

Uncovering Identity Within the Experience of Chronic Illness:  
Art Therapy and Integration

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## ABSTRACT

Uncovering Identity Within the Experience of Chronic Illness:  
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Ariella Assouline

The experience of chronic illness can affect identity on many levels. The present research has sought to explore the clinical utility of art therapy as a means of addressing and working through the identity concerns evoked by this experience. Using a theoretical model, this paper has analysed the current literature on identity and illness, and the literature on medical art therapy, seeking out points of convergence in order to situate art therapy as an effective tool for helping individuals with chronic illness to unpack and redefine their identities. This research has shown art therapy to be uniquely suited to this task. Art making, within the context of the therapeutic relationship, provides a safe, nonverbal means expressing difficult emotions, allowing individuals to confront, work through, and eventually integrate aspects of the illness experience that may have previously seemed unspeakable. Art therapy further offers individuals opportunities to regain a sense of personal agency, to explore existential concerns, and to reconnect to the physical body. This process allows individuals to find strength in their losses, and to create cohesive images of their evolving selves, allowing them to both integrate and move through the experience of illness, and orienting them towards a deeper understanding of the self.

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## CHAPTER ONE: INTRODUCTION

According to Erikson (1968), the developmental psychologist largely responsible for our modern conception of identity:

An optimal sense of identity . . . is experienced merely as a sense of psychosocial well-being. Its most obvious concomitants are a feeling of being at home in one's body, a sense of 'knowing where one is going' and an inner assuredness of anticipated recognitions from those who count. (p. 165)

If, as Erikson suggests, identity is linked to wellbeing, what happens to one's identity when illness impedes one's ability to be well? Diagnosis with chronic illness calls into question each of these most basic elements of wellbeing: physical symptoms bring about bodily discomfort; the uncertain nature of chronic conditions presents the future as unpredictable; and significant others may react erratically when faced with these reminders of pain and mortality. Living with chronic illness presents many challenges, and these may deeply affect the way individuals define themselves. The stigma associated with illness, as well as our cultural obsession with "positive thinking" often leads people to focus on recovery, rather than confronting the experience directly. As one woman living with illness writes, "because the experience of illness is so difficult to accept, communicate, and integrate, it sinks in to the mute flesh of our bodies as we recover. In fact, the word 'recover' literally means 'to cover up again'" (Duff, 1993, p. 17). The purpose of the following paper is thus to explore the ways in which identity can be uncovered, revealed, and discovered within and through the experience of chronic illness, using art therapy as a tool for healing and self-discovery.

In contrast with disease, which is described as a "state of non-health" (Dimond & Jones, 1983, p. 3), illness has been defined as an "altered state of perception" (p. 5).

According to Kleinman, Eisenberg and Good (1978), “disease in the Western medical paradigm is malfunctioning or maladaptation of biologic and psychophysiologic processes in the individual; whereas illness represents personal, interpersonal, and cultural reactions to disease or discomfort” (p. 252). This connection between illness and subjective experience points to an ability to contextualize and reframe one’s perspective on illness and identity. This perceptual agency is one of the central tenets of Constructivism, a theory which has strongly oriented the present paper. Schwandt (1994) outlines the constructivist position on perception and reality in the following quote:

...what we take to be objective knowledge and truth is the result of perspective. Knowledge and truth are created, not discovered by mind. They [constructivists] emphasize the pluralistic and plastic character of reality—pluralistic in the sense that reality is expressible in a variety of symbol and language systems; plastic in the sense that reality is stretched and shaped to fit purposeful acts of intentional human agents. (p. 125)

Mahoney (2003), a constructivist psychotherapist, asserts that even when faced with transformations and experiences that are outside of our control, we still have “voice and choice” (p. 5). He adds that through therapy, people may “weave new possibilities for experiencing,” thus altering the “web of meanings” they had previously constructed (p. xii). This theory suggests that people with illness have the power to construct their own identities, ascribing their own meanings to the experience of illness. Further, as Schwandt suggests, constructivist theory allows for multiple meanings. This is linked to the notion of identity as deriving from not one, single definition of self, but from an understanding of self as made up of multiple pieces which fit together to form a textured, composite picture. Thus people may identify with their ethnicities, their genders, their careers, their hobbies, their social milieus, their religious affiliations, and also their experiences of illness. As Maalouf (1996/2001) argues, the list is “virtually unlimited” (p. 10). This



notion of multiplicity is key to integrating illness into identity, while maintaining a sense of self that is not consumed by the experience of illness.

This process requires individuals to find valued elements of their identities that are separate from illness, but that are not limited by social structures that define success in terms of independence and productivity (Charmaz, 1994). As Charmaz (1991) writes, “the self is more than its body and much more than an illness. Thus illness does not fill or flood the self, even though it may fill and flood experience” (p. 258). While it may sometimes be easier to ignore the impact of illness in an attempt to hold on to one’s previous self-definitions, true wellness can only come from acknowledging the illness and integrating it into one’s total identity.

It is the aim of this paper to explore not only the ways in which chronic illness affects one’s sense of self, but also how art therapy can help individuals to unpack the experience of illness and to contextualize it as one among many variables that comprise the total identity. Through a thorough examination of the current literature, I will show that art therapy provides a safe structure for exploring the range of difficult emotions associated with illness. As a means of nonverbal expression, it allows for a deeper examination of unconscious material than nonverbal methodologies, and allows thoughts that individuals might not even be able to admit to themselves to emerge. Art therapy further presents a way to visually represent the shifting and evolving self. Moreover, it offers a means of reconnecting to the body through physical engagement with art materials. Finally, I will show that the process of creating images can actually be used to mirror the notion of the construction of the self, empowering individuals with chronic illness to create themselves in the images they need to bring wholeness into their lives.

## Statement of Purpose

The goal of the present research is to address the question of how art therapy can help people living with chronic illness to explore and define their identities. As part of this inquiry, I will explore the relationship between art therapy and the integration of the self. While much has been written on the relationship between chronic illness and identity the literature on this topic is largely limited to the fields of health psychology (Corbin, 2003; Salick & Auerbach, 2006), medical sociology (Bury, 1982; Charmaz, 1983, 1991, 1994, 1995, 1999, 2006; Frank, 1995, 2007; Galvin, 2005; Mathieson & Stam, 1995; Williams, 2000; Yoshida, 1993), and nursing (Asbring, 2001; Kralik, & Telford 2005c; Paterson, 2001). And although there has recently been a strong movement to incorporate art therapy into the medical system, the research in this area has mostly focussed on working with specific population groups, like women with breast cancer (Collie, Bottorf, & Long, 2006; Cruze, 1998; Malchiodi, 1996; Puig, Lee, Goodwin, & Sherrard, 2006), people with HIV/AIDS (Aldridge, 1993; Edwards, 1993; Piccirillo, 1999; Predeger, 1996), patients in medical isolation (Gabriel et al., 2001; Hill, 1945; Rosner-David & Ilusorio, 1999), or on topics like pain reduction and symptom control (Berstein, 1995; Luzatto, 1998), and general support (Borgman, 2002; Ferris & Stein, 2002; Hildebrand, 1999; Long, 2004; Malchiodi, 1993, 1999, 2007; McGraw, 1999; Salmon, 1993). To this date there has been no research that explicitly links art therapy with identity and chronic illness. By drawing from the current literature, I would like to elucidate the connections between these topics, and in so doing I hope to contribute to the field of medical art therapy, and to expand the available body of literature in art therapy.

## Definition of Key Terms

*Identity:* The individual's self-definition. This definition takes place within context; meaning identity is about how the individual defines his or her self in relation to his or her experiences and affiliations. Adams and Marshall (1996) describe five functions of identity: (a) self-understanding; (b) a sense of meaning and direction derived from commitments, values, and goals; (c) a sense of control and autonomy; (d) a sense of consistency between values, goals, and commitments; and (e) recognition of one's future and potential (p. 433). Hereafter, whenever the term identity is used in this paper, it will reflect the definition proposed by Baumeister and Muraven (1996) in the following quote, which synthesizes the most salient elements discussed above: "Identity is a set of meaningful definitions that are ascribed or attached to the self, including social roles, reputation, a structure of values and priorities, and a conception of one's potentiality" (p. 406).

*Self-conception, self-definition:* because identity involves one's conception and definition of the self, these terms may be used interchangeably with the word identity.

*Identity formation, identity development, and identity definition:* These terms will be used interchangeably to denote the process of exploring identity.

*Chronic illness:* Long term illness with no known cure, and/or illness that leaves residual symptoms which limit the individual's functioning (Dimond & Jones, 1983). For the purposes of this paper, this term shall include persistent, serious illnesses that may also be life threatening, such as cancer and HIV/AIDS.

*Patient:* This term has been criticised for its tendency to position the person with illness as the passive recipient of care. With this in mind, it will not be used in this paper unless it is my intention to explicitly represent the socially imposed features of patienthood. In order to position the person at the centre of this dialogue, and to situate individuals as active agents in their lives, I will hereafter refer to *people* or *individuals (living) with (chronic) illness*, or when speaking of recipients of art therapy, I shall refer them as *clients*. I will refrain from using the terms *ill people*, *sick people*, or *victims of illness*.

## Methodology

The present research follows a theoretical methodology, whereby current literature is examined and analysed in order to find points of convergence and to integrate existing research into a cohesive narrative. According to Hart (2001), “analysing the literature can have as much intellectual and practical value as collecting first-hand data. A thorough critical evaluation of existing research often leads to new insights by synthesizing previously unconnected ideas” (p. 2). This paper shall attempt to locate the clinical utility of art therapy as a means of helping people with chronic illness to explore and integrate their identities. Given that much has been written on each of the topics of illness, identity, and art therapy, but there has yet to be any research focussed on combining the three, a theoretical analysis seems appropriate.

According to Cohen and Manion (as cited in Gilroy, 2006), theoretical research follows three stages: (a) identification and limitation of the research area, (b) “collection, selection, organisation, verification, validation and analysis of the data,” and (c) interpretation of the material (p. 105). In this kind of the research the data is text based, thus the theories outlined in the literature, as well as the findings of current studies, form the raw material of the research (Gilroy; Junge & Linesch, 1993). For the present study, I have included texts spanning multiple formats and multiple disciplines. While the bulk of my data came from peer-reviewed journal articles, data was also collected from edited books and textbooks, dissertations and theses, published lectures, reports, online journals, and illness narratives and memoirs. I should note that because I was limited to documents available in English, there is likely a North American/Eurocentric bias within the texts.

