Information Management and the Moral Self:

A story of uncertainty in chronic illness

Agnieszka Bill-Duda

A Thesis
In
The Department of Sociology and Anthropology
Presented in Partial Fulfillment of the Requirements
for the Degree of Master of Arts (Sociology)
at Concordia University
Montreal, Quebec, Canada

June 2019

CONCORDIA UNIVERSITY

School of Graduate Studies

This is to certify that the thesis prepared

By: Agnieszka Bill-Duda

Entitled: Information Management and the Moral Self: a story of uncertainty in chronic illness

and submitted in partial fulfillment of the requirements for the degree of

Master of Arts (Anthropology)

complies with the regulations of the University and meets the accepted standards with respect to originality and quality.

Signed by the final Examining Committee:

Chair: Prof. Jean-Philippe Warren
Examiner: Prof. Valerie de Courville Nicol
Examiner: Prof. Julie Archambault
Supervisor: Prof. David Howes

Approved by ____
Chair of Department or Graduate Program Director

___________2019 ____
Dean of Faculty

Abstract

This thesis follows the stories of three main interlocutors who are afflicted by chronic illness. The purpose of this ethnographic research is to shed light on the work that patients do to receive care from their health practitioners. Participants use information technologies to assess whether their needs are being met on their terms, whether their diagnoses are believable and whether they are being taken seriously. I argue that, in the context of managing chronic conditions, it is incumbent upon patients to use every means of information available to them to secure the best outcomes for their health and their futures. However, the use of information is mediated by experience, emotion, positionality and responsibility, all of which impact the ‘best good’ outcome for the patient. As such, information and the act of googling produce a moral practice. In the case of my participants, this moral practice also curbs uncertainty as regards their experience of daily pain.

Table of Contents

Acknowledgements

I heard someone say once that graduate school is 60% mental health management and 40% theoretical work. It is not easy moving cities and building new social supports in such a stressful time but I have met some amazing people without whom this degree would not have been possible: Matthieu Guerin, Marion Carrier and Sarah Carrier (for giving me a fantastical escape), Marianne Barker (for Friday night free food at McKibbins), Lauren Chatterton (for the many random items that my hoarder self really enjoys), Daniel Harvey (for impromptu coffee pop-ins), Arturo Esquivel (for post-tutorial conversations and fishing trips) Emanuel Lucas (for early morning social analysis).

And then there are the people who pushed me through my writing process: Rena Saad, our constructive Friday thesis workshops; it was the perfect way to start writing. Thank you for reading my ideas in their infancy. Heather Wallman, you sat down and read everything I had, reminding me that there is a different perspective from the one I’ve made burrowing in a hole of my own making. Diane Carru, you were my library, lunch and yoga buddy for so many months. I can’t count the days I would not have made it to the library had it not been for you.

I thank my family: Maggie Thomson-Kurz, Simon Faucher, Michalina Duda, Wojtek Pietrasik, Ania Fiedorek, Andrzejka Axt, Heather & Steph and my parents, Ewa Pietrasik and Przemek Duda, who were there whenever I was bored or burning out or needed somebody to talk to. It has been a long, stressful and beautiful time of growth and I am so lucky to have had you through it.

I want to thank my supervisor and mentor Dr. David Howes for guidance and patience throughout this process and my committee members, Dr. Julie Soleil Archambault for suggestions and ideas and Dr. Valerie Courville Nicol for taking time to read and provide feedback to my work.

Finally, I would like to thank my research participants: without your openness, patience and willingness to share your stories, this thesis would not be here. This is as much my work as it is yours. Thank you.

Introduction

My fieldwork began in the Comox Valley, located on Vancouver Island, British Columbia in June 2017. I drove through the mountains from Edmonton, Alberta, and arrived in a small town late at night where a couple of friends met me at the Herb Festival. The festival, a small community celebration, was centred on health, wellbeing and herbal remedies. During the day, festival-goers equipped with paper and pens attended various workshops and took notes on the presentations. There were workshops on how honey is made, on flower pollination, menstrual cycle tracking, fermenting food, etc. At night some local artists performed on stage, children ran around dancing to music, and adults drank cider from compostable or renewable containers around a bonfire.

The next morning I went to the parking lot to enjoy a cigarette and coffee since the festival grounds were smoke-free. A man came up to me. He balanced a pyramid-shaped metal frame on his head. I asked him about the pyramid on his head, and he seemed happy to talk about it. The pyramid story began a few years back when this man was in a car accident:

> *Man*: I was in a car accident a few years back, and my back was like, basically broken. I went to see all kinds of doctors but nothing else helped me.
>
> *Ag*: But the pyramid works?
>
> *Man*: Yes. People think I'm crazy, but I've given that up, caring about what people think. It works.
>
> Later he asked me if I mind that he goes to pee behind the car. I said of course not. When he came back, I noticed that he was drinking from glass, vase-shaped vessel.
>
> *Ag:* Are you drinking green tea?
>
> *Man*: No, it's my urine.

I was about to ask him questions about this, but he jumped straight into it, telling me about the benefits of urine therapy, swirling liquids in specifically-shaped vessels and washing one's face with urine. He told me to Google it and told me about resources available online if I wanted to learn about it.

