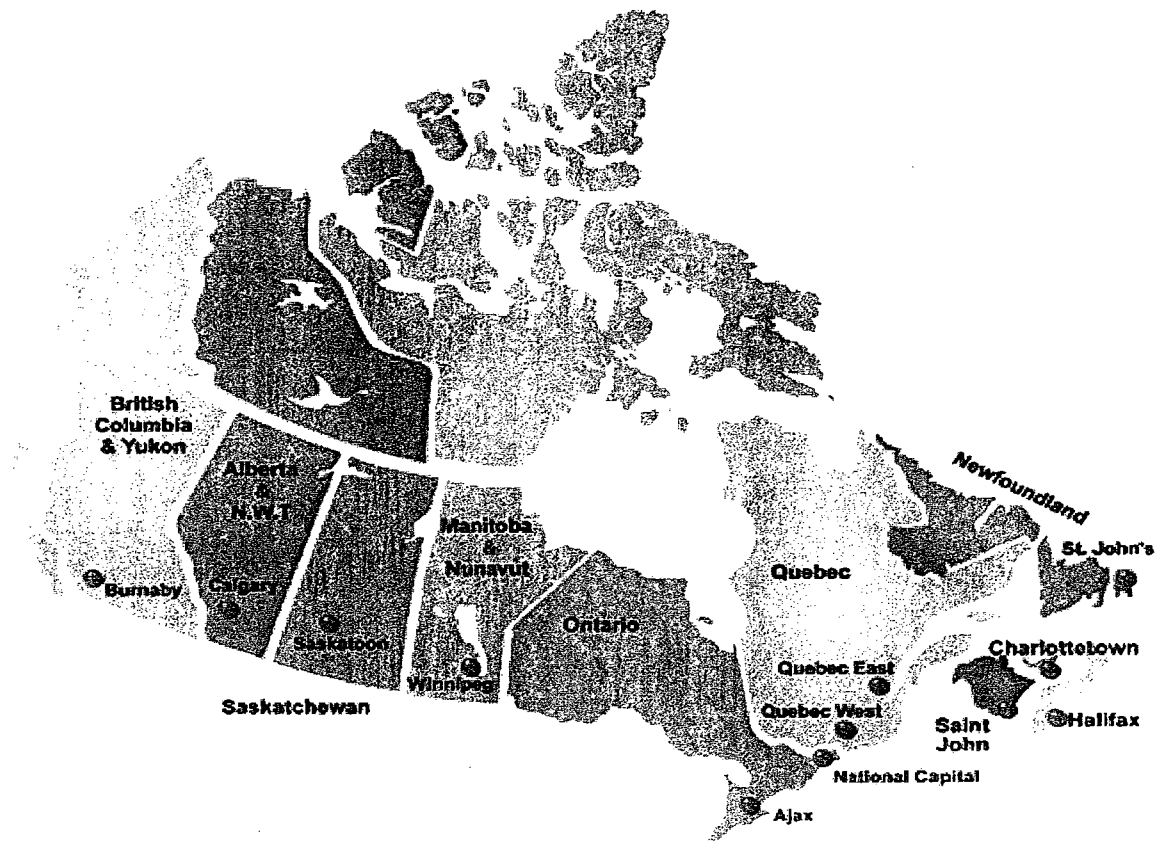
1. Wishes in numbers

Since 2005, the CWF has started systematically analyzing statistics on the wishes granted across the country. The following table outlines those which are most popular.

Table A.1: Most popular wishes (in number of wishes)[iv]

Wishes	2005-2006	2006-2007	2007-2008
Disney World	275	250	270
Computer (desktop or laptop)	110	70	80
Disney Cruise	80	60	75
Entertainment centre	55	55	70
Trailer	60	25	30
Disneyland	-	35	25
Shopping excursion	-	-	20
Swimming pool	20	25	20
Bedroom redecoration	20	15	10
Meet a celebrity	50	-	-
Hawaii	35	33	-

As this table suggests, Disney-related wishes (Disney World, Disney Cruise and Disneyland) are the most popular. Computers, trailers, entertainment centres and bedroom redecorations are also consistently among the top wishes.

The Foundation further categorizes these wishes into three mutually exclusive groups: items, celebrities, and travels. Basic statistics regarding these three categories are also available. The following table shows the proportion of wishes granted by category from 2003 to 2008.

Table A.2: Distribution of wishes by category (%)[v]

Wish category	2004	2005	2006	2007	2008
Travel	58	59	63	63	57
Item	39	37	32	30	38
Celebrity	3	4	5	7	5

Despite some variation, the proportions are quite consistent from one year to the next. Travel wishes stand out as a clear favourite, followed by items. Examples of travel wishes include Disney trips, fishing excursions, and holidays to such destinations as the Bahamas, Morocco, Paris, and Italy. Items can include anything from computers to electric guitars, from video cameras to a Nintendo Wii, from camping equipment to pets, and so on. Finally, wish children meet all kinds of celebrities from the public arena: pop

singers, bands, high-profile athletes (hockey, basketball, baseball, etc.), movie stars, and business celebrities like Bill Gates, to name a few.

Existing literature on the study of wishes and desires differs from the above statistics. d'Astous and Deschenes (2005), consistent with Fournier and Guiry (1993), found that material possessions like houses, cars, chalets, and home renovations form the most popular type of wish (accounting for 46.2%) among consumers; whereas they occupy second rank with wish children. These researchers have also attempted to categorize wishes. Fournier and Guiry (1993) identified four categories—possessions, experiences, ideals, and money. d'Astous and Deschenes (2005) proposed a slightly different categorization to the former, where possessions and experience can be merged into a single category (experiential possessions) to form a fifth category in addition to the four individual categories identified by Fournier and Guiry. Based on this categorization system, the wishes granted by the CWF would fall under the experience (travel and celebrities) and possession category/categories, leaving the ideals and money wish categories untapped. These differences in the popularity of experience wishes, and the absence of ideals and money wishes can be understood at two levels. First, existing literature has focused essentially on adult populations, while the present research examines the wishes of children with serious illnesses. Adults and children have different tastes, aspirations, and preoccupations. What is desirable for an adult (e.g. owning a house) is likely to be far down on the list of a seven-year-old child. The opposite is also true: no adult in the d'Astous and Deschenes (2005) study ever mentioned going to Disney as their wish. The second explanation for the observed distinction is that institutional boundaries imposed by the CWF have a direct impact on wish fulfillment, as

we saw in the previous chapter. Restrictions in the nature of the wishes that can be granted force them into these three categories even though, for instance, some children might be interested in owning a house or having more money. In fact, some accounts of rejected wishes reveal such interests. One child's deepest wish would have been to see his parents come back together (an "ideal" wish); a wish that could not realistically be granted by the CWF.

2. The CWF's relationship with the marketplace

The overall description of the relationship between charities and the marketplace introduced in chapter 1 can be aptly applied in the context of the Children's Wish Foundation. To demonstrate its relevance, in the following lines I briefly introduce the partnership developed between the CWF and Air Transat and also sketch a more general outline of the business relationships built by the CWF with the marketplace.

2.1. The case of Air Transat: Mutual values creating value

Air Transat is one of the major partners of the CWF. Their association started in 2004 and is based on three programs. The first, called "Change for Kids program,"[vi] is the main program and generates the biggest share of annual donations. Since June 2004, it has helped raise more than $1.7 million. This program generates money in two ways. First, at the end of each flight, Air Transat invites passengers to donate their loose change by showing a short video on the CWF and Air Transat's benefactor role. The second way consists in donating the proceeds from the recycling of cans on the ground and in the air. In 2008 alone, the company donated $900 million to the CWF, which represents 50% of its total social investments.[vii]

Second, once a year, during the Christmas season, they organize a highly publicized special trip called the *Flight in search of Santa*. Based in Montreal, Toronto and Vancouver, this event invites dozens of wish families, in addition to members of the media, to take part in a fantasy trip to the "North Pole." During this one-hour flight, the stewards are dressed as elves and they play games and sing along with the guests until Santa Claus boards the plane and offers a gift to every child. CWF volunteers are invited to participate prior to the event by making solicitation calls to families and helping during the event (e.g., by helping with the distribution of snack food, by supervising games and toys in the boarding area before the flight, etc.).

The third program consists in sponsoring two golf tournaments, one in Ontario and one in Quebec. To qualify as the main sponsor of the event, they donate $20,000 in total (divided equally between the two provinces). In addition, they purchase two foursomes (around $1,500 each) for employees of the company.

The partnership with the CWF is highly beneficial for the airline company. Their substantial fundraising earns the company important sympathy capital to the extent that it is perceived as a good "corporate citizen." Each flight is an opportunity to further improve Air Transat's corporate image by showing the short video of their involvement with the CWF to passengers. In addition, the *Flight in search of Santa* event provides great media visibility and a chance to disclose the amount of the company's annual donation. The partnership also has a more fundamental impact for the corporation. Its mission, "to bring families and dreams together in a friendly, affordable, reliable and ecologically appropriate manner,"[viii] is aligned with that of the CWF and reflects its core values. In the eyes of Air Transat's president and CEO, Allen B. Graham, the CWF

represents a natural fit and the partnership makes it possible to rally employees around the cause:

> *There are very few things in an organization that you can get 100% of your employees to rally around. So I really had to find... that... foundation that touched me the most, because, I've got to stand up in front of 2,500 employees and say "this is what it's all about." And I want to get all my employees on board. So, it had to have the value system that I had. The mission of the CWF is so much aligned with the mission of our airline, which of course, you know, is creating dreams. We try to create dream vacations and we try to unite families. So, after that first meeting, it was absolutely obvious to me that we were a perfect fit.*
> (Excerpt of the video *A Logical Partnership*)

In addition, the "price to pay" for these benefits is actually quite limited. The fundraising, as substantial as it may be, requires very little direct spending: the donations come from passengers and from recycling money. The only money spent is $20,000 for the sponsorship of the golf tournaments, plus the purchase of two foursomes and the operational fees associated with the *Flight in search of Santa.*[ix] Furthermore, the partnership even provides extra revenue to Air Transat, since the CWF pays for each family member flying with them (although they receive the special employee rate). Finally, the employees also devote their time on a volunteer basis for specific charity activities such as the *Flight in search of Santa* and fundraising golf tournaments.

However, Air Transat is not the only one to benefit from this association. There are also many advantages for the CWF in the deal, not only because of the substantial

amount raised by its partner, but also because of the great experience created by the company for the wish families during travelling. For example, families are pre-identified as VIP travellers by means of the "Club" label on their luggage and children under 12 are automatically registered as members of the Air Transat Kids Club which offers promotions, activities, draws, etc. On board, wish kids receive special treatment in the form of games, food and refreshment. The employees also pay extra attention to the families by coming to play with the kids and talking with the parents. The company even upgrades their tickets to first class whenever possible.[x] Occasionally, they let the family board first and announce the special guest (by naming the ill child) over the intercom so that everyone in the boarding area can see them. The CWF also receives the employee rate for the purchase of tickets as well as the free seat selection option. In addition, no exclusivity contract forces the CWF to book flights with Air Transat (i.e., the Foundation can book flights with other airlines if the schedule or prices offered by Air Transat are not satisfactory).

Finally, the *Flight in search of Santa* provides great media coverage to the CWF from coast to coast, as well as an opportunity to offer a second extraordinary experience to a limited number of wish families. This activity allows the CWF to keep in contact and sometimes build relationships with families, who often tend to vanish after the fulfilment of their wish.[xi]

The deal is labelled "too good to be true" by Wendy. Generally speaking, as far as I could observe, the CWF employees were very pleased with the partnership. The CWF-Air Transat relationship is a good example of cause-related marketing. The values of the Foundation are consistent with the values of the company. As a result of the partnership,

which is mainly communicated through *cause promotional events* (Daw 2006), value is created for each partner.

Figure A.2: Application in the context of the CWF–Air Transat partnership

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        │  │  │     CWF        │   │      │ (dream, family,  │     │
        │  │  │               │   │      │ togetherness,etc.)│          ┌──────────────┐
        │  │  └───────────────┘   │─────▶│ through cause    │─────────▶│ Creation of  │
        │  │         ↕            │      │ promotional      │          │   value      │
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        │  │  │  Air Transat  │   │      │ - Flight in search│
        │  │  │               │   │      │ of Santa         │
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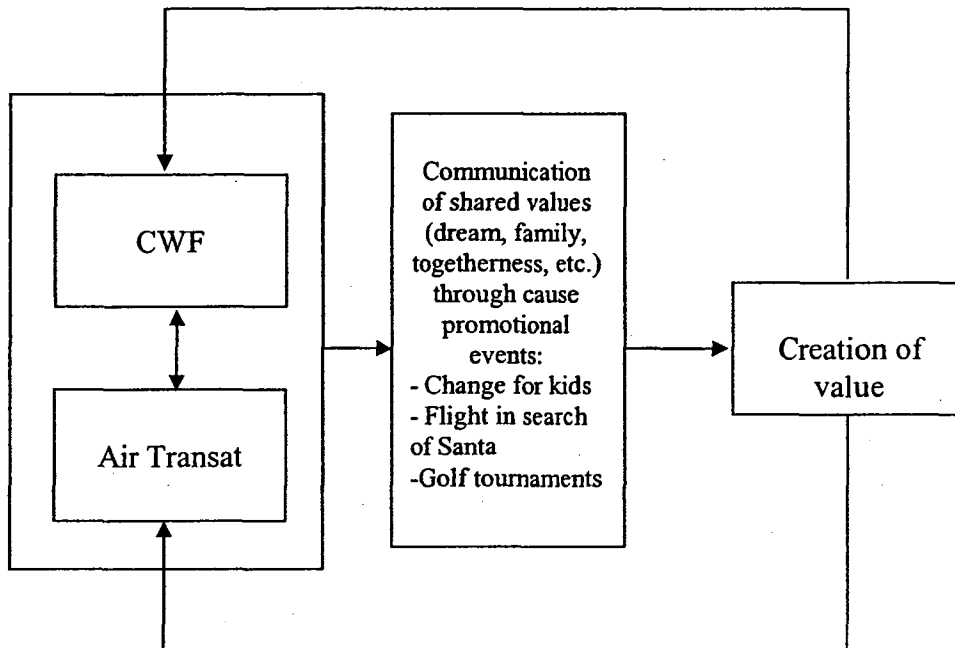
2.2. Other relations between the CWF and the marketplace

The Air Transat case shows that the relationship between the CWF and the marketplace can be beneficial to both parties, who build on each other in order to create the value necessary to meet their objectives. On a larger scale, the CWF develops and maintains various relationships with many other corporate donors. These donors are divided into categories depending on the amount donated. On the national level, four categories are identified: platinum ($100,000 +), gold ($50,000-$99,999), silver ($10,000-$49,999), and bronze ($5,000-$9,999). Nationwide, the Foundation has more than 50 partners in very diversified industries (air transportation, travel and life insurance, chocolate, luxury clothing, electricity, steel, direct sales home products and decoration, furniture, clothing,

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accounting and investing, banking, greeting cards, accommodation, diamonds, restaurants, etc.) that help it to secure its financial sustainability.[xii] At the provincial level, each chapter also creates partnerships with hundreds of companies that become responsible for raising money in their local community. These associations, called *third parties*, also bring in substantial revenues to the charity and are quite diverse. They can represent an employee's initiative to organize an event at his or her workplace, a school activity in support of a local wish child, the president of a small business organizing an annual fundraiser with suppliers and clients, an individual organizing a cyclothon or a volleyball tournament in support of the CWF, the manager of a major retail chain (Costco) or food chain (McDonald's, Tim Horton's, etc.) organizing a fundraiser in his or her community, and so forth. Within each CWF chapter, an employee is responsible for managing the relationships with those constituents.

In addition to third-party events, the CWF also organizes and manages two major fundraising activities, or *first-party events*. The first is a golf tournament held in May in most provinces. The formula is simple. The CWF sells foursome and hole sponsorship to companies and organizes an auction during the dinner. A wish child and his or her family, who spend the day golfing and talking with the donors, are also invited to make a speech before the auction. The speech normally involves describing the child's illness, the wish, as well as the importance of the wish for the child.

The second event is a walk called the *Wishmaker Parade*, which is synchronized across Canada and held in October. The event, which started four years ago on a national basis,[xiii] is growing in popularity. The 2008 edition was mainly sponsored by XanGo, a multi-level marketing network mangosteen juice distributor, and Sameday Worldwide, an

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express courier service. Advertising was provided free of charge by Neo Advertising, *Today's Parent* and *Reader's Digest*. It raised $1.4 million. For this event, various companies are also solicited to sponsor the walk by providing free (or discounted) food, air-inflated games, snacks, bottled water, cookies, coffee, etc. The Wishmaker Parade is described by my informants as a "family gathering day," during which wish families are invited[xiv] to come to walk alongside sponsored walkers on a roughly one kilometre circuit. Sponsored walkers can be described as typical walkers for this kind of event: in order to participate in the walk, they have to pledge money by soliciting their network (individuals or companies) to make a donation, which is given to the CWF on the day of the walk. They can register online, create a walk team, set individual and team objectives, etc.

All in all, the Foundation benefits from the multiple one-on-one associations and partnerships it builds with corporations, which can generate value based on their association with the Foundation: the CWF receives funding, acquires visibility within various communities and preserves relationship with families; through their association with the CWF, companies boost their visibility, improve their brand image, etc.

2.3. Constructing the cause: An upstream and backstage role

The relationships developed between the CWF and the marketplace are symptomatic of the common relationship between charities and the marketplace. In essence, the role of the marketplace depicted in those relations, whether approached from an individual (i.e., charity vs. one corporation) or macro (charities vs. the marketplace) perspective, is one of *construction of value*. It allows charities to gather the necessary financial and human resources – either by partnering with a for-profit or by borrowing from business-like

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practices – to operate and fulfil their mission. Overall, the marketplace is channelled by the charities as a constructive force that can help maintain and improve their mission and service to their beneficiaries. In the case of the CWF, this construction function makes it possible to *put together the money, people, knowledge, and know-how necessary in order to fulfil the CWF mission and create wish opportunities.*

At the level of the CWF, these relationships mainly operate upstream and back-stage. *Upstream*, because of their backbone position and critical necessity in order to make it possible to grant any wish (i.e., no wish can be granted if no prior fundraising work is performed). *Backstage*, because they normally operate behind the curtain, in the procedural gap. Indeed, most families are not exposed to these relations; the rare exceptions are the families invited to provide testimonials during fundraising events or to participate in specific activities such as the Wishmaker Parade.

2.4. Managing like a business

The CWF incorporates a business-like approach in its daily operations. It develops strategic fundraising campaigns, scrutinizes its financial performance by keeping a record of and communicating its administrative ratio,[xv] constantly reflects on the development and improvement of its brand and hires (or gets for free) the services of advertising agencies and uses marketing tools (such as market segmentation, direct marketing, public relations, etc.) in its daily activities in order to improve its efficiency. The head office in Ajax, Ontario, is responsible for structuring the Foundation and determining the long-term strategic planning. In order to support these operations, the head office employs a devoted team of people with specific roles no different from those in the for-profit world: a national executive director, a director of development, a regional development

specialist, a director of communications, accounting assistants, an IT manager, a computer specialist, a controller, and a director of human resources and volunteer services. It also hires people whose responsibilities are specifically related to wish granting: a director of wish granting, wish granting assistants, a national Wishmaker Parade coordinator, and a celebrity wish coordinator.

Hence, the macro-framework introduced in Chapter 1 can also be aptly applied in the context of the CWF. As we observed, on the one hand, corporations want to associate themselves with the cause. They understand the population's sympathy for ill children and see in such cooperation a means to generate great value. On the other hand, the CWF incorporates marketplace values by developing profit-driven practices.

Appendix 2

Many wishes, many ways

In order to provide the reader with an idea of the range and variety of wishes, I will describe in this appendix the granting of three additional wishes: Bobby's trip to Disney, Lindsay's meeting with her favourite singer, and Emily's purchase of a swimming pool.

1. Bobby's trip to Disney World

Bobby's was the first family I accompanied on a wish fulfillment. To better appreciate this event, we first need to look at the context of the situation. This family is composed of a single mother and two sons. A few months before I met the family, Bobby's mother Mary lost her job at the factory after moving to a new house. She decided to stay on social assistance until the end of the school year to take care of her children, and then return to the job market or to go back to school to specialize in a new field of work. At that time, her income was very limited and the main focus of the spending was on the children. Mary's mother Susan is a very important figure in the family and has been present throughout her grandchildren's lives. That is why they decided it was fitting that she participate with the rest of the family in the realization of Bobby's wish.

After a few phone conversations, we decided to meet. At the time of the meeting, they already knew they were going to Disney World. Bobby's 11-year-old brother Jeff

explained to me the origin of the wish and their reaction when they received the confirmation of its approval:

Jeff told me he knew where Bobby's wish to go to Disney World comes from. His little brother received a Disney package from an aunt, and he regularly watches it 5 or 6 times a day. Jeff added that he didn't believe his mother when she said she was taking them to Disney World. He was the one who answered the phone when Wendy called to confirm the wish. It was only then that he realized it was true. He added that he and his mother cried. (Field notes, July 5, 2006)

Mary said she was as excited as the kids. However, she also spoke about her fears. Nobody in the family had ever been on a plane before, nor had they really travelled far away from their home town. She was worried about the luggage check-in, customs, the flight, etc. As much as going to Disney World was a sheer thrill for them, every bit of the trip was a source of anxiety. Therefore, during this conversation, I focused on trying to reassure them by telling them about the usual travel procedures. There was then a three week interval before our second meeting. In that time, Mary went to her bank to discuss the family situation in the goal of requesting money for the trip. She wrote a letter to this effect, and after assessing the case, the bank agreed to donate $500.

I returned to see the family to deliver the wish paraphernalia and ask them to sign the required forms. This second meeting was held nine days before departure. The children knew precisely how many nights' sleep remained before their trip. During the meeting, we discussed the details of the trip: which theme parks we would visit, the itinerary for the trip, where we would be eating, etc. The family realized that the trip

would be rolling on a pretty tight schedule. Two days later, I called the family to inform them that the reservations in the restaurants were confirmed.

1.1. On our way to Orlando

Although everything ultimately went well, passing through customs was stressful for everyone. In addition, nobody had slept very well at the hotel the night before. To begin, the people at the reservation desk were not aware that Bobby's family was the recipient of a CWF wish, and they had hard time finding the family's room. As we had to take a shuttle at 5 a.m., the night was very short, and the family could not really sleep. As a matter of fact, the mother and the grandmother had not been able to sleep for three days. Apparently, Bobby also had a turbulent night and talked about "Walt Disney", "plane" and "sleep" in his sleep.

We flew with Air Canada. Before boarding the plane, I spoke to the gate attendant about Bobby. She said that the flight attendants would do everything to make sure the flight was enjoyable. As a result, we were the first to board and were offered a visit to the cockpit. The following photos show Bobby smiling and his older brother playing with the captain's hat.

After an uneventful flight, we landed in Orlando and took a shuttle to Hertz Rental Company to pick up the rental car, a Pontiac Montana. Then we talked to an employee at a Disney information booth who gave us directions to the Star Island Hotel. The children were exhausted and complained about the time. The older brother was especially impatient and irritable. After driving around and getting a bit lost, we arrived at the hotel past 3 p.m. Before accessing our room, we walked around the grounds and

saw many small lizards scuttling around the parking lot. The children were fascinated by these unusual encounters.
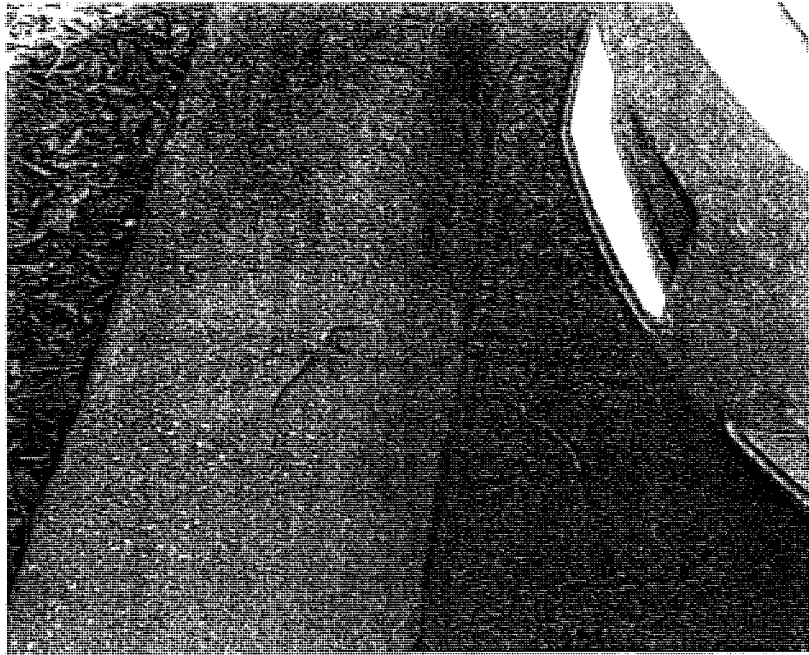
After waiting 45 minutes for our rooms to be ready, we settled down, and then spent the rest of the afternoon at the swimming pool[xvi].