While most of my data came from North America and the United Kingdom, a few texts originated in other European countries as well as Australia and North Africa. In the interest of extending the reach of the present study, I expanded the scope of my literature search to include works from a broad range of disciplines, including art therapy and the creative arts therapies, medical sociology, clinical and health psychology, psychoanalysis, nursing, medicine, occupational therapy, disability theory, and art history.

As noted above, once data has been gathered the next step in the research process involves analysis and interpretation. According to Gilroy (2006), “rigorous logical analysis” allows the researcher to synthesize existing knowledge and to develop new, “comprehensive and powerful theory” (p. 66). My process initially involved systematic and extensive note taking in order to retrieve pieces of text that related to various aspects of the topic of chronic illness, identity, and art therapy. Following this, I associated keywords to these snippets of original text, selecting words that reflected common or recurring elements. I then further distilled this information by selecting themes that encapsulated groups of keywords. Finally, I reduced these themes into larger categories. Each of the chapter headings in the following paper essentially reflects the latter, while the subheadings generally correlate to the former. This process allowed me to draw connections between elements of the existing literature and to integrate my findings into a coherent narrative that aims to situate art therapy as a relevant and effective tool for people living with chronic illness to explore and integrate their identities.

## Overview

This analysis of the literature will begin in Chapter Two with an exploration of various responses to diagnosis with chronic illness. I will touch upon the varied ways in which people react, ranging from outright denial to tentative acknowledgement of the illness. I will then move to a discussion of the role of art therapy in helping people to confront the illness experience, allowing them to explore the difficult range of thoughts and emotions that chronic illness brings up. In Chapter Three, I will look at the relationship between illness, identity, and the loss of personal autonomy. I will then address the ways in which art therapy can provide a means of regaining a sense of autonomy, thus helping to restore one's sense of agency and competence. In Chapter Four, I will examine the dissociation between body and mind that often follows diagnosis with chronic illness, and will look at how art therapy can help to bridge the gap by offering a physical outlet for emotional expression. Chapter Five will explore some of the existential issues triggered by illness experience, and will look at the paradoxical relationship between relinquishing control over the illness and regaining control over one's life. This chapter will end with a discussion of the role of art therapy in confronting the existential and helping to integrate the self. In Chapter Six I will look at how the self and identity can shift, transform, and evolve within the illness experience. This process of transformation will be presented through the lens of constructivist theory, and I will touch upon notions of narrative agency and construction of the self through image and metaphor. Finally, in Chapter Seven, I will look at how art therapy may help individuals to move through the pain and suffering of illness toward a deeper understanding of the self, culminating in a sense of personal renewal.

## CHAPTER TWO: PROCESSING THE EXPERIENCE OF ILLNESS: RESPONSES TO DIAGNOSIS

### Illness and Denial

#### *Illness and Shame*

Medical sociology has been profoundly influenced by the work of Talcott Parsons (1951/1991) who developed a theory of illness as a social role. In this *sick role* theory, he affords people with illness both exemptions—from the responsibilities of daily life (i.e. work, inside and outside the house) and obligations—to focus their energies completely on getting well and to cooperate with medical professionals in following their treatment recommendations. These criteria paint the person with illness as predominantly passive and dependant. Within the context of a society that holds personal strength and independence as the fundamental values, Parsons' concept of the sick role positions people with illness as legitimated social deviants (Frank, 1997; Parsons). As Turner (1991) writes in his contemporary introduction to Parsons' work:

Given the achievement and activist values of individualistic American culture, being sick was, in an important sense, being deviant. Sickness typically involves withdrawal from work and passivity. Sickness involving a temporary, passive withdrawal from work is potentially a threat to the values of the whole system. (p. xxxii)

Contemporary medical sociologists and illness theorists have strongly critiqued Parsons' theory for this very reason. They argue the theory has largely contributed to the disempowerment of people with illness, designating compliance to medical authority as their primary obligation and positioning them as secondary actors in the dramas of their own illnesses (Frank). Further criticism of his theory asserts that the sick role is not applicable to the experience of chronic illness, for only in cases of acute illness can recovery be a realistic outcome (Charmaz, 1991).



While the theory might be outdated, the attitude it represents is very much alive. For the person adjusting to chronic illness, social stigma can be internalized into feelings of guilt and shame. Because societal values of success and career are also experienced on a personal level, the new reality of life with illness can cause feelings of intense anxiety and dissonance (Ferris & Stein, 2002; Kralik & Telford, 2005b). In her analysis of qualitative interviews with people with severe and debilitating chronic illness, Charmaz (1983) reports that many blame themselves for their dependency. She further notes that dissonance often arises from an incongruity between individuals' current self-images and their "criteria for possessing a valued self" (p. 170). However, the stigma of illness goes beyond notions of deviance and personal inadequacies. As Ferris and Stein observe, illness represents a "disturbing reminder of mortality" and, "society often unconsciously shames the person who is sick" (p. 43). With feelings of shame deriving both internally and externally, it is often easier to deny the impact of one's illness, than to confront its impact on one's life and one's identity.

### *Denial*

Denial can take many forms. In reaction to diagnosis, some people might choose never to speak about their illness. Charmaz (1994) suggests that this is because telling others about a diagnosis reifies it, whereas ignoring it minimizes its effect (p. 235). When illness cannot be entirely denied, because its effects creep into one's daily life, attempts can still be made to minimize the experience. Kralik and Telford (2005c) published a report summarizing the themes arising from discussions in an online community of people living with chronic illness. The members of this community suggest that minimizing and downplaying the effects of their illness is an attempt to cling to their "familiar lives," when what was once familiar has become unreliable and uncertain (p. 3).

While denial might be frowned upon, the line between denial and positive refocusing is sometimes unclear. Both are coping mechanisms used by people struggling to keep hold of themselves and their grasps on the familiar world in the midst of significant bodily changes (Fife, 1994, p. 312). Focussing on the positive is not only socially acceptable, but expected. People attempt to “stay strong” in order not to burden others with the reality of their suffering. They are also apt to avoid discussing illness in attempt to counter the stereotypes of illness as weakness. As Murphy (1990), an anthropologist who has written an autobiographical ethnography of his own experience with progressive paralysis (the result of a slow growing tumour of the spine) points out, “a key rule for being a successful sick person is: Don’t complain!” (p. 20).

In fact, some people feel the need to present themselves as extra-strong, in order to make up for their increasing levels of disability. Yoshida (1993) calls this the adoption of the *supernormal identity*. They might seek out extraordinary activities in order to negate stigmatized images and to construct an image of themselves as personally and socially valued. In this context, even negative *thoughts* relating to the illness are deemed unacceptable (Luzzatto, 1998). The doctrine of the positive attitude can lead people to believe that there is a right and a wrong way of thinking and feeling (Ferris & Stein, 2002). This can lead to denial of one’s actual thoughts, in favour of thoughts that conform to dictates about illness outlined by a society terrified by suffering and death.

#### *Defining Illness as Interruption*

If suffering and death are unthinkable, and a positive attitude is compulsory, then focussing on recovery might seem like the only option. Charmaz (1991) likens this attitude to an internalization of Parsons’ (1951/1991) sick role, whereby individuals define their illnesses in terms of interruption. As she points out, this definition assumes

that, “illness is temporary, of short duration and with a predictable outcome: *recovery*. Hence, ill people expect to get better—soon. They have little or no concept of chronic illness or disability” (Charmaz, p. 13). The very chronicity of their conditions is ignored in favour of a mythical belief in recovery.

Defining the illness as temporary, may serve as a coping mechanism, countering threats to one’s past sense of identity. Williams (2000) describes this process as “bracketing off the impact of illness” (p. 44). Charmaz (1991) calls it taking a “timeout,” whereby individuals put both their lives and their identities on hold (p. 13). In his analysis of illness narratives, Frank (1995), outlines a similar phenomenon which he names the *restitution narrative*. He depicts narratives as self-stories, through which people both describe and create experience. In his own words, “the plot of the restitution has the basic storyline: ‘Yesterday I was healthy, today I’m sick, but tomorrow I’ll be healthy again’” (p. 77). He contends that the restitution formula is “culturally preferred” (p. 83), in that health is viewed as, “the normal condition that people ought to have restored. Thus the ill person’s own desire for restitution is compounded by the expectation that other people want to hear restitution stories” (Frank, p. 77).

By defining identity in the past, people may hold onto valued aspects of their preillness selves. However, the self of the present remains associated with loss, and the self-concept becomes out of synch with lived experience. Charmaz (1994) calls this the development of the *fictional identity*. While the past self might be seen as the ideal, the self of the present is however, the real self. Adams and Marshall (1996) maintain that transformations in identity are the result of the perceived incongruity between these two self-images (p. 435).

Eventually this discrepancy leads to a desire to find coherence, and thus the concept of the ideal self shifts, leading to a reformulation of the relationship between illness and self. Both Charmaz (1991) and Frank (1995) regard bracketing off as one stage among several in the process of adapting to illness. Similarly, Yoshida (1993) has developed a model in which what she calls the *former self* is represented as only one position among five within the spectrum of acceptance and denial that people move between while processing the experience of illness. She presents this movement as happening in a fluid nonlinear manner, much like the undulations of a pendulum.

### Acceptance and Loss

#### *Illness, Intensity, and Acknowledgment*

Mahoney (2003) is a constructivist psychotherapist who has written extensively on the process of human change. He argues that in times of crisis people react by both “rigidifying” and “disorganizing” (p. 8). Thus, the process of denial outlined above, can be seen as a normal reaction to an overwhelming experience. However, he suggests that when the situation intensifies and persists, it can no longer be ignored. Correspondingly, Fife (1994) establishes that serious illness so deeply disrupts “the continuity of everyday life” that it forces people to redefine meanings attached to their previous ways of life (p. 309). Thus the intensity of the illness itself demands that it be acknowledged, as aspects of physical functioning that were once taken for granted move to the foreground of consciousness (Kelly & Field, 1996; Little, Jordens, Paul, Montgomery, & Philipson, 1998; Murphy, 1990). The following excerpt from Duff’s (1993) autobiographical narrative of her experience living with fibromyalgia, illustrates this intensity:

Illness is a world of its own, another plane of reality, that is quite apart from the one we normally inhabit in the ordinary dailiness of health. It has its own geography “beneath the deeps of darkness,” its own gravity “at the farthest bottom of life.” And it offers us an extraordinary—if at times frightening—vantage point from which to view the terrain of one’s life. (p. 4)

In a similar example, Murphy admits that his disability essentially overshadows all aspects of his being, that since the onset of his paralysis, he has “never once dreamed of anything else,” and that “even in sleep, disability keeps its tyrannical hold over the mind” (p. 105).