Later that day, I attended a workshop on cycle-tracking. Cycle tracking is a method of birth control (according to some sources[1]), a method for getting pregnant (according to some other sources[2]) and a method for nothing useful at all (according to yet other sources[3]). At this festival, cycle tracking was framed as an empowering thing for women to do, whether it was to prevent pregnancy, to get pregnant, or to regulate any irregularities in the menstrual cycle. At one point during the workshop, a woman in the audience put her hand up and questioned the validity of temperature tracking of the vagina; according to the workshop leader, vaginal temperature increases slightly during ovulation. The workshop leader picked up a very large and heavy book, lifted it to her chest:

> *The workshop leader:* I base myself off of this textbook which is based on a lot of research, and she [the author] argues that temperature varies according to which point in the cycle the woman is.
>
> *The lady in the audience:* But I have heard that this might not be true anymore because there has been research done on this and apparently vaginal temperature doesn't change.
>
> *The workshop leader:* Ya, I have not heard this information before, so I'm not the best person to ask about it. But you all can go and research it yourselves. But in the way that I understand cycle tracking and in the way I teach it, it is important.

As the conversation about vaginal temperature dissipated, the workshop leader set the book down and continued her lecture.

A few questions arose from the events at the Herb Festival: would researching this information myself allow me to make better judgements? Would I be able to parse out the 'truth' from my online research about vaginal temperature and cycle-tracking? Could I make a judgement on these issues? On what would I base my judgement? Could the timing and temperature tracking

---

[1] https://www.plannedparenthood.org/learn/birth-control/fertility-awareness; https://www.yourfertility.org.au/everyone/timing

[2] https://www.everydayhealth.com/womens-health/tracking-your-menstrual-cycle.aspx; https://www.webmd.com/baby/charting-your-fertility-cycle#1

[3] https://www.webmd.com/infertility-and-reproduction/news/20030710/menstrual-cycle-proves-more-complex#1

of ovulation ‘work’ for someone and not ‘work’ for someone else? If it did or didn’t work, was it *because* temperature tracking works or doesn’t work, or because of other things such as not doing it right or eating things on the wrong day at the wrong time of day? In any case, the audience was left with this pressing question unanswered: did temperature tracking work or not work? And according to whom? In the end, as the workshop leader framed it, the audience decided to make a judgement on whether this method worked or didn’t work. The workshop leader withdrew her authority in this situation, and we were provided with two arguments and told to make up our minds about this issue through research. And in the first anecdote, would Googling urine therapy help me make a better judgement about it rather than reacting unfavourably by gagging?

I chose these two anecdotes because they illustrate how responsible information management is something *expected* of people. Whether choices are made about what kind of diet to pursue or what kind of practitioner to see for the kink in the neck, people are expected to know already what they want and to be aware of arguments and discussions surrounding that topic. Our access to and ubiquitous use of information technologies in the form of cellphones, tablets, laptops and computers, along with Google and other information technologies paired with consumerism and a sense of personal responsibility exasperate expectations that we are already knowledgeable in what we want from our health services. This knowledge, as will be illustrated throughout the thesis, produces a new kind of engagement with information.

In this thesis, I argue that in the context of managing chronic conditions, it is incumbent upon patients to use the information available to them to secure the best outcomes for their health and their futures. Making choices that encompass the ‘best good’ in moments of existential uncertainty is a moral imperative. This moral imperative is exacerbated by the use and availability of information with which to make choices and by the neoliberal paradigm of self-care. I examine the ways that people suffering from chronic conditions use online information when searching for diagnoses and therapies. The process of research relies on several factors, including life experiences, motivations, needs, positionality and advocacy. Emotions, such as trust and hope, are also important in the process of health attainment because they connect people’s experiences to larger structures. Finally, through the use of online information, morality is produced, maintained, and managed.

The central theme of this thesis, and one that I will continue to come back to is that of uncertainty. Uncertainty, seen as indeterminacy about the future, guides the kinds of decisions and actions that we make. These actions are not abstractions, but rather, are pragmatic endeavours based on faith, trust, belief and emotion guided by a moral imperative to lead a good life, to make the 'right' choices, and essentially, to survive and thrive in an uncertain world.

Arthur Kleinman (2006; 1) writes that uncertainty and suffering are inevitable aspects of human life. After all, human life ends in death, marking all of our days with its creeping (*ibid* 5). In his work, Kleinman takes the stance that a problem of modernity is its quest for certainty and management of misfortune. Risk management, magical belief in technological supremacy, denial of the existence of vulnerability, self-control, mastery of the environment, social order and denial of human limits are all myths of Western modernity that create illusory lifescapes that people find themselves in (*ibid* 6-7). Suffering is an important part of human experience. In existential anthropology, the ordinary and mundane matters because it is here that the world and politics are lived and experienced (Das 2006). Mundane experience and societal myths reinforce each other, but we also resist those myths. While we may *believe* in the myth of self-control, we know that something bad might happen that is completely out of our control. These two things can exist within one moment at the same time and not be paradoxical.