Later that evening, Mary and I drove to the nearest grocery store to get some provisions for the following days. The aim was to pack our lunches and eat on site to save our money for dinners at the restaurants.

1.2. Day at Magic Kingdom

The next morning, Mary was awake at 4 a.m. She went for a walk and took pictures of the surroundings. After everyone woke up, we ate and then left the hotel at 9 o'clock to go to Magic Kingdom. Once there, our first order of business was to go to the guest relations office to get our tickets (3-day pass hoppers) and the Guest Assistance Card. We had to present our personal ID and the official doctor's letter stating that the family needed "special care." In Bobby's case, the letter stipulated that due to his condition, he should not be exposed to sun for long periods of time. This important pass is worn around the neck and allows the bearer and his party to avoid waiting in line for the main attractions and roller coaster rides.
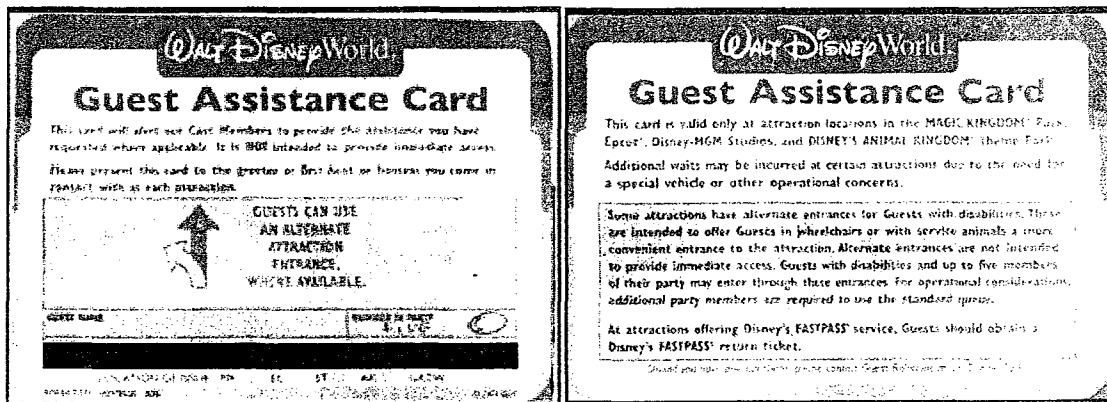
After sorting out our paperwork, we walked around the main entrance area to take pictures and get autographs from the Disney characters. We then headed towards the

Cinderella Castle. The sun was blazing hot and the sky was a beautiful blue. Despite the heat, the site was packed with visitors.
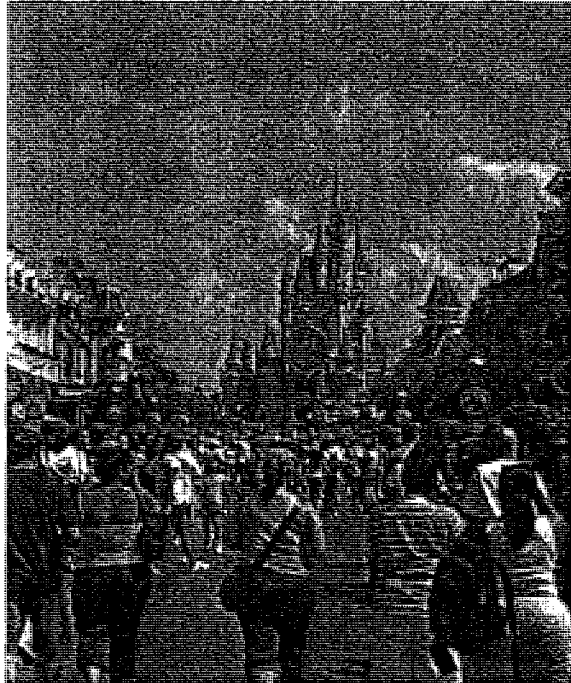
Then all of a sudden, an antique train made its way through the crowd of people and a dance performance started. The mother caught the show on camera.

We then continued our way. Upon arriving at the Castle, a show began that involved such famous Disney characters as Mickey, Peter Pan, Donald Duck, Cinderella, Sleeping

Beauty, and Aladdin. We watched the show together. Most of the time, Bobby was sitting in his wheelchair. To protect him from the sun, his mother fixed an umbrella to the side of the chair. After the show, we started visiting the various sections of the park and saw some attractions. The special passes allowed us skip the lines. Normally, when we arrived at the location of a specific attraction, I would show the CWF pin and the Guest Assistance Card to the Cast Member (title given to the Disney employees) who would then take us to the attraction through the "fast line", which often meant entering through the exit gate. We also got autographs from Aladdin and his friends.

During this time, a menacing formation of clouds accumulated in the sky. A few minutes after the autograph session, the skies opened and a heavy shower forced us to find refuge under a roof.

Jeff was getting more and more impatient. He was talking about eating all the time and the closer we got to mealtime (either lunch or dinner), the more impatient he got. He repeated this behaviour every day of the trip.

The rain eased up and we went in search of a place to eat our lunch. We found an open area covered with a roof and ate our sandwiches. During the lunch, birds were flying over our heads and landing close to us in the hope of getting some food. These birds scared Bobby who cried and yelled during the entire meal. His grandmother spent a lot of energy trying to reassure him.

In the afternoon, we went to the Splash Mountain attraction, which is a dramatic water ride in a log-like wagon that ends with a five-story, almost vertical splashy plunge. After going through the exit pathway, we promptly arrived at the wagon. Just before going ahead, we noticed a warning sign mentioning that people with heart defects should avoid this ride. After deliberation, only the mother and Jeff mounted the wagon. The grandmother, Bobby and I went back outside to wait for them. After the ride, we followed a path that led us to another mascot. The children took the opportunity to get some more autographs.

We walked our way around, and ended up in another mascot session, this time with the Toy Story characters. After this, we attended a parade involving the main Disney characters. During the parade, Bobby mainly remained seated in his wheelchair. During this time Mary and Jeff filmed and photographed the event. Bobby spent the entire time smiling, waving at the mascots and yelling, "Hello Mickey! Hello Donald!" On numerous occasions, the characters came directly over to him to shake hands. After the parade, we

headed to the Tom Sawyer's Island. We took the small boat and visited this site for a short while. By this time, it was becoming increasingly difficult to convince Bobby to get out of his wheelchair to climb stairs or participate in attractions like walking on a rope bridge, or going in a cave. To make matters worse, his brother was teasing him more and more and making him upset.

We then returned to the main site and slowly made our way to the restaurant. Afterwards, Jeff became increasingly irritable. He wouldn't listen to his mother and started silently protesting by isolating himself.

We arrived at the restaurant for our 4 p.m. reservation. The place was a huge old-fashioned diner serving all-American food like macaroni & cheese, ham, turkey, and pork and beans in an all-you-can-eat buffet. It was crowded with mascots. Throughout the dinner, Bobby was actually more interested in them than in the food. Of all the characters, Pluto was the one whom Bobby really got a kick out of. He took Bobby by surprise by "licking" is face like an actual dog would do. Bobby was flabbergasted and laughed out loud. He asked Pluto to do it again and again and laughed each time.

During dinner, Bobby frequently made Mary and Susan smile and laugh. In fact, each time he reacted positively to his environment by getting excited, laughing, yelling, or being surprised, his mother and grandmother reacted in kind. His pleasure seemed to be a great source of joy for them.

After dinner, we took the train to Mickey's Toontown Fair, where we met a series of other mascots. In the Mickey House, we not only skipped the waiting line, but we were also granted a private photo session with Mickey. We were told by the Cast Member that

this type of photo session would normally involve 20 to 30 people in the room at the same time.

We then left Toontown for Tomorrow Land and visited some attractions there. In particular, we attended the Stitch show (from the movie *Lilo and Stitch*). In this performance, Stitch, an extraterrestrial monster, escapes from his prison capsule and walks around the darkened audience. The show uses a variety of sensory stimuli like wind, sounds, and smells to make the participants feel like they are actually part of the show and that Stitch is really walking around them, even though he is not. Jeff was impressed by the experience. Bobby, on the other hand, was terrified. He screamed and cried throughout most of the performance. His mother commented that he probably reacted this way because he was scared of the dark. Her intuition proved quite accurate. After this show, Bobby refused to attend most attractions. He would only participate in activities that were held in daylight and was reluctant to get involved in indoor activities where, for instance, we would have to sit in a wagon that would lead to some unpredictable place.

Day became night, and after Tomorrow Land we slowly made our way back to the Cinderella Castle to get ready for the night performances. We reached one of the wheelchair sections at 8:15 p.m. and waited there until the night parade started. While waiting for the event to begin, some children started playing with balloons in the middle of the street.

The employees gradually started to block the access to the street in order to prepare the way for the parade. In the meantime, the Castle became illuminated with colours that changed from blue to purple to yellow to orange, and back again.

At 9 o'clock, all the lights went out and the drummers arrived to introduce the show. For about 30 minutes we saw the main Disney characters transported by a spectacularly lit car.
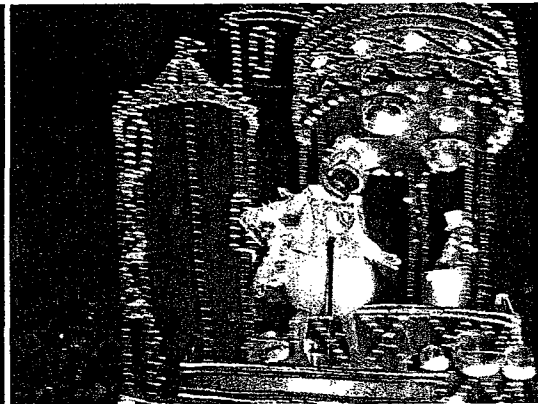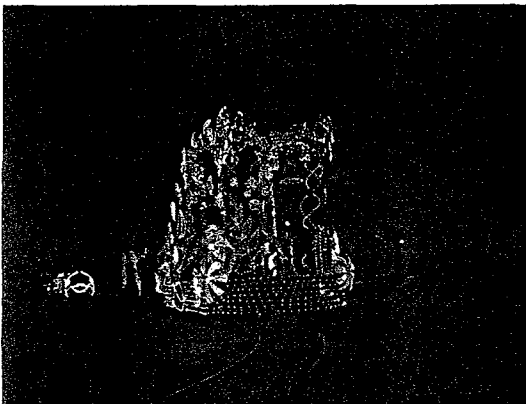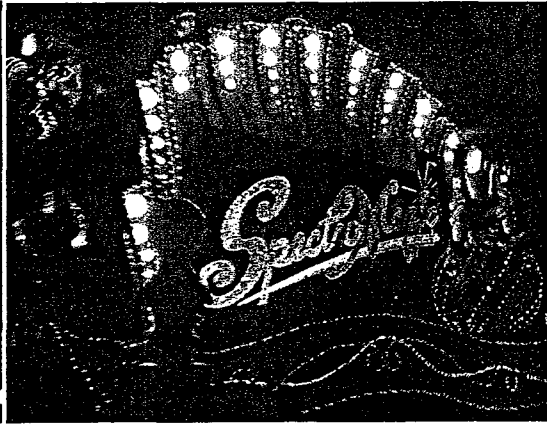
At 10 o'clock the parade ended and was followed by a 15-minute fireworks display with music and other Disney characters like Tinkerbelle. Every time we heard a fireworks explosion, Bobby would yell with surprise "Hey! Hey!" These reactions made his mother and grandmother laugh a lot. Mary filmed the whole parade and fireworks. After the events, we slowly exited the park. We waited in line for more than 20 minutes to take the ferry back to the parking lot. We finally left the park and arrived at the hotel at 11:30 p.m. Everybody was exhausted and went straight to bed to rest up for the next day. For

the first time in a while, Bobby's mother slept right through to morning. Our next target: Epcot Center...

1.3. The following days

Just like the first day, we left early every morning to go to one of the theme parks and came back late and exhausted. As the week progressed, the boys became increasingly impatient and irritable. On the second day I took the following notes that describe the family dynamics:

> *Jeff was impatient almost all day–mainly when we were not doing some activities he wanted to do. Since we had an early dinner with characters (4:30 p.m.), he spent the day stressing about the time. He also complained a lot about back pain and lamented that his brother was allowed to have access to the wheelchair and not him.* (Field notes, August 8, 2006)

Indeed, the wheelchair became a source of conflict. On many occasions, Jeff tried to usurp the chair from his brother. In the next picture, we see Jeff on the wheelchair, pushed by his mother while Bobby is crying to have it back. At the end of that day, the mother was truly exhausted and suggested they take a day off on Thursday.

Bobby remained affected by the Stitch show for the remaining days in Florida. Despite the fact that his fear diminished, he continued to refuse to take part in most of the attractions, and his mother and grandmother constantly needed to try to persuade him to participate. As a result, his grandmother frequently stayed behind with him while Jeff and his mother took in the rides and attractions. We also realized that Pluto left a lasting imprint on Bobby. In fact, each time we would see Pluto at a Disney park, Bobby would

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get excited and expect him to repeat the "licking game". This became an interesting source of confusion, because Bobby did not realize that there were different employees wearing the mascot uniforms, and the employees in turn, were not aware of the game he had developed with the employee in the first encounter.

On the third day, the children were really hard to wake up. Bobby said, "Tomorrow I go home." We spent the day at Animal Kingdom. Since the park closes early, we came back before dinner and went to an all-you-can-eat buffet. At night, the mother told me that she noticed that Bobby was making some improvements. I took the following notes regarding this observation:

> *The mother said that Bobby's language skills have improved since we arrived.*
>
> *He's started speaking in longer and more complete sentences. I've noticed the*
>
> *same thing! How amazing!* (Field notes, August 9, 2006)

On Thursday, Bobby slept until 10 a.m. At around 11:15, the mother and I went to the grocery store to buy some spaghetti and get some provisions for the following days. The children watched TV until early afternoon. We then spent three hours by the swimming pool. During the afternoon Jeff often asked his mother to buy him some souvenirs. At 4 p.m., we went to an all-you-can-eat buffet just down the road from the hotel. After the meal, we went to Wal-Mart. The mother bought two t-shirts and a *Pirates of the Caribbean* cap for Jeff. In the car on the way back, Mary observed again that Bobby had made progress since we arrived in Orlando. Susan added that he was becoming more autonomous. Next, we went to Disney Town for some window shopping. That night, everyone was asleep by 10 o'clock.

The next day was spent at Sea World. We attended many animal shows. Contrary to the Disney parks, Sea World is designed to mainly offer outdoor seated performances with dolphins, otters, killer whales, a circus, etc. This facilitated Bobby's participation. The following photos show the dolphin and killer whale shows. After most of the performances, we stayed to take pictures with the actors or acrobats.
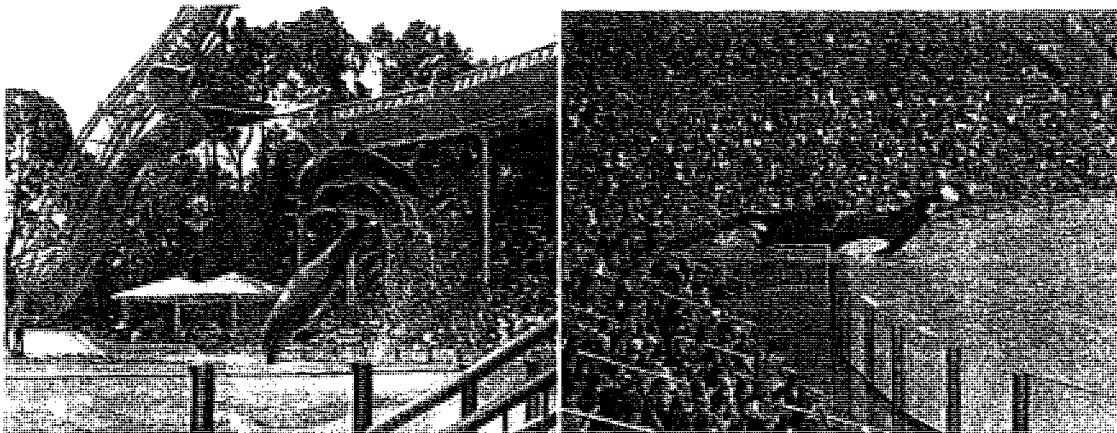
That day, the family experienced a powerful moment when they fed dolphins at Dolphin Cove. The mother had mentioned even before going to Florida that it was one of her

dreams. We went to the cove right after the dolphin show. After showing the CWF pin to an employee, we were directed to a special area where we could be assisted by an expert tamer. This is the lady dressed in the black and blue scuba-diving suit with a white hat. She stayed with us during the whole feeding time, helping attract the dolphins, and showing us how to pet and feed them. Bobby was a little scared at first, but with the help of his grandmother, he touched and fed them. This event lasted around 30 minutes.

We stayed until the late night show, which consisted of an immense video about a killer whale named Shamu (the mascot of Sea World) and was projected on a water jet screen.

1.4. The last day

The last day was spent at Universal Studios. There again, we took photos with various Universal mascots, such as Woody Woodpecker, Dora, Shrek, and others. During those encounters, Bobby was always very happy and forever hugging the mascots. We also took in some performances, like the Barney Show. Bobby was really impressed by this one. He stood up immediately from his wheelchair and started dancing and waving at the mascots. After the show, we were treated to a private meeting with Barney—normally, the children have to exit the room and wait in a public area to meet the mascots all together.

In the afternoon, we spent more than an hour in the kids' play zone. The temperature was scorching and this allowed the children to cool down by playing in the water.

We returned to the hotel at dusk for our last night, exhausted once again. The next day we left Florida for home...

2. An evening with my idol: Lindsay's dream concert

After two hours of driving through forest, Becky and I finally arrived in the city where we would meet, for the first time, the family who had flown thousands of miles to meet the daughter's idol. Becky is a 25-year-old woman who has been with the CWF for almost two years now. She is the "First-party Fundraising Activities Coordinator" and

joined the team in order to do what she likes best: organizing events[xvii]. "This is a special family," she had told me over a month ago. We actually started discussing this family in January 2007, three months before the wish was granted. At that time, Wendy told us the head office would require a volunteer CWF representative to accompany the family, which is not common practice[xviii]. "It's a *difficult* mother and she is likely to ask a lot of the artist," she said. "The people from Headquarters even suspect that this is more the mother's wish than the daughter's," she added. Lindsay's mother Janet had a rather extensive list of things she wanted her daughter to be allowed to do with her idol (e.g. go onstage, sing with him, etc.) but the artist was not comfortable with the request. Despite that the artist had expressed his malaise, the mother insisted on organizing a special meeting during which her daughter would at least sing him a song. After a series of negotiations, the family finally accepted to cease pressuring the artist, who simply wanted to organize a small chat with the family after his show. Although the family agreed to this on principle, the CWF was afraid something might go awry during the encounter and preferred to send someone they trusted to oversee the experience.

The family arrived in town the night before and spent time with their relatives. Overall, this wish consisted in Lindsay attending the show with her close family and relatives, who live close by. After the performance, 19-year-old Lindsay and her mother would meet the artist in person, chaperoned by us. In the days that followed, they were to go to the "big city" to do some sightseeing and shopping, since it was their first time visiting the province. They would then fly back home. Shortly after being diagnosed with a sarcoma (cancer of the connective tissues), Lindsay heard one of this artist's songs and became an instant fan. She'd been listening to his music ever since.

Becky and I arrived at the concert venue at 7:40 p.m., parked the car and joined the queue to enter the building. By chance, we ran into the family in the line and greeted each other. We then went inside. Several hundred people crowded the place, and the atmosphere was festive.

Roughly 20 of Lindsay's relatives came for the special event from all over the region. Even Lindsay's boyfriend surprised her by making the long drive by himself to join the family in the celebration. The owners of the venue were aware of Lindsay's presence and reserved a long table in the first row, close to the stage. After talking to her uncles, aunts, and cousins, Lindsay took her seat at the end of the table right next to the stage. The show began at 8 p.m. After an approximately 20-minute opening act, the artist arrived on stage and gave a dynamic one-and-a-half hour performance. It was the first night of his new tour, which was rather symbolic to Lindsay's experience.

When the show ended, the audience gradually started leaving. The artist's manager came to talk to us. He told us we had to wait 30 minutes before seeing him. He wanted to make sure that most of the crowd would be gone before taking us to see him. In addition, we would have to go discreetly in order to avoid being seen by the groupies, who could react negatively. For this reason, we could not go directly backstage to see him, but would have to meet him downstairs in a quiet room instead. Lindsay asked the manager whether it would be possible to do a jam session with him or sing him a song. He said he would check and get back to us. He came back later and said it would not be possible and did not offer any explanation. Moments later, another person came to accompany us to the room where we could see him. The room was large and quite dark. It was almost completely empty except for a few chairs and tables. The person told us to

wait a bit longer, and the artist then arrived accompanied by two other people. We all introduced ourselves. Janet and Lindsay explained the importance of the song to them. Janet spoke a lot during the brief meeting, mentioning several times how happy she was to have finally met him. She also said she would have liked her daughter to sing him her favourite song and was sad she could not. The artist told her he was a very sensitive[xix] person and that it was the very first night of a new tour. He added that he had to meet his other fans too. One of the artist's people told Lindsay to visit his Myspace page and send him her demos. He would communicate with her that way. We took some pictures and he left. We stayed a few minutes longer to reflect on how happy they were to have finally met him.

We then went upstairs to the coat check. Janet told Becky she knew he would be playing in a city nearby a few days later, and she asked whether they could attend that concert as well. Becky mentioned that she was not in charge of the wish and could not answer that question. Afterwards, Janet realized she had brought her video camera but had forgotten to use it. They also realized that they would like to have a poster autographed by the artist. They decided to go wait in line. "You again?" teased the singer when he saw them. On the poster he wrote "See you soon."

We left at midnight and the family returned to their hotel room in a limousine. Two hours later Becky and I arrived back in the city...

3. A refreshing wish: Emily's swimming pool shopping excursion

May 7, 2006. We left Emily's house. Debbie and I had a good time in the company of Emily, her mother Rose, and their white little poodle. Debbie, a CWF volunteer, was

familiar with this situation. Over the last four years or so, she had visited dozens of families to finalize the preparations of their wish. A single mother of two sons, she was juggling her career and the care of her children, while volunteering for the CWF whenever the time called. In addition to visiting families, she also coordinates various fundraising activities for the benefit of the CWF in her suburban area.

On this day, the purpose of our visit was to ask Rose to sign the legal forms (since Emily was under 14 at the time) and give Emily her wish paraphernalia. Emily is a 12-year-old girl living with cystic fibrosis. Her mother assured us she was currently doing fine, although she had spent lots of time in the hospital over the last few months. We could see from the greenish tint to her skin and her thin figure that the beginning of the 2006 had indeed been pretty challenging. Contrary to most cases encountered at the CWF, cystic fibrosis has the particularity of being a chronic, degenerative, illness. For that reason, instead of realizing her wish at the moment of the diagnosis, Emily waited until she was older and more aware of her situation to define her wish.

A swimming pool seemed like the ideal wish: it lasts longer than a trip and can be enjoyed for years to come. The family used to have a swimming pool, which they enjoyed whenever the weather permitted. A swimming pool had not been her first choice, however. In fact, Emily would have preferred to have a spa, but her doctor objected, citing her health condition as a major problem.

Once the idea of a swimming pool was approved by the doctor, the CWF planned a meeting to discuss the final arrangements of the wish. To accompany the pool, Emily

also wanted to have various accessories, including goggles, a snorkelling tube, flippers, patio chairs and a table. Her list was pretty clear.

Two days later, we met again at the swimming pool store to officially grant the wish. We arrived early to prepare the store for Emily's arrival. With the help of the store manager, we decorated the placed balloons and CWF logos everywhere. The manager also put out some chips and beverages.

The manager, whose name is also Emily, is the store owner's daughter. This wish was one of the first they had organized. Debbie hoped they would value the experience enough to be able to develop a long-term relationship with the CWF. Around the same time, the store owner decided to organize a fundraising activity to help cover the cost of the swimming pool. This was to take place in the coming days. Before the family arrived, Debbie informed me of her game plan: in order to respect the budget[xx], she wanted Emily to prioritize among the list of accessories she wanted. Debbie also gathered information regarding the water cleaning technologies available on the market. She thought that between the two main technologies (chlorine and sodium), sodium would be the best, given Emily's condition. She also wanted to consult the family on their preferences.

The family arrived 50 minutes later. Emily was smiling and looked radiant. The store owner greeted them and returned to her office. The manager then invited us to sit at the service counter (which happened to be a section of an above-ground pool). We looked at a scaled plan of Emily's backyard. To do so, Emily had taken all the measurements of the yard by herself. Debbie was delighted that she had done her "homework". Debbie asked her to pinpoint the future location of the pool. We then discussed the features of the

pool: the pump, the filter, the heater, the liner, etc. She said it was important to discuss these elements in order to meet the budget objectives. She added that Emily might have to make some choices at certain points, since not everything she wanted could be purchased. She asked Emily to sort them in order of importance. Once done, she asked Emily to do the same with the accessories. At that point, the manager suggested that they could browse the aisles instead but Debbie insisted on making the list. Once the sorting was completed, Debbie gave a surprise gift to Emily: two Harley Davidson t-shirts. She explained that she had gone to the Harley Davidson store a few days before and solicited a donation from them. She pointed out that she had to negotiate with an "important person" in order to get the t-shirts. She was really proud of her work. She said it was her way of contributing to the wish. Emily was happy and hugged her in return.