### *Loss of Self*

When chronic illness is acknowledged, rather than rationalized away as temporary, feelings of grief and loss for the self often ensue. Dissonance between one’s values and one’s abilities can shatter one’s sense of self worth (Charmaz, 1983; Kralik & Telford, 2005c). In this situation, the past-present dichotomy is confronted and with this confrontation comes a disruption to one’s sense of continuity and identity (Corbin, 2003, p. 259). Furthermore, anxiety surrounding these feelings may be compounded by the fact that the intensity of this loss is rarely recognized by a society still caught in the Parsonian framework of illness as temporary (Charmaz). Moreover, Kralik and Telford report that feelings of loss can also arise from becoming physically unable to participate in activities with others. Murphy’s (1990) description elucidates the complexity of this loss:

I had lost much more than the full use of my legs. I had also lost a part of my self. It was not just that people acted differently toward me, which they did, but rather that I felt differently toward my self. I had changed in my own mind, in my self image [sic], and in the basic conditions of my existence. (p. 85)

### *Grief and Loss as Unspeakable*

In the face of the intensity of these losses, Frank (1995) describes a second narrative emerging, the *chaos narrative*. He conveys this narrative as “the opposite of restitution: its plot imagines life never getting better” (p. 99). Within this narrative, the individual experiences a level of suffering in the present that overwhelms both past memories and hopes for the future. Thus in this state, the individual feels trapped in “an incessant present” (p. 99). Frank proposes that the chaos narrative cannot be told with words because the person living it needs distance in order to be able to reflect upon it. Similarly, Charmaz (1999) points out that some stories cannot be told; certain “inchoate experiences” are too painful to be put into words (p. 232).

This notion of wordlessness, of the inability to speak about the depth of the experience of illness, has been expressed in many of the works surveyed for the present research (Charmaz, 1999; Christie, Hood, & Griffin, 2006; Little et al., 1998; Piccirillo, 1999; Reynolds & Prior, 2003; Sibbett, 2005b). For example, Little et al. conducted an exhaustive narrative analysis of the experience of living with cancer. They initially surveyed multiple texts, including illness narratives and cultural materials such as film, television and radio—dramas and interviews, and then conducted qualitative interviews with 10 people living with colorectal cancer. From their analysis, the theme of “communicative alienation” emerged, in which informants described an inability to communicate the true nature of the experience of illness (p. 1488). As Little et al. write, “sometimes language ‘collapses’ in the face of the recollection of the incommunicable” (p. 1488). The stigma of illness and the depth of the losses it brings, create the conditions for a suffering that is unspeakable. Thus fear and shame lead to silence.

## Art Therapy and the Expression of the Unspeakable

### *A Way out of Chaos*

Frank's (1995) notion of the chaos narrative suggests that the immediacy of suffering engulfs all other experience such that people living through it are unable to see beyond the present. In this state, they are too close to the suffering to be able to narrate, or to make sense of their experiences with words. In this situation, art making and art therapy can provide a means of wordless expression that may, in fact, offer a way out of the chaos. Sibbett (2005b) cites a client with cancer as saying that art therapy "has been a way of expressing things that are unspeakable, also emotions that you are sometimes not even aware of until they come out of your art" (p. 66). Moreover, Reynolds (2002) interviewed 30 women living with chronic illness who were involved in the textile arts, as part of a qualitative study of the relationship between art making and coping with illness. A major theme that came out of this analysis was that art making was responsible for the transformation of the *empty present*, a term Reynolds used to describe a state akin to Frank's chaos narrative. According to several of her participants, making art helped to bring them out of their suffering and into a new frame of mind where hope for the future was possible. One participant revealed that through drawing she was able to imagine herself where she wanted to be and that completing the image was like starting a new chapter in her life (p. 104). A similar outcome was reported in a recent study (Collie, et al., 2006) on art therapy and art making with women living with cancer in which in-depth open-ended interviews of 17 women were conducted and analyzed using a narrative model. One such interview yielded the following quote by a participant:

I found I didn't know who I was anymore. It was like the person I was before the cancer was gone, and I thought, 'What is my life going to be?' I didn't see a life. I

didn't see a future. A lot of the time I just felt I was drowning and the art helped me to stay, you know, not totally submerged. (p. 766)

For this woman, making art, within the safe frame of art therapy, provided a means of emerging from the overwhelming identity losses that illness had brought. In these examples, art making and art therapy provided an alternate means of expression that not only felt safer than verbal discourse, but offered a path away from the chaos of the suffering the participants had been experiencing.

### *Art Therapy and Silence*

There are many ways in which the experience of illness may come to be shrouded in silence. As outlined above, because people with chronic illness are responding to societal pressures to “focus on the positive” and to “stay strong,” they often fear expressing the full nature of their suffering. In the case of HIV/AIDS, shame and stigma often drive people to keep their diagnosis secret. Piccirillo (1999) an art therapist who has written extensively on working with this population, notes that within the safe context of art therapy “for those responding to family and societal pressures to keep the secret, they can both have their silence and break it through creative expression” (p. 180). Luzatto, (1998) an art therapist who has developed a group art therapy method for working with cancer patients called *The Creative Journey*, describes the symbolic function of artistic expression in a similar manner. She contends that her clients often suffer from ambivalent feelings about illness, pain, powerlessness, and death, because they believe that they are supposed to stay away from negative thoughts in order to put on a “brave face” for those around them. However, through imagery, they can express these negative thoughts on a symbolic level without having to name them (pp. 173–174). A balance is thus struck between silence and expression.



### *Externalization and Containment*

When ideas are expressed on the symbolic level, the person can relate to them without having to explicitly link the symbol to the self. During the art therapy session, feelings and thoughts about illness can be ascribed to the image alone, creating a separation between the person and the problem (Salmon, 1993). The distance provided by this externalization allows people to express difficult emotions in a way that feels safe (Ferris & Stein, 2002, p. 45). Pole (2000), an oncologist who recommends creative techniques to his patients, describes the empowering nature of this process:

What you've created is in some way no longer a part of your inner chemistry. In putting distance between you and it, you've externalized it. This action, this process of art making, has a weakening effect on any negative images or ideas that may have been lurking inside you. (p. 38)

The image functions much in the same way as the narrative, which Frank (2007) describes as both containing and deferring lived experience. Encapsulated within the image, the experience can be examined, explored, and put away, if necessary. Luzatto (1998) points out that the frame of the paper itself may serve as a safe container for the expression of pain. Once placed at a distance on the page, client and therapist can move together toward deeper explorations of the meaning of the illness. Moreover, within the therapeutic relationship, the art therapist further contains difficult emotions and experiences, providing a context in which the client can use images to freely play out aspects of the inner world (Dreifuss-Kattan, 1990, p. 212). Once internal suffering has been given an external form, it can be understood and eventually transformed (Aldridge 1993). According to Aldridge, "suffering made external as expression and brought into form by art gives the individual the chance to grapple with the meaning of that suffering and thereby bring about change" (p. 289).

*Image and Insight*

When images are explored from this safe distance, new levels of insight often emerge. Thoughts and feelings about illness might be so deeply buried that the person has no conscious recognition of their existence. The very process of making art can sometimes bring about images that reflect unconscious material. Malchiodi (1999), an art therapist who has contributed greatly to the field of medical art therapy, suggests that peoples' verbal explanations of their illnesses rely upon rational intellectual descriptions, whereas their private, sometimes unconscious anxieties, fears, and confusions are more easily expressed through nonverbal channels like art making (pp. 15–16). The creative process has been described as “offering a bridge between the conscious and unconscious” such that extremely difficult emotions surrounding identity losses are more easily accessed (Reynolds & Prior, 2003, p. 786). This is thought to occur because visual information is processed in the right cerebral hemisphere whereas thoughts and ideas are linked with the verbal, linear, left hemisphere. Emotional experiences are usually remembered visually, but when people think about them, or talk about them, the left hemisphere gets involved, and censorship occurs (Birtchnell, 2002/2003). In art therapy, the image is first expressed visually, and then reflected upon verbally, so that both hemispheres become involved and the previously unconscious information is made available to the verbal mind. Working with and through images, people are able to deepen their understanding of the illness experience. Lynn (1994), a painter who published the narrative of her experience with lymphoma in an illustrated memoir, described painting as a way to “translate” the aspects of her illness which she did not understand (p. ix). Collie et al. (2006) conducted a narrative research project with women with cancer. One theme that emerged from their narrative analysis was the notion of art

therapy as a means of “getting a clearer view” (p. 766). Participants in their study variably depicted art as “a mirror that reflected [their] experience back to them” and as “a lens that could magnify, or a probe that could see past the surface” (Collie et al., p. 766).

### *Safety and Witness*

While the image itself offers a form for externalization and insight, the support of an art therapist provides a context in which the client can feel safe to explore that which has been externalized. The art therapist, by creating a space that is free from judgment, brings about the conditions in which clients feel safe to both create, and to communicate. Collie et al. (2006) describe art therapy as a safe “haven” in which clients can find acceptance of their total selves, including their illness and their fears (p. 765). This acceptance offers a necessary contrast to the stigma and shame that people living with chronic illness experience in their daily lives.

Acceptance is often linked to the experience of being heard, or being given a voice, but in the case of art therapy the notion of being seen is also very important (Sibbett, 2005b, p. 66). Long (2004), an art therapist writing about medical art therapy, notes that a patient with chronic illness once told her that art therapy was the only aspect of her treatment in which she had felt “seen and heard” (p. 333). This concept of *witness* is key to helping people to learn to accept their total selves. They must be seen and mirrored so that the reality of their illnesses and their suffering can be validated. Frank (1995) suggests that in order to move out of chaos, the narrative must be witnessed by a caring other, and only then can the individual move forward, and be able to tell new stories (p. 98). He notes that the chaos can never be fully transcended, but that it can slowly fade into the background. Art therapy provides witness on two levels. On one level, the art therapist is there to observe, listen and reflect, and on the other level, the

image itself provides a tangible record of the therapeutic process. Put simply, art making accesses deeply recessed emotions, and “provides permanent witness to unspoken pain” (Edwards, 1993, p. 332).