Uncertainty is something that marks human existence; suffering and pain occur in one way or another, from heartbreak, death of family, bodily harm, to persecution and injustice. And yet, it would be unreasonable for humans to not search for ways to alleviate uncertainty and move towards something more certain. Uncertainty is oriented towards the future and experienced in the present moment; uncertainty is a future-making concept that can mobilize the resources available to avoid misfortune in favour of a more certain outcome. I argue that the people approach this issue pragmatically by gathering resources/information to make decisions when faced with uncertainty (also see Whyte 1997). Potentiality, like uncertainty, is a future-oriented concept that opens doors for imagination, problem-solving and reinforces a moral order.

The original question for this research was: how do people make health choices? And more precisely, how do people choose alternative medicines? This question slowly shifted as I listened to my interlocutors' stories throughout the summer. I noticed that "choices" were sometimes strategies that they have had to engage to be taken seriously and have their needs met. The main question for this thesis is: how do people ensure that they are taken seriously in medical contexts? What routes do people take to ensure that their needs are met?

I became interested in alternative medicine because of the polarization that certain practices seemed to cause. I noticed my friends (in Edmonton, Alberta and various large cities in Europe) talking about alternative medicine, organic food and lifestyle changes as important practices in their lives, both socially and intimately. Some people stuck by their beliefs and convictions in the practices in which they participated and excluded other people through these convictions. On the other hand was my family (amongst others) who do not believe in many of these practices and react strongly against them, calling them Quackery (as opposed to their evidence-based approaches). At the same time, they selectively participated in some practices that they found meshing with their lifestyles or that they believed in based on their positionality (communist/post-communist Poland, urban middle class). This schism between Quackery and evidence, magic and science, created a tension that I wanted to explore. I was interested in how these conversations create and perpetuate schisms is practices, discourse and conviction. By focusing on one node in this complex equation (alternative medicine), I wanted to look at what creates belief and how moral are questions negotiated.

Methods

Anthropology uses ethnographic fieldwork to gather empirical data about social and cultural issues. Ethnographic fieldwork includes participant observation and interviews conducted with research participants. Clifford Geertz (1998) referred to ethnography as ‘deep hanging out,’ which requires the ethnographer to immerse themselves into the lives of participants and their social worlds. For this ethnographic fieldwork, I drew on interviews and ‘deep hanging out’ (participant observation) to gather empirical data about the ways that people use information in the context of health. I recruited main participants through local online ads (such as Craigslist and UsedVictoria), notices in public places (such as libraries and markets), and through snowball techniques. Following a debriefing about the purpose of the research study, participants were able to read the consent form and ask any questions they had about the study. Consent forms were provided for participants, approved by Concordia University Office of Research before my arrival at the field site. Both the participants and I kept a copy of the signed consent forms. I conducted a series of interviews with each participant, recording the interviews throughout the interview process and taking field notes throughout the participant observation process.

I arrived in the Comox Valley on Vancouver Island early June 2017. The valley itself consists of a series of villages and farms connected by larger cities and towns (Courtenay, Cumberland and Comox). Small farms dot the landscape alongside swaths of forests and parks. In the summer, various bays and rivers become refreshing bodies of water, places to plunge into during the heat of the day. The K'omoks First Nations straddle their territory next to a freeway which connects the city of Courtenay with the town of Comox. The tiny airport is located near the military base, where much of the population of the Valley is employed. While the valley thrived in the 1960s from the mining, logging and fishing industries, these declined to make way for tourism and construction as the main industries. However, the health-centred orientation of the valley makes it an interesting context to study for this project. The islands surrounding the mainland of Vancouver Island are dotted with farms, where various families and individuals participate in small business. The socio-cultural context of the Valley can be situated into the larger context of the history of the West coast of the United States and Canada. This historical context puts us in the present-day health conscious movements, conscious eating and local farming, and availability of alternative therapies (with some, such as acupuncture, being included in various benefits packages for employees).

There are a few reasons why I chose the Comox Valley for the location of my fieldwork. The first and most important one was that I knew people in the valley and knew that I could receive lodging through my time there. The second important reason was that I had already set up a social network in the valley. Finally, Comox Valley (along with Vancouver Island in general) is known for its "hippie" vibe and, as outlined above, provided plenty of opportunities to recruit participants who showed interest in my research.

Following the data collection process, both field notes and interviews were transcribed digitally and coded. The data was kept in a locked file on the researcher's computer during the data analysis process. Anonymity was ensured by providing each participant with a pseudonym and by changing the names of locations and only disclosing the general area of my research. Furthermore, participant occupations and any identifying character aspects were changed in the writing process. I did not change the gender of my participants, their age-group, nor their class background. In Chapter 2, I follow the lives and stories of my main participants to paint a picture of their struggles, pain and uncertainty. This was a choice that I made as a writer and anthropologist; rather than telling all the stories I gathered, I chose to tell a select few but delve deeply into them, bringing out the humanity and precarity in them. My focus on participants' lives was both a stylistic and an analytical choice: by being able to delve deeper into the personal stories and quotes, I could delve deeper into the theoretical frameworks that I wanted to draw on in this [thesis.