The manager, Debbie, and Emily then went together to do the shopping. In the meantime, I stayed with Rose. With the help of the list, they went from aisle to aisle selecting the items and accessories. The manager proposed various options and at some point Emily had to give up the patio table because it would be over budget. During this time, Rose realized that she had forgotten her camera and had to rush home to get it. After the shopping, we all went back to the service counter together. Rose then arrived and took some pictures. The store owner also came back and asked to have a picture with Emily.

The family was told that the swimming pool would be delivered and installed in a month. They then brought the accessories to their car. Debbie asked the family to send her a picture of them playing in the pool and told them the CWF would laminate it and

return it to them. We hugged and kissed each other goodbye after a few more words and left the store...

Appendix 3

Summary Protocol Form

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Summary Protocol Form

- ***For faculty and staff research:*** *Submit to the University Human Research Ethics Committee (UHREC), c/o the Office of Research, GM 1000.*

- ***For graduate or undergraduate research:***

    - *For projects covered under a faculty member's previously approved SPF, no new SPF is required.*

    - *For new projects which are supported by external (e.g. Tri-council) or internal (e.g. CASA or FRDP) funds, the supervising faculty member must submit a new SPF on behalf of the student to the UHREC, c/o the Office of Research, GM 1000.*

    - *For new projects which are NOT supported by external (e.g. Tri-council) or internal (e.g. CASA or FRDP) funds, the student must submit a new SPF to the relevant departmental or faculty ethics sub-committee.*

> For more information on the above, see
>
> http://oor.concordia.ca/REC/human_research.shtml.

> If using the MS Word form, please tab between fields (do not use the enter key) and click on check boxes. If not using the MS Word form, please TYPE your responses and submit on a separate sheet.

Date: **2006 / 02 / 21**

What type of review do you recommend that this form receive? Expedited ☐ or Full ☒

Basic Information

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Title of Research Project

The Dream factory: An Exploration of Institutionalized Ill Children Wish Granting (Working Title)

Granting Agency, Grant Number and Title OR Contractor and Contract Title (if applic.):

FQRSC

Description of the Project

Research Problem

In North America, over the last decades a significant number of non-profit organizations –like *Starlight Starbright Children's Foundation, Make A Wish, Children's Wish Foundation, Carolina Sunshine for Children, Cystic Fibrosis Dream Holidays, The Dream Foundation, Dream Come True, Wishes & More, Wishes Can Happen, Inc., The Wishing Well, Children's Dream Fund,* etc.– have sprouted up and begun offering various activities and programs dedicated precisely to "enlightening" the life of ill children through the granting of wishes (i.e. offering the possibility for seriously ill children to realize deeply-held dreams). Those organizations have begun to organize collectively in order to further increase the professionalism of their work. Indeed, in 1995, in the United States, the *Association of Wish Granting Organizations* (http://www.awgo.org/) was created with the objective of "providing the highest

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standards in wish granting throughout the world". Nowadays wish granting organizations are capable of raising important amounts of money. For instance, *Make A Wish* alone reported over $150 million in fundraising activities, donations, lotteries and other revenues in its 2004-2005 annual report. They are expanding all over the world. For example, *Starlight Starbright Children's Foundation* has chapters in Canada, United States, Australia, United Kingdom, and Japan and *Make A Wish Foundation International* (http://www.worldwish.org/) serves 27 countries including, for instance, Argentina, Australia, Austria, Belgium, Canada, Chile, Denmark, France, Greece, India, Ireland, and Israel. These organizations provide support to tens of thousands of seriously ill children. For example, The *Children's Wish Foundation* alone grants approximately one thousand dreams annually. In parallel, dozens –if not hundreds– of companies operating in various industries such as banking and financial services (e.g. TD Bank Financial Group, ING Direct, VISA), travel and resort (e.g. Fairmount Hotels and Resorts, Royal Caribbean, Disney), sports (e.g. Major League Baseball), jewellery (e.g. Swarovski), computer, electronics, toys and gaming (e.g. Sony, Pogo, Nintendo, Toys "R" Us), food and beverage (e.g. McCain, Laura Secord, Starbuck Coffee), news and information (e.g. WIRED Magazine), and transportation (e.g. Avis Rental Car System, Air Transat, Delta Airlines, American Airlines, GM), are increasingly contributing to this cause through sponsorship and partnership programs. The 21st century is witnessing the emergence and growth of the "Ill Children's Dream Industry".

Despite the importance of this major social and economic phenomenon, no research yet exists to document and reflect upon it. These, mostly charitable, organizations are evolving in an ever increasingly competitive market in which donations

are more and more difficult to obtain (Andreasen and Kotler 2003). The relationship between charities and profit-oriented corporations is also becoming increasingly close-knit (Pringle and Thompson 2001). The scientific community possesses no information or theorization on the granting of the wishes, its impact on this vulnerable population, or the role of the market in that process. In this context, it becomes necessary to delve into institutionalized wish granting of ill children in order to evaluate the relationship between the ill children, their families, the wish granting organizations, and the other major actors including the market for both individual and corporate donations. There is a pressing need for the scientific community to investigate this important type of wish granting and its effects: How can we describe the process of wish realization of ill children? Who are the left-outs in the process? Who are the principal actors involved in the process? How are the actors affected by and affecting the process? What is the importance of the wish for the various actors involved? How is the wish evolving throughout the process? What is the importance of the wish for the people affected by life-threatening illnesses? What is the role of childhood in this process? How is the illness affecting and affected by the wish and its realization? How are morality and ethics negotiated during the process? What is the role of consumption? What is the role of the market? The objective of this research is to provide answers to these questions by exploring the process of realization of the wishes of ill children in the context of institutionalized wish granting.

Method

As argued by anthropologists and sociologists such as David Howes (1996), Arjun Appadurai (1988), Daniel Miller (1987) and Bruno Latour (1979, 1991, 2005), every social phenomenon is the result of a complex construction process involving a variety of

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actors, actions, contexts, history, and discourses. In other words, in order to fully appreciate what is visible as a social outcome, one has to investigate the process that led to its current state. The social phenomenon is dialectically created through encounters with the various actors involved (who are to a certain extent also transformed by it). Close to one hundred years of theory building, epistemological debates, and empirical investigations in anthropology have shown that ethnography –that is, open-ended, direct, participant, contextualized, prolonged, and intimate, contact with studied people– is the most valuable and objective method to grasp those social construction processes. An ethnographer (i.e. the person who conducts the ethnography) stays as close as possible to the phenomenon under investigation. S/he has to get personally involved in the daily activities and routines of the informants in order to experience as much as possible the events in their lives, the various contexts, and the diverse emotions. In so doing, s/he develops a sensitive, human, contextualized, and respectful, understanding of the lives of the others.

Most importantly, as Malinowski (1922) notes, "being there" through participant observation gives the possibility for the ethnographer to witness "on the spot" the multitude of daily –and often unpredictable– activities, ceremonies, and transactions that occur naturally in the life of the community (e.g. the daily routines at work, the official and casual meetings or encounters between individuals and groups, the ways of preparing the logistics of an event, performing during daily routines and extraordinary events, dressing and grooming for particular events, the emotional reactions and social interactions emerging during everyday life and special events, the ways of managing challenges and crisis, etc.). Being there gives access to the unsaid, the daily routines

taken for granted by the informants –if not unconsciously incorporated (Merleau-Ponty 1945)– and which can become difficult, if not impossible, to verbally articulate. Hence, objective ethnographic accounts rely not only on discourse and textual analysis of archives, but also on what individuals *do* and on the *gap between what they say and what they do*. Summarizing the contrast between ethnography and other methodologies, Arnould and Wallendorf (1994: 486) point out that:

> *"instead of observing people doing what they might do or say if real-world complexities did not impose on them, as in laboratory experiments, ethnographers observe actual people's behaviour in real time; and rather than asking respondents to generalize about their behaviour as in survey research, ethnographers record the particulars of naturally occurring behaviours and conversations."*

Anthropologists like Latour and Miller further argue that in order to develop an objective ethnographic understanding of a process, one has to gather the information available from all significant sources. Research-wise, deliberately removing significant individuals or constituents of the process would impair the objectivity of theorization of processes in social sciences, and would be unethical (in the sense of *justice*[xxi]) and disrespectful to the informants and to the researched population.

In the case of the wish granting process, in order to develop the most objective, generalizable, and respectful, understanding of how the wish is ultimately granted, we need to *understand in depth* and *contextualize*: 1) how and why the wish is originally conceived by the ill child; 2) how it is discussed and negotiated with his/her family; 3)

how the family approaches the wish granting organization to formulate a wish granting request; 4) how the organization evaluates the request; 5) how the organization gets the monetary, medical, legal, ethical, and human resources to be able to grant the wish; 6) what the challenges and difficulties that are encountered during the process are; 7) how the wish granting is materialized and performed on the wish granting day; 8) how the wish affects and is affected by the lives of the people –directly or indirectly– involved in the process; and finally 9) we need to be open to include any other unexpected but relevant element that could emerge during the investigation of the process.

Each actor provides a distinct perspective to the process. Ill children and their families are the initiators and ultimate beneficiaries of this process. Their presence is hence central in this research. The children come up with a wish based on their own understanding and internalization of life, family, society, and their own condition. The ill children are also likely to be surrounded by friends (other healthy or ill children) who can influence the process in one way or another (e.g. giving ideas to the ill child). The parents and other family members envision the wish and the wish granting process based on their contextualized understanding of the child's condition, the world, and themselves. They are also surrounded by friends and health specialists (e.g. physicians, oncologists, psychologists, social workers, etc.) who are also likely to affect their worldview.

The wish granting organization is also an important element in the process. It will have its own contextualized (and institutionalized) understanding of the wish and the family's condition, and will mobilize all necessary resources including money (from individual and corporate donation), manpower (from organization staff, volunteers), and medical and legal expertise (from physicians, oncologists, psychologists, lawyers, etc.).

These external actors can significantly affect the process directly and/or indirectly. For instance, donors directly and positively affect the process with their donations and partnership programs. Simultaneously, they can also affect the process more indirectly and more pervasively in that they represent a pressure group that can stop granting money at any time. All these external actors in interaction with the foundation will also have a particular contextualized understanding of the situation and affect the process accordingly.

Due to the idiosyncrasy of each perspective, one actor's view cannot substitute for another. The parents' view differs from that of the children. Research on ill children in general argues that children have an understanding of the world that differs from that of adults (Eiser and Twamley 1999). For instance, it has been shown in the case of families dealing with juvenile illness, that every "layer" of actors (i.e. ill children, siblings, parents) has a different understanding of the illness and of the family unit and context. For example, parents often believe that their children are oblivious to the state of the illness and its prognosis if they and the medical staff don't talk about it. However, young children (as young as three years old) are in most cases aware of their condition despite the lack of communication with parents and healthcare specialists (Bluebond-Langer 1978). Healthy siblings also have a perspective that differs from that of the parents and ill child (Bluebond-Langer 1996).

It is also claimed that "asking adults [parents, teachers] for their views about a child's beliefs and behaviors but not also asking the child" is even disrespectful (Alderson 2004: 108). More generally, researchers on children criticize the lack of direct attention to children's worldviews by questioning the "children-as-objects" paradigm,

which sees children as "dependent, incompetent, and not able to deal appropriately with information" (Robinson and Kellett 2004:85). Rather they argue in favour of the "children-as-actors" paradigm, for children "act, take part in, change and become changed by the social and cultural world they live in" (Christensen and Prout 2002:481).

The wish granting organization also has a perspective that differs from that of the children, the families, and the other external actors. They have to balance various and competing interests. On the one hand they need to achieve financial sustainability and maximize revenues while keeping in mind their non-profit nature. On the other hand they try to mobilize all resources to succeed in their wish granting mission while keeping in mind their ethical code. Their understanding of the children and their families comes from the vantage point of the institution. They might try to develop a good understanding of the children's wish and their needs, but their understanding is also likely to be limited to functional aspects (i.e. aspects that will lead to the realization of the wish). Their understanding of external actors is also likely to be functional and de-contextualized (i.e. not fully taking their personal reality and worldview into consideration). Interactions with volunteers will probably be discontinued and associated with precise tasks[xxii].

Generally speaking, it is through the understanding of all of these diverse contexts and viewpoints that the ethnographer can document and make sense of the overall ill children's wish granting process. It is through the comparison and contrast of each actor's standpoint that the other perspectives can be become meaningful.

Ethnographic Setting

In order to realize his research objective, the investigator has garnered the support of the *Children's Wish Foundation of Canada* (http://www.childrenswish.ca/) to be the setting for his ethnographic fieldwork. This foundation is an ideal collaborator for this project for two reasons. First, its core mission parallels the investigator's own research goals. The Foundation is "dedicated to working within the community to fulfill heart-felt wishes of children [from 3 to 17 years old] diagnosed with a high-risk, life-threatening illness" (http://www.childrenswish.ca/national/our-story-mission.php). Consequently, direct and prolonged involvement with the CWF will allow him to explore diverse cases of ill children's wish realization. Second, the CWF's extensive links with multiple actors in the community will help better understand the entire process of wish realization. Owing to this partnership with the CWF, the researcher will be able to attend events (e.g. fundraising activities, wish granting preparation and planning, wish granting day, meetings, etc.) and meet with all actors involved in the process – beneficiaries (i.e. ill children and families), donors, volunteers, staff members, and medical and legal experts (e.g. oncologists, therapists, psychologists, lawyers)– in order to develop an in-depth understanding of the process from all pertinent perspectives.

In exchange for the privileged access to all of these actors, the investigator will serve as a research consultant on a volunteer basis for the Foundation. This reciprocal service will allow him to give back to the community. Based on the results of the research, reports will be given to the Foundation concerning the various perceptions of CWF and other charities, the strengths and weaknesses of the Foundation and the wish granting process, the impacts of wishes on the families, and the key success factors in order to:

- Maximize understanding of the needs of wish families

- Maximize wish families' satisfaction with the wish granting process

- Maximize volunteers' satisfaction

- Identify potential volunteer training programs

- Maximize communication with medical experts, donors, and volunteers

- Identify potential strategies to increase donation

It is important to note that despite his collaboration with the Foundation, the researcher will conduct his study on an independent basis. His work as a volunteer research consultant will be separate from his work of researcher. The Foundation will have no access to identity-revealing or confidential information about volunteers, donors, staff, and ill children and families. In order to reciprocate the CWF's generous collaboration, the researcher will produce reports with global recommendations concerning the improvement of the overall performance of the Foundation (see above).

In order to pursue his research, the investigator plans to conduct a field study of approximately 12 months within the broad context of the Children's Wish Foundation. As suggested by anthropologists (e.g. Van Maanen 1988), a full year cycle allows the researcher to be exposed to most of the events and rituals that happen within a community. To gather the information he will use formal semi-structured interviews, mail and email interviews, informal non-structured interviews, as well as projective techniques. He will also use field notes and diaries to record his observations of behaviours, social interactions, and his personal feelings (to provide a reflective account of the research process). Following the principles of grounded theory (Glaser and Strauss

1967), he will iteratively proceed with analysis through ongoing back and forth movements from data to theory. Finally, all types of artifacts, including websites, newsletters, press releases, letters to donors, donor campaign literature, information on spacial layout and architecture, etc., will be incorporated in the research databank and included in his analysis and communications (following participants' consent and respect of confidentiality).

Additional Elements of Scientific Contribution

In addition to documenting for the first time the process of institutionalized ill children's wish granting, this research will offer potential contributions to various areas of knowledge.

First, research on wishes and desires has principally been done with overall healthy individuals. However, the way a person diagnosed with life-threatening disease envisions her dreams and their fulfillment may diverge greatly from the way healthy individuals do. Research in medical anthropology and sociology on chronically and terminally ill adults and children (e.g. Bluebond-Langer 1978, 1996; Glaser and Strauss 1965) reveals that awareness of life-threatening disease affects many aspects of the life of the person diagnosed with the disease as well as her social environment (siblings, parents, friends, etc.). One important aspect, among others, is the re-conceptualization of the future (Charmaz 1991): the critically-ill person and her significant others have to redefine their conception of the future due to the menace of the life interruption caused by the illness. In this case, an understanding of wishes in the context of illness will be enlightening.

Also, recently some consumer research scholars have started exploring phenomena and behaviours related to vulnerable populations such as teenagers (Ritson and Elliott 1999), children (Schor 2005, Linn 2004), homosexuals (Kates 2002), immigrants (Oswald 1999), physically disabled people (Vezina, d'Astous and Deschamps 1995), delinquents (Ozanne, Hill and Wright 1998) and fairly illiterate individuals (Adkins and Ozanne 2005). This research will contribute to broadening the scope of consumer research with sensitive populations by exploring the universe of ill children.

Secondly, due to the centrality of consumerism in Western society (Baudrillard 1970; Featherstone 1991), a consumer research perspective is well suited to study the wishes of ill children. These children have dreams. They long for objects (e.g. having computers, playgrounds, etc.), travel experiences (e.g. going to Disneyland, to Europe, etc.) encounters with movie actors and sports stars, and so on (Spizman 2005). For better or worse, corporations are aware of this reality and propose alliances with the charities that are granting such consumption-related wishes. Hence, these children are, directly or not, being incorporated into the market. Their being in various developmental stages is likely to shed light on their level of incorporation into consumer culture, the impact of the consumption driving force that permeates the Western world, and the role of consumption in crisis situations (e.g. Pavia and Mason 2004). It will also draw attention on the delicate relationship that the corporate world is developing with ill children.

Thirdly, in existing literature of consumer research, wishes and desires have always been explored on the basis of discourse or surveys; leaving the *practice of dreams* (i.e. what people actually do when they realize a wish) aside. Moreover, the commonly used prospective (i.e. how the individual anticipates future aspirations) or retrospective

perspectives (i.e. how the individual recalls the realization of past aspirations) of this research leave the entire real-time process unexplored[xxiii]. This project will contribute to science by documenting the process in a real-time perspective by combining what people say about the wishes with what they do in practice.

Finally, this research also finds its legitimacy in the emerging field of positive psychology –how pursuing goals can lead individuals to live happier lives (Schmuck and Sheldon 2001). It will contribute to this field by documenting the effect of wishes on ill children and their families, and also on the various other actors involved in the process of wish granting.

Overall Risks and Benefits of this Research

Ill children and their families represent a vulnerable population. It is expected that some aspects of the interactions with the researcher will lead to strong emotions (i.e. when discussing the illness). It also has to be pointed out that the interaction between the investigator and the vulnerable informants can lead to unbalanced power relationships that could benefit the researcher over the informants. For these reasons, the researcher is planning to apply strict and precise measures. He will be trained in order to maximize his interview and general interaction skills in dealing with seriously ill children and their families. He will also develop a supportive, subject-centered, collaborative, research paradigm that will inform and empower ill children and families by including –and strongly considering– their voice throughout the research process. These measures will minimize potential harmful situations and rebalance the power. They are further detailed in sections 2 and 3 of this proposal.

In order to counterbalance the risks, like other social scientists working with children, the investigator is expecting to contribute to their lives (Fraser 2004). In fact, in addition to its scientific contribution, this research will bring valuable advantages to the vulnerable subgroup of ill children and families. First, the involvement of the researcher with the Children's Wish Foundation will directly contribute to ill children and their families. The researcher's understanding of the reality of the actors involved in the process will provide significant information concerning the perception of the Foundation, the level of satisfaction with the wish granting process as well as its consequences. This information will benefit the children and their families at three levels. First, it should lead to increasing the Foundation's capacity to raise money: by better understanding the perceptions and wants of the donors and the needs of the beneficiaries, the Foundation should be able to develop more efficient communication strategies with donors, and hence, increase donation. All things being equal, increased financial capacities will lead to a higher number of wish granting[xxiv]. Second, through a better understanding of the volunteers' reality, the Foundation should be able to develop effective training programs that could lead to heightened satisfaction and loyalty of volunteers, better fundraising capacities, and improved interactions with families and children. Third, with a more accurate knowledge of the families' needs and the satisfaction with the wish granting process, the Foundation will be able to develop stronger support and higher quality of social services to ill children and their families.

Second, the *United Nations Convention on the Rights of Children* (General Assembly, 1989) recommends that children should be informed, involved, and consulted, about all activities that affect their lives. This research can contribute to informing

children (as well as parents) about the implications, challenges, risks, and benefits that could be associated with undergoing a wish granting process. The investigator is hoping to write a public-oriented essay about the wish granting process (the "wish granting manual") and its implications to help prepare families and children for the wish granting challenge.

Third, the research will not only benefit future "wish families". It can benefit children and families directly participating in the research. First, it is likely that during this stressful time of their lives, the families would neither have the energy nor the time to seek to document the images and words of their ill child, yet this could be a priceless keepsake. In order to give back to the participants, the researcher will keep the images, pictures, diaries, drawings, excerpts from interview tapes, etc., of children and will offer to create photo albums, scrapbooks, etc. that will be given to the families. Second, the health psychology literature shows that conducting interviews with ill people often fosters a strong positive therapeutic effect. Talking to an interviewer offers solace since it is not a hierarchical context such as between a patient and physician and does not always involve relatives (Campbell 2002). In fact, the interview is sometimes the first moment where ill children have an opportunity to express their feelings about illness. Bluebond-Langer's ethnographies of children with leukemia (1978) and cystic fibrosis (1996) show that it is often hard for children to speak about illness with their parents and siblings (and vice-versa) since it is a taboo topic and because of the high emotions surrounding illness and death (see also Glaser and Strauss 1965). She found that the ethnographer can become an important human resource for the children and their families. Even though it is not the primary focus of most of the social research on illness, the researcher often

becomes a listener (Mathieson 1999) and the interview can be a cathartic experience for the interviewee (Lee 1993). It is also argued that telling one's life story helps the ill or trauma-affected individuals to vent their emotions and establish order in their sometimes chaotic lives (Murray 1999). In a more general reflection about human communication, it is often pointed out that discussion between two individuals can lead to a greater consciousness of one's own life and improved self-understanding (Gadamer 2004; Agar 1982). In the present case, the investigator hopes that his privileged contact with ill children and their families will mirror this positive, cathartic, effect with participants. Telling their story could help them become more reflective, take a distanced perspective about their current life, and find solutions to their problems. Please note however that following Masson's (2004) strong warning, the researcher will never seek to play the role of a therapist during his encounters with participants. He will instead recommend participant to consult experts if needed and will provide a referral list if requested.

All in all, this study is designed to better understand the reality of people involved in the process of ill children's wish granting. It will provide information on the people directly dealing with life-threatening juvenile illnesses in their everyday lives and the role of wishes in the coping process. As strongly advocated by qualitative health psychologists, it is necessary to document the reality of the ill as they experience it. To do so, one cannot rely solely on a distanced, de-contextualized, impersonal, survey-based or experimental study. One has to develop an in-depth, personal, and intimate understanding of their reality (Campbell 2002; Oakley 1988; Radley 1999). The more we understand their world, the better equipped we are to develop and apply relevant public policies. Marketing and consumer researchers are more and more involved in the public domain

and take an active role in publishing in managerially- and socially-relevant journals like the *Health Marketing Quarterly*, the *Journal of Public Policy & Marketing*, the *Journal of Marketing for Mental Health*, *Voluntary Sector and Nonprofit Marketing*, the *Journal of Health Care Marketing*, etc. As feminist researchers have argued over the last 30 years, this type of research provides an opportunity for the too-often-voiceless to be heard[xxv] and for concrete action to be taken (Ussher 1999; Joy, Sherry, Troilo and Deschenes, In progress). Consumer researchers can contribute to social problems through their understanding of consumption phenomena (Bazerman 2001; Denzin 2001; Moorman 2002; Murray and Ozanne 1991). It is then hoped that this research will initiate further reflection and interest among consumer researchers –as well as other social scientists– in the wish reality of ill children in Western, consumer-centred, societies.

Research Participants

Sample of Persons to be Studied

The study will include various categories of participants:

1) Ill children: Children (aged 3 to 17 years old) with life-threatening illnesses[xxvi]

2) Family members: Adults and children that are related to the ill children (including close friends)

3) Foundation Volunteers

4) Foundation staff (paid employees)

5) Donors: Individuals who donate on a personal basis or on the behalf of a corporate entity

6) Health specialists: Experts working in areas such as medical science (e.g. physicians, oncologists, etc.), psychology, social work, etc. Note: No confidential information on patients will be requested to respect patient-specialist confidentiality relationships.

7) Outsiders: Individuals who are not formally involved in the research (i.e. individuals who are encountered in the background of the research but whose participation is not formally required and whose identity is not explicitly uncovered), for instance: rally participants, one-time volunteers (i.e. participants who are seen only once and informally interviewed), etc.

Method of Recruitment and Treatment of Participants during the Course of the Research

No assistant will be required for the research.