To summarize, diagnosis with chronic illness can be extremely difficult. It brings with it both physiological and psychological changes that can threaten one’s sense of self. People react in many different ways, often choosing to deny the impact of the illness, both to themselves and to the people around them. However, the nature of chronic illness is such that it remains ever-present, and eventually its impact must be acknowledged. As a safe alternative to purely verbal discourse, art therapy can help individuals to confront and unpack their feelings about illness. This discussion will now turn to an exploration of the relationship between autonomy and identity, and how these are impacted by the experience of chronic illness.

## CHAPTER THREE: ILLNESS, AUTONOMY, AND IDENTITY

### Illness and Loss of Autonomy

#### *Illness, Identity, and Work*

In chapter two, I introduced Parson's (1951/1991) sick role theory, which ascribes a special role to people with illness—a role in which they are obligated to take temporary leave from the responsibilities of work and to passively submit to their caregivers and physicians. Entrenched within the values of the Protestant work ethic, Parsons himself, acknowledged this role as a form of social deviance. Charmaz (1983) argues that when society values hard work, independence, and individual responsibility above all else, those who are living with chronic illness apply these values to their own lives. Consequently, they construe their dependency as negative. When these beliefs are internalized, self-blame ensues.

In this culture, career and job are deeply linked to identity and sense of self. When illness forces people to stop working, they may begin to question who they are at the deepest level (Asbring, 2001; Charmaz, 2006; Ferris & Stein, 2002). Christiansen (1999) states:

If our identities are crafted by what we do and how we do it, then it follows that any threat to our ability to engage in occupations and present ourselves as competent people becomes a threat to our identity. (p. 553)

Asbring looked at the effect of fibromyalgia on identity and found this to be true for the women she interviewed. They associated leaving their jobs with feelings of isolation, uselessness, marginalization, and eventually lowered self-esteem. As Charmaz (1983) proposes, when illness forces passivity it may bring with it feelings of loss of self, but

those feelings of loss may themselves lead to resignation and passivity, such that one may reinforce the other in a vicious cycle.

### *Illness and Loss of Control*

During illness, changes occurring in the body can affect one's ability to conduct tasks previously taken for granted. This may be expressed as a general slowing down, or in terms of loss of mobility and a sense of limited productivity and achievement, culminating in feelings of helplessness (Borgmann, 2002, p. 245). Fife (1994) conducted a study on meaning and identity within the context of serious illness. She interviewed 38 people living with various types and stages of cancer and found "loss of personal control" to be a major theme (p. 312). Participants expressed that their feelings of dependency on medical professionals, family members, and friends deeply affected the way they viewed themselves.

Frank (1995) uses the term *contingency* to describe a state in which the body is "subject to forces that cannot be controlled" (p. 31). He notes that this is the usual state in infancy, whereby babies are not expected to have control over their bodily functions and fluids. For adults, however, this contingency can feel like the ultimate regression. That which is contingent, is dependent, and submitting to the care of others can be a deeply infantilizing and shameful experience. For people with chronic illness this dependency often extends beyond the physical into the larger realm of personal autonomy. The losses to dignity and sense of self can be immense. According to Ferris and Stein (2002), in this traumatic circumstance, "what we know of as the self contracts, becomes less actor than acted on" (p.47).

*The Patient Identity*

Adrian Hill, (1945) is considered one of the fathers of modern art therapy. As an artist who underwent a lengthy hospitalization for tuberculosis, Hill discovered that art making helped him to deal with the doldrums of his convalescence and went on to teach art in sanatoriums after he had recovered. He variously described his experience of patienthood as of “existing rather than living,” and of being, “an impotent spectator . . . to . . . events [that] . . . impinge on his own well being . . . like a frustrated witness at his own trial” (p. 14). With repeated contact with the medical establishment, contingency and passivity can become internalized into a new identity, that of the patient. While the sick role is socially proscribed, the *patient identity* affects individuals on an inherently personal level which makes it more insidious. It pervades the experience of hospitalization and treatment, whereby compliance is mandatory and one’s sense of autonomy is secondary to deference to the medical authorities. This passage from Duff’s (1993) narrative elegantly illustrates the point:

We do not dip our feet into the waters of illness, we are fully immersed in them, as if pulled under by the relentless undertow. As we become sick, sickness becomes us and redefines us, so we say we are not ourselves anymore. In a few short hours I was transformed from a hardworking counsellor and avid swimmer into a “patient”—one hundred pounds of warm, white, shuddering flesh. (p. 5)

Like Duff, Murphy (1990) writes about the loss of his own authority as an anthropologist and an academic upon entering the hospital in the early stages of his paralysis. He relates that in the hospital, the individual “is shorn of all other social roles and is regarded as one sick body among many” (p. 20). He further affirms that lengthy hospitalisations lead to a state in which patients “become somewhat estranged from their other selves” (Murphy, p.1). Finally, Murphy divulges that his own loss of autonomy in the hospital was so great that he felt trapped and divorced of “even the illusion of free will” (p. 18).

Being “reduced to a patient” means that patients are no longer viewed as people (Collie et al., 2006, p. 765). In the hospital, one’s body is poked, prodded, and exposed so frequently, that this routine becomes predictable, normal. Patients are expected to give their bodies over to be acted upon, regardless of the effect this may have on their dignity or their self-esteem. Fife (1994) notes that patients sometimes feel like they have become the property of their caregivers; they have lost ownership of their essential selves (p. 312). One of Fife’s interviewees describes her experience thus, “I remember lifting myself to the surgery table totally naked but at that point you are just naked to everything. You just give yourself up to God and the surgeons” (p. 312). This total loss of dignity becomes internalized, and patients feel like they have lost power over their bodies, and more importantly, feel they have lost their sense of personal agency.

#### Agency as Identity

In order not to give up, it is necessary to retain some spark of autonomy. Even small choices can represent a kernel of agency that may serve to counter the insidious nature of patienthood. Christiansen (1999) asserts that, “when we create, when we control, when we exercise choice, we are expressing our selfhood and unique identities” (p. 550). She calls this the “agential aspect of identity” (p. 550), whereby autonomy is essentially linked to identity. Charmaz (1991) insists that for the person living with chronic illness, control is necessary to the shaping of self (p. 7). It follows then, that giving patients the opportunity to create can bolster their sense of autonomy, allowing them to move forward with the process of identity exploration. Frank (1995) describes this form of action as *metacontrol*, whereby any action serves to contradict the contingent



state, shifting the individual from a state of passivity to a state of activity (p. 32). He suggests the narrative as one avenue for achieving this. Through story, people move away from victimhood and transform “fate into experience” (Frank, p. xi). In the following section, I will outline how art making and art therapy can fulfil a similar function.

### *Art Therapy and Regaining Autonomy*

While medical treatment can seem dehumanizing, reducing people to patients, such that they may feel they are nothing more than the sum of their bodily defects and symptoms, art therapy provides an outlet for expression of the whole self. By giving people a space in which they can be truly heard and seen, art therapy can restore a sense of lost voice (Long, 2004; Reynolds & Prior, 2003). Further, by providing a channel for creative expression, art therapy helps to counter the overwhelming feelings of passivity brought on by the experience of illness and hospitalization. Gabriel et al. (2001) carried out a short-term (nine week) art therapy program with hospitalized patients receiving bone marrow transplants. In their analysis of the art therapy process, they observed “change from an active to a passive mood” as one the most significant results (p.118). In art therapy, the creative act itself becomes a metaphor for personal agency. The following quote sums it up nicely:

The very core of the art therapy process involves being active, converting ‘This is happening to me’ into ‘I am influencing my world.’ It involves ‘doing and undoing’ which directly counteracts feeling helpless, passive or victimized, proving that personal motivation pays off. (Piccirillo, 1999, p. 178)

When people use art materials to build tangible pieces of art, their images evidence their continued abilities to engage in creative, productive activities.

### *Art Making as an Exploration of Potential*

With the onset of limited mobility and decreased energy, illness and hospitalization can highlight all those activities that people are unable to do. Art making, however, requires little range of motion, and can be done in almost any setting, including the hospital bed (Hill, 1945). Therefore, as an accessible outlet for creative expression, art making and art therapy provide opportunities for people to explore “notions of potential rather than concepts of pathology” (Aldridge, 1993, p. 285). The very act of *making* appears to be the most significant factor. Reynolds, Lim and Prior (2008) interviewed women who had produced art while living with cancer. The participants had not been in contact with art therapists during the time they had made their art pieces, but they were interviewed on their perceptions of the significance of the art making process within the context of their cancer experiences. A common theme was the notion of art making as providing a tangible record of the participants’ abilities, thus contradicting beliefs held by themselves and others that illness had rendered them useless (Reynolds et al., p. 216). Coming to terms with the limitations of one’s body is a necessary step in moving toward an integrated identity, and seeking out new activities can ease this process. Artistic endeavours provide evidence of personal achievement, while taking the place of more physically demanding occupations, which may previously have served as sources of pride (Asbring, 2001; Kralik & Telford, 2005c).

Art therapy offers opportunities for success, from which people may draw sources of pride and increased self-esteem. The significance of this is not to be underestimated, for people who are living with illness and disability often find their sense of self-worth to be deeply compromised. In his illness narrative, Murphy (1990) reveals his own loss of self-esteem as being “radical,” “pervasive,” and “destructive” (p. 90). In a recent study,

Charmaz (2006) explored the connection between pursuits and identity within the context of chronic illness. She found that people would measure their pursuits (i.e. daily activities) as a way of assessing their own potentialities. These activities became entrenched in their self-concepts as significant features of their identities (Charmaz, p. 27). In the following quote, Christiansen (1999) aptly describes the relationship between success, personal efficacy and identity:

As we experience successes, our views of ourselves as efficacious or competent become strengthened. Thus, completing a task successfully adds to our sense of being competent human beings and, in a sense, prepares us for new challenges by bolstering our self-confidence. The term self-confidence is an interesting expression because it establishes a clear link between our identity and our belief in the things that we can do. (p. 553)

In art therapy, people are often surprised at the success of their final products. This can lead to an incredible sense of accomplishment and pride at having mastered a new set of skills (Edwards, 1993; Rosner-David & Ilusorio, 1999). In Collie's (2006) research on art therapy with women with breast cancer, participants' narratives reveal the art as counteracting feelings of emptiness. Collie affirms that by providing sources of pride and renewed personal agency through artistic expression, the "diminished self could be pumped up and re-inflated" (p. 768). Similarly, Reynolds et al. (2008) found that for the women with cancer they interviewed, artwork provided evidence that illness "was not wholly defining nor defeating them psychologically" (p. 104). Thus art making provides a psychological antidote to the feelings of lost efficacy that people with illness often experience.