As I began my fieldwork, I was ready to marathon interview participants and gather as much data as possible. That turned out to be impossible. It was summer, and it was the West Coast, where time seemed to drag on much more slowly than the urban life I had just arrived from. After fighting some anxiety, I began to slow down enough to enjoy the beaches and sunshine. After all, fieldwork was partly participant observation, and I had to participate in beach activities as well. Even in the most mundane exchanges, I noticed the ways that people use information technologies in times of doubt and uncertainty. For example, this is an excerpt from a casual exchange about trees and their differences:

Person 1: Is this aspen?
Person 2: No, I think that's birch. I think aspen leaves are different.
Person 1: Are they?
Person 2: Yeah, I think so. Google it.

In this example, uncertainty is managed with the use of Google, an information technology, that can provide an answer to settle the question about trees. Caliandro (2018; 553) argues that the internet is a source of new modalities and languages which we cannot ignore when studying contemporary society. I found this to be the case during the participant observation process. Access to the internet was always available, at most people's fingertips. Information was accessed through the smartphone and mediated through the process of Googling answers to all kinds of questions. People discussed and shared online posts, conversations and memes. These ideas resonate with Haraway's (1984; 7) manifesto in which she writes:

> By the late twentieth century, our time, a mythic time, we are all chimeras, theorized and fabricated hybrids of machine and organism—in short, cyborgs. The cyborg is our ontology; it gives us our politics. The cyborg is a condensed image of both imagination and material reality, the two joined centers structuring any possibility of historical transformation.

Through this research, I found it compelling to examine ways that information technology played a part in people's lives. Drawing on the above quote, I found it inevitable to study humans as part machines whose politics are a discrete part of their ontology. Along with politics come moral and ethical questions; a close look at the moral implications of making choices about health with the use of technology became an important aspect of this research.

If it is impossible to ignore technology and information during the process of fieldwork, it is also impossible to ignore it in my thesis. This research also draws on data obtained online mainly in the form of textual analysis of a debate occurring on social media. Both the website and the social media platforms are public domain, and the information is accessible to the public. To protect the identities of individuals posting on the platforms, I have changed handle names to "Post 1," Respondent 1,2,3." Information obtained through social media is public; however, I decided to change the handles of individuals and the name of the platform for the sake of anonymity.

Literature Review

What is health? There are many ways that anthropologists, sociologists, and philosophers have examined health and illness. Kleinman (1988; 8) argues that illness has many meanings it is multivocal in that the social, personal and clinical vocalities of illness all differ from each other and illness is negotiated in clinical settings through its vocalities. Crawford (2006; 402) states that health is a meaningful social practice and that health practices are constitutive of identity and formation of the self. Mattingly (1998; 273, see also Mattingly 1998; Kleinman 1988) examines the ways that discourse within the clinic shifts between rational "chart talk" and storytelling, thereby constructing different clinical objects and a distinct form of rationality. Beyond these symbolic and constructionist definitions, however, lies the pain and existential uncertainty that people feel when they are faced with illness or disease. How do the social sciences address those issues?

In 1987, Nancy Scheper-Hughes and Margaret Lock published a seminal article in medical anthropology entitled "The Mindful Body: a Prolegomenon to Future Work in Medical Anthropology." In this article, the authors describe three separate ways in which to view the body: the body as phenomenological experience, the body as social, and the body as a body politic or an artifact of social control (Scheper-Hughes & Lock 1987; 6). They suggest new ways in which medical anthropology can incorporate these theoretical conversations about the body and how it can offer its insights into the field of embodiment. This article was seminal in that it urged medical anthropologists to take the body and its experience seriously and to think about the body in different ways.

Good et al. (1992; 1) argue that "pain is a universal feature of the human condition." They differentiate between acute and chronic pain, arguing that the former is something ubiquitous that everyone experiences, whereas the latter is not ubiquitous, but it is not uncommon. They argue that chronic pain highlights the "fault lines of society" (*ibid*; 3) in that social class, poverty, access to resources, labour issues are evident through research conducted on chronic pain, its prevalence, and people's access to social resources. Chronic pain is also important in the literature on embodiment as it shows how "bodily experience is influenced by meanings, relationships, and institutions" (*ibid* 7). Years later, Manderson & Smith Morris (2010; 2) challenge the dichotomy of acute vs chronic pain, seeing it as a dichotomy that does not reflect the reality of pain experience. They argue that chronic pain patients are often only able to access resources to have their acute symptoms addressed, but not their ongoing, chronic problems. This leads to people interpreting their symptoms and diagnoses themselves, as they lack ongoing health care.

Medicalization is a process through which defines normality and pathology (Foucault 1977, Hacking 1986). Illich (1973) argues that medical categories originate from the physician and the treatment. Kleinman (2006) is interested in how sadness and suffering can be diagnosed and medicalized (in this case, prescribed drugs that will alleviate this sadness). Maturo (2012; 4-5) outlines 3 'engines of medicalization': consumerism, new technologies, and management of care in medical settings. This process is exacerbated by the market forces and neoliberalization of state infrastructure that operate the world of late modernity. To add to this literature, scholars argue that biomedicine shapes forms of subjectification (Rose 2007; Shilling 2002). People increasingly understand and talk about their bodies with the language of biomedicine to maintain the body's functioning and maintenance (Rose 2007; 25-26). According to Rose (2007; *ibid*) the body, wellbeing and health have become centers of 'moral judgements' encouraging people to become responsible consumers of their health (*ibid*; see Merrild et al. 2016). To understand the process of health consumption and responsibilisation, we need to examine how neoliberalization affects social and health services.