No incentive will be offered for participation.

The principal investigator will be the only researcher in contact with the participants.

Participants will be told that the study aims to explore the realization of wishes in the context of the Children's Wish Foundation.

A first set of participants will be recruited on the basis of convenience and snowball sampling will ensue as more participants come in contact with the principal investigator during the fieldwork. Children and families will be introduced to the researcher mainly through the CWF's "wish coordinator". That person's role is to establish communication with the families and to coordinate the process from the Foundation's perspective. Other CWF staff members may play this introductory role (e.g. Chapter Director). The investigator himself may also recruit participants depending on the context.

Participation will be on a volunteer basis: official consent will be sought prior to including informants in the research and they will always have the right to withdraw from the research at any time without any negative consequences.

There is no a priori criteria for selecting informants for this research. The investigator respects the principle of *justice* (i.e. everyone's voice has the right to be heard) as well as the grounded-theory principle of *emergence* (i.e. include any significant actor in the process without a priori framework).

Explicit parental or legal guardian consent (through the signing of a consent form) will be sought prior to approaching any participant under 14 years of age. A consent form will also be presented to any individual over 14 years who is approached for the research (except for the "outsiders"). In all cases, participation will always be set on a volunteer basis: official consent will be sought prior to including a participant (adult or child) in the research. Oral consent will be sought prior to conducting participant observation. Furthermore, participants will always have the right to withdraw from the research at any time and without any negative consequences whatsoever.

A second set of participants might be recruited through the use of the Foundation's database (if available). This list will neither be owned nor kept by the investigator after the completion of the research. The persons on the list (potentially including recipients of the Foundation's help, volunteers and donors) will likely be contacted by telephone and/or email. If such is the case, a confidentiality form will be signed by the investigator in order to guarantee privacy and non-dissemination of the information contained in the database. Every email that is sent will be kept by the principal investigator only and stored in a secure place after the completion of the research. In order to avoid any potential conflict between families and the Foundation, the investigator will contact with the families on the confidential list.

Given that ethnography is the principal method of investigation, the researcher will have different levels of contact (and of intrusion) with the participants and the outsiders, depending on the context and possibility to build long-term relationships with them. Probable types of contact are:

1. Single (or multiple) formal interview(s): Single (or multiple) meeting(s) with a participant in order to collect information through semi-structured interview(s)

2. Single (or multiple) mail or email interview(s): Single (or multiple) email or letter(s) sent to participants in order to collect information through mail or email letter(s)

3. Single (or multiple) informal interview: Single (or multiple) "on-the-spot" discussion(s) with either participants or outsiders

4. Single (or multiple) behavioural observation(s): Single (or multiple) behavioural observation(s) of either participants or outsiders

5. Brief (or lengthy) behavioural observation: Short (or lengthy) behavioural observation of either participants or outsiders

Formal interviews may be tape-recorded (based on participant's oral consent). Formal interviews will be realized in a comfortable environment approved before-hand by the participant. In the case of ill children and families, interviews may be conducted in the children's hospital rooms, in hospital playroom, home, the Foundation's facilities, restaurants and cafés, etc., depending on the will of the participants. Children under 14 may be interviewed alone subject to parental consent and the child's willingness. Participants will be informed of the approximate length of the interview and will be briefed concerning

the type of questions that will be asked. A consent form will be signed by the participants prior to the interview. Participants will have the right to withdraw from the interview at any time without any negative consequences whatsoever. Participants will be informed that they can obtain copies of recorded material in which they have directly participated (e.g. tape-recorded interviews, photographs, videos, etc.) upon request.

The researcher will ask for permission to quote interviewees before adding transcription of verbatim in a report to the Foundation or in written communication with the scientific community.

In order to avoid any potential conflict between the Foundation and the informants and/or exploitation of informants by the Foundation, the identity of the informants will not be communicated to the Foundation. In order to ensure confidentiality, the name of the participant as well as any other information that would potentially disclose their identity will be purposefully changed or omitted when the researcher communicates any results in verbal or written form to the Foundation or the scientific community.

The themes and types of questions will depend on the informant being interviewed and the context. For instance, in the case of longitudinal relationship with the informant, a first interview might focus more on the individual's background while subsequent interviews may be directed at specific themes like the relationship between the informant and the Foundation or the wish realization process. On the other hand, in the context of a one-time interview, the investigator might select questions that will allow him to cover all the themes. The list provided here is a detailed but not exhaustive list

(due to the emergent design of ethnographies and to the semi-structured nature of the interviews). See Appendix 1 for a detailed list of questions.

During the participant and non participant observation with the principal actors (volunteers, donors, and staff), the following information will be sought:

- Observation of social interactions: What are the actors saying to each other in regards to the wish, the illness, and other topics? How are the actors behaving with each other?

- Observation of events (e.g. fundraising activity, wish granting day, etc.): What happens during this event? What is the basic script of the event? Who gets involved, why, when, and how? Who does not get involved and why? What are the observed emotional reactions of participants? How does everyone else respond to these reactions? How do interactions and behaviours evolve over time?

Oral consent will be sought prior to the participant observation activity. For instance, the investigator will discuss the purpose of his research and the extent and implications of participant observation with families before attending meetings or events with them. Observation may sometimes be complemented with photographs and videos (subject to participants' oral consent). These visuals will be used as part of the analysis and for communication purposes (e.g. presented in thesis, conferences, etc.). Images are useful in that they help convey differently (and sometimes more experientially) certain situations. They can also be used as auto-driving techniques when they are shown to informants (Heisley and Levy 1991). The researcher will ask for permission before adding images to a report to the Foundation or in a communication with the scientific community.

Observation may consist in taking part in rallies, parades and other fundraising activities, meetings, daily work within the Foundation's office, wish granting planning and preparation, wish granting day event, etc. Participants will have the right to ask for a copy of any photograph or video footage in which they can be seen.

After the research is completed, the information gathered through tape-recording, photographs or videos will be removed from the investigator's computer, stored on CDs and placed in a secure place.

Written consent will be sought for the first formal interview. Follow-up interviews will be conducted subject to oral consent. In the case of children and families, a detailed description of the follow-up interview will be sent in advance to the informants. The investigator will recommend informants to discuss the content of follow-up interviews with relatives and health specialists before giving their consent.

Particular Attention to Ill Children and Families

In approaching ill children and their families additional precautions will be taken. In fact due to their potential level of vulnerability, they may not be able to evaluate the consequences of participating in this project. They may underestimate the negative feelings that could surface during an interview when discussing issues related to illness. They may feel powerless in face of the interviewer and not be able to refuse to answer a painful question that could have been avoided otherwise. For these reasons, they will be orally and officially (through a statement in the consent form) encouraged to seek external advice before accepting to participate in the research and before signing the consent form.

Interactions with children and families will happen in one of two different ways: 1) in the institutional setting and 2) in the independent setting. In the first case, the researcher will be exposed to families during meetings with the Foundation and families. During such meetings, the researcher will collect data by observation. He will not deliberately ask questions related to the research. He will observe actions and listen (and participate) to normal discussions (as any CWF staff would do). In the second case, the researcher will seek interactions with the families outside of the Foundation's premises. In this case, he will meet families in order to conduct interviews with them independently from the CWF in order to protect their anonymity and to preserve their dignity. In both cases, the first contact with the families will be established by the CWF. An employee will contact parents and inform them of the researcher's identity and of the purpose of this research. In the institutional setting, the employee will ask the family whether the researcher can be present during the meeting or not. The family will also be assured that a refusal will not affect the wish granting process (since the research is conducted independently from the CWF work). In the independent setting, a staff member will briefly inform the potential participant about the research, and request their permission to have their contact information given to the researcher. They will also be assured that a refusal will not affect the wish granting process.

Prior to any contact made in an independent setting[1], families will receive a document describing the research and the main questions that will be asked (keeping in mind the semi-structured nature of the interviews). They will be encouraged to share this

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[1] In the institutional setting (i.e. when the researcher is only observing the interaction between CWF and the families), it will not be "anthropologically sound" to send complete information package to families and to run information sessions since the researcher's role will be minor and secondary in this condition.

information with relatives and health specialists (e.g. physicians, social workers, psychologists, psychotherapists, etc.) before accepting to meet with the investigator.

When working with a vulnerable population, the researcher and informants are often in an unequal power relationship. In order to overcome this problematic situation, Curtis, Bryce, and Treloar (1999) suggest that the best way to rebalance the relationship is to *work collaboratively with informants*. Contextualized and collaborative research with vulnerable people leads to more flexible, balanced, respectful and beneficial processes and outcomes (Owens and Payne 1999). Child researchers also strongly recommend adopting this procedure with children (e.g. Eiser and Twamley 1999; Fraser 2004).

In the independent setting, the research with children and families will be a two-step collaborative process. After the recruitment by CWF' staff or the investigator, the first step will be an information meeting during which all questions regarding the project and the principal investigator will be answered. It will predate the signature of the consent form. Extended family and/or health specialists (e.g. physicians, social workers, psychologists, etc) will be invited to participate. During this meeting, the researcher's dual identity (researcher/volunteer) will be disclosed:

1) His work as a social scientist is to explore the place and process of the wish in the particular context of the family facing childhood illness. This project will hopefully result in conference presentations and publications in scientific journals.

2) His role as a research consultant for the CWF is to document the perception of the Foundation and the satisfaction with the social service it delivers. Global analyses

will be presented to the Foundation in order present recommendations to improve its overall capacity to raise money, support volunteers and fulfill its mission (i.e. granting wishes to children diagnosed with life-threatening diseases)

3) The investigator will inform participants that his primary role is that of an academic researcher and that his ultimate obligation is towards the informants, not the organization (as stipulated in the American Anthropological Association's code of ethics).

Other important issues will be examined:

1) In order to avoid any potential conflict between the Foundation and the families and/or exploitation of families, the identity of children and families will not be communicated to the Foundation. In order to ensure confidentiality, the name of the participants as well as any other information that would potentially disclose their identity will be purposefully changed or omitted when the researcher communicates any results in verbal or written form to the Foundation or the scientific community.

2) Participants may choose to keep their stories completely secret from the Foundation and/or from scientific record. The investigator has the obligation to respect their will.

3) The objective is to do research *with* children and families, not *on* them. They will be informed that, ultimately, they have control over the course of the project: 1) They decide whether they want to get relatives' and/or specialists' advice before accepting to participate in this research. 2) They decide whether they want to be

accompanied by relatives and/or specialists during the interactions with the investigator. 3) They decide to participate or to withdraw. Participants can withdraw at any time from the research process without any negative consequences whatsoever. 4) They decide whether or not they answer questions during interviews and observations. 5) They also choose whether they want to participate in activities (e.g. diary, drawing, etc.). 6) They decide whether they wish to grant researcher with access to meetings and events in which they are involved. 7) They participate in the process of selecting the questions and activities depending on their personal context. 8) If they don't feel comfortable with the face-to-face interview, they can choose to do mail or email interviews.

4) They will be encouraged to ask questions during interviews and observation sessions. This research is designed to be collaborative, not unilateral.

5) Upon request, participants will have access to all transcript and video material in which they are involved.

6) The researcher will ask for permission to quote participants before adding verbatim transcriptions in a report to the Foundation or in a communication with the scientific community.

7) Written consent will be sought prior to first interview. Oral consent will be sought for any other follow-up interviews. Oral consent will be requested for observation sessions.

8) In order to avoid unmet expectations, children and families will be informed that participation in this research is not related to the wish granting process. The researcher shall be independently collecting information. The identity of participants will not be revealed to the Foundation. The investigator communicates only global analyses to the Foundation. Hence, the fact that

participants decide to participate or not will not affect in any way the screening process: 1) the illness has to be recognized as an official life-threatening illness by the physicians collaborating with the Foundation; 2) the physician must agree to let the child realize his/her wish; 3) the parents must give their approval too. Every participant has to know that this research has no correlation with the wish granting acceptation rate.

9) Participants will be encouraged to get support throughout the research process from relatives or health specialists. Support people can attend every encounter, ask questions and give advice to informants.

10) If participants are not currently consulting psycho-social health specialists (e.g. psychotherapists, psychologists, social workers) but would like to get their advice and/or support, a referral list will be provided in order to help them identify the best resource for their needs.

As evidenced by Campbell (2002) explanation of research method is likely to positively affect the relationship between the investigator and the participants by informing and comforting them. In the current case, the various ways of conducting the research will be openly discussed and negotiated with all family members and other support attendants. The definitions and implications of semi-structured interviews, mail and email interviews, and observation will be discussed. The objective is to negotiate with the families what would be *the most acceptable way(s) of conducting this research according to their personal life context.* The various possible researcher-informant interactions will be addressed. See Appendix 2 for the list of the optional types of interactions.

After jointly evaluating all possibilities, the investigator and the families (and support attendants) will establish a preliminary schedule of meeting(s). This schedule will be flexible and subject to change by the family without negative any consequences whatsoever.

The second phase will consist of the subsequent interactions with family, including interviews and/or observations (e.g. family-CWF meetings, rallies, fundraising activities, wish granting days, wish granting preparation activities, in-hospital observations, etc.). During the participant and non-participant observations with families, the following information will be sought:

1) Observations of family-Foundation staff/volunteers interactions:

   o What is the Foundation saying to the families in regards to the wish, illness, and other topics? How is the Foundation behaving with them? How are the families responding?

   o What do family members say to the Foundation in regards to the wish, illness, and other topics? How are family members behaving with the Foundation? How is the Foundation responding?

   o How are interactions and behaviours evolving over time?

2) Observations of events (e.g. fundraising activity, wish granting day, etc.)

   o What happens during this event? What is the basic script of the event?

   o Who gets involved, why, when, and how? Who does not get involved and why?

   o What are the observed emotional reactions of participants? How does everyone else respond to these reactions?

3) Observations of within-family interactions

- o What do family members say to each other? How does everyone respond?

- o What is the general mood within the family?

- o How does every one behave towards each other?

- o How do the interactions and behaviours evolve over time?

Interviews are also important to access mental representations and latent feelings. During interviews, participants will be encouraged to be accompanied by relatives, friends, or health specialists (e.g. physicians, psychologists, social workers, etc.). This recommendation will be given orally and will be written on the consent forms. To develop a collaborative relationship with informants, the researcher intends to provide parents in advance (i.e. prior to the interview) with a detailed, but incomplete, list of the themes and precise examples of questions that will be covered during the interview. They will be informed that in the context of semi-structured interviews, the list of questions can never be exhaustive. The researcher will recommend to parents that they discuss the content of the interview with their relatives and/or health specialists (physicians, social workers, psychologists, etc.). Any theme that is deemed inappropriate by the participants will be removed without question and without any negative consequences whatsoever. Any restriction within a theme will also be respected without any negative consequences whatsoever.

A second important aspect of collaboration in the case of research concerning children is to consider the research as a negotiated process with the children to help balance the power relationship between the interviewer and child (Fraser 2004). The

investigator will propose a few activities including interviews and projective techniques and see with the children which activity(ies) they prefer. Since every child is at a different stage of development and of illness (considering the child's wellness), this negotiation has to take place *in situ* with him/her and the parents and cannot be determined in advance (Fraser 2004). Such activities will sometimes also be used with other actors (e.g. family members, volunteers, staff members, etc.) depending on the situation. In this case, the type of activity will also be negotiated with the participants. The following projective techniques will be considered (see Appendix 3 for description of tasks):

A) Telling a story about the wish.

B) Writing a story about the wish.

C) Keeping a diary during the wish realization process.

D) Making a collage concerning the wish and its realization.

E) Drawing and/or painting scenes concerning the wish and its realization.

F) Taking photographs and videos during events.

In the case of interviews, a strict protocol will be followed (see Appendix 4). Depending on the context and negotiation with children and families, some questions will be chosen from the list available in Appendix 1.

Researcher's Position in Situations of Conflict

In the case of ill-treated or abused children, the position of the researcher is clear: the protection of the children supersedes all other ethical and methodological concerns. If, in

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the course of his interactions with children and families, he witnesses situations in which children are ill-treated or abused, his/her duty will be to inform relevant authorities (e.g. child protection agency).

In a case of dispute between families and the Foundation (e.g. frustration caused by the refusal of the granting of a wish, dissatisfaction with the delivery of the wish granting service, etc.), the researcher's obligation will be to keep a neutral position. However, he will do everything in his power to help distressed families with the best of his knowledge and ethical position. He will disclose any helpful information publicly accessible concerning the Foundation, the wish granting process, and the professional – legal and psychological– resources that could be used by families. Please note that the researcher will at no time play the role of therapist during the course of this research. Instead, he will refer families to professional competent resources.

The *Ministère de la Santé et des Services Sociaux* cogently argues that justice is an important notion in scientific research. Everyone should have the right to be represented in the research. Everyone's voice should have the chance to be heard. For this reason, no consenting family will be discarded during the course of this research. Every family will have the right to participate. In order to avoid unmet expectations, the investigator will inform families about his dual role and the non-relation between the scientific research and the wish granting acceptance ratio.

Ethical Concerns

Informed Consent

Informed consent will be sought for both participant observations and formal interviews. A consent form will be signed prior to conducting interviews. Vulnerable participants will be invited to consult relatives and health specialists before participating in the research and before signing the consent form (see previous section). During interviews with children and families, relatives and health specialists will be invited to participate and welcomed to interfere in the course of the interaction. Participants will have the right to withdraw from the interview or from the research process at anytime without any negative consequences whatsoever. Breaks will be offered to participants during the interviews. The investigator will also offer to stop the interview if he feels the need to do so (e.g. if interviewee shows fatigue, embarrassment, or strong emotional reaction). Once the official consent form is signed, follow-up interviews will be subject to oral consent by informants.

Oral consent will be sought before participant observations.

See Appendices 5 and 6 for a complete list of consent forms: INT01 to INT06 and OBS01 (English consent forms, Appendix 5) and INT01F to INT06F and OBS01F (French consent forms, Appendix 6).

Deception

Not applicable

Freedom to Discontinue

Every participant will have the right to withdraw from the research at any time without any negative consequences. This information will be verbally provided as well as indicated on the consent form. Moreover, every participant will have the right to refrain from answering any question at any time during formal and informal interactions with the researcher without any negative consequences whatsoever. If a participant decides to withdraw from the research process, all the material collected during this interview will be removed from the analysis.

Children and families can also ask relatives or health specialists to attend to formal interviews. These individuals will have to right to object to the process by suggesting to stop the interview or by limiting the participant's answers without any negative consequences whatsoever. They will also have the opportunity to verify the questions in advance and give their advice to the participants before the latter sign the consent form.

Assessment of Risks to Subjects' Physical Wellbeing, Psychological Welfare, and/or Reputation

Strong emotional reactions can surface during the course of interviews when discussing illness. Moreover, research on death awareness in the context of chronically and seriously ill children reveals that families and children often avoid discussing death or prognosis by using, for instance, cognitive and communicative strategies like compartmentalization of

death-related information (Bluebond-Langer 1996) and mutual pretence (Glaser and Strauss 1965). These coping strategies are part of a delicate equilibrium embedded within the larger context of social interactions of families, friends, acquaintances, and healthcare specialists.

Some volunteers and donors are likely to be parents of ill children or former beneficiaries of the Foundation. Being unaware of this situation could result in undesirable effects on participants (e.g. asking a sensitive question that could not have been anticipated by the interviewee, generating unexpected emotions during the course of the interview).

The abovementioned risks could occur in the normal course of life of the children and families. In fact, ill children, siblings and parents are likely to be questioned (expectedly or not) by various relations about the illness and the wish process. They are then likely to experience the same type of emotions that could potentially emerge during the interview with the investigator.

The risks that are not likely to occur in the course of everyday life situations of the participants are found in the nature of the relationship between the researcher and informants. As mentioned earlier, due to inherent power differentials informants may feel unable to withdraw from an interview or avoid answering unwanted questions. It is partly for this reason that the researcher is developing a research context in which a balance of power will be maximized through a collaborative, proactive, and supportive protocol (see subsection *Particular Attention to Ill Children and Families* in Section 2).

Protecting and/or Addressing Participant "At Risk" Situations

Participants will be notified in advance of the potential emotional effects of the interview.

The researcher will suggest participants consult relatives and health specialists before participating in the research. A detailed list of questions will be provided before the interview and subject to approval.

The researcher will suggest to participants that they be accompanied by relatives or specialists if they feel the need to get support and/or protection.

The researcher will also be trained by a registered profesional (child clinical health psychologist) in order to maximize his interview and interaction skills in response to emotionally charged interviews with vulnerable adults and children.

Throughout the research, the investigator will be supported by a resource teacher (i.e. a profesional trained in helping children with learning difficulties) who has four years of experience in dealing with CWF families.

Referral information will be available to participants seeking health specialists' help (this list will be put together in collaboration with health specialists such as physicians, psychologists, and social workers). The investigator will also check with health psychologists whether any measurement tool or procedure indicating the need for professional intervention is available.

The researcher will respect privacy concerning death and illness prognosis. He will deliberately initiate a "mutual pretence" context (i.e. situation in which everyone is aware of the potential consequence of illness without discussing it overtly with the

others). The investigator will never initiate a discussion on the topic of death or prognosis. He will not take the initiative of asking questions concerning death or illness prognosis. Furthermore, he will be trained in order to maximize his interview and interaction skills in dealing with death-related dicsussions with adults and children.

The researcher will offer an alternative to semi-structured interviews if participants don't feel comfortable with the format. He will offer to conduct mail or email interviews. This format is expected to reduce the tension and anxiety caused by face-to-face encounters with the researcher. It will also provide another way to balance power between participants and researcher by giving the former more freedom to choose whether to answer questions or not and to answer at their own pace. However, due to the intrinsic limitations of this approach (e.g. loss of depth of answers, potential for follow-up questions, direct contact with overt emotions and behaviours, and opportunity to build positive and trusting researcher-interviewee rapport, etc.), mail and email interviews cannot systematically replace face-to-face interviews. For this reason, mail and email interviews will be considered an optional approach offered to participant in order to maximize their well-being.

In a preventive manner, in order to avoid any potential undesirable situations, screening questions will be asked before interviewing each donor and volunteer in order to evaluate their level of sensitivity in regards to childhood illness. In cases where volunteers and donors are former beneficiaries or relatives of ill children, the ill children and family protocol will be applied to them (see subsection *Particular Attention to Ill Children and Families* of Section 2).

Post-Research Explanation and/or Debriefing

Participants will be offered copies of recorded material (e.g. interviews, photos, videos) in which they have directly participated upon request.

Analysis will be subject to a "member check", that is, some participants will receive a summary of the data analysis with a request to provide feedback.

The researcher will provide copies of reports and the thesis to any participant who is interested in receiving more information concerning the research findings (conditional to the respect of privacy and confidentiality considerations of other participants).

Participants will be informed of the researcher's phone number and email and will be welcomed to contact him if needed.

The researcher has a commitment to respect the anonymity of participants by following usual protocols. Confidentiality will be addressed in the consent form. In order to ensure confidentiality, the name of the participant as well as any other information that could potentially disclose her/his identity will be purposefully changed (e.g. with the use of pseudonym) or omitted when the researcher communicates any results in verbal or written form.

Confidentiality of Results

Data will be owned by the researcher, removed from his computer, downloaded on CDs, and kept in a secure place when the research is finished. The name of the participant as well as any other information (e.g. pictures, drawings, movies, stories, etc.) that could potentially disclose her/his identity will be purposefully changed (e.g. with the use of

pseudonym) or omitted when the researcher communicates any results in verbal or written form.

Data Handling

Data will include interview transcripts, videos, photographs, home movies, and personal artefacts such as drawings and letters. All data will be kept by the researcher. It will be scanned and stored in his personal computer in a password-protected file. All scanned documents will be removed from his computer and stored in a secure place when the research is completed.

Other Comments

This research will be subjected to the AAA's (American Anthropological Association) code of ethics. Therefore, the following issues will be adressed throughout the research:

A) Responsibility to people with whom researcher works and whose lives and cultures they study:

1. The researcher has primary ethical obligations to the people he studies and to the people with whom he works. These obligations can supersede the goal of seeking new knowledge, and can lead to decisions not to undertake or to discontinue a research project when the primary obligation conflicts with other responsibilities, such as those owed to sponsors or clients. These ethical obligations include:

- To avoid harm or incorrect understanding that the development of knowledge can lead to change which may be positive or negative for the people worked with or studied

- To respect the well-being of humans

- To consult actively with the individuals or group(s) concerned, with the goal of establishing a working relationship that can be beneficial to all parties involved

2. The researcher must do everything in his power to ensure that his research does not harm the safety, dignity, or privacy of the people with whom he works, conducts research, or performs other professional activities.

3. The researcher must determine in advance whether his hosts/providers of information wish to remain anonymous or receive recognition, and make every effort to comply with those wishes. He must present to his research participants the possible impacts of their choices, and make clear that despite his best efforts, anonymity may be compromised or recognition fail to materialize.