### *Art Therapy and Control*

During art therapy, the process of creation takes on new meaning. The art therapist provides a range of material, techniques and media, from which the client is able

to choose (Daykin, McClean, & Bunt, 2007; Malchiodi, 2007). This element of choice is extremely significant in that it may act as a metaphor for control in the person's life. This stands in stark contrast to the lack of control over the body that results from illness and hospitalization (Malchiodi). In working with this population, it is therefore crucial to allow the client to make as many choices as possible. These choices may relate to style, subject matter, form, medium, and materials. Moreover, the theme of choice may extend to empowering clients to make decisions about the extent of their participation in activities, even affording them the right to refuse to participate in a given session (Hiltebrand, 1999, p. 124). Hiltebrand points out that this deeply contrasts the lack of choice given to patients with regard to most hospital procedures. Hill (1951) has argued that for hospitalized patients, by "exercising their powers of choice and criticism," they can achieve "a sense of power . . . and with it a sense of well-being" (p. 95).

When feelings of chaos become overwhelming, the simple act of making images, might lend a sense of structure to one's life (Zausner, 1998, p. 26). The notion of control is not just played out in the choices offered, but also within the symbolism of the image. Images may become arenas for working through feelings of chaos (Aldridge, 1993; Sibbett, 2005a). Making art involves problem solving. As people explore materials and techniques, they learn to deal with unexpected outcomes and work toward finding new solutions. This process can be seen as a form of rehearsal for problem solving in other areas of one's life (Piccirillo, 1999, p. 178). Thus ordering and structuring the image can represent the ability to create order in life. As each success builds upon the last, a growing sense of personal agency is expressed. Similarly, mastery of artistic techniques

may come to represent the potential to master the stress of illness (Reynolds, 2002, p. 104; Rosner-David & Ilusorio, 1999, p. 192).

When confidence is bolstered, a sense of autonomy begins to return, and people are more likely to be able to confront difficult emotions relating to illness. At the same time, when people use images to explore feelings about their illness and treatment processes, they may gain feelings of control over the illness itself. Thus confidence and control reinforce each other in helping individuals to work through illness identity issues. While patients often feel like passive recipients of care, art therapy can help them to feel as though they are more actively participating in their treatment (Hiltebrand, 1999, p. 122). In her narrative, Lynn (1994) described painting as way to “translate” the aspects of her lymphoma which she did not understand, consequently helping her gain control over her illness (p. ix). She further elucidated this process in an interview with Malchiodi (Lynn, as cited in Malchiodi, 2007):

Doctors controlled my body, but I controlled my soul. Painting offered me a world of my making—an escape from the angst, yet, at the same time, a way for me to show myself what was happening and how strong I was. (pp. 172–173)

Similarly, Baron (1989) describes a client who used art therapy to make multiple images about chemotherapy, as having become the “symbolic director” of her own treatment (p. 164). Symptoms can be externalized through colour, shape and line, and contained within the paper (Luzzatto, 1998, p. 170). Additionally, through visualization, and relaxation techniques, and even simply through distraction, art therapy might help to reduce pain and other physical symptoms (Hiltebrand; Long, 2004). Sibbett (2005b) contends that for many patients, whether due to lack of control over bodily fluids or invasion by needles and tubes, the physical boundary of the skin is compromised. In view of this, she suggests that the art image can provide a metaphorical container which may help to “bound” the

body (p. 59). In a more literal example of this, Cruze (1998) describes a sculptural project about the loss of her breast following breast cancer in which a plaster mould was made of her naked torso. She reveals that the experience of being covered with the plaster casting mesh felt like it was giving her a “new tight skin that [she] found strangely comforting” returning some of the “insulation” that had been lost with the mastectomy (p. 402). These art interventions can restore feelings of control and may ultimately lead to increased hope. Thus, a new more profound sense of autonomy and strength may emerge, and with it, the possibility of discovering a valued self-identity. Drawing an example from the art history literature, Frida Kahlo’s self-portraits exemplify the nuanced relationship between strength and suffering. In her analysis of Kahlo’s paintings, Siltala (1998), interprets the images as acts of defiance in which Kahlo refuses to submit to pain and illness, and rather, declares to suffering, “I rule you, you do not rule me” (p. 154).

In sum, by restoring a sense of agency and autonomy to the person with illness, art making provides a positive source for identification. In the face of the many disruptions that illness presents, art making can provide a connection to one’s sense of ongoing productivity, and engagement in “normal life” leading to an increased “continuity of self” (Reynolds, et al., 2008; p. 216). Additionally, through art making, the art therapy process deepens possibilities for self-exploration. Moreover, by providing opportunities for success, self-esteem is bolstered. This increased confidence, in conjunction with the support of an empathic therapist, allows the person to move toward confronting the difficulties of illness experience. When the illness process is explored within the safety of the therapeutic frame, the person may begin to feel that they have some control over the illness. This sense of control may then allow the individual to look

more closely at confusing and often dissonant feelings that the illness has brought about.

I will now shift the focus of this paper toward a discussion of the complex relationship between body and mind, as it presents itself throughout the course of chronic illness.

## CHAPTER FOUR: BODY, MIND, AND IDENTITY

### Dissonance and the Body

Proust (1920/1981) famously wrote that:

It is in moments of illness that we are compelled to recognise that we live not alone but chained to a creature of a different kingdom, whole worlds apart, who has no knowledge of us and by whom it is impossible to make ourselves understood: our body. (p. 308)

In becoming patients and dealing with the contingencies of illness, the once taken-for-granted-body moves to the forefront of awareness (Corbin, 2003; Kelly & Field, 1996). Previous self-definitions may become threatened by newly acquired bodily defects, resulting in a form of dissociation between body and mind (Kelly & Field). Williams (2000) describes this “psychophysical dualism” as *bodily alienation* (p. 43). To be alienated from one’s body is a bizarre experience because no matter how much one intellectualizes, the self cannot exist outside of the body. Little et al. (1998) express this phenomenon as “alienation of the self from the vehicle of the self” (p. 1493). In my survey of the literature on chronic illness, the theme of alienation came up again and again. It was reported in case studies, narratives, and qualitative analyses, by people with a range of chronic conditions, including cancer (Gwyn, 2003; Mathieson & Stam, 1995), paralysis (Murphy, 1990), chronic fatigue syndrome (Asbring, 2001; Duff, 1993), asthma (Charmaz, 1995), and tuberculosis (Rosner-David & Ilusorio, 1999). Gwyn cites a cancer narrative by French in which the hopelessness of this situation is expressed very simply. French writes, “I was not inside myself... A person who is ‘not inside herself’ is (presumably) absent, elsewhere, consigned to an anonymous otherness” (French, as cited in Gwyn, 2003, p. 214). Art therapy can provide an outlet for expressing this altered self-image. Rosner-David and Ilusorio illustrate this point by describing a client who first



drew himself as an alien with a green face and pointed ears, before verbalizing his feelings otherness.

### *Body-Mind Dualism as an Obstacle to Integration*

These feelings of dissonance can be understood within the social framework of body-mind dualism. Duff (1993) calls this a “false dichotomy inherited from the Scientific Revolution” (p 30). Likewise, Kelly and Field (1996) criticize the trend in medical sociology which positions the body in the background of analytical discourse (p. 242). Similarly, medical professionals tend to see physical symptoms and psychological reactions as separate, unrelated issues. Cassel (1991), a doctor and scholar of medical ethics who has written extensively on the experience of suffering in illness, argues that illness defies the division between body and mind, because both body and mind are implicated in the experience of suffering (p. 34). He blames the medical profession for continuing to reinforce this dichotomy, thereby dehumanizing the both the experience of illness and its consequent suffering. Within this context, a psychological splitting can occur, in which the valued self is associated only with the mind, and the body becomes the site of all that is bad. However, in order to truly adapt to illness, and to develop an integrated identity, bodily experience must be acknowledged (Charmaz, 1995). Loffer (2000) suggests, that the process of “rebalancing” one’s over-reliance on the mind, eventually leads to deeper self-discoveries than were possible before the onset of illness (p. 291).

### *Art Therapy and Reconnecting to the Body*

Luzatto (1998) admits that when she first started practising art therapy with medical populations she had a tendency to focus the therapy on the mind. She eventually realized that her clients’ physical suffering was playing a significant role in the

therapeutic dynamic, and needed to be addressed. She found that art therapy techniques could be used to address the pain itself. She now uses relaxation techniques as well art making to help clients externalize and contain their symptoms, after which they are more able to explore the meaning of the pain and the illness. By focussing first on the body, her clients are able to more fully integrate the experience of illness. Additionally, Piccirillo (1999) argues that the physical nature of art making creates a “flow” which itself promotes the flow of verbal expression (p. 181). Collie et al. (2006) report that for the women with cancer they interviewed, the act of seeing their images was key to their understanding of their illnesses. One of their participants stated that, “it’s looking you in the face, so you can’t deny that what you have created is what’s happening for you, and so you’re forced to accept it almost” (p. 766). By bridging the sensory and the verbal, art therapy opens a path to acceptance of the ill body.