Lee Mudge (2008; 704) argues that "neoliberal policies ... aim to 'desacralize' institutions that had formerly been protected from the forces of private market competition, such as education and health care." As a market-centric politics, neoliberalism is an attempt to refocus the role of the state as a nation and as a governing body. In this framework, states withdraw resources from the Keynesian welfare system, thereby opening a void in which free market forces begin to operate. Former institutions concerned with welfare and social support are privatized, and their operations change due to the influence of market competition. The responsibilities of citizen well being of such a state are lifted from powerful institutions and passed onto individuals, who are made responsible for taking care of themselves via the resources available to them through the market. Responsibility is intimately tied to the self-governing subject playing the roles of both subject and power (Foucault 1977; 202-3). An important point to remember in this analysis is that social control and power exhorted in a neoliberal framework is not coercive nor forceful, but rather, self-regulation and responsibility are enacted willfully in the best interest of the state and the self (Lupton 1999).

Freedom of choice is an important concept in this power analysis. Individuals are free to choose from the many things that capitalism has to offer. Rose (1999) argues that freedom is a discourse that operates through capitalism, which produces subjugation. Rose suggests that to define the liberal idea of freedom, we need to "distinguish freedom as a formula of resistance from freedom as a formula of power" (Rose 1999: 65). Ideology of freedom rests on the individual as a unit whose *choices* and *actions* constitute the basis of a free life. In the modern world, choices become routes for coping with illness. Choices also become questions about self-fashioning and creating identity through choice and action (Rose 1999; 42). The market is based on competition, which relies on individual choices. As responsibility passes onto the individual, the individual must learn how to navigate the choices that are available for them in the market to make to live a good and moral life. Choice becomes a consumerist behaviour. To have 'choice' is to discern in what kind of services to participate. In the context of health, paired with the prolific use of the information available on the internet, the consumer becomes a responsible patient (Coulter & Willis 2007).

Individuals become consumers of health and social services which have been withdrawn from public funding and which require people's engagement as consumers purchasing a service. Chris Shilling (2002; 625) brings up the notion of a 'consumerist patient' whose body, to function optimally and access self-gratification and pleasure, is a locus of consumerism. A consumer is also a subject "concerned with health and engaged in and able to seek information about the body's maintenance and optimization, and so consumes health care as a service that may maximize well-being and protect the subject from the adversities of poor health" (Merrild et al. 2016; 519). However, as Deborah Lupton (1997; 379-80) cautions, these macro approaches to health, its consumption and reproduction of power may ignore or overlook the affective, emotional and embodied dimensions of illness as well as people's experiences within these systems as subjects.

Merrild et al. (2016) examined people's engagement with health-seeking behaviours in Denmark. They found that people in the higher classes engaged in health-seeking behaviours reminiscent of health consumerism practices. However, the narrative became more complex when they examined these behaviours among the lower working class. They argue that "health care seeking was often shaped by the inseparability of physical, political, and social dimensions of discomfort, making these practices difficult for the health care system to accommodate" (Merrild et al. 2016; 517). Therefore, income and wellbeing are importantly linked, and a macro approach might have overlooked this issue.

Responsible consumer literature is often used in the social sciences when examining alternative medicines and practices. Being implicated into, and a result of, the growing self-care[4] movements of postmodernity, alternative practices are understood to exacerbate the responsibilization framework. First, I ask, what are alternative medicines? This is a slippery definition because, in order to define something alternative, we have to define what it is alternative. In Chapter 4, I will explore my participants' definitions of alternative therapies. Barcan (2011; 9) argues that the boundaries of biomedicine and alternativity fluctuate on their context of use. Sointu (2012; 14) argues that defining these practices focuses attention "away from the manner in which many complementary and alternative health practices represent and reproduce wider societal understandings of health and illness, the self and the body."

Wiles & Rosenberg (2001; 212) offer reasons as to why people use alternative therapies that include a focus on health consciousness where health concerns go hand in hand with other popular issues such as environmentalism, feminism, spirituality, personal psychology and holistic approaches to health. Coulter & Willis (2007) give three explanations for the rapid proliferation of these therapies: 1) consumerist movement paired with weakening legitimacy of medicine; 2)

---

[4] The concept of self-care,coined by Audre Lorde, was originally intended to encompass self-preservation: "Caring for myself is not self-indulgence, it is self-preservation, and that is an act of political warfare" (Mirk 2016).

Postmodern thesis - decline of faith in science and technology in part due to the growth of individualism, less acceptance of traditional authority, and control and empowerment movements; and 3) gendered spirituality thesis, where health has a spiritual component.

Within the power analysis literature, scholars look at how the use of alternative therapies reproduces normative power (see Wiles & Rosenberg 2001; 221, Fries 2007; 2013, Sointu 2012). Since alternative therapies operate in the private sector, they offer treatment as a commodity, and it is "to their economic advantage to locate causes or treatment of illness in factors outside their patients' immediate control" (Wiles & Rosenberg 2001; 221). This gives rise to 'smart consumers' who know how to draw on resources to make health decisions; this concept is similar to the responsible patient, this time reimagined as a responsible consumer. Fries (2008; 353) argues that "integrative medicine is discursively represented by its biomedical architects so as to ensure good cultural fit with neoliberal strategies of governance in which the focus is on enabling citizens to accept personal responsibility for their health." In this power analysis of health, alternative medicine exacerbates the governmentality paradigm.