4. The researcher should obtain in advance the informed consent of persons being studied, for providing information, owning or controlling access to material being studied, or otherwise identified as having interests which might be impacted by the research. It is understood that the degree and breadth of informed consent required will depend on the nature of the project and may be affected by requirements of other codes, laws, and ethics of the country or community in which the research is pursued. Further, it is understood that the informed consent process is dynamic and continuous; the process should be initiated in the project

design and continue through implementation by way of dialogue and negotiation with those studied. The researcher is responsible for identifying and complying with the various informed consent codes, laws and regulations affecting his projects. Informed consent, for the purposes of this code, does not necessarily imply or require a particular written or signed form. It is the quality of the consent, not the format, that is relevant.

5. The researcher who has developed close and enduring relationships (i.e., covenantal relationships) with either individual persons providing information or with hosts must adhere to the obligations of openness and informed consent, while carefully and respectfully negotiating the limits of the relationship.

6. While the researcher may gain personally from his work, he must not exploit individuals, groups, or cultural materials. He should recognize his debt to the societies in which he works and his obligation to reciprocate with people studied in appropriate ways.

B. Responsibility to scholarship and science

1. The researcher must expect to encounter ethical dilemmas at every stage of his work, and must make good-faith efforts to identify potential ethical claims and conflicts in advance when preparing proposals and as projects proceed. A section raising and responding to potential ethical issues should be part of every research proposal.

2. The researcher bears responsibility for the integrity and reputation of his discipline, scholarship, and science. Thus, he is subject to the general moral rules of scientific and scholarly conduct: he should not deceive, knowingly misrepresent (i.e., fabricate evidence, falsify, plagiarize), attempt to prevent reporting of misconduct, or obstruct the scientific/scholarly research of others.

3. The researcher should do all he can to preserve opportunities for future fieldworkers to follow him into the field.

4. The researcher should utilize the results of his work in an appropriate fashion, and whenever possible disseminate his findings to the scientific and scholarly community.

5. The researcher should seriously consider all reasonable requests for access to his data and other research materials for purposes of research. He should also make every effort to ensure preservation of his fieldwork data for use by posterity.

C. Responsibility to the public

1. The researcher should make the results of his research appropriately available to sponsors, students, decision makers, and other (non)scholars. In so doing, he must be truthful; he is not only responsible for the factual content of his statements but also must consider carefully the social and political implications of the information he disseminates. He must do everything in his power to ensure that such information is well understood, properly contextualized, and responsibly utilized. He should make clear the empirical bases upon which his reports stand,

be candid about his qualifications and philosophical or political biases, and recognize and make clear the limits of his expertise. At the same time, he must be alert to possible harm his information may cause people with whom he works or colleagues.

2. The researcher may choose to move beyond disseminating research results to a position of advocacy. This is an individual decision, but not an ethical responsibility.

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Appendix 1:

List of Questions per Type of Informant

Donors

A) <u>Screening questions</u> (if the answer to one of these questions is yes, the researcher will refer to the section on ill children and families and take extra precautions)

- Have you ever been beneficiary of the Children's Wish Foundation program in the past?

- Do you plan to request CWF services in the future?

- Is one of your children diagnosed with a chronic or life-threatening illness?

B) <u>Personal background</u>

- What type of work do you do for living?

- How old are you?

- Where do you live?

- What is your marital status?

- Do you have children? How many? Can you talk about them?

C) <u>Information related to donations and the Children's Wish Foundation</u>

- How much do you donate in total per year? What is the CWF share?

- Since when have you been donating to the CWF? For what reason?

- Are you giving to other causes? For what reason?

- On what basis do you choose to give to charities? Is it an individual or family-based decision? What is your overall charity donation decision making process?

- In your opinion, what is the impact of your donation? To what extent is your donation useful?

- Do you volunteer for charities and other non-profit organizations?

- How do you choose for which charities or non-profit organization you wish to donate?

- What does the CFW cause mean to you? What is the importance of this cause? Are there things you don't like about the cause?

- What does the CWF as an organization mean to you? What is the importance of the Foundation? What place does the CWF occupy in your life? Are there things you don't like about the Foundation?

- Have you ever attended an event organized by the CWF? How did the event go? Please describe the event.

D) <u>Information related to realization of wishes</u>

- What types of wishes are granted by CWF? What do you think about these wishes?

- To what extent can you describe the wish granting process? What would be the typical scenario of the realization of a wish? Who would be involved? How much would it cost? How long would the process take?

- Have you ever met a "wish kid"? How much do you know about the ill children supported by the CWF?

- If you had to pick one wish granting story you witnessed or heard about, which one would you pick? How could you describe this episode? How did it affect you? How did it affect the other people you know?

- What is the most wonderful wish granting story you ever witnessed or heard about? Can you describe it? How did it affect you? How did it affect the other people you know?

- Can you think of a less positive wish granting story? Can you describe it? How did it affect you? How did it affect the other people you know?

- In your opinion, what does the realization of a wish mean to or change in the life of an ill child? What is its meaning or impact for other people involved in the process?

- How would you describe your involvement in the wish granting process? How would you describe the involvement of donors in general in the wish granting process?

- Do you know any other charity that is providing comparable services to ill children? Who are they? What are they doing exactly? How would you compare them to the CWF?

- What are other people expecting from you in the wish granting process? What are you expecting from these others (e.g. staff, wish families, volunteers, health specialists)?

E) Information related to illness

- Do you know a chronically or critically ill child? Could the CWF change something in the life of this ill child? Can the CWF change something in the life of any ill child?

- Are there or would there be other ways of helping ill children? How would you compare those other ways to the services currently offered by CWF?

- What does childhood illness mean to you?

Volunteers

A) Screening questions (if the answer to one of these questions is yes, the researcher will refer to the section on ill children and families and take extra precautions)

- Have you ever been beneficiary of the Children's Wish Foundation program in the past?

- Do you plan to request CWF services in the future?

- Is one of your children diagnosed with a life-threatening illness?

B) Personal background

- What type of work do you do for living?

- How old are you?

- Where do you live?

- What is your marital status?

- Do you have children? How many? Can you talk about them?

C) Information related to volunteering and Children's Wish Foundation

- How would you describe your involvement with the CWF? What is your role as a volunteer for the CWF?

- When did you begin volunteering for the CWF? For what reason?

- Are you volunteering for other causes? For what reason?

- On what basis do you choose to volunteer for charities?

- Are you donating to charities and other non-profit organizations?

- How do you choose to which organization you wish to donate?

- What does the CFW cause mean to you? What is the importance of this cause? Are there things you don't like about the cause?

- What does the CWF as an organization mean to you? What is the importance of the Foundation? What place does the CWF occupy in your life? Are there things you don't like about the Foundation?

- Have you ever attended an event organized by the CWF? How did the event go? Please describe this event.

D) Information related to realization of wishes

- What types of wishes are granted by CWF? What do you think about those wishes?

- To what extent can you describe the wish granting process? What would be the typical scenario of the realization of a wish? Who would be involved? How much would it cost? How long would the process take?

- Have you ever met a "wish kid"? How much do you know about the ill children supported by the CWF?

- If you had to pick one wish granting story you witnessed, which one would you pick? How could you describe this episode? How did it affect you? How did it affect the other people you know?

- What is the most wonderful wish granting story you ever witnessed or heard about? Can you describe it? How did it affect you? How did it affect the other people you know?

- Can you think of a less positive wish granting story? Can you describe it? How did it affect you? How did it affect the other people you know?

- In your opinion, what does the realization of a wish mean to or change in the life of an ill child? What is its meaning or impact for other people involved in the process?

- What does your involvement change in the realization of wishes?

- Do you know any other charity that is providing comparable services to ill children? Who are they? What are they doing exactly? How would you compare them to the CWF?

- What are the challenges that you face in the realization of wishes?

- What are other people expecting from you in the wish granting process? What are you expecting from these others (e.g. staff, wish families, donors, health specialists)?

E) Information related to illness

- Do you know a chronically or critically ill child? Could the CWF change something in the life of this ill child? Can the CWF change something in the life of any ill child?

- Are there or would there be other ways of helping ill children? How would you compare those other ways to the services currently offered by the CWF?

- What does childhood illness mean to you?

- In your own perspective, how does illness affect the wish granting process?

Staff

A) <u>Personal background</u>

- How old are you?

- Where do you live?

- What is your marital status?

- Do you have children? How many? Can you talk about them?

- How would you summarize your professional life? What are the types of jobs that you have had over the course of your life so far?

B) <u>Information related to staff and Children's Wish Foundation</u>

- How long have you been working for the CWF? For what reason?

- How would you describe your work for the CWF? What is your role within the CWF? How would you describe your daily life at work with the CWF?

- Do you donate to charities and other non-profit organizations?

- Do you volunteer for other charities and non-profit organizations? For what reasons?

- How do you choose to which charities or non-profit organization you wish to donate?

- What does the CWF cause mean to you? What is the importance of this cause? Are there things you don't like about the cause?

- What does the CWF as an organization mean to you? What is the importance of the Foundation? What place does the CWF occupy in your life? Are there things you don't like about the Foundation?

C) Information related to realization of wishes

- What types of wishes are granted by CWF? What do you think about these wishes?

- To what extent can you describe the wish granting process? What would be the typical scenario of the realization of a wish? Who would be involved? How much would it cost? How long would the process take? According to you, who are the most important persons involved in the process of realization of a wish? What are their roles?

- Have you ever met "wish kids"? How much do you know about the ill children supported by the CWF?

- If you had to pick one wish granting story you witnessed, which one would you pick? How could you describe this episode? How did it affect you? How did it affect the other people you know?

- What is the most wonderful wish granting story you ever witnessed or heard about? Can you describe it? How did it affect you? How did it affect the other people you know?

- Can you think of a less positive wish granting story? Can you describe it? How did it affect you? How did it affect the other people you know?

- In your opinion, what does the realization of a wish mean to or change in the life of an ill child? What is its meaning or impact for other people involved in the process?

- How does your involvement impact the realization of wishes?

- Do you know any other charity that is providing comparable services to ill children? Who are they? What are they doing exactly? How would you compare them to the CWF?

- What are the challenges that the Foundation faces in the wish realization process?

- What are other people expecting from you? What are you expecting from the others (e.g. donors, volunteers, health specialists)

D) Information related to illness

- What are the challenges (related to health or not) that ill children and their families face in the realization of the wish?

- Do you know a chronically or critically ill child? Could the CWF change something in the life of this ill child? Can the CWF change something in the life of any ill child?

- Are there or would there be other ways of helping ill children? How would you compare those other ways to the services currently offered by the CWF?

- What place does illness occupy in your life as a CWF employee? Do you discuss illness with other employees? With your friends and relatives?

- How do you feel about illness? How is illness affecting your life?

- What does juvenile illness mean to you?

- In your own perspective, how does illness affect the wish granting process?

Health specialists

A) <u>Personal background</u>

- How old are you?

- Where do you live?

- What is your marital status?

- Do you have children? How many? Can you talk about them?

B) <u>Information related to specialist and Children's Wish Foundation</u>

- What is your training? What is your area of expertise? Are you dealing with seriously ill children?

- Are you currently involved with the CWF? If so, how long have you been involved with them? For what reason are you collaborating with the CWF?

- How would you describe your work in the context of the CWF? What is your role within the context of the CWF?

- What does the CWF cause mean to you from both a professional and personal point of view? What is the importance of this cause? Are there things you don't like about the cause?

- What does the CWF as an organization mean to you from both a professional and personal point of view? What is the importance of the Foundation? What place does the CWF occupy in your life? Are there things you don't like about the Foundation?

- What are other people expecting from you? What are you expecting from the others (e.g. staff, donors, volunteers, wish families)

C) Information related to realization of wishes

- What types of wishes are granted by CWF? What do you think about those wishes?

- To what extent can you describe the wish granting process? What would be the typical scenario of the realization of a wish? Who would be involved? How much would it cost? How long would the process take? According to you, who are the most important persons involved in the wish realization process? What are their roles?

- Have you ever met any "wish kids"? How much do you know about the ill children supported by the CWF?

- If you had to pick one wish granting story you witnessed or heard about, which one would you pick? How could you describe this episode? How did it affect you? How did it affect the other people you know?

- What is the most wonderful wish granting story you ever witnessed or heard about? Can you describe it? How did it affect you? How did it affect the other people you know?

- Can you think of a less positive wish granting story? Can you describe it? How did it affect you? How did it affect the other people you know?

- What does the realization of a wish mean to or change in the life of an ill child, in your professional and personal points of view? What is its meaning or impact on other people involved in the process?

- How does your involvement impact the realization of wishes?

- Do you know any other charity that is providing comparable service to ill children? Who are they? What are they doing exactly? How would you compare them to the CWF?

D) Information related to illness

- What are the challenges (related to health or not) that ill children and their families face in the realization of the wish?

- Do you know a chronically or critically ill child? Could the CWF change something in the life of this ill child? Can the CWF change something in the life of any ill child?

- Are there or would there be other ways of helping ill children? How would you compare those other ways to the services currently offered by the CWF?

- What place does illness occupy in your life as health specialist? Do you discuss illness with colleagues? With your friends and relatives?

- How do you feel about illness? How does illness affect your life?

- What does juvenile illness mean to you?

- How does illness affect the realization of the wish?

Children

A) Personal background

- Can you describe your everyday life? What activities do you enjoy doing? What games do you enjoy playing?

B) Information related to children and Children's Wish Foundation

- When did you start interacting with the CWF?

- What do you know about the CWF?

- How would you describe your relationship with the CWF? Do you know the staff well?

- What does the CWF as an organization mean to you? What is the importance of the Foundation? What place does the CWF hold in your life? Are there things you don't like about the Foundation?

- Do you know what cause the CWF is supporting? What does that mean to you? What is the importance of this cause? Are there things you don't like about the cause?

C) Information related to realization of wishes

- Has your wish been accepted by the Foundation? If not, why not?

- Can you describe what your wish is? How did you come up with this wish?

- What does this wish mean to you? What is the importance of this wish in your life? What is the importance of this wish in the lives of the people you know?

- Are you talking about your wish with other people? With whom? Are there people with whom you don't want to share your wish?

- What do you have to do and plan in order to prepare the realization of your wish? According to you, who is involved in the realization of your wish? How long do you think it will take to realize your wish?

- Can you describe how you realized your wish? What happened on the day you got your wish?

- How do you expect your wish will come true? What do you expect will happen on that day?

- Have you ever met other "wish kids"? Have they realized their wish yet? What are their wishes? Do you talk about your wish with them? Are they helping you? Do you help them?

- If you had to pick one wish granting story you witnessed or heard about, which one would you pick? How could you describe this episode? How did it affect you? How did it affect the other people you know?

- What is the most wonderful wish granting story you ever witnessed or heard about? Can you describe it? How did it affect you? How did it affect the other people you know?

- Can you think of a less positive wish granting story? Can you describe it? How did it affect you? How did it affect the other people you know?

- Do you know any other charity that is providing comparable services to children like you? Who are they? What are they doing exactly? How would you compare them to the CWF?

- What are the challenges that you will be facing during the wish realization process?

D) Information related to illness

- Can you describe your condition? What is it to live with your condition? How do you feel about illness? How is illness affecting your life?

- How is your illness affecting the process of realizing your wish?

- Aside from the CWF, are you getting support from other organizations? What type of support do they provide? How would you compare those organizations to the CWF?

Family

A) Personal background

- What do you do for living?

- How old are you?

- Where do you live?

- What is your marital status?

- How many children do you have? Can you talk about them?

B) Information related to family members and Children's Wish Foundation

- How long have you been involved with the CWF?

- How would you describe your relationship with the CWF? Do you know the staff well?

- Do you donate to charities and other non-profit organizations? Which one? For what reason? How do you choose the cause to which you want to donate?

- Do you volunteer for charities and non-profit organizations? Which one? For what reasons?

- How do you choose to which charities or non-profit organization you wish to donate?

- What does the CWF cause mean to you? What is the importance of this cause? Are there things you don't like about the cause?

- What does the CWF as an organization mean to you? What is the importance of the Foundation? What place does the CWF occupy in your life? Are there things you don't like about the Foundation?

C) <u>Information related to realization of wishes</u>

- Has the wish of your child (or brother or sister etc.) been accepted by the foundation? If not why?

- What types of wishes are granted by CWF? What do you think about those wishes?

- Can you describe what your child's (or brother's or sister's or nephew's etc.) wish is? How did s/he come up with this wish? Have you participated in the definition of the wish?

- What does this wish mean to your child? What does it mean to you? What is the importance of this wish in your child's (or brother's or sister's or nephew's etc.) life? What is the importance of this wish in your life? What is the importance of this wish in the lives of other people you know?

- Are you communicating your child's (or brother's or sister's or nephew's etc.) wish with other people? With Whom? Are there people with whom you don't want to share this wish?

- What do you have to do and plan in order to prepare the realization of the wish? According to you, who is involved in the realization of the wish? According to you, how long will it take to realize the wish?

- Can you describe how the wish was realized? What happened on the day the wish was granted?

- How do you expect the wish will come true? What do you expect will happen on that day?

- Have you ever met other "wish parents" (or wish brothers, or wish sisters, etc.)? Have they realized their wish yet? What is/are their wish(es)? Do you talk about your child's (or brother's or sister's or nephew's etc.) wish with them? Are they helping you? Do you help them?

- If you had to pick one wish granting story you witnessed or heard about, which one would you pick? How could you describe this episode? How did it affect you? How did it affect the other people you know?

- What is the most wonderful wish granting story you ever witnessed or heard about? Can you describe it? How did it affect you? How did it affect the other people you know?

- Can you think of a less positive wish granting story? Can you describe it? How did it affect you? How did it affect the other people you know?

- Do you know any other charity that is providing comparable services to people like you? Who are they? What are they doing exactly? How would you compare them to the CWF?

- What are the challenges that you will be facing during the wish realization process?

- What is your place and role in the realization of the wish? What are other people expecting from you? What are you expecting from these others (e.g. staff, donors, volunteers, health specialists)

- What does the realization of a wish mean to or change in your life? What does it change in the ill child's life according to you? What is its meaning or impact on other people involved in the process?

- How does your involvement impact the realization of the wish?

- What are the challenges that you face in the wish realization process?

D) <u>Information related to illness</u>

- Can you describe the illness of the child? How does this illness affect his/her life? How does illness affect your life? What place does the illness hold in your life? How does life change with an ill child? Do you discuss

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illness with other people? How do you feel about illness? How is illness affecting your life? What does juvenile illness mean to you?

- Do you know any other chronically or critically ill child? Could the CWF change something in the life of this ill child? Can the CWF change something in the life of any ill child?

- Are there or would there be other ways of helping ill children? How would you compare those other ways to the services currently offered by the CWF?

Appendix 2:

List of Optional Types of Researcher-Informant Interactions in the Course of the Research

1) <u>Mail or email interview</u>: A list of questions will be sent by mail or email to the families. They will have the opportunity to answer the questions at their own pace, without the pressure of the face-to-face interview. Children under 14 can be interviewed alone subject to parental consent and the children's willingness to do so.

2) <u>One-time group interview</u>: A single interview with some or all family members at the same time. No follow-up except for transmission of interview transcript and analysis of results (upon request). Composition of group is to be negotiated (e.g. one interview with parents only, with children only, with parents and children, etc.).

3) <u>One-time, one-informant, interview</u>: A single interview with only one family member. No follow-up except for transmission of interview transcript and analysis of results (upon request). The choice of the person to be interviewed will be decided by the family. In the case of children under 14, parents can attend the interview and interfere in the process (subject to children's approval). Children under 14 can be interviewed alone subject to parental consent and the children's willingness to do so.

4) <u>One-time, multiple-informant, separate interviews</u>: A single one-on-one interview with various family members. The choice of the person to be interviewed will be decided by the family. In the case of children under 14, parents can attend the interview and interfere in the process (subject to children's approval). Children under 14 can be interviewed alone subject to parental consent and the children's willingness to do so. No follow-up except for transmission of interview transcript and analysis of results (upon request).

5) <u>Longitudinal group interview</u>: A series of repeated and follow-up interviews will be conducted before, during and after the wish granting with some or all family members at the same time. The number and times of the interviews will be negotiated with the family and subject to change depending on the context and the family's will. The composition of the group will be at the discretion of the family and will be subject to change depending on the context and on the family's will. Every single interview will be subject to the family's consent.

6) <u>Longitudinal one-informant interview</u>: A series of repeated and follow-up interviews will be conducted before, during and after the wish granting with only

one family member. The number and time of the interviews will be negotiated with the family and subject to change depending on the context and on the informant's will. Every single interview will be subject to the family's consent. In the case of children under 14, parents can attend the interview and interfere in the process (subject to children's approval). Children under 14 can be interviewed alone following subject to consent and the children's willingness to do so.

7) Longitudinal multiple-informant separate interviews: A series of one-on-one repeated and follow-up interviews will be conducted before, during and after the wish granting with various family members. In the case of children under 14, parents can attend the interview and interfere in the process. The number and time of the interviews will be negotiated with the family and subject to change depending on the context and on the informants' will.

8) One-time non-participant observation: The researcher attends one meeting between family and the Foundation or one event in which the family is involved (e.g. fundraising activities, wish granting day, etc.) without interfering in the process. The researcher will be strictly observing interactions between the family and Foundation, and other persons (e.g. friends, volunteers, donors, health specialists). Access will be negotiated with the family.

9) Longitudinal non-participant observation: The researcher attends meetings between family and the Foundation and events in which the family is involved (e.g. fundraising activities, wish granting day, etc.) without interfering in the process. The researcher will be strictly observing interactions between the family

and Foundation, and other persons (e.g. friends, volunteers, donors, health specialists). Access will be negotiated with the family.

10) One-time participant observation: The researcher attends meetings between family and the Foundation and events in which the family is involved (e.g. fundraising activities, wish granting day, etc.). He might participate in the process (e.g. help the family and/or the Foundation, ask questions, etc.). Extent of participation and access will be negotiated with the family.

11) Longitudinal participant observation: The researcher attends meetings between family and the Foundation and events in which the family is involved (e.g. fundraising activities, wish granting day, etc.). He might participate in the process (e.g. help the family and/or the Foundation, ask questions, etc.). Extent of participation and access will be negotiated with the family.

Appendix 3:

Description of the Tasks in Projective Techniques

A) Telling (orally) a story about the wish. Possible tasks:

- "Could you please tell me the story of the realization of your wish?"

- "Could you please tell me a story in which you would describe how your child/brother/sister/nephew/friend's wish was (would be) realized?"

- "Could you please tell me a story that would describe how important the wish is to you?"

- "Could you please tell me a story that would describe your wish?"

- Could you please tell me a story that would describe your child/brother/sister/nephew/friend's wish?"

- "If your wish were a movie and if you were the director/screenplay writer of that movie, what would be the movie script of the realization of your wish?"

- "If your child/brother/sister/nephew/friend's wish were a movie and if you were the director/screenplay writer of that movie, what would be the movie script of the realization of this wish?"

B) Writing a story about the wish. Possible tasks:

- "Could you please write the story of the realization of your wish?"

- "Could you please write a story in which you would describe how your child/brother/sister/nephew/friend's wish was (would be) realized?"

- "Could you please write a story that would describe how important the wish is to you?"

- "Could you please write a story that would describe your wish?"

- Could you please write a story that would describe your child/brother/sister/nephew/friend's wish?"

- "If your wish were a movie and if you were the director/screenplay writer of that movie, what would be the movie script of the realization of your wish?"

- "If your kid/brother/sister/nephew/friend's wish were a movie and if you were the director/screenplay writer of that movie, what would be the movie script of the realization of this wish?"

C) Keeping a diary during the wish realization process. Possible task:

- "You will be asked to keep record of your own observations and feelings for the following _____ (period of time) in a personal journal. After that period, you will show your diary to the researcher and discuss its content with him during an interview."

D) Making a collage concerning the wish and its realization. Possible tasks:

- "You will be asked, over the _____ (period of time) to select images from magazines, websites, photo albums (or personal shootings), etc. that best represent your wish." You will be asked to talk about those images in an interview and put them together in a collage in a way that would be meaningful to you." You will be asked to talk about that collage."

- "You will be asked, over the _____ (period of time) to select images from magazines, websites, photo albums (or personal shootings), etc. that best represent the realization of your wish." You will be asked to talk about those images in an interview and put them together in a collage in a way that would be meaningful to you." You will be asked to talk about that collage."

- "You will be asked, over the _____ (period of time) to select images from magazines, websites, photo albums (or personal shootings), etc. that best represent your child/brother/sister/nephew/friend's wish." You will be asked to talk about those images in an interview and put them together in a

collage in a way that would be meaningful to you." You will be asked to talk about that collage."

- o "You will be asked, over the _____ (period of time) to select images from magazines, websites, photo albums (or personal shootings), etc. that best represent the realization of your child/brother/sister/nephew/friend's wish." You will be asked to talk about those images in an interview and put them together in a collage in a way that would be meaningful to you." You will be asked to talk about that collage."

E) Drawing and/or painting scenes concerning the wish and its realization. Possible tasks:

- "You will be asked to draw or paint something that would best represent your wish." You will be asked to talk about it in an interview."

- o "You will be asked to draw or paint something that would best represent your child/brother/sister/nephew/friend's wish." You will be asked to talk about it in an interview."