#### *Art Therapy and Embodiment*

Art interventions are particularly effective because they are in themselves physical. By activating the senses, they mirror the multisensory nature of the symptoms themselves (Sibbett, 2005b, p. 54). Dreifuss-Kattan (1990) contends that making art brings about a heightened sensitivity to bodily sensations, leading to a search for harmony between “bodily states and the forms of the external world” (p. 135). Moreover, through its tactile qualities, art making offers a means of reducing intellectual defences, and thus can eventually help to reconnect body and mind (Loffer, 2000; Wix, 2003). The notion of art making as *embodied knowing* is encapsulated in the following quote:

In making art, hands are almost always involved, whether they are holding a marking tool or rubbing the back of a paper or pulling a print from a plate; often the whole body is involved in wedging clay, in standing to paint at a paper on the wall or in running to grab the paper towel to wipe up a spill. When knowing is embodied, that knowing is different from a rational, heady knowing. An

embodied knowing does not make sense in the same way, it tends to be more about feeling into knowing; what is sensuous cannot be left out of artistic knowing. (Wix, 2003, pp. 62–63)

Furthermore, the art object is tangible, and as such it provides physical evidence of the process that led to its creation. But it is also wrought with symbolic meaning; it carries the memory of the emotions of its creator. In this way, the image mirrors the experience of illness, at once concrete—bound to its physical symptoms, and abstract—linked to a complex network of thoughts and emotions.

To summarize, people living with illness often experience a split between body and mind. This division is habitually reinforced by medical professionals, who largely ignore the psychological effects of illness in favour of focusing on symptoms and treatment. Moreover, a philosophical notion of dualism permeates much of Western thinking, such that the mind, and therefore the self, is seen to be situated outside of the body. By providing opportunities for embodied expression, art therapy can help to bridge this gap. In reconnecting to the body, people are able to more deeply examine the experience of illness. This examination may lead to a search for meaning, and a questioning of the greater purpose of one's life. Given this, the following chapter will shift the focus of this discussion toward existential experience in chronic illness, and its relationship to identity and integration.

## CHAPTER FIVE: EXISTENTIAL ISSUES AND INTEGRATION

### Illness as Liminal Experience

Accepting the body means accepting it in its ill state. This can be extremely difficult, because it forces the individual to confront the erratic nature of chronic illness. Charmaz (1983) notes that this unpredictability can be frightening and that individuals may feel confined by not knowing when a period of remission will end and a return to illness will begin (p. 174). Duff (1993) reveals that the unrelenting cycle of relapse and remission can be devastating to one's optimism (Duff, 1993). Similarly Murphy (1990) writes:

The most profound effect [of my illness] was upon my consciousness, my self-awareness, the way I apprehended and constructed the world and my position in it. It was as if a mortgage had been placed on my thinking, as if a great uncertainty, an unspoken contingency, had entered my life. (p. 13)

This uncertainty is, of course, linked to the larger contingency of one's own existence (Frank, 1995, p. 85). Consciousness of illness inevitably brings about an awareness of both the fragility of life, and the proximity of one's own death. Living with illness can feel like being somewhat in between life and death (Ferris & Stein, 2002; Sibbett, 2005). This in-between-ness, or *liminality*, has been described by Sontag (as cited in Gwyn, 2003) as the "night-side of life" and as a, "dual citizenship, in the kingdom of the well and the kingdom of the sick" (p. 211). Similarly Duff calls it a "familiar yet foreign landscape" (p. xii) and Murphy (1990) describes it as feeling "alien" and "exiled" in one's own land (p. 111).

### *Liminality and Transition*

Sibbett (2005a), an art therapist who studied her personal experiences with cancer in an arts-based autoethnography, has written extensively on liminality and cancer. She suggests that liminality is the middle of three stages in a “right of passage,” whereby the first is a stage of separation from one’s previous life, and the following stage involves a new integration of the self (p. 14). Correspondingly, Ferris (2002) asserts that cancer can be seen as a “wake up call” encouraging people to live life to the fullest (p. 47). Duff (1993) suggests that the symptoms themselves force people to “reorient” toward life (p. 33). She writes, “the longer I am sick the more I realize that illness is to health what dreams are to waking life—the reminder of what is forgotten, the bigger picture working toward resolution” (p. 33). Liminality, then, can be seen to precipitate transition and growth.

### Art Therapy, Confronting the Existential, and Moving Forward

In her groundbreaking feminist narrative on breast cancer, Lorde (1980) asked “once we accept the actual existence of our dying, who can ever have power over us again?” (p. 53). Talking about death can be seen as the ultimate taboo, but the value of confronting one’s fears about dying is immeasurable. As described in an early section, art therapy offers a safe space for exploring difficult and painful thoughts and feelings. As such, it can provide an opening to existential introspection and a frame for processing feelings of grief and loss (Borgmann, 2002, p. 245). For example Rosner-David & Ilusorio (1999) describe a client with tuberculosis who expressed his fears about an uncertain future by drawing “a path to nowhere” (p. 199). They indicate that this process

helped the client to externalize his emotions and provided him with some psychic relief as he confronted the severity of his illness (Rosner-David & Ilusorio, pp. 199–200). Beyond this, Dreifus-Kattan (1990), points to the transitional nature of art making as a means of negotiating one's "final aloneness" (p. 118). Drawing from Winnicott's (as referenced in Dreifus-Kattan) theory of transitional phenomena, she suggests that art pieces as transitional objects help individuals to mediate between separation and togetherness (p. 130) in the same way that young children use play to self-soothe in the face of separation from their mothers. Similarly, Malchiodi (1996) proposes that when confronting one's mortality, art therapy can be used to review one's life and to reclaim a sense of wholeness.

#### *Art Therapy and Legacy*

Art therapy provides a means of reaffirming the self (Reynolds, 2002, p. 99). When chronic illness brings about fears of annihilation, this self-validation can be vital. Collie et al.'s (2006) research presents art therapy as a means of counteracting the fear of annihilation by, "(a) reducing feelings of threat to existence; (b) affirming and proclaiming present existence; and (c) enhancing the possibility of ongoing physical and psychological existence" (p. 765). In drawing, painting, or sculpting, one marks the world, and through this action declares one's own existence (Malchiodi, 1996; Siltala, 1998). The act of creation can provide a connection to personal power (Machiodi) and to life itself (Aldridge, 1993). Moreover, the image, as a physical object, can provide a "lasting visual legacy" (Machiodi, p. 51), strengthening one's sense of continuity, even beyond death. As Piccirillo (1999) states, "art becomes survival itself. By transcending time, art is durable and tangible proof of one's existence" (p. 184).

*Art Therapy, Risk Taking, and Accepting Loss of Control*

Frank (2007) writes that:

*Only when one's own life is felt to be fragile can life be fully embraced, because only then are humans unafraid to see how fragile everything is...In our everyday, embodied human lives, fragility is near impossible to entertain, much less to embrace. But within the safe space of the theater or the novel or other artistic genre, humans can tolerate the fragility of events and take pleasure in the possibility that things might turn out differently. People can learn how to tell the kind of stories that will take care of them, when fragility becomes immanent. (p. 393)*

Frank suggests, paradoxically, that there is strength within fragility, and only in accepting one's own lack of control can one gain true control. In an earlier work (Frank, 1995), he argues that, "illness is about learning to live with lost control" (p. 30) and that only by accepting contingency as a natural part of life, can the body become "fully associated with itself" (p. 49). Similarly, Charmaz (1995) contends that letting go of this need for mastery over the body "allows receptivity to bodily experiences" (p. 663). Thus, surrendering to illness is seen as an act of empowerment, allowing for the whole body to be integrated into the identity (Charmaz, p. 673). Charmaz adds that this surrender frees the individual from external pressures and social mandates, allowing the internal voice to emerge (p. 673). Duff's (1993) narrative illustrates this process of relinquishment. In it she admits that her illness changed her, but that she also willingly allowed herself to be "transformed—twisted and transfigured" by things that she knew she would "never fully understand" (p. 18).

As suggested in the opening quote to this chapter, creative experimentation can provide a safe outlet for exploring the unknown. Art therapy is even better suited to this task, because the therapist provides an additional level of safety and containment. In her study of art therapy with women with breast cancer, Predeger (1996) found that the

theme of “losing control, gaining control” (p. 54) predominated her participants’ visual and verbal expressions. As such, experimentation with art materials can lead in unknown directions, forcing clients in art therapy to let go of preconceptions and to allow themselves to be taken in new directions. As Sibbet (2005a) states, “*losing* control to the art materials during spontaneous art making might also help a person come to terms with lack of control” (p. 22.). While this can at times be frightening, especially to those who have unresolved fears (Piccirillo, 1999, p. 175), within the safe space of the therapy, clients can learn to tolerate risk (Ferris & Stein, 2002 p. 44). In their group art therapy for people with cancer, Ferris and Stein actively encourage this creative risk taking as a means of reinforcing and reflecting their clients’ abilities to tolerate change and the unknown in their lives. As clients learn that taking risks with art materials leads to creative growth (Edwards, 1993, p. 223), they may come to generalize this learning to other parts of their lives. Through art making, the paradoxical relationship between relinquishing and gaining control is made visible, tangible, and ultimately, understandable.

### Healing and Integration

For people with chronic illness, cure is not a realistic outcome. The illness will remain a part of them forever. Healing, however, is about more than recovery and cure. Accepting the ill body in all of its contingency opens the door to integration of the whole self. It is this integration that is healing. Predeger (1996) writes that:

...healing is not synonymous with cure; rather, it is a process of discovery through awareness, expression, and transformation leading to an integration and inward power. Healing can be a coming to peace or an acceptance of death when a cure is not forthcoming. (p. 49)



Similarly, Graham (as referenced in Malchiodi, 1993) suggests that healing is about gaining psychological wholeness, even as the body loses strength (p. 30). Moreover, Medich and Chase (1998) describe healing as the integration of the “physical, mental, emotional, social, and spiritual” into a cohesive whole (p. 370). In order to find this wholeness, one must accept the ill body as one part of the total self, but must also recognize the many other facets that contribute to one’s identity. Identity is not singular, but complex and multifaceted, thus integration involves an acknowledgment of this multiplicity.

### *Finding a Balance*

People with chronic illness face the difficult task of acknowledging illness without allowing it to consume and overwhelm their identities (Charmaz, 1995). In order to succeed they must “define themselves as more than their bodies, and much more than an illness” (Charmaz, p. 660). As Yoshida (1993) suggests, integration involves striking a balance between the newly accepted disabled self, and reclaiming elements of the nondisabled (pre-illness) self (p. 232). Frank (1995) insists that the self that needs to be reclaimed is plural in nature, and that people need, in fact, to reconnect with their “multiple selves” (p. 66).