What do these therapies give? Sointu (2013; 531) argues that they give a sense of control, personalized services, personal illness narratives, allow for linking of psychological and physical aspects of illness, give 'symbolic efficacy' and ensure a cognitive order (generate experiences of healing), and give performative efficacy. Phenomenological approaches view "the body as more than physical matter that forms the object of biomedical treatments and procedures" (Sointu 2013; 532). Social science literature since the early 1990s has centralized the body as the locus of "perspective, insight, reflection, desire, agency" (Grosz 1994; xi; see also, McGuire 1996; Leder 1990; Leder and Krucoff 2008; Crossley 2006). In medical anthropology and sociology, phenomenological approaches allowed scholars to talk about how pain and discomfort are co-constituted through a cultural meaning system and embodied experience. Furthermore, the subjective experience of living with an illness is different from the one within the medical establishment (McGuire 1996; 104, Mol 2002). Scholars in this school of thought have worked to link the cultural context (including power analysis) to the experiences of embodiment and emotions of everyday lived life (as examples, see Fox & Ward 2006; Fainzang 2013).

In this final section, I briefly outline the use of information technologies in the context of health in both medical anthropology and sociology. Fainzang (2013) argues that the use of health technologies allows for self-medicalization and self-medication. The governmentality thesis is applied to medicalization via emerging technologies due to their enabling health tracking behaviours and allowing for population (self)surveillance. Such technologies might be apps that are downloadable onto phones (Lupton & Jutel 2015) or personal health technologies such as near-body devices and applications designed for use by people to monitor their bodily processes and activity (Fox 2017). Fox & Ward (2006; 112) argue that these new health technologies may forge health identities through their consumption (Fox & Ward 2006; 463). People with chronic illness receive training from their health providers as expert patients that allows them to track their health and rely on themselves for daily care (Shaw and Baker 2004). Technologies produce both empowered consumers (Lupton & Jutel 2015; 130) who make responsible decisions (Eleling 2011; 825) as well as "foster subversive micropolitics and encourage collective and resisting 'citizen health'" (Fox 2017; 136, see also Fainzang 2013). The ways in which technology constitutes subjects while at the same time possessing intimate and affective qualities is an important issue.

In Chapter 1, I construct a theoretical framework in which I explore moral future making. I set up this framework while asking one of the main questions pertinent to this thesis: what does it mean to manage the future? The answer is that we do this by using means, whether social, experiential, or emotional, which we justify morally and which are available to us through our social milieu.

Chapter 2 introduces the main characters on whose lives and stories this thesis is comprised. I explore how each of my participants makes choices in the context of what they know and have experienced. Therefore, I define a theory of knowledge that operates in this thesis and use it to show how each of my interlocutors defines their needs in the context of the knowledge they possess. Finally, I introduce and define responsibility and hope as two concepts that can equip people with the ability to imagine a moral future.

Chapter 3 looks at the process of diagnosis. Diagnosis, according to Mol (2002), is a process that *is* different depending on *who* it is for: the doctor, the scientist, or the patient. Kleinman (1988) argues that illness has different meanings to different actors involved in the diagnostic process. Using both of these understandings of illness, I look at how illness is constituted (both through meaning and ontologically) in the lives of my interlocutors. Diagnosis doesn't mean much if it can't be made *sense of* in the background of someone's life. Furthermore, what *caused* illness and pain is an answer that people seek. On the other hand, diagnosis is not always given, and this chapter will explore the struggles of patients when they are not able to receive a diagnosis at all. I demonstrate the role of trust in the diagnostic process to argue that a diagnosis has an important emotional dimension, without which the process collapses.

Chapter 4 is about advocacy and alternative therapies. I argue that engaging in the medical system with an uncertain illness compels people to advocate for themselves. The process of advocacy has two separate results that I have observed: 1) it can make the patient be seen as responsible in the eyes of health providers, and thereby allow the patient to be taken seriously and open doors into the medical system; and 2) lead the patient to do their research online that aids in their redefining their needs and looking for alternative forms of care elsewhere. I examine how people use alternative therapies to have their needs met.

In Chapter 5, I focus on information management and how engagement with information technologies produces new moralities and relationalities. Moral codes operate through people's perception of robust data as value-free, through the affective design of information (such as its ability to produce doubt and trust) and through moral debates that define 'right' and 'wrong' conduct with data.

Chapter 1

Moral Futures

> "Ordinary experience frequently thrusts people into troubling circumstances and confounding conditions that threaten to undo our thin mastery over those deeper things that matter most, such as our self-esteem, intimate relations, or religious values. Divorce, the death of a loved one, injustice and discrimination, dead-end jobs, unemployment, accidents, chronic illness, artistic failure, alienation from faith community: any of these common calamities can break our grip on what we hold dear, and destroy our sense that we are in control of our fate."
>
> - Kleinman 2006; 4

In this chapter, I construct a theoretical framework to show how humans imagine the future morally. When everyday life is marked by pain, misfortune, and uncertainty, the at-stakeness (Kleinman & Kleinman 1991; 1996) of imagining becomes heightened. In Chapter 2, I will introduce the characters who struggle with their bodies and their health, and in this pain and uncertainty, they need to make choices for themselves (and their families as well) that will alleviate suffering. To do that, I construct a theoretical framework from which future choice and morality can be viewed. In this chapter, I argue that imagining (and hoping) for a future has a moral dimension because we wish for the 'best good' to ourselves, our lives and our loved ones. Indeterminacy about the future and life in general also allows us to engage creatively with the future through our moral imaginations.