F) Taking photographs or videos during events. Possible task:

- o "You will be asked to take photographs or videos during the event _____ (e.g. fundraising activity, wish granting day, etc.). You will be asked to talk about the footage later during an interview."

Appendix 4:

Interview Protocol

1) The interview meeting will start by greetings, warm-up questions (weather, movies, music, daily news, etc.) and acknowledgments.

2) The interviewer will check if interviewee feels comfortable with the physical setting of the interview. The interview should be realized in a comfortable environment approved beforehand by the participant.

3) Participant will be informed of the approximate length of the interview, the methodological consideration of semi-structured interviews (in the case of a first encounter) and will be briefed concerning the type of questions that will be asked. A detailed list of questions will be submitted in advance for approval and discussed before the official meeting. At this point, informants will have been encouraged to consult relatives and health specialists concerning the list of questions. Participants will also have been encouraged to bring relatives and/or health specialists to support and advise them during the interview.

4) Participant will be reminded that s/he can withdraw at anytime without any negative consequences. Support attendants will also be invited to interfere in the process whenever they feel the need to do so.

5) Following Alderson's (2004: 106) suggestions, the rights of the child will be discussed with him or her:

   a. "It is for you to decide if you want to talk to me.

   b. You do not have to say 'yes'.

   c. If you say 'yes', you do not have to do the whole interview.

   d. We could stop when you want to, or have a break.

   e. If you do not want to answer any of the questions, you can just say, 'pass'.

f. Before you decide whether you want to participate in this project, you might like to talk about this project with your parents or with a friend.

g. I will keep tapes and notes of the interviews in a safe, locked place.

h. When I talk about the research and write reports, I always change people's names to keep their views anonymous.

i. I will not talk to anyone you know about what you have said, unless you talk about the risk of someone being harmed. If so, I will talk with you first about what could be done to help."

6) The participant and support attendants will be welcomed to ask questions during the process.

7) Oral approval to record the interview with a voice-recording machine will be sought.

8) The consent form will then be signed by the interviewee or by parents (for children under 14).

9) The interview will proceed. During the interview the investigator will take personal notes. Breaks will be offered if participants show fatigue, embarrassment, or strong emotions, and if they (or support attendants) ask for it.

10) In the closing of the interview, the investigator will ask for feedback from the interviewee and support attendants concerning the realization of the interview. He will offer to send written or taped version of the interview to the interviewee. The possibility of subsequent interviews will be discussed and subject to later consent by the informant.

11) The researcher will have a list of professional health specialists to provide if the participant needs it.

12) Researcher will thank interviewee and support attendants for their participation and interview will be terminated.

Appendix 5:

English Consent Forms

INT01- Volunteers and Staff

Consent form to participate in research

Interview consent form

(Please note – each participant will be given two copies of the consent form – one to keep, and one to sign and return to the researcher)

This is to state that I agree to participate in a program of research being conducted by Jonathan Deschênes of the John Molson School of Business at Concordia University, Montreal, Quebec (514.389.2902, johat_de@jmsb.concordia.ca).

A. PURPOSE

I have been informed that the purpose of the research is as follows: This is an academic program of research that aims to explore the process of ill children wish granting in the context of the Children's Wish Foundation of Canada.

I have been informed that Jonathan will serve as a volunteer research consultant for the Children's Wish Foundation of Canada during his academic research. I have been informed that the information I provide to Jonathan might be used to produce a global report of recommendations to the Children's Wish Foundation.

I have been informed that I am free to decide whether any information provided to Jonathan will be disclosed to the foundation. I have been informed that my identity will not be revealed to the Children's Wish Foundation of Canada without my consent.

B. PROCEDURES

The informant will be requested to participate in a formal interview that should last no more than one hour. During this interview, information related to the participant's background and to her/his reasons for volunteering or working as a paid employee for the organism will be asked.

For purposes of analysis, the interview will be tape-recorded with the consent of the participant. The researcher will be the only person enabled to listen to the tape and this tape will be kept in a secure place to insure privacy. In order to insure confidentiality, the name of the participant as well as any other information that would potentially allow any disclosure of her/his identity will be purposefully changed (e.g. with the use of pseudonym) or omitted when the researcher communicates any results in verbal or written form.

Participants will be offered copies of recorded material in which they have directly participated upon request.

C. RISKS AND BENEFITS

Participation will help the researcher better understand the relationship between the donors, the Foundation and the beneficiaries. Since a written report will be given to the Children's Wish Foundation following completion of the research, participation in the research project will potentially allow the Foundation to better understand the specific actors' roles and needs, and hence, enable them to work towards improving the quality of life of both volunteers and beneficiaries.

If the participant experiences any discomfort to discuss any issues or questions arising from the interview, at any time during the interview, s/he will always have the right to withdraw from the process or avoid providing direct answers without negative consequences.

D. CONDITIONS OF PARTICIPATION

- I understand that I am free to withdraw my consent and discontinue my participation at anytime without negative consequences.

- I understand that my participation in this study is CONFIDENTIAL (i.e., the researcher will know, but will not disclose my identity)

- I understand that the data from this study may be published.

I HAVE CAREFULLY STUDIED THE ABOVE AND UNDERSTAND THIS AGREEMENT. I FREELY CONSENT AND VOLUNTARILY AGREE TO PARTICIPATE IN THIS STUDY.

NAME (please print) _____

SIGNATURE _____

If at any time you have questions about your rights as a research participant, please contact Adela Reid, Research Ethics and Compliance Officer, Concordia University, at (514) 848-2424 x7481 or by email at areid@alcor.concordia.ca.

INT02- Beneficiaries' Family

Consent form to participate in research

Interview consent form

(Please note – each participant will be given two copies of the consent form – one to keep, and one to sign and return to the researcher)

This is to state that I agree to participate in a program of research being conducted by Jonathan Deschênes of the John Molson School of Business at Concordia University, Montreal, Quebec (514.389.2902, johat_de@jmsb.concordia.ca).

A. PURPOSE

I have been informed that the purpose of the research is as follows: This is an academic program of research that aims to explore the process of ill children wish granting in the context of the Children's Wish Foundation of Canada.

I have been informed that Jonathan will serve as a volunteer research consultant for the Children's Wish Foundation of Canada during his academic research. I have been informed that the information I provide to Jonathan might be used to produce a global report of recommendations to the Children's Wish Foundation.

I have been informed that I am free to decide whether any information provided to Jonathan will be disclosed to the foundation. I have been informed that my identity will not be revealed to the Children's Wish Foundation of Canada without my consent.

I have been informed in advance to consult with relatives and healthcare specialists (e.g. physician, social worker, psychologist) before accepting to participate in this research. I have been informed that relatives and healthcare specialists can attend to the interview if I feel the need to.

I have been informed that participation to this research is independent from the Children's Wish Foundation wish granting process. For instance, participation to this research will not affect the speed of wish granting or the chances that the wish will be granted. Every wish is processed in same the way, no regard to participation to this research.

I have previously attended to a meeting with Jonathan during which he explained the research process, the optional methodological approaches available, and their implications. I have been informed that I can discuss openly my preferences concerning any methodological approach and that this preference will be respected without any negative consequences whatsoever.

B. PROCEDURES

The informant will be requested to participate in a formal interview that should last no more than one hour. During this interview, questions related to the participant's background, to the child's history (including questions related to his condition), to the wish, and to the relationship between her/him, the child, and the Foundation will be asked.

For purposes of analysis, the interview will be tape-recorded with the consent of the participant. The researcher will be the only person enabled to listen to the tape and this tape will be kept in a secure place to insure privacy. In order to insure confidentiality, the name of the participant as well as any other information that would potentially allow any disclosure of her/his identity will be purposefully changed (e.g. with the use of pseudonym) or omitted when the researcher communicates any results in verbal or written form.

Participants will be offered copies of recorded material in which they have directly participated upon request.

C. RISKS AND BENEFITS

Participation will help the researcher better understand the reality of the persons involved in the process and will provide significant information concerning the perception of the Foundation, the level of satisfaction with the wish granting process as well as its consequences. Overall, participation to this research can contribute to increasing the

fundraising capacities of the Foundation, improving the training of volunteers, and offering more and better quality wish granting.

Participation to this research can also contribute to the writing of an essay about the ill children wish granting process, its challenges, its risks, and its benefits. Jonathan is also offering to return pictures, drawings, diaries, etc. about the child directly or in the form of a photo album or a scrap book.

As the interview will partly cover questions related to illness, strong emotional reactions may be generated. If the participant experiences any discomfort to discuss any issues or questions arising from the interview, at any time during the interview, s/he will always have the right to take breaks or to withdraw from the process or avoid providing direct answers without negative consequences. Relatives and healthcare specialists are also welcomed to interfere in the process if they feel the need to do so.

D. CONDITIONS OF PARTICIPATION

- I understand that I am free to withdraw my consent and discontinue my participation at anytime without negative consequences.

- I understand that my participation in this study is CONFIDENTIAL (i.e., the researcher will know, but will not disclose my identity)

- I understand that the data from this study may be published.

I HAVE CAREFULLY STUDIED THE ABOVE AND UNDERSTAND THIS

AGREEMENT. I FREELY CONSENT AND VOLUNTARILY AGREE TO

PARTICIPATE IN THIS STUDY.

NAME (please print) _____

SIGNATURE _____

If at any time you have questions about your rights as a research participant, please

contact Adela Reid, Research Ethics and Compliance Officer, Concordia University, at

(514) 848-2424 x7481 or by email at areid@alcor.concordia.ca.

INT03- Parental (or Legal Guardian) Approbation for Child under 14 Years Old

Consent form to participate in research

Interview consent form

(Please note – each participant will be given two copies of the consent form – one to keep, and one to sign and return to the researcher)

This is to state that I agree to participate in a program of research being conducted by Jonathan Deschênes of the John Molson School of Business at Concordia University, Montreal, Quebec (514.389.2902, johat_de@jmsb.concordia.ca).

A. PURPOSE

I have been informed that the purpose of the research is as follows: This is an academic program of research that aims to explore the process of ill children wish granting in the context of the Children's Wish Foundation of Canada.

I have been informed that Jonathan will serve as a volunteer research consultant for the Children's Wish Foundation of Canada during his academic research. I have been informed that the information I provide to Jonathan might be used to produce a global report of recommendations to the Children's Wish Foundation.

I have been informed that I am free to decide whether any information provided to Jonathan will be disclosed to the foundation. I have been informed that my identity will not be revealed to the Children's Wish Foundation of Canada without my consent.

I have been informed to consult with relatives and healthcare specialists (e.g. physician, social worker, psychologist) before accepting to participate in this research. I have been informed that relatives and healthcare specialists can attend to the interview if I feel the need to.

I have been informed that participation to this research is independent from the Children's Wish Foundation wish granting process. For instance, participation to this research will not affect the speed of wish granting or the chances that the wish will be granted. Every wish is processed in same the way, no regard to participation to this research.

I have previously attended to a meeting with Jonathan during which he explained the research process, the optional methodological approaches available, and their implications. I have been informed that I can discuss openly my preferences concerning any methodological approach and that this preference will be respected without any negative consequences whatsoever.

B. PROCEDURES

Parental (or legal guardian) permission is requested to enable the researcher to conduct the interview with the child under the age of fourteen. The interviewee will be asked to participate in a formal interview that should last no more 35 minutes. During this interview, questions related to the importance of the child's wish and to his condition will be pursued.

For purposes of analysis, the interview will be tape-recorded with the consent of the participant and his/her parent (or legal guardian). The researcher will be the only person enabled to listen to the tape and this tape will be kept in a secure place to insure privacy. In order to insure confidentiality, the name of the participant as well as any other information that would potentially allow any disclosure of her/his identity will be purposefully changed (e.g. with the use of pseudonym) or omitted when the researcher communicates any results in verbal or written form.

Participants will be offered copies of recorded material in which they have directly participated upon request.

C. RISKS AND BENEFITS

Participation will help the researcher better understand the reality of the persons involved in the process and will provide significant information concerning the perception of the Foundation, the level of satisfaction with the wish granting process as well as its consequences. Overall, participation to this research can contribute to increasing the

fundraising capacities of the Foundation, improving the training of volunteers, and offering more and better quality wish granting.

Participation to this research can also contribute to the writing of an essay about the ill children wish granting process, its challenges, and its benefits. Jonathan is also offering to return pictures, drawings, diaries, etc. about the child directly or in the form of a photo album or a scarp book.

As the interview will partly cover questions related to illness, strong emotional reactions may be generated. If the participant experiences any discomfort to discuss any issues or questions arising from the interview, at any time during the interview, s/he will always have the right to take breaks or to withdraw from the process or avoid providing direct answers without negative consequences. Relatives and healthcare specialists are also welcomed to interfere in the process if they feel the need to do so.

The child's parents (or legal guardians) have the right to be present during the interview and can decide to stop the interview process at any time if they judge it necessary without negative consequences. Moreover, if the participant experiences any discomfort to discuss any issues or questions arising from the interview, at any time during the interview, s/he will always have the right to withdraw from the process or avoid providing direct answers without negative consequences.

D. CONDITIONS OF PARTICIPATION

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- I understand that I am free to withdraw my consent and discontinue my child's participation at anytime without negative consequences. This implies removing the child under my responsibility from the process of the interview.

- I understand that my child's participation in this study is CONFIDENTIAL (i.e., the researcher will know, but will not disclose my child's identity)

- I understand that the data from this study may be published.

I HAVE CAREFULLY STUDIED THE ABOVE AND UNDERSTAND THIS AGREEMENT. I FREELY CONSENT AND VOLUNTARILY AGREE TO LET MY CHILD PARTICIPATE IN THIS STUDY.

NAME (please print) _____

SIGNATURE _____

If at any time you have questions about your rights as a research participant, please contact Adela Reid, Research Ethics and Compliance Officer, Concordia University, at (514) 848-2424 x7481 or by email at areid@alcor.concordia.ca.

INT03S- Simplified Verbal Consent Child under 14 Years Old

Oral consent to participate in research

Interview consent form

My name is Jonathan. I do a research on how children like you realize their wishes with the Children's Wish Foundation. I would like to know more about you and the dream you wish to realize.

It is for you to decide if you want to talk to me.

You do not have to say 'yes'.

If you say 'yes', you do not have to do the whole interview.

We could stop when you want to, or have a break.

If you do not want to answer some of the questions, you can just say, 'pass'.

Before you decide whether to help me, you might like to talk about this project with your parents or with a friend.

I will keep tapes and notes of the interviews in a safe, lockable place.

When I talk about the research and write reports, I always change people's names to make sure we cannot recognize them.

I would not talk to anyone you know about what you have said, unless you talk about the risk of someone being harmed. If so, I would talk with you first about what could be done to help.

If you want, your parents or friends can be present during our conversation.

INT04- Child over 14 Years Old

Consent form to participate in research

Interview consent form

(Please note – each participant will be given two copies of the consent form – one to keep, and one to sign and return to the researcher)

This is to state that I agree to participate in a program of research being conducted by Jonathan Deschênes of the John Molson School of Business at Concordia University, Montreal, Quebec (514.389.2902, johat_de@jmsb.concordia.ca).

A. PURPOSE

I have been informed that the purpose of the research is as follows: This is an academic program of research that aims to explore the process of ill children wish granting in the context of the Children's Wish Foundation of Canada.

I have been informed that Jonathan will serve as a volunteer research consultant for the Children's Wish Foundation of Canada during his academic research. I have been informed that the information I provide to Jonathan might be used to produce a global report of recommendations to the Children's Wish Foundation.

I have been informed that I am free to decide whether any information provided to Jonathan will be disclosed to the foundation. I have been informed that my identity will not be revealed to the Children's Wish Foundation of Canada without my consent.

I have been informed to consult with relatives and healthcare specialists (e.g. physician, social worker, psychologist) before accepting to participate in this research. I have been informed that relatives and healthcare specialists can attend to the interview if I feel the need to.

I have been informed that participation to this research is independent from the Children's Wish Foundation wish granting process. For instance, participation to this research will not affect the speed of wish granting or the chances that the wish will be granted. Every wish is processed in same the way, no regard to participation to this research.

I have previously attended to a meeting with Jonathan during which he explained the research process, the optional methodological approaches available, and their implications. I have been informed that I can discuss openly my preferences concerning any methodological approach and that this preference will be respected without any negative consequences whatsoever.

Participants will be offered copies of recorded material in which they have directly participated upon request.

B. PROCEDURES

The informant will be requested to participate in a formal interview that should last no more than 35 minutes. During this interview, questions related to his/her personal history, to his/her wish and to his/her relationship with the Foundation and the volunteers will be asked.

For purposes of analysis, the interview will be tape-recorded with the consent of the participant. The researcher will be the only person enabled to listen to the tape and this tape will be kept in a secure place to insure privacy. In order to insure confidentiality, the name of the participant as well as any other information that would potentially allow any disclosure of her/his identity will be purposefully changed (e.g. with the use of pseudonym) or omitted when the researcher communicates any results in verbal or written form.

Participants will be offered copies of recorded material in which they have directly participated upon request.

C. RISKS AND BENEFITS

Participation will help the researcher better understand the reality of the persons involved in the process and will provide significant information concerning the perception of the Foundation, the level of satisfaction with the wish granting process as well as its consequences. Overall, participation to this research can contribute to increasing the

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fundraising capacities of the Foundation, improving the training of volunteers, and offering more and better quality wish granting.

Participation to this research can also contribute to the writing of an essay about the ill children wish granting process, its challenges, and its benefits.

As the interview will partly cover questions related to illness, strong emotional reactions may be generated. If the participant experiences any discomfort to discuss any issues or questions arising from the interview, at any time during the interview, s/he will always have the right to take breaks or to withdraw from the process or avoid providing direct answers without negative consequences. Relatives and healthcare specialists are also welcomed to interfere in the process if they feel the need to do so.

D. CONDITIONS OF PARTICIPATION

- I understand that I am free to withdraw my consent and discontinue my participation at anytime without negative consequences.

- I understand that my participation in this study is CONFIDENTIAL (i.e., the researcher will know, but will not disclose my identity)

- I understand that the data from this study may be published.

I HAVE CAREFULLY STUDIED THE ABOVE AND UNDERSTAND THIS

AGREEMENT. I FREELY CONSENT AND VOLUNTARILY AGREE TO

PARTICIPATE IN THIS STUDY.

NAME (please print) _____

SIGNATURE _____

If at any time you have questions about your rights as a research participant, please contact Adela Reid, Research Ethics and Compliance Officer, Concordia University, at (514) 848-2424 x7481 or by email at areid@alcor.concordia.ca.

INT05- Experts

Consent form to participate in research

Interview consent form

(Please note – each participant will be given two copies of the consent form – one to keep, and one to sign and return to the researcher)

This is to state that I agree to participate in a program of research being conducted by Jonathan Deschênes of the John Molson School of Business at Concordia University, Montreal, Quebec (514.389.2902, johat_de@jmsb.concordia.ca).

A. PURPOSE

I have been informed that the purpose of the research is as follows: This is an academic program of research that aims to explore the process of ill children wish granting in the context of the Children's Wish Foundation of Canada.

I have been informed that Jonathan will serve as a volunteer research consultant for the Children's Wish Foundation of Canada during his academic research. I have been informed that the information I provide to Jonathan might be used to produce a global report of recommendations to the Children's Wish Foundation.

I have been informed that I am free to decide whether any information provided to Jonathan will be disclosed to the foundation. I have been informed that my identity will not be revealed to the Children's Wish Foundation of Canada without my consent.

B. PROCEDURES

The informant will be requested to participate in a formal interview that should last no more than one hour. During this interview, questions related to the participant's professional background and to her/his role with regards to ill children and to the Children's Wish Foundation will be asked.

For purposes of analysis, the interview will be tape-recorded with the consent of the participant. The researcher will be the only person enabled to listen to the tape and this tape will be kept in a secure place to insure privacy. Since the informant will be interrogated on the basis of his/her expertise in relation with the topic under investigation, his/her identity might be revealed during written and/or oral communication of research results.

Participants will be offered copies of recorded material in which they have directly participated upon request.

C. RISKS AND BENEFITS

Participation will help the researcher better understand the reality of the persons involved in the process and will provide significant information concerning the perception of the Foundation, the level of satisfaction with the wish granting process as well as its consequences. Overall, participation to this research can contribute to increasing the fundraising capacities of the Foundation, improving the training of volunteers, and offering more and better quality wish granting.

Participation to this research can also contribute to the writing of an essay about the ill children wish granting process, its challenges, and its benefits.

If the participant experiences any discomfort to discuss any issues or questions arising from the interview, at any time during the interview, s/he will always have the right to withdraw from the process or avoid providing direct answers without negative consequences.

D. CONDITIONS OF PARTICIPATION

- I understand that I am free to withdraw my consent and discontinue my participation at anytime without negative consequences.

- I understand that my participation in this study is NON-CONFIDENTIAL (i.e., my identity will be revealed in study results)

- I understand that the data from this study may be published.

I HAVE CAREFULLY STUDIED THE ABOVE AND UNDERSTAND THIS
AGREEMENT. I FREELY CONSENT AND VOLUNTARILY AGREE TO
PARTICIPATE IN THIS STUDY.

NAME (please print)   _____

SIGNATURE   _____

If at any time you have questions about your rights as a research participant, please

contact Adela Reid, Research Ethics and Compliance Officer, Concordia University, at

(514) 848-2424 x7481 or by email at areid@alcor.concordia.ca.

INT06- Director of the Foundation

Consent form to participate in research

Interview consent form

(Please note – each participant will be given two copies of the consent form – one to keep, and one to sign and return to the researcher)

This is to state that I agree to participate in a program of research being conducted by Jonathan Deschênes of the John Molson School of Business at Concordia University, Montreal, Quebec (514.389.2902, johat_de@jmsb.concordia.ca).

A. PURPOSE

I have been informed that the purpose of the research is as follows: This is an academic program of research that aims to explore the process of ill children wish granting in the context of the Children's Wish Foundation of Canada.

I have been informed that Jonathan will serve as a volunteer research consultant for the Children's Wish Foundation of Canada during his academic research. I have been informed that the information I provide to Jonathan might be used to produce a global report of recommendations to the Children's Wish Foundation.

I have been informed that I am free to decide whether any information provided to Jonathan will be disclosed to the foundation. I have been informed that my identity will not be revealed to the Children's Wish Foundation of Canada without my consent.

B. PROCEDURES

The informant will be requested to participate in a formal interview that should last no more than one hour. During this interview, questions related to the participant's professional background and to her/his role with regards to ill children and to the Children's Wish Foundation will be asked.

For purposes of analysis, the interview will be tape-recorded with the consent of the participant. The researcher will be the only person enabled to listen to the tape and this tape will be kept in a secure place to insure privacy. Since the informant occupies a social position that is easily identifiable his/her identity might be revealed during written and/or oral communication of research results.

Participants will be offered copies of recorded material in which they have directly participated upon request.

C. RISKS AND BENEFITS

Participation will help the researcher better understand the reality of the persons involved in the process and will provide significant information concerning the perception of the

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Foundation, the level of satisfaction with the wish granting process as well as its consequences. Overall, participation to this research can contribute to increasing the fundraising capacities of the Foundation, improving the training of volunteers, and offering more and better quality wish granting.

Participation to this research can also contribute to the writing of an essay about the ill children wish granting process, its challenges, and its benefits.

If the participant experiences any discomfort to discuss any issues or questions arising from the interview, at any time during the interview, s/he will always have the right to withdraw from the process or avoid providing direct answers without negative consequences.

D. CONDITIONS OF PARTICIPATION

- I understand that I am free to withdraw my consent and discontinue my participation at anytime without negative consequences.

- I understand that my participation in this study is NON-CONFIDENTIAL (i.e., my identity will be revealed in study results)

- I understand that the data from this study may be published.

I HAVE CAREFULLY STUDIED THE ABOVE AND UNDERSTAND THIS
AGREEMENT. I FREELY CONSENT AND VOLUNTARILY AGREE TO
PARTICIPATE IN THIS STUDY.

NAME (please print) _____

SIGNATURE _____

If at any time you have questions about your rights as a research participant, please
contact Adela Reid, Research Ethics and Compliance Officer, Concordia University, at
(514) 848-2424 x7481 or by email at areid@alcor.concordia.ca.

OBS01- Verbal Consent for Observation

Oral consent to participate in research

Observation session oral consent

I am Jonathan Deschenes, PhD student of the John Molson School of Business at Concordia University. I am conducting an academic program of research that aims to explore the process of ill children wish granting in the context of the Children's Wish Foundation of Canada.

I am here today to help the Foundation and to observe the course of the event. I would like to ask your permission to attend to this event and to take part in its realization as a researcher and as a participant.

If you accept, I might ask you informal questions during the course of the day. I would also be pleased to offer my assistance if you need help during the event.

I want you to know that during the realization of this project I serve as a volunteer research consultant for the Foundation. The information you provide might be used to produce a global report of recommendations to the Children's Wish Foundation. You are free to decide whether any information provided will be disclosed to the foundation. Your identity will not be revealed to the Children's Wish Foundation of Canada without my consent.

I want you to know also that participation to this research is independent from the Children's Wish Foundation wish granting process. For instance, participation to this research will not affect the speed of wish granting or the chances that the wish will be granted. Every wish is processed in same the way, no regard to participation to this research.