The notion of the self as multiple can be traced to Gergen (1971), who argues that, “the assumption of a single, or global, concept of self seems misleading. Rather than speaking of *the* self or self-concept, it is much more fruitful to speak of multiple conceptions” (p. 20). Garai (1973) an art therapist who has looked at the process of identity development, refers to Gergen’s multiplicity as helping to reconcile dissonant aspects of the self, which in turn leads to opportunities for growth (p. 261).

Correspondingly, Maalouf (1996/ 2001) describes identity as emerging from the totality

of one's experiences and allegiances. In this framework illness and disability are seen as one variable among many that contribute to the total self (Maalouf, p. 10). He describes the composite nature of identity this way:

. . . identity is made up of a number of allegiances. But it is just as necessary to emphasize that identity is also singular, something that we experience as a complete whole. A person's identity is not an assemblage of separate affiliations, nor a kind of loose patchwork; it is like a pattern drawn on a tightly stretched parchment. Touch just one part of it, just one allegiance, and the whole person will react, the whole drum will sound. (Maalouf, 2001, p. 26)

Moreover, Christiansen (1999) suggests that it is identity itself that integrates diverse experiences (p. 554). Through internal dialogue people choose to define themselves in a way that present a coherent story, which in turn, allows them to preserve a relatively stable sense of self (Charmaz, 1999; Christiansen, 1999).

#### *Art Therapy and Integration*

Through art therapy, this internal dialogue can be made external, facilitating the process of integration. In visually representing multiple aspects of the self, the art work can bridge past and present elements of the identity (Ferris & Stein, 2002; McGraw, 1999; Reynolds et al., 2008). Ferris and Stein point out that the word metaphor originates from the Latin, meaning to "cross-over," (p. 44) thus the image, as metaphor, helps to transcend boundaries of self. Maslow (as cited in Silverstone, 1997) wrote that, "creating tends to be the act of the whole person. He is then most unified, most integrated. In moments of here and now, we don't reject or disapprove, we become more accepting" (p. 6). Moreover, Aldridge (1993) notes that art therapy offers a means of confronting feelings of emptiness by providing a structure with which to integrate the physical, psychological, and spiritual elements of the self (p. 289). He adds that when faced with the constant changes brought about by illness, making art can anchor experience and

encourage self-acceptance, while at the same time opening avenues for a new, creative self to emerge (p. 288).

These claims have been corroborated by research on art therapy with hospitalized and chronically ill people (Breslow, 1993; Gabriel et al., 2001). These studies report a movement from feelings of fragmentation toward a sense of wholeness and integration as the most significant outcomes of the therapy. One participant in Collie et al.'s (2006) narrative study of art therapy with women with breast cancer, illustrated this process as "picking up the pieces of her 'broken' self and using art to put herself back together as 'a more me, me' that was less superficially practical but was deeper and more reliable" (p. 768). Through manipulation of art media, abstract concepts of fragmentation and integration can be processed concretely. Riley (1999) suggests that specific art media contribute to specific therapeutic outcomes, and contends that the plasticity of clay, for example, reinforces the client's ability to tangibly work through issues of change and transformation. Similarly, in her work with dissociative clients, Gerity (1999) found that the external art process could literally mirror the internal movement toward integration, so that through pottery, "the shattered sense of self could be projected into the clay and put back together with 'slip' [clay glue] and 'care'" (p. 85).

In summary, confronting illness often brings about recognition of one's own fragility. This can be terrifying, but paradoxically, accepting the reality of death and dying, can be a liberating experience. Once we let go of our need to control our bodies and our lives, we can in fact regain a deeper, more substantial sense of personal agency, and a true acceptance of our total selves. Art therapy can help to bring about both the exploration of the existential and the integration of the whole self. By providing tangible

proof of one's present existence, and by creating physical objects that may serve as personal legacy, art therapy can help to counteract fears of annihilation. Moreover, transformation of the art materials can function as a rehearsal for change and growth in life, and visualisation and manipulation of symbolic aspects of the self can mirror the integration of the multiple facets of one's identity. This discussion will now turn toward narrative agency, and construction of the self.

## CHAPTER SIX: TRANSFORMATION, NARRATIVE, AND CONSTRUCTION OF THE SELF

The notion of multiplicity fits within the larger theoretical framework of Constructivist thought. Constructivists argue that there is no objective reality; rather, individuals actively construct their own realities based on their perceptions of their experiences (Richert, 2006; Riley, 1997). This fluid process of construction and reconstruction is viewed by constructivists as normal, and thus changes to self and identity are equally seen as normal (Kelly & Field, 1996, p. 245). Exploration of the self is regarded not as a process of discovery, but a process of construction, in which individuals create the selves they wish to identify with (Milner, Campling, & O'Byrne, 2002).

### *Constant Change as Normal*

Mahoney (2003) asserts that life does not follow a linear path, rather human transformation is a complex, dynamic, and sometimes chaotic process. Likewise, as people react to transformative life experiences like illness and disability, identity shifts and evolves (Kelly & Field, 1996; Yoshida, 1993). With chronic illness, as the body enters a state of constant transformation, the identity also evolves continuously (Kralik & Telford, 2005c, p. 7). Williams (2000) describes this as, “a never-ending cycle of biographical appraisals and re-appraisals, assessments and re-assessments” (p. 57). As a case in point, Duff (1993) admits to feeling instability in her sense of self as she realizes that her illness is “not so much a state of being as a process of transformation” (p. 78). However, through her own narrative process, Duff comes to normalize the experience of illness. She writes:

I have heard it said that illness is an attempt to escape the truth. I suspect it is actually an attempt to embody the whole truth, to remember all of ourselves. For illness is not just something that happens to us, like a sudden sneeze or passing storm, it is part of who we are all the time. (Duff, p. 5)

### *Narrative Agency*

Narratives are much more than stories, they are the structures through which individuals come to understand their experiences. Galvin (2005) describes identity as a narrative that is under constant construction and reconstruction (p. 394). As such, the relationship between identity and illness shifts in time with changes in the individual's perception of reality (Paterson, 2001, p. 23). Constructivist therapists argue that individuals are active agents in the creation of this narrative, and that even as life presents new challenges, they have the power to determine the meanings they ascribe to their experiences (Mahoney, 2003). This process of *reauthoring* is essential to the creation of an integrated, post-illness identity.

Many social narratives empower medical professionals to dictate the stories of illness and essentially construct people with illness as passive. As a means of counteracting these ubiquitous narratives, the reauthoring process returns power and voice to the person living with the illness (Frank, 1995). While traditionally, narrative therapy is verbal, art therapy provides an alternate format for reauthoring life stories (Malchiodi, 1999; Reynolds, 2002). Junge and Linesch (1993) suggest that art therapy is particularly suited to this task because just as art therapists encourage clients to explore diverse combinations of line, shape, and colour, art therapy embraces diverse perspectives, and opens clients to multiple ways of knowing (p. 62). In the following quote, Ferris and Stein (2002) illustrate the narrative potential of art therapy for people with serious illness:

In times of great crisis and trauma, what we know of as the self contracts, becomes less actor than acted on, and inner listening brings only a welter of frightening and chaotic voices. Further withdrawal may result. Therefore, our primary intention is to help each participant unfold the cramped self, uncover losses and strengths, and gain the courage to begin a process of reclamation of story and life. (p. 47)

Negative stories that were once trapped within the mind can be transformed through the image (Long, 2004; Luzzatto, 1998). Wix (2003), an art therapist who wrote her doctoral dissertation on the notion of the creation of self through art, writes that, “like self, image is not static but is always shifting and changing. In constructed knowing, knowledge is not absolute; like image it shifts and changes” (p. 61). As part of her group art therapy approach for people living with cancer, *The Creative Journey*, Luzzatto describes a two-step intervention which illustrates this process of transformation. She first asks clients to draw their stress, then encourages them to take the image and transform it in some way, so that the new image represents a movement from, for example, “tension to peacefulness,” or from “confusion to clarity” (p. 174). Similarly, she often asks clients to use techniques like scribbling or drawing blindfolded, to make “meaningless” images (p. 172). Then, by finding elements within these images, to which they can associate stories, her clients are able to lend meaning to that which initially seemed meaningless (p. 172). Techniques such as these allow people to change the stories that are dominating their experiences and to find new, more positive expressions of their selves (Cruze, 1998). Gerity’s (1997) work provides another pertinent example. She uses puppet making to help people to work through issues of identity transformation, and finds that this technique allows people to witness their own growth and change through the metaphor of the emerging puppet (p. 102). Finally, Reynolds has found that making art, even without the presence of a therapist, may help women with chronic

illness to project new, more constructive meanings onto their illness experiences, thereby allowing them to reauthor their life stories (p. 105).

### *Art Therapy and Construction of the Self*

As Frank (1995) argues, “the self-story is not told for the sake of description, though description may be its ostensible content. The self is being *formed* in what is told” (p. 55). Thus the self is in fact, constructible, and individuals, when made aware of their power to do so, may choose how they wish to define themselves. When living with chronic illness, people are forced to reevaluate their lives in terms of their changing experience, and “piece together a different view [of themselves] for the future” (Kralik & Telford, 2005c, p. 10). Likewise, Charmaz (1994) points out that chronic illness often leads to the discovery and creation of new facets of the self (p. 227).

Collie et al. (2006) propose that through the constructive properties of art, meaning is literally *made* (p. 769). Along the same lines, Dreifus-Kattan (1990) contends that within the therapy, “artistic expression always contains the unconscious wish that the finished product might re-establish the physical intactness that is being destroyed by the cancerous process” (p. 135). As a case in point, Cruze (1998) describes her experience of being covered with plaster casting medium for a sculptural project, as “re-setting” the parts of herself that had been broken by cancer (p. 402). Making art, can thus be seen a reparative process, helping to heal those aspects of the self that have been injured by disease.

The frame of art therapy provides the conditions not just for reparation, but also for the construction of the self. In her capacity as an art therapist and researcher, Ellis (1989) has found through drawing and painting, women are empowered to create images of themselves that, in turn, shape their “ways of being in the world”(p. 275). She further



argues that their portraits may help to free them from socially imposed images of perfection (p. 275). This is particularly relevant to people with illness who must move beyond social stigmas in order to integrate their less-than-perfect ill bodies into their self-conceptions. This fits nicely with McGraw's (1999) assertion that artwork can help people to recreate themselves with their own "strengths, issues, and solutions" (p. 248). To illustrate this notion of self-creation, Siltala (1998) describes a painting by Frida Kahlo, in which she has reproduced her birth, but juxtaposed her own face onto her mother's body in order to assert that she (Frida) was responsible for her own creation, rather than her mother (p. 136). Along the same lines, Wix (2003) asserts that art making is constructive in that it is a means of creating knowledge, and through this new meaning, self (p. 61). In her own words, "constructing a reality is constructing a world is constructing a self. Selfing through art has to do with giving form to matter and in so doing giving form to self" (p. 45).