Moral future making

The concept of risk emerged alongside the Enlightenment and allowed for the objectification of knowledge and rationalization, which became tools that shaped how humans could control and understand the cosmos. Dangers and hazards associated with the future existed, but as Deborah Lupton (1999) argues, were dealt with and feared in different ways. With the onset of risk thinking, the cosmos had, for the first time, become manageable, calculable and predictable (Lupton 1999; 6). It was no longer up to deities to ensure a safe future. Rather, the task of calculating and managing uncertainty about the future was institutionalized. According to Luhmann (1979), we can see the workings of powerful institutions by understanding how they manage futures. In this view, risk is intrinsic to modernity because it is through the management of risk power is exhorted, and a specific form of governmentality is made possible (Zinn 2008; 15; O'Malley 2008). This kind of governmentality relies on calculability, on insurance, and the prediction of futures and facts. Power relies on future prediction to govern the present.

Risk, however, should not be conceptualized as an ontological reality, but rather should be understood as an epistemological category (Reith 2014; 385). Luhmann's second-order observation is a useful tool to think through this: rather than thinking of risk as a thing that exists in the world, we can think of it as something that exists in different forms to each different system (such as law, politics, science) within society. Risk is not a reified thing, but rather a concept that circulates through knowledges and practices acts as objectively true knowledge and is calculable to make present decisions and exhort power (Samimian-Darash & Rabinow 2015; 3). Orwell (1949) easily summarises this idea "Who controls the past controls the future. Who controls the present controls the past" through risk management. Risk is a future-oriented concept that relies on the calculability and management of the present in anticipation of the future.

Uncertainty, like risk, deals with something forthcoming, something that has not yet occurred. However, the two concepts are not the same (Samimian-Darash and Rabinow 2015; 4). Humans are uncertain creatures because they can think towards the future where, eventually and quite, unfortunately, all life ends in death. The mundane of life is marked by dangers and uncertainties, and uncertainties make life matter (Kleinman 2006; 1). Foresight is an indispensable human feature, and it allows us to imagine a future that *can* be, even if it is not yet. We can imagine and act upon the world through the resources at our disposal. Dewey (1929) argues that the world is precarious and perilous, and experience itself is characterized by uncertainty (from Whyte 1997; 18). Uncertainty fuels knowledge and ideas about certainty that have the power to construct and control realities (think about cults). Uncertainty draws on emotional dimensions of human experience. Uncertainty is both individual and relational and exists in the affective encounters between people and things in the world. Finally, uncertainty is managed socially and morally, through whichever cultural and social means are available to people. Understanding uncertainty in this way allows us to ask of the kinds of technologies, experiences and modes of subjectivity that emerge in response to uncertainty (Samimian-Darash & Rabinow 2015; 4). Uncertainty is the *experienced dimension of the unknown* where ways to making sense of the world are used and acted upon the gain control over existential indeterminacy; we exist in the intersection of many social relations that become the moral good.

It is in moments of uncertainty that humans are compelled to attempt to control outcomes. In the coming chapters, my interlocutors will demonstrate what this means in the context of chronic illness. The means that are available to my interlocutors are medical, psychological, existential and temporal. They (or at least some of them) have been able to creatively craft an outcome with the means that were available to them. I will explore those means as information management, or techniques that create certainty and potentiality about the future, and various affective techniques through which information is processed. Here, I turn to potentiality as providing the means for creatively managing future outcomes. Potentiality, like uncertainty, is a future-oriented concept that opens up a creative space to imagine a future.

Potentiality, as defined in The Merriam Webster Online Dictionary, is “the ability to develop or come into existence”[5]. The state of potential is a concept that, like risk and uncertainty, is future-oriented. According to Taussig et al. (2014; 4), potentiality can be defined in three ways: 1) Hidden force determined to manifest itself; something that, without intervention, has a ‘future’ built into it; 2) Plasticity, the ability to transmute into something completely different; 3) Possibility imagined as open to choice, available to human modification and direction. For my research, I view potentiality as a future-orientation that creatively imagines a moral/ethical outcome.

Potential relies on knowledge and its management. While potential is calculable and can reproduce power, it is also something that possesses an emotional dimension. Taussig et al. (2013; 5) argue that

> ... potentiality indexes a gap between what is and what might, could or even should be. Such a gap opens up an imaginative space of magic and mystery in which future

---

[5] https://www.merriam-webster.com/dictionary/potentiality?utm_campaign=sd&utm_medium=serp&utm_source=jsonld

> building activities related to animating bodies and extending life in new ways loom large.