Appendix 6:

French Consent Forms

INT01F– Bénévoles et Employés

Formulaire de consentement de participation à une recherche

Formulaire de consentement pour entrevues

(Prendre note : Chaque participant recevra deux copies du présent formulaire – une à conserver et une à signer et à remettre au chercheur)

Par la présente, je déclare consentir à participer à un programme de recherche mené par M. Jonathan Deschênes de la John Molson School of Business de l'Université Concordia (514.389.2902, johat_de@jmsb.concordia.ca*).*

A. BUT DE LA RECHERCHE

On m'a informé(e) du but de la recherche, soit : Cette recherche est un projet académique ayant pour objectif d'étudier la réalisation des rêves d'enfants atteints de maladies graves dans le contexte de la Fondation Canadienne Rêves d'Enfants.

On m'a informé(e) que Jonathan agira en tant que consultant en recherche pour la Fondation Canadienne Rêves d'Enfants de manière bénévole pour la durée de sa recherche académique. On

m'a informé(e) que les informations que je fournirai pourront être utilisées dans le but de produire des recommandations à la Fondation Rêves d'Enfants.

On m'a informé(e) que je suis libre de décider si je souhaite ou non que ces informations soient transmises à la Fondation Rêves d'Enfants. On m'a informé(e) que mon identité ne sera pas révélée à la Fondation Rêves d'Enfants sans mon consentement.

B.   PROCÉDURES

Par la présente, le chercheur sollicite la permission de réaliser une entrevue formelle d'une durée maximale d'une heure avec l'informateur[2]. Au cours de cette entrevue, l'informateur sera questionné sur les raisons l'ayant poussé à offrir ses services en tant que bénévole ou employé pour la Fondation Rêves d'Enfants et sur son historique personnel.

Pour des fins d'analyse, l'entrevue sera enregistrée sur bande sonore suivant l'approbation de l'informateur. Le chercheur sera l'unique personne autorisée à écouter l'enregistrement qui sera conservé dans un endroit sécuritaire afin de protéger la vie privée de l'informateur. Le nom du participant ainsi que toute autre information pouvant mener à son identification seront modifiés (par exemple grâce à l'usage de pseudonyme) ou omis lors de la présentation écrite ou orale des résultats afin d'assurer la confidentialité des données.

Une copie papier ou sonore de la présente entrevue sera remise à l'informateur sur demande.

C.   RISQUES ET BÉNÉFICES

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[2] Veuillez noter que pour des fins de concision, les termes « informateur » et « participant » sont employés de façon générique afin de représenter autant le sexe masculin que celui féminin. Merci de votre compréhension.

La participation à cette étude permettra au chercheur de mieux comprendre la relation entre les donateurs, la fondation et les bénéficiaires. Une fois l'étude terminée, un rapport sera remis à la Fondation Rêves d'Enfants afin d'améliorer sa compréhension des besoins et des rôles des différents acteurs et, conséquemment, d'améliorer la qualité de vie autant des bénévoles que des bénéficiaires des œuvres de l'organisme.

Le participant aura droit en tout temps de se retirer de l'entrevue sans ne subir aucun préjudice s'il en ressent le besoin. Il aura aussi la possibilité de ne pas répondre aux questions qui lui seront posées durant l'entrevue s'il en ressent le besoin et sans ne subir aucun préjudice.

D. CONDITIONS DE PARTICIPATION

- Je comprends que je puis retirer mon consentement et interrompre ma participation à tout moment, sans conséquences négatives.

- Je comprends que ma participation à cette étude est CONFIDENTIELLE (c.-à-d. le chercheur connaît mon identité mais ne la révélera pas)

- Je comprends que les données de cette étude puissent être publiées

- Je comprends le but de la présente étude ; je sais qu'elle ne comprend pas de motifs cachés dont je n'aurais pas été informé(e).

J'AI LU ATTENTIVEMENT CE QUI PRÉCÈDE ET JE COMPRENDS LA NATURE DE L'ENTENTE. JE CONSENS LIBREMENT ET VOLONTAIREMENT À PARTICIPER À CETTE ÉTUDE.

NOM (caractères d'imprimerie) _____

SIGNATURE _____

Si vous avez des questions concernant vos droits en tant que participants à l'étude, S.V.P. contactez Adela Reid, Agente d'éthique en recherche/conformité, Université Concordia, au 514-848-2424 poste 7481 ou par courriel au adela.reid@concordia.ca

INT02F- Famille du Bénéficiaire

Formulaire de consentement de participation à une recherche

Formulaire de consentement pour entrevues

(Prendre note : Chaque participant recevra deux copies du présent formulaire – une à

conserver et une à signer et à remettre au chercheur)

Par la présente, je déclare consentir à participer à un programme de recherche mené par M. Jonathan Deschênes de la John Molson School of Business de l'Université Concordia (514.389.2902, johat_de@jmsb.concordia.ca*)*.

A.   BUT DE LA RECHERCHE

On m'a informé(e) du but de la recherche, soit : Cette recherche est un projet académique ayant pour objectif d'étudier la réalisation des rêves d'enfants atteints de maladies graves dans le contexte de la Fondation Canadienne Rêves d'Enfants.

On m'a informé(e) que Jonathan agira en tant que consultant en recherche pour la Fondation Canadienne Rêves d'Enfants de manière bénévole pour la durée de sa recherche académique. On m'a informé(e) que les informations que je fournirai pourront être utilisées dans le but de produire des recommandations à la Fondation Rêves d'Enfants.

On m'a informé(e) que je suis libre de décider si je souhaite ou non que ces informations soient transmises à la Fondation Rêves d'Enfants. On m'a informé(e) que mon identité ne sera pas révélée à la Fondation Rêves d'Enfants sans mon consentement.

On m'a informé(e) à l'avance qu'il aurait été préférable de consulter des proches ainsi que des spécialistes de la santé (ex : médecin traitant, travailleur social, psychologue) avant d'accepter de participer à cette recherche. On m'a informé(e) que mes proches ainsi que des spécialistes peuvent assister à cet entretien si j'en ressens le besoin.

On m'a informé(e) que la participation à cette recherche est entièrement indépendante du processus de réalisation de rêves de la Fondation Rêves d'Enfants. Par exemple, ma participation n'affectera en rien le délai de réalisation du rêve ou les chances qu'il soit accepté par la Fondation. Chaque rêve est assujetti à la même procédure sans égard à la participation à cette recherche.

J'ai préalablement assisté à une rencontre avec Jonathan durant laquelle ce dernier a expliqué le processus de recherche, les options méthodologiques offertes ainsi que leur implication. On m'a informé(e) que je peux discuter ouvertement de mes préférences concernant les approches méthodologiques et que ces préférences seront respectées sans ne subir aucun préjudice.

B.   PROCÉDURES

Par la présente, le chercheur sollicite la permission de réaliser une entrevue formelle d'une durée maximale d'une heure avec l'informateur[3]. Au cours de cette entrevue, l'informateur sera questionné sur l'histoire de son enfant ainsi que sur les liens qui les unissent avec la Fondation Rêves d'Enfants.

Pour des fins d'analyse, l'entrevue sera enregistrée sur bande sonore suivant l'approbation de l'informateur. Le chercheur sera l'unique personne autorisée à écouter l'enregistrement qui sera conservé dans un endroit sécuritaire afin de protéger la vie privée de l'informateur. Le nom du participant ainsi que toute autre information pouvant mener à son identification seront modifiés (par exemple grâce à l'usage de pseudonyme) ou omis lors de la présentation écrite ou orale des résultats afin d'assurer la confidentialité des données.

Une copie écrite ou audio de la présente entrevue sera remise à l'informateur sur demande.

C.   RISQUES ET BÉNÉFICES

La participation à cette étude permettra aux chercheurs de mieux comprendre la relation entre les donneurs, la fondation et les bénéficiaires. Une fois l'étude terminée, un rapport sera remis à la fondation. Toute collaboration à cette étude permettra d'aider la Fondation à améliorer sa compréhension des besoins et des rôles des différents acteurs et, conséquemment, d'améliorer la qualité de vie autant des bénévoles que des bénéficiaires des œuvres de l'organisme.

Participer à cette étude permettra de contribuer à la rédaction d'un essai sur le processus de réalisation des rêves des enfants gravement malades, sur ces défis, sur ces risques ainsi que sur

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[3] Veuillez noter que pour des fins de concision, les termes « informateur » et « participant » sont employés de façon générique afin de représenter autant le sexe masculin que celui féminin. Merci de votre compréhension.

ces bénéfices. Jonathan offre aussi la possibilité de retourner les images, dessins, journaux, etc. concernant l'enfant de manière directe ou sous forme d'album photo ou de « scrap book ».

Cette entrevue abordera des thèmes en relation avec la maladie, ce qui est susceptible de générer des réactions émotives fortes chez certains. Le participant aura droit en tout temps de se retirer de l'entrevue sans ne subir aucun préjudice s'il en ressent le besoin. Il aura aussi la possibilité de ne pas répondre aux questions qui lui seront posées durant l'entrevue s'il en ressent le besoin et sans ne subir aucun préjudice. Les proches et les spécialistes de la santé sont invités à assister à l'entrevue et à intervenir comme bon leur semble.

D.   CONDITIONS DE PARTICIPATION

- Je comprends que je puis retirer mon consentement et interrompre ma participation à tout moment, sans conséquences négatives.

- Je comprends que ma participation à cette étude est CONFIDENTIELLE (c.-à-d. le chercheur connaît mon identité mais ne la révélera pas)

- Je comprends que les données de cette étude puissent être publiées

- Je comprends le but de la présente étude ; je sais qu'elle ne comprend pas de motifs cachés dont je n'aurais pas été informé(e).

J'AI LU ATTENTIVEMENT CE QUI PRÉCÈDE ET JE COMPRENDS LA NATURE DE L'ENTENTE. JE CONSENS LIBREMENT ET VOLONTAIREMENT À PARTICIPER À CETTE ÉTUDE.

NOM (caractères d'imprimerie) _____

SIGNATURE _____

Si vous avez des questions concernant vos droits en tant que participants à l'étude, S.V.P.

contactez Adela Reid, Agente d'éthique en recherche/conformité, Université Concordia, au 514-

848-2424 poste 7481 ou par courriel au adela.reid@concordia.ca

INT02FP– Famille du Bénéficiaire (avec photos)

Formulaire de consentement de participation à une recherche

Formulaire de consentement pour entrevues

(Prendre note : Chaque participant recevra deux copies du présent formulaire – une à conserver et une à signer et à remettre au chercheur)

Par la présente, je déclare consentir à participer à un programme de recherche mené par M. Jonathan Deschênes étudiant de la John Molson School of Business de l'Université Concordia, maintenant professeur à HEC Montréal (514.389.2902, jonathan.deschenes@hec.ca).

A. BUT DE LA RECHERCHE

On m'a informé(e) du but de la recherche, soit : Cette recherche est un projet académique ayant pour objectif d'étudier la réalisation des rêves d'enfants atteints de maladies graves dans le contexte de la Fondation Canadienne Rêves d'Enfants.

On m'a informé(e) que Jonathan agira en tant que consultant en recherche pour la Fondation Canadienne Rêves d'Enfants de manière bénévole pour la durée de sa recherche académique. On m'a informé(e) que les informations que je fournirai pourront être utilisées dans le but de produire des recommandations à la Fondation Rêves d'Enfants.

On m'a informé(e) que je suis libre de décider si je souhaite ou non que ces informations soient transmises à la Fondation Rêves d'Enfants. On m'a informé(e) que mon identité ne sera pas révélée à la Fondation Rêves d'Enfants sans mon consentement.

On m'a informé(e) à l'avance qu'il aurait été préférable de consulter des proches ainsi que des spécialistes de la santé (ex : médecin traitant, travailleur social, psychologue) avant d'accepter de participer à cette recherche. On m'a informé(e) que mes proches ainsi que des spécialistes peuvent assister à cet entretien si j'en ressens le besoin.

On m'a informé(e) que la participation à cette recherche est entièrement indépendante du processus de réalisation de rêves de la Fondation Rêves d'Enfants. Par exemple, ma participation n'affectera en rien le délai de réalisation du rêve ou les chances qu'il soit accepté par la Fondation. Chaque rêve est assujetti à la même procédure sans égard à la participation à cette recherche.

J'ai préalablement assisté à une rencontre avec Jonathan durant laquelle ce dernier a expliqué le processus de recherche, les options méthodologiques offertes ainsi que leur implication. On m'a informé(e) que je peux discuter ouvertement de mes préférences concernant les approches méthodologiques et que ces préférences seront respectées sans ne subir aucun préjudice.

B. PROCÉDURES

Par la présente, le chercheur sollicite la permission de réaliser une entrevue formelle d'une durée maximale d'une heure avec l'informateur[4]. Au cours de cette entrevue, l'informateur sera questionné sur l'histoire de son enfant ainsi que sur les liens qui les unissent avec la Fondation Rêves d'Enfants.

Pour des fins d'analyse, l'entrevue sera enregistrée sur bande sonore suivant l'approbation de l'informateur. Le chercheur sera l'unique personne autorisée à écouter l'enregistrement qui sera conservé dans un endroit sécuritaire afin de protéger la vie privée de l'informateur. Le nom du participant ainsi que toute autre information pouvant mener à son identification seront modifiés (par exemple grâce à l'usage de pseudonyme) ou omis lors de la présentation écrite ou orale des résultats afin d'assurer la confidentialité des données.

Une copie écrite ou audio de la présente entrevue sera remise à l'informateur sur demande.

C.   RISQUES ET BÉNÉFICES

La participation à cette étude permettra aux chercheurs de mieux comprendre la relation entre les donneurs, la fondation et les bénéficiaires. Une fois l'étude terminée, un rapport sera remis à la fondation. Toute collaboration à cette étude permettra d'aider la Fondation à améliorer sa compréhension des besoins et des rôles des différents acteurs et, conséquemment, d'améliorer la qualité de vie autant des bénévoles que des bénéficiaires des œuvres de l'organisme.

Participer à cette étude permettra de contribuer à la rédaction d'un essai sur le processus de réalisation des rêves des enfants gravement malades, sur ces défis, sur ces risques ainsi que sur

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[4] Veuillez noter que pour des fins de concision, les termes « informateur » et « participant » sont employés de façon générique afin de représenter autant le sexe masculin que celui féminin. Merci de votre compréhension.

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ces bénéfices. Jonathan offre aussi la possibilité de retourner les images, dessins, journaux, etc. concernant l'enfant de manière directe ou sous forme d'album photo ou de « scrap book ».

Cette entrevue abordera des thèmes en relation avec la maladie, ce qui est susceptible de générer des réactions émotives fortes chez certains. Le participant aura droit en tout temps de se retirer de l'entrevue sans ne subir aucun préjudice s'il en ressent le besoin. Il aura aussi la possibilité de ne pas répondre aux questions qui lui seront posées durant l'entrevue s'il en ressent le besoin et sans ne subir aucun préjudice. Les proches et les spécialistes de la santé sont invités à assister à l'entrevue et à intervenir comme bon leur semble.

D.   CONDITIONS DE PARTICIPATION

- Je comprends que je puis retirer mon consentement et interrompre ma participation à tout moment, sans conséquences négatives.

- Je comprends que ma participation à cette étude est PARTIELLEMENT CONFIDENTIELLE (c.-à-d. le chercheur connaît mon identité mais ne la révélera pas directement. Cependant il pourra utiliser des photos de notre rêve pouvant ultimement nous identifier).

- Je comprends que les données de cette étude puissent être publiées.

- Je comprends le but de la présente étude ; je sais qu'elle ne comprend pas de motifs cachés dont je n'aurais pas été informé(e).

J'AI LU ATTENTIVEMENT CE QUI PRÉCÈDE ET JE COMPRENDS LA NATURE DE L'ENTENTE. JE CONSENS LIBREMENT ET VOLONTAIREMENT À PARTICIPER À CETTE ÉTUDE.

NOM (caractères d'imprimerie) _____

SIGNATURE _____

Si vous avez des questions concernant vos droits en tant que participants à l'étude, S.V.P. contactez Adela Reid, Agente d'éthique en recherche/conformité, Université Concordia, au 514-848-2424 poste 7481 ou par courriel au adela.reid@concordia.ca

INT03F– Enfants de moins de 14 Ans

Formulaire de consentement de participation à une recherche

Formulaire de consentement pour entrevues

Prendre note : Chaque participant recevra deux copies du présent formulaire – une à conserver et une à signer et à remettre au chercheur.

Par la présente, je déclare consentir à participer à un programme de recherche mené par M. Jonathan Deschênes de la John Molson School of Business de l'Université Concordia (514.389.2902, johat_de@jmsb.concordia.ca).

A.   BUT DE LA RECHERCHE

On m'a informé(e) du but de la recherche, soit : Cette recherche est un projet académique ayant pour objectif d'étudier la réalisation des rêves d'enfants atteints de maladies graves dans le contexte de la Fondation Canadienne Rêves d'Enfants.

On m'a informé(e) que Jonathan agira en tant que consultant en recherche pour la Fondation Canadienne Rêves d'Enfants de manière bénévole pour la durée de sa recherche académique. On m'a informé(e) que les informations que je fournirai pourront être utilisées dans le but de produire des recommandations à la Fondation Rêves d'Enfants.

On m'a informé(e) que je suis libre de décider si je souhaite ou non que ces informations soient transmises à la Fondation Rêves d'Enfants. On m'a informé(e) que mon identité ne sera pas révélée à la Fondation Rêves d'Enfants sans mon consentement.

On m'a informé(e) à l'avance qu'il aurait été préférable de consulter des proches ainsi que des spécialistes de la santé (ex : médecin traitant, travailleur social, psychologue) avant d'accepter de participer à cette recherche. On m'a informé(e) que mes proches ainsi que des spécialistes peuvent assister à cet entretien si j'en ressens le besoin.

On m'a informé(e) que la participation à cette recherche est entièrement indépendante du processus de réalisation de rêves de la Fondation Rêves d'Enfants. Par exemple, ma participation n'affectera en rien le délai de réalisation du rêve ou les chances qu'il soit accepté par la Fondation. Chaque rêve est assujetti à la même procédure sans égard à la participation à cette recherche.

J'ai préalablement assisté à une rencontre avec Jonathan durant laquelle ce dernier a expliqué le processus de recherche, les options méthodologiques offertes ainsi que leur implication. On m'a informé(e) que je peux discuter ouvertement de mes préférences concernant les approches méthodologiques et que ces préférences seront respectées sans ne subir aucun préjudice.

B.   PROCÉDURES

Par la présente, le chercheur sollicite la permission des parents afin de réaliser une entrevue formelle d'une durée maximale de 35 minutes avec l'enfant de moins de 14 ans. Au cours de cette entrevue, l'informateur[5] sera questionné sur son histoire et sur l'importance de son rêve.

Pour des fins d'analyse, l'entrevue sera enregistrée sur bande sonore suivant l'approbation de l'informateur et de ses parents (ou tuteurs légaux). Le chercheur sera l'unique personne autorisée à écouter l'enregistrement qui sera conservé dans un endroit sécuritaire afin de protéger la vie privée de l'informateur. Le nom du participant ainsi que toute autre information pouvant mener à son identification seront modifiés (par exemple grâce à l'usage de pseudonyme) ou omis lors de la présentation écrite ou orale des résultats afin d'assurer la confidentialité des données.

Une copie de la présente entrevue sera remise à l'informateur sur demande.

C.   RISQUES ET BÉNÉFICES

La participation à cette étude permettra aux chercheurs de mieux comprendre la relation entre les donneurs, la fondation et les bénéficiaires. Une fois l'étude terminée, un rapport sera remis à la fondation. Toute collaboration à cette étude permettra d'aider la Fondation à améliorer sa compréhension des besoins et des rôles des différents acteurs et, conséquemment, d'améliorer la qualité de vie autant des bénévoles que des bénéficiaires des œuvres de l'organisme.

Participer à cette étude permettra de contribuer à la rédaction d'un essai sur le processus de réalisation des rêves des enfants gravement malades, sur ces défis, sur ces risques ainsi que sur

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[5] Veuillez noter que pour des fins de concision, les termes « informateur » et « participant » sont employés de façon générique afin de représenter autant le sexe masculin que celui féminin. Merci de votre compréhension.

ces bénéfices. Jonathan offre aussi la possibilité de retourner les images, dessins, journaux, etc. concernant l'enfant de manière directe ou sous forme d'album photo ou de « scrap book ».

Cette entrevue abordera des thèmes en relation avec la maladie, ce qui est susceptible de générer des réactions émotives fortes chez certains. Le participant aura droit en tout temps de se retirer de l'entrevue sans ne subir aucun préjudice s'il en ressent le besoin. Il aura aussi la possibilité de ne pas répondre aux questions qui lui seront posées durant l'entrevue et de prendre des pauses s'il en ressent le besoin et sans ne subir aucun préjudice. Les proches et les spécialistes de la santé sont invités à assister à l'entrevue et à intervenir comme bon leur semble.

Les parents ou (tuteurs légaux) ont le droit d'être présents durant l'entrevue et peuvent décider d'interrompre l'entretien en tout temps s'ils le jugent nécessaire sans ne subir aucun préjudice. De plus, si le participant ne se sent pas à l'aise de discuter de certains thèmes ou de certaines questions soulevés durant l'entrevue, il aura la possibilité de se retirer ou d'éviter de répondre sans ne subir aucun préjudice.

D.   CONDITIONS DE PARTICIPATION

- Je comprends que je puis retirer mon consentement et interrompre ma participation à tout moment, sans conséquences négatives.

- Je comprends que ma participation à cette étude est CONFIDENTIELLE (c.-à-d. le chercheur connaît mon identité mais ne la révélera pas)

- Je comprends que les données de cette étude puissent être publiées

- Je comprends le but de la présente étude ; je sais qu'elle ne comprend pas de motifs cachés dont je n'aurais pas été informé(e).

J'AI LU ATTENTIVEMENT CE QUI PRÉCÈDE ET JE COMPRENDS LA NATURE DE L'ENTENTE. JE CONSENS LIBREMENT ET VOLONTAIREMENT À PARTICIPER À CETTE ÉTUDE.

NOM (caractères d'imprimerie) _____

SIGNATURE _____

Si vous avez des questions concernant vos droits en tant que participants à l'étude, S.V.P. contactez Adela Reid, Agente d'éthique en recherche/conformité, Université Concordia, au 514-848-2424 poste 7481 ou par courriel au adela.reid@concordia.ca

INT03F– Enfants de moins de 14 Ans (avec photos)

Formulaire de consentement de participation à une recherche

Formulaire de consentement pour entrevues

Prendre note : Chaque participant recevra deux copies du présent formulaire – une à conserver et une à signer et à remettre au chercheur.

Par la présente, je déclare consentir à participer à un programme de recherche mené par M. Jonathan Deschênes, étudiant de la John Molson School of Business de l'Université Concordia, maintenant professeur à HEC Montréal (514.389.2902, jonathan.deschenes@hec.ca).

A.   BUT DE LA RECHERCHE

On m'a informé(e) du but de la recherche, soit : Cette recherche est un projet académique ayant pour objectif d'étudier la réalisation des rêves d'enfants atteints de maladies graves dans le contexte de la Fondation Canadienne Rêves d'Enfants.

On m'a informé(e) que Jonathan agira en tant que consultant en recherche pour la Fondation Canadienne Rêves d'Enfants de manière bénévole pour la durée de sa recherche académique. On m'a informé(e) que les informations que je fournirai pourront être utilisées dans le but de produire des recommandations à la Fondation Rêves d'Enfants.

On m'a informé(e) que je suis libre de décider si je souhaite ou non que ces informations soient transmises à la Fondation Rêves d'Enfants. On m'a informé(e) que mon identité ne sera pas révélée à la Fondation Rêves d'Enfants sans mon consentement.

On m'a informé(e) à l'avance qu'il aurait été préférable de consulter des proches ainsi que des spécialistes de la santé (ex : médecin traitant, travailleur social, psychologue) avant d'accepter de participer à cette recherche. On m'a informé(e) que mes proches ainsi que des spécialistes peuvent assister à cet entretien si j'en ressens le besoin.

On m'a informé(e) que la participation à cette recherche est entièrement indépendante du processus de réalisation de rêves de la Fondation Rêves d'Enfants. Par exemple, ma participation n'affectera en rien le délai de réalisation du rêve ou les chances qu'il soit accepté par la Fondation. Chaque rêve est assujetti à la même procédure sans égard à la participation à cette recherche.

J'ai préalablement assisté à une rencontre avec Jonathan durant laquelle ce dernier a expliqué le processus de recherche, les options méthodologiques offertes ainsi que leur implication. On m'a informé(e) que je peux discuter ouvertement de mes préférences concernant les approches méthodologiques et que ces préférences seront respectées sans ne subir aucun préjudice.

B. PROCÉDURES

Par la présente, le chercheur sollicite la permission des parents afin de réaliser une entrevue formelle d'une durée maximale de 35 minutes avec l'enfant de moins de 14 ans. Au cours de cette entrevue, l'informateur[6] sera questionné sur son histoire et sur l'importance de son rêve.