To recap, the constructivist perspective empowers individual to create their own realities, and thus they are able to define themselves in ways that are personally meaningful. This can be achieved by reauthoring the story of one's illness, such that it is reframed as part of the total experience, rather than overwhelming all other aspects of the self. Through image making, art therapy can help individuals to explore and re-create their self-images. In witnessing and constructing the transformation of images, a sense of personal agency may be returned, providing avenues for hope and a means for positive reframing of the illness experience. In light of this, the concluding section of this paper will examine the positive shifts in perspective that have been reported to emerge from the experience of living with chronic illness.

## CHAPTER SEVEN: TRANSCENDENCE, GROWTH, AND RENEWAL

### Post Traumatic Growth

As we have seen thus far, chronic illness presents tremendous challenges to self and identity. However, in forcing reevaluation of previously held beliefs about the self, illness may also present opportunities for growth and self-discovery (Asbring, 2001; Charmaz, 1983, 1994). Ironically, it is sometimes through illness that people come to know themselves best, and to learn to appreciate their lives more fully. Frank (2007) argues that the crisis of illness can be deeply enabling, in that it requires individuals to recognize and draw from strengths they never knew they had (pp. 133–134). Similarly, Charmaz (1995) notes that, “because of their physical losses they [people with chronic illness] reassess who they are and who they can become” (p. 660). In support of these claims, Loffer (2000) whose heuristic study looked at the experience of living with rheumatoid arthritis, reported that illness led to the discovery of strengths like “perseverance, patience, tolerance, assertiveness, emotional vulnerability, and emotional fortitude” which helped participant researchers to move beyond their physical losses (p. 293). Loffer further suggested that these discoveries led to a greater sense of fulfillment in all of their lives (p. 293). In this way, illness can be seen as a “turning point” (Zausner, 1998, p. 23), or a “wake-up-call” (Ferris & Stein, 2002, p.47), leading to a fuller appreciation of one’s self and one’s life. As one participant in Charmaz’s (1994) study declared, “for me, illness was the gift that brought me together with myself” (p. 226).

#### *Acknowledging Illness Related Achievements*

Once the illness has been truly accepted and integrated, people often undergo a major shift in perspective, or *cognitive reframing* (Salick & Auerbach, 2006, p. 1022).

This reframing involves focusing on strengths which defy socially-imposed criteria relating success to productivity and achievement (Charmaz, 1994; Kralik & Telford, 2005a). People begin to recognize the strengths inherent to their struggles with illness; that they are in fact, “confronting and conquering challenges that would seem overwhelming to any human being” (Kralik & Telford, p. 12). Frank (1995) suggests that this can be achieved through what he calls the *quest narrative*, in which individuals construct themselves as the “heroes of their own stories” (p. 134). He describes this heroism as deriving from the notion of “perseverance through suffering” (p. 134), whereby individuals use illness as a springboard for self-discovery (p. 115). The self that is discovered must learn to value its ability to *be*, rather than the things that it can or cannot *do* (Kralik & Telford, 2005c, p. 16). Murphy’s (1990) assertion, through his narrative, that, “in [his] passage into paralysis [he has] discovered the ebullience and power of the rage to live” (p. 3) illustrates his quest and discovery of a new source of strength.

#### *Art Therapy, Self-Discovery, and Renewal*

Like the written word, art therapy records experiences and gives form to personal narratives. In this way the image can provide a concrete record of the individual’s experience, highlighting strengths and courage (Borgmann, 2002, p. 245). Further, as a tool for self-discovery, art therapy can help to unpack the illness experience and to unearth hidden aspects of the self (Ferris & Stein, 2002). According to Ferris and Stein, art therapy renders people:

. . . more capable of meeting the unknown, of stitching new meaning from old cloth. Thus, cancer can be a form of expansion rather than contraction of meaning. The use of myth, metaphor, and symbol work because they draw what is inside to the outside. (p. 45)

Beyond this, art therapy provides opportunities for creative self-expression and creative growth, which can in itself, be deeply esteem building. Artwork can thus serve as a new source of pride. Moreover, while people with illness may not be able to *do* many of the things that used to fill their time, art making and art therapy can serve as both occupation, and opportunity for quiet reflection, allowing individuals to truly *be* in the moment. In this way, art therapy can provide a space in which the illness and the pain can be accepted and acknowledged, while at the same time offering an opportunity to shift the focus toward the image. On the flip side, Zausner (1998) suggests that the intensity of the illness experience might itself lead to a heightened sensitivity, essentially catalyzing creative exploration (p. 24). He argues that:

The drive to produce art despite physical impediments is what may transform a potential disorder into a creative chaos. As chaos contains the seeds of the new order, so may illness contain the seeds of the new artists and the new art. (p. 27)

Similarly, Predeger (1996) contends that diagnosis with chronic illness might bring about a strong desire for self-expression, which might subsequently inspire people to make art (p. 52). Whatever the initial impetus, once art making is accepted as a meaningful occupation, people can let go of the significance they once ascribed to other occupations, (like their careers) and allow themselves permission to immerse themselves in their art (Reynolds & Prior, 2003, p. 790). As such, art making can become prioritized, and according to Reynolds (2004), the person can “break free from her limited categorization as a ‘person who is ill’ and instead [gain] a fresh and valued identity as an artist” (p. 88). Furthermore, Puig et al. (2006) advocate art therapy as a means of reframing the illness experience and encouraging “personal transformation and growth” (p. 224). Similarly, Reynolds (2002) found that art making allowed women with illness to express and clarify

their “core concerns and values” thus transforming their illness experiences, and reflecting and evidencing new “self-actualizing” selves (p. 104).

To summarize, for some, illness may be seen as a turning point. By forcing individuals to slow down, illness may provide them with the opportunity to get to know their true selves. And by acknowledging all that they have learned to endure, people may eventually derive strength from their suffering. The slower pace of the illness experience might also provide an opening to making art. In turn, through art making and art therapy, people may transform the chaos and uncertainty of illness into powerful images that reflect their own growth, courage, and strength, and in so doing they may re-create themselves and move forward with their lives.

## CHAPTER EIGHT: CONCLUSION

This paper has woven together insights gathered from a huge body of literature on chronic illness, identity and art therapy. This literature has shown that chronic illness significantly impacts identity on multiple levels, including one's sense of agency, one's relationship to one's body, to the social world, and to the existential. More significantly, the evidence gleaned from the literature has shown art therapy to be an effective means of exploring, uncovering, and expanding possibilities for self-definition.

Chronic illness can call in to question the most basic self-definitions. It can shake us to the core of our beings, but in that shaking we might just find our true selves. While chronic illness can be extremely difficult to accept, art therapy can offer a distinct vantage point from which people may safely begin to decipher the meanings of their illness experiences. As a means of wordless expression, image making provides an alternative to verbal psychotherapy, allowing individuals to share their fears, anxieties, and losses. In this way they can grieve the self of the past, and slowly come to terms with the entirety of their shifting realities.

In contrast with a medical profession that virtually reduces patients to the sum of their symptoms and bodily defects, art therapy aims to depathologize the experience of illness, opening the door to healing, wholeness, and integration. When illness may highlight things that people are unable to do, art making can reinforce individuals' continuing strengths, abilities, and creative potentials. This can help build esteem as well as help reestablish a sense of personal autonomy and, consequently, a feeling of integrity. Through the images created and the art therapist's total acceptance, the illness experience can be witnessed. This witness can help to contain emotions that might otherwise feel

overwhelming, and people can eventually begin to confront deeply painful questions about their own mortalities. Art therapy can become the stage upon which individuals may rehearse the many challenges presented by chronic illness. By playing with the art materials and creating images, they can gain a sense of control and personal agency, as well as an ability to let go. They can learn to take risks with art materials and find strength and beauty in the unknown. Moreover, through imagery they can test out different aspects of themselves and visually represent the multiplicity of their experience. The process of image making can mirror the evolution and transformation of the self. Furthermore, the tactile qualities of working with art materials, offer a link to exploring and expressing physical experience. This sensory engagement may help individuals to overcome feelings of dissociation between body and mind, thus bringing them closer to integrating the illness experience into their total identities. In this way they may come to understand, as Charmaz (1995) has established, that “the self is of the body yet beyond it” (p. 675).

Loffer (2000) describes the process of coming to terms with illness as a spiral. She writes that, “in coming to acceptance, we spiral back through the themes of self-discovery, as if the spiral bends forward toward its beginning, forming a circle. Knowing and accepting ourselves means knowing and accepting our disease” (p. 307). Through art therapy, individuals can open themselves to artistic ways of knowing that defy the limits of socially imposed standards and mores. They can learn to accept the slower pace of living that chronic illness often brings about and come to find value in the capacities that have allowed them to endure the trials of illness. They can acknowledge the incredible strength and achievement that comes from enduring physical suffering, and the flexibility

and power that comes from embracing the unknown. They can learn not only to know themselves, but how to construct their self-images and their lives. Thus the illness experience, although painful and deeply challenging, can come to be seen as process of discovery, and ultimately an opportunity for growth.

### Avenues for Future Research

This review of the literature has clearly shown that art therapy is a relevant and useful modality for addressing the identity concerns of individuals living with chronic illness. But it has merely scratched the surface of the topic, evidencing the need for future investigations. Medical art therapy is a growing field and as the present study has shown, it has yet to directly address the relationship between chronic illness and identity. Future avenues for research could involve putting this theory into practice, and providing clinical case examples of individuals with chronic illness using art therapy to explore their identities. Moreover, it would be interesting to evaluate whether individual or group art therapy is most suited to this task, so a comparative case study could be useful. Another possibility would be to assess whether there are different identity issues for individuals whose illnesses are diagnosed early in life and those who are diagnosed following middle age, and to explore the different ways in which these groups use art therapy. It is my hope that this research has opened the door to new insights into the relationship between chronic illness and identity, and that it will inspire both clinicians and researchers to further explore the healing potential of art therapy.



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