Pour des fins d'analyse, l'entrevue sera enregistrée sur bande sonore suivant l'approbation de l'informateur et de ses parents (ou tuteurs légaux). Le chercheur sera l'unique personne autorisée à écouter l'enregistrement qui sera conservé dans un endroit sécuritaire afin de protéger la vie privée de l'informateur. Le nom du participant ainsi que toute autre information pouvant mener à son identification seront modifiés (par exemple grâce à l'usage de pseudonyme) ou omis lors de la présentation écrite ou orale des résultats afin d'assurer la confidentialité des données.

Une copie de la présente entrevue sera remise à l'informateur sur demande.

C.   RISQUES ET BÉNÉFICES

La participation à cette étude permettra aux chercheurs de mieux comprendre la relation entre les donneurs, la fondation et les bénéficiaires. Une fois l'étude terminée, un rapport sera remis à la fondation. Toute collaboration à cette étude permettra d'aider la Fondation à améliorer sa compréhension des besoins et des rôles des différents acteurs et, conséquemment, d'améliorer la qualité de vie autant des bénévoles que des bénéficiaires des œuvres de l'organisme.

Participer à cette étude permettra de contribuer à la rédaction d'un essai sur le processus de réalisation des rêves des enfants gravement malades, sur ces défis, sur ces risques ainsi que sur

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[6] Veuillez noter que pour des fins de concision, les termes « informateur » et « participant » sont employés de façon générique afin de représenter autant le sexe masculin que celui féminin. Merci de votre compréhension.

ces bénéfices. Jonathan offre aussi la possibilité de retourner les images, dessins, journaux, etc. concernant l'enfant de manière directe ou sous forme d'album photo ou de « scrap book ».

Cette entrevue abordera des thèmes en relation avec la maladie, ce qui est susceptible de générer des réactions émotives fortes chez certains. Le participant aura droit en tout temps de se retirer de l'entrevue sans ne subir aucun préjudice s'il en ressent le besoin. Il aura aussi la possibilité de ne pas répondre aux questions qui lui seront posées durant l'entrevue et de prendre des pauses s'il en ressent le besoin et sans ne subir aucun préjudice. Les proches et les spécialistes de la santé sont invités à assister à l'entrevue et à intervenir comme bon leur semble.

Les parents ou (tuteurs légaux) ont le droit d'être présents durant l'entrevue et peuvent décider d'interrompre l'entretien en tout temps s'ils le jugent nécessaire sans ne subir aucun préjudice. De plus, si le participant ne se sent pas à l'aise de discuter de certains thèmes ou de certaines questions soulevés durant l'entrevue, il aura la possibilité de se retirer ou d'éviter de répondre sans ne subir aucun préjudice.

D. CONDITIONS DE PARTICIPATION

- Je comprends que je puis retirer mon consentement et interrompre ma participation à tout moment, sans conséquences négatives.

- Je comprends que ma participation à cette étude est PARTIELLEMENT CONFIDENTIELLE (c.-à-d. le chercheur connaît mon identité mais ne la révélera pas directement. Cependant il pourra utiliser des photos de notre rêve pouvant ultimement nous identifier).

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- Je comprends que les données de cette étude puissent être publiées

- Je comprends le but de la présente étude ; je sais qu'elle ne comprend pas de motifs cachés dont je n'aurais pas été informé(e).

J'AI LU ATTENTIVEMENT CE QUI PRÉCÈDE ET JE COMPRENDS LA NATURE DE L'ENTENTE. JE CONSENS LIBREMENT ET VOLONTAIREMENT À PARTICIPER À CETTE ÉTUDE.

NOM (caractères d'imprimerie) _____

SIGNATURE _____

Si vous avez des questions concernant vos droits en tant que participants à l'étude, S.V.P. contactez Adela Reid, Agente d'éthique en recherche/conformité, Université Concordia, au 514-848-2424 poste 7481 ou par courriel au adela.reid@concordia.ca

INT03FS– Consentement Verbal Simplifié pour Enfants de moins de 14 Ans

Consentement verbal de participation à une recherche

Formulaire simplifié de consentement pour entrevues

Je m'appelle Jonathan. Je fais une recherche sur comment les enfants comme toi réalisent leur rêve avec la Fondation Rêve d'Enfants. J'aimerais en savoir plus sur le rêve que tu souhaites réaliser.

C'est toi qui décides si tu veux me parler.

Tu n'es pas obligé(e) de dire « oui ».

Si tu dis « oui », tu n'es pas obligé de faire toute l'entrevue.

On peut arrêter l'entrevue quand tu le veux. On peut aussi prendre des pauses quand tu le veux.

Si tu ne veux pas répondre à une question tu n'as qu'à dire « passe ».

Avant que tu ne décides de m'aider, tu aimerais peut-être parler de ce projet avec tes parents ou amis.

Je conserverai les enregistrements et les notes concernant l'entrevue dans un endroit sécuritaire.

Quand je parle de la recherche et quand j'écris des rapports, je change toujours le nom des gens afin que l'on ne puisse pas le reconnaître.

Je ne parlerai as de ce que tu me diras à personne que tu connais, à moins que tu me parles de quelqu'un à qui on fait du mal. Dans ce cas, nous discuterons tous les deux de ce qu'on peut faire pour l'aider.

Si tu préfères tes parents ou des amis peuvent être présents durant notre conversation.

INT04F– Enfants de plus de 14 Ans

Formulaire de consentement de participation à une recherche

Formulaire de consentement pour entrevues

(Prendre note : Chaque participant recevra deux copies du présent formulaire – une à

conserver et une à signer et à remettre au chercheur)

Par la présente, je déclare consentir à participer à un programme de recherche mené par M. Jonathan Deschênes de la John Molson School of Business de l'Université Concordia (514.389.2902, johat_de@jmsb.concordia.ca).

A.   BUT DE LA RECHERCHE

On m'a informé(e) du but de la recherche, soit : Cette recherche est un projet académique ayant pour objectif d'étudier la réalisation des rêves d'enfants atteints de maladies graves dans le contexte de la Fondation Canadienne Rêves d'Enfants.

On m'a informé(e) que Jonathan agira en tant que consultant en recherche pour la Fondation Canadienne Rêves d'Enfants de manière bénévole pour la durée de sa recherche académique. On m'a informé(e) que les informations que je fournirai pourront être utilisées dans le but de produire des recommandations à la Fondation Rêves d'Enfants.

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On m'a informé(e) que je suis libre de décider si je souhaite ou non que ces informations soient transmises à la Fondation Rêves d'Enfants. On m'a informé(e) que mon identité ne sera pas révélée à la Fondation Rêves d'Enfants sans mon consentement.

On m'a informé(e) à l'avance qu'il aurait été préférable de consulter des proches ainsi que des spécialistes de la santé (ex : médecin traitant, travailleur social, psychologue) avant d'accepter de participer à cette recherche. On m'a informé(e) que mes proches ainsi que des spécialistes peuvent assister à cet entretien si j'en ressens le besoin.

On m'a informé(e) que la participation à cette recherche est entièrement indépendante du processus de réalisation de rêves de la Fondation Rêves d'Enfants. Par exemple, ma participation n'affectera en rien le délai de réalisation du rêve ou les chances qu'il soit accepté par la Fondation. Chaque rêve est assujetti à la même procédure sans égard à la participation à cette recherche.

J'ai préalablement assisté à une rencontre avec Jonathan durant laquelle ce dernier a expliqué le processus de recherche, les options méthodologiques offertes ainsi que leur implication. On m'a informé(e) que je peux discuter ouvertement de mes préférences concernant les approches méthodologiques et que ces préférences seront respectées sans ne subir aucun préjudice.

B.   PROCÉDURES

Par la présente, le chercheur sollicite la permission afin de réaliser une entrevue formelle d'une durée maximale de 35 minutes avec l'informateur[7]. Au cours de cette entrevue, l'informateur sera questionné sur son histoire, sur sa relation avec la Fondation Rêves d'Enfants et l'importance de son rêve.

Pour des fins d'analyse, l'entrevue sera enregistrée sur bande sonore suivant l'approbation de l'informateur. Le chercheur sera l'unique personne autorisée à écouter l'enregistrement qui sera conservé dans un endroit sécuritaire afin de protéger la vie privée de l'informateur. Le nom du participant ainsi que toute autre information pouvant mener à son identification seront modifiés (par exemple grâce à l'usage de pseudonyme) ou omis lors de la présentation écrite ou orale des résultats afin d'assurer la confidentialité des données.

Une copie de la présente entrevue sera remise à l'informateur sur demande.

C.   RISQUES ET BÉNÉFICES

La participation à cette étude permettra aux chercheurs de mieux comprendre la relation entre les donneurs, la fondation et les bénéficiaires. Une fois l'étude terminée, un rapport sera remis à la fondation. Toute collaboration à cette étude permettra d'aider la Fondation à améliorer sa compréhension des besoins et des rôles des différents acteurs et, conséquemment, d'améliorer la qualité de vie autant des bénévoles que des bénéficiaires des œuvres de l'organisme.

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[7] Veuillez noter que pour des fins de concision, les termes « informateur » et « participant » sont employés de façon générique afin de représenter autant le sexe masculin que celui féminin. Merci de votre compréhension.

Participer à cette étude permettra de contribuer à la rédaction d'un essai sur le processus de réalisation des rêves des enfants gravement malades, sur ces défis, sur ces risques ainsi que sur ces bénéfices.

Cette entrevue abordera des thèmes en relation avec la maladie, ce qui est susceptible de générer des réactions émotives fortes chez certains. Le participant aura droit en tout temps de se retirer de l'entrevue sans ne subir aucun préjudice s'il en ressent le besoin. Il aura aussi la possibilité de ne pas répondre aux questions qui lui seront posées durant l'entrevue et de prendre des pauses s'il en ressent le besoin et sans ne subir aucun préjudice. Les proches et les spécialistes de la santé sont invités à assister à l'entrevue et à intervenir comme bon leur semble.

D.   CONDITIONS DE PARTICIPATION

· Je comprends que je puis retirer mon consentement et interrompre ma participation à tout moment, sans conséquences négatives.

· Je comprends que ma participation à cette étude est CONFIDENTIELLE (c.-à-d. le chercheur connaît mon identité mais ne la révélera pas)

· Je comprends que les données de cette étude puissent être publiées

· Je comprends le but de la présente étude ; je sais qu'elle ne comprend pas de motifs cachés dont je n'aurais pas été informé(e).

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J'AI LU ATTENTIVEMENT CE QUI PRÉCÈDE ET JE COMPRENDS LA NATURE DE L'ENTENTE. JE CONSENS LIBREMENT ET VOLONTAIREMENT À PARTICIPER À CETTE ÉTUDE.

NOM (caractères d'imprimerie) _____

SIGNATURE _____

Si vous avez des questions concernant vos droits en tant que participants à l'étude, S.V.P. contactez Adela Reid, Agente d'éthique en recherche/conformité, Université Concordia, au 514-848-2424 poste 7481 ou par courriel au adela.reid@concordia.ca

INT05F- Experts

Formulaire de consentement de participation à une recherche

Formulaire de consentement pour entrevues

(Prendre note : Chaque participant recevra deux copies du présent formulaire – une à conserver et une à signer et à remettre au chercheur)

Par la présente, je déclare consentir à participer à un programme de recherche mené par M. Jonathan Deschênes de la John Molson School of Business de l'Université Concordia (514.389.2902, johat_de@jmsb.concordia.ca*)*.

A.   BUT DE LA RECHERCHE

On m'a informé(e) du but de la recherche, soit : Cette recherche est un projet académique ayant pour objectif d'étudier la réalisation des rêves d'enfants atteints de maladies graves dans le contexte de la Fondation Canadienne Rêves d'Enfants.

On m'a informé(e) que Jonathan agira en tant que consultant en recherche pour la Fondation Canadienne Rêves d'Enfants de manière bénévole pour la durée de sa recherche académique. On m'a informé(e) que les informations que je fournirai pourront être utilisées dans le but de produire des recommandations à la Fondation Rêves d'Enfants.

On m'a informé(e) que je suis libre de décider si je souhaite ou non que ces informations soient transmises à la Fondation Rêves d'Enfants. On m'a informé(e) que mon identité ne sera pas révélée à la Fondation Rêves d'Enfants sans mon consentement.

B.   PROCÉDURES

Par la présente, le chercheur sollicite la permission des parents afin de réaliser une entrevue formelle d'une durée maximale d'une heure avec l'informateur[8]. Au cours de cette entrevue, l'informateur sera questionné sur son profil professionnel, sur sa relation avec les enfants malades et avec la Fondation Rêves d'Enfants.

Pour des fins d'analyse, l'entrevue sera enregistrée sur bande sonore suivant l'approbation de l'informateur. Le chercheur sera l'unique personne autorisée à écouter l'enregistrement qui sera conservé dans un endroit sécuritaire afin de protéger la vie privée de l'informateur. En raison du fait que l'informateur sera interrogé sur les bases de son expertise en relation avec le sujet de recherche, le nom du participant ainsi que son affiliation professionnelle pourront potentiellement être dévoilés lors de la présentation écrite ou orale des résultats.

Une copie de la présente entrevue sera remise à l'informateur sur demande.

C.   RISQUES ET BÉNÉFICES

La participation à cette étude permettra aux chercheurs de mieux comprendre la relation entre les donneurs, la fondation et les bénéficiaires. Une fois l'étude terminée, un rapport sera remis à la

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[8] Veuillez noter que pour des fins de concision, les termes « informateur » et « participant » sont employés de façon générique afin de représenter autant le sexe masculin que celui féminin. Merci de votre compréhension.

fondation. Toute collaboration à cette étude permettra d'aider la Fondation à améliorer sa compréhension des besoins et des rôles des différents acteurs et, conséquemment, d'améliorer la qualité de vie autant des bénévoles que des bénéficiaires des œuvres de l'organisme.

Participer à cette étude permettra de contribuer à la rédaction d'un essai sur le processus de réalisation des rêves des enfants gravement malades, sur ces défis, sur ces risques ainsi que sur ces bénéfices.

Le participant aura droit en tout temps de se retirer de l'entrevue sans ne subir aucun préjudice s'il en ressent le besoin. Il aura aussi la possibilité de ne pas répondre aux questions qui lui seront posées durant l'entrevue s'il en ressent le besoin et sans ne subir aucun préjudice.

D.   CONDITIONS DE PARTICIPATION

- Je comprends que je puis retirer mon consentement et interrompre ma participation à tout moment, sans conséquences négatives.

- Je comprends que ma participation à cette étude est NON CONFIDENTIELLE (c.-à-d. mon identité sera révélée avec les résultats de l'étude)

- Je comprends que les données de cette étude puissent être publiées

- Je comprends le but de la présente étude ; je sais qu'elle ne comprend pas de motifs cachés dont je n'aurais pas été informé(e).

J'AI LU ATTENTIVEMENT CE QUI PRÉCÈDE ET JE COMPRENDS LA NATURE DE

L'ENTENTE. JE CONSENS LIBREMENT ET VOLONTAIREMENT À PARTICIPER À

CETTE ÉTUDE.

NOM (caractères d'imprimerie) _____

SIGNATURE _____

Si vous avez des questions concernant vos droits en tant que participants à l'étude, S.V.P.

contactez Adela Reid, Agente d'éthique en recherche/conformité, Université Concordia, au 514-

848-2424 poste 7481 ou par courriel au adela.reid@concordia.ca

INT06F– Directeur de la Fondation

Formulaire de consentement de participation à une recherche

Formulaire de consentement pour entrevues

(Prendre note : Chaque participant recevra deux copies du présent formulaire – une à conserver et une à signer et à remettre au chercheur)

Par la présente, je déclare consentir à participer à un programme de recherche mené par M. Jonathan Deschênes de la John Molson School of Business de l'Université Concordia (514.389.2902, johat_de@jmsb.concordia.ca*)*.

A.   BUT DE LA RECHERCHE

On m'a informé(e) du but de la recherche, soit : Cette recherche est un projet académique ayant pour objectif d'étudier la réalisation des rêves d'enfants atteints de maladies graves dans le contexte de la Fondation Canadienne Rêves d'Enfants.

On m'a informé(e) que Jonathan agira en tant que consultant en recherche pour la Fondation Canadienne Rêves d'Enfants de manière bénévole pour la durée de sa recherche académique. On m'a informé(e) que les informations que je fournirai pourront être utilisées dans le but de produire des recommandations à la Fondation Rêves d'Enfants.

On m'a informé(e) que je suis libre de décider si je souhaite ou non que ces informations soient transmises à la Fondation Rêves d'Enfants. On m'a informé(e) que mon identité ne sera pas révélée à la Fondation Rêves d'Enfants sans mon consentement.

B. PROCÉDURES

Par la présente, le chercheur sollicite la permission de réaliser une entrevue formelle d'une durée maximale d'une heure avec l'informateur[9]. Au cours de cette entrevue, l'informateur sera questionné sur son profil professionnel, sur sa relation avec les enfants malades et avec la Fondation.

Pour des fins d'analyse, l'entrevue sera enregistrée sur bande sonore suivant l'approbation de l'informateur. Le chercheur sera l'unique personne autorisée à écouter l'enregistrement qui sera conservé dans un endroit sécuritaire afin de protéger la vie privée de l'informateur. En raison du fait que la position sociale de l'informateur sera facilement identifiable, le nom du participant ainsi que son statut professionnelle pourront potentiellement être dévoilés lors de la présentation écrite ou orale des résultats.

Une copie de la présente entrevue sera remise à l'informateur sur demande.

C. RISQUES ET BÉNÉFICES

La participation à cette étude permettra aux chercheurs de mieux comprendre la relation entre les donneurs, la fondation et les bénéficiaires. Une fois l'étude terminée, un rapport sera remis à la

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[9] Veuillez noter que pour des fins de concision, les termes « informateur » et « participant » sont employés de façon générique afin de représenter autant le sexe masculin que celui féminin. Merci de votre compréhension.

fondation. Toute collaboration à cette étude permettra d'aider la Fondation à améliorer sa compréhension des besoins et des rôles des différents acteurs et, conséquemment, d'améliorer la qualité de vie autant des bénévoles que des bénéficiaires des œuvres de l'organisme.

Participer à cette étude permettra de contribuer à la rédaction d'un essai sur le processus de réalisation des rêves des enfants gravement malades, sur ces défis, sur ces risques ainsi que sur ces bénéfices.

Le participant aura droit en tout temps de se retirer de l'entrevue sans ne subir aucun préjudice s'il en ressent le besoin. Il aura aussi la possibilité de ne pas répondre aux questions qui lui seront posées durant l'entrevue s'il en ressent le besoin et sans ne subir aucun préjudice.

D.   CONDITIONS DE PARTICIPATION

- Je comprends que je puis retirer mon consentement et interrompre ma participation à tout moment, sans conséquences négatives.

- Je comprends que ma participation à cette étude est NON CONFIDENTIELLE (c.-à-d. mon identité sera révélée avec les résultats de l'étude)

- Je comprends que les données de cette étude puissent être publiées

- Je comprends le but de la présente étude ; je sais qu'elle ne comprend pas de motifs cachés dont je n'aurais pas été informé(e).

J'AI LU ATTENTIVEMENT CE QUI PRÉCÈDE ET JE COMPRENDS LA NATURE DE L'ENTENTE. JE CONSENS LIBREMENT ET VOLONTAIREMENT À PARTICIPER À CETTE ÉTUDE.

NOM (caractères d'imprimerie) _____

SIGNATURE _____

Si vous avez des questions concernant vos droits en tant que participants à l'étude, S.V.P.

contactez Adela Reid, Agente d'éthique en recherche/conformité, Université Concordia, au 514-848-2424 poste 7481 ou par courriel au adela.reid@concordia.ca

OBS01F- Consentement verbal pour observation

Formulaire de consentement de participation à une recherche

Formulaire de consentement pour entrevues

Je suis Jonathan Deschênes, un étudiant au doctorat de la John Molson School of Business de l'Université Concordia. Je réalise une étude académique sur le processus de réalisation des rêves d'enfants gravement malades dans le contexte de la Fondation Canadienne rêves d'Enfants.

Je suis ici aujourd'hui pour aider la Fondation et pour observer le cours des événements. J'aimerais demander votre permission pour assister à cet événement et pour prendre part à sa réalisation en tant que chercheur et participant.

Si vous acceptez, il sera possible que je vous pose quelques questions durant la journée. Je serai aussi très heureux de vous offrit mon assistance si vous avez besoin d'aide durant cet événement.

Je tiens à ce que vous sachiez que durant la réalisation de ce projet je travaille aussi comme consultant de recherche pour la Fondation. L'information que vous me fournirez sera susceptible d'être utilisée dans le cadre d'un rapport de recommandations produit pour la Fondation. Vous êtes libre de décider si vous souhaitez que l'information soit

transmise ou non à la Fondation. Votre identité ne sera pas révélée à la Fondation sans votre consentement.

Je tiens à ce que vous sachiez aussi que la participation à cette recherche est entièrement indépendante du processus de réalisation de rêves de la Fondation Rêves d'Enfants. Par exemple, votre participation n'affectera en rien le délai de réalisation du rêve ou les chances qu'il soit accepté par la Fondation. Chaque rêve est assujetti à la même procédure sans égard à la participation à cette recherche.

End Notes to the Appendices

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[i] Source : http://www.childrenswish.ca/national/our-story-mission.php

[ii] Please note that all information provided in this section can be publicly accessed on the Foundation's official website, which contains no personal details (e.g. chat rooms private conversations) that could potentially raise privacy or confidentiality issues.

[iii] Source: http://www.childrenswish.ca/index_2007.php/en/national/page/39

[iv] Source: The Children's Wish Foundation of Canada annual reports from 2005 to 2008.

[v] Source: Children's Wish Foundation annual reports.

[vi] Source: http://www.childrenswish.ca/index_2007.php/en/partners/highlight/2 as of May 28, 2009.

[vii] Other areas of investment include: sustainable tourism projects, research in tourism, international and Canadian humanitarian causes, and health. Source: *Transat Corporate Social Responsibility Report, 2008.*

[viii] Source: http://www.airtransat.ca/en/Info/join-air-transat-kids-club.aspx?ExitID=47&ContentType=voyageur consulted June 25.

[ix] For example, the maintenance of the aircraft, the purchase of the food and gifts offered to the children, the airport fees for landing and takeoff, etc.

[x] Once, we saw our tickets being torn by the agent at the gate and we were given a first-class upgrade, to the great surprise of the family, who still talks about it two years later.

[xi] At the time of my fieldwork, many conversations during the weekly meetings revolved around the challenges of building a community of wish families.

[xii] Source: http://www.childrenswish.ca/index_2007.php/en/national/page/17 last consulted on June 26, 2009.

[xiii] The event was originally developed in the eastern provinces.

[xiv] Wish families can also raise money if they desire, but they are not systematically solicited to do so. Their presence is the CWF's priority.

[xv] The administrative ratio is maintained at around 15%.

[xvi] Image of the swimming pool taken from the Star Island Resort website: http://www.starislandresortorlando.com/star-island-resort-orlando-gallery.asp# (last consulted on March 7, 2009).

[xvii] Becky left in 2008 to work in the private sector.

[xviii] Normally, the families meet their favourite artist in private.

[xix] Later, I learned that in the past he had become close to a sick child who died, and that he was deeply affected by the situation.

[xx] She never informed me or the family of the specifics of the budget.

[xxi] Systematically excluding a group can hinder the generalizability of the findings and the redistribution of research benefits.

[xxii] Obviously what is pointed out here is hypothetical and will need to be explored in-depth.

[xxiii] A caveat on the prospective and retrospective methods: A focus on the expectation of future realization of a wish (prospective perspective) relies heavily on imaginative hypothetical scenarios that might not happen during the actual realization. In fact, one can hardly forecast what will be one's emotional and behavioural reactions during the wish realization event and even less what will be the others' reactions. A focus on past realized wishes (retrospective perspective) is relying heavily on memory and hence is subject to unduly modifications and reconstructions caused by memory decay and re-actualization.

[xxiv] The CWF's policy is to keep the administration-cost-to-revenue ratio to a maximum of 15%, which means that a minimum of 85 cents out of every dollar donated to the foundation will be used in wish granting activities (http://www.childrenswish.ca/national/our-story-quick-facts.php#administration). Hence, the more the Foundation earns, the more it can grant wishes. At this point the researcher hypothesizes that wish granting is mostly a positive thing in the life of ill children (see also the Foundation statement about the benefits of wish granting http://www.childrenswish.ca/national/our-story-quick-facts.php). Consequently, helping the foundation to increase revenues will positively affect the children and their families.

[xxv] Only recently have consumer researchers really started considering the importance of special vulnerable subpopulations. The 2005 *Advances for Consumer Research* presidential address was concerning the need for consumer researchers to get involved in the community by first giving a voice to those groups. A task force was created to

develop a "transformative consumer research program" with financial research granting

capacities.

xxvi The children all have in common to be diagnosed with life-threatening illnesses. Their

idiosyncratic health condition will vary from one child to the other. Some can be in

treatment, others in remission, and others in relapse. Some of them can also be in

terminal phase.