Debates about potential are often morally heavy, and there are two main perspectives on potentiality that I want to address here. The first is the potential of a fetus development into a human: if it has the *potential* to become human, is it human? The second is that of potential and cancer: We don't say "you have the potential to get cancer" but rather, "the tumour has the potential to turn malignant." In this sense, the capacity of the tumour is something that follows a scientifically (and patrichically) constructed morality: tumours either turn or don't turn malignant and their existential (and moral) imperative is to multiply, here turning biology into a deterministic force. The moral dimension of potentiality, however, lies between human and cancer and what the cancer is doing. In this example, saying, "you have the potential to get better" restores the moral order. The above instances of potentiality imagine a moral/ethical outcome, an outcome that encompasses the 'best good,' depending on the speaker. Potentiality mobilizes that which has not yet occurred to creatively imagine and influence a moral future. This mysterious, magical space opens up for moral debates, but the important question here is of who fills this space and at the stake of what/whom?

Morality

In recent years, a discussion around ethics and morality has been resurging in anthropology. A central feature of anthropological thought throughout the years has been to examine how people have constructed morality in different cultures. There is no single way to define morality as it is not just a social construct nor a just sociopolitical concept. Ethics and morality have plural facets because they speak both to structures and larger societal processes as well as the personal experience of the world. Even in Durkheim's [1953 (1906)] writings, morality is not singular, but rather a complementary idea where the various versions and definitions of morality are "only mutually exclusive in the abstract. They only express different aspects of a complex reality, and consequently, all will be found in their various places when one brings one's mind to bear … [on that] complexity." Scholarly definitions and understandings of morality, ethics and moral lives can differ, but they can coexist in the same moment without being paradoxical. In the recent moral/ethical turn, anthropologists have questioned how morality and ethics can be experienced in the world.

Kleinman (2006) examines uncertainty and morality as inevitable facets of human existence. Morality can be viewed in two ways: morality is contained within our values about what matters to us the most. In the second meaning of morality, “moral refers to our sense of right and wrong” (Kleinman 2006; 2). The second type of morality requires imagination of what it means to us to live a life that embodies our moral commitments. Kleinman’s version of *morality is ordinary* as it is lived and experienced through every day in negotiations and decisions that may not even be conscious to the people feeling them.

Scholars have been trying to understand the *locations and beginnings* of moral and ethical lives. Where do ethics reside and how do they connect the powerful, intersubjective, and the personal and visceral experiences of people? Mattingly (2013) attempts to answer how a moral self is born. To do this, she examines three ‘scenes’ through which moral imaginary comes into being: the trial (through Butler's [2005] work), the artisan workshop (calling upon Foucault’s [1990] notion of self-crafting’) and the moral laboratory. Mattingly’s moral laboratories framework offers an embodied, acted, and experienced understanding of knowledge and its connection to morality. She argues that it is through the *process of becoming* that people make sense of their worlds and their actions. Mattingly asks how people “struggle with and try to make judgements in the ambiguous circumstances of everyday life about how to realize the ‘best good’ (*ibid* 308). This occurs through action, and since action is social, it depends upon the actions of others and has consequences. *To be moral, then, is to balance the ‘best good’ for the self with the best good for others*. The moral laboratory, she argues, “is a metaphorical realm in which experiments are done in all kinds of places and in which participants are not the objects of study … It is a sense of action in which the ‘new’ is inaugurated, where new experiences are created” (*ibid* 309). This laboratory is a way of looking at life and experience as an experiment. These ideas are reminiscent of Dewey’s (1929) pragmatism and experimental nature of knowledge. Mattingly argues that moral laboratories produce acts that have the potential of transforming social space into a moral scape and, in the process, marking moral selves with ‘radical uncertainty’ (Mattingly 2013; 309). This understanding of the moral self one a person can experience as the moral self is “living within possible narrative plotlines that stretch backward and forward in time, within a field of narrative potentiality” (*ibid* 318). Borrowing from Das’ (2006) notion of the ‘descent into the ordinary,' Mattingly shows that people can remake their lives through the ordinary, everyday life, despite and alongside subjugation of power (*ibid* 324).

Mattingly (2013) looks at how experiences and experiments create a moral world through a trial and error process, where the 'best good' is at stake. Elaborating on the ideas of constitutive morality, Throop (2014) suggests that moods are excellent vehicles for the emotional dimensions of morality. He argues that

> The complex temporal expanse of moods might provide a way for moral problems to remain viscerally bound to one's being, while extending moments of transgression, worry, and/or concern into both past and possible future horizons of experience that stretch well beyond the confines of the present or even the particularities of an ongoing interaction or narrative (Throop 2014; 68).

In Throop's framework, morality is viscerally experienced as it affects us through the everyday. In this view, moral codes are not prescribed by powerful institutions (although, Throop does not exclude power from his analysis) but rather, moral codes are acted upon, sometimes with the actors not realizing the moral drama that has just occurred. Throop argues that moral moods are "existential modalities" that have the possibility to transform through time as well as through the social, cultural and political worlds into a lived experience (Throop 2014; 65). Moral moods can fold the future, past and into a present into an experience.

As mentioned above, morality has many different definitions that operate together to create a moral life/being in the world. In Kleinman's view, morality is both a value and a sense of right and wrong. For Mattingly, morality can be encompassed by the experience and acting towards a 'best good.' For Throop, morality lives through affects, emotions and moods that are viscerally bound to temporalities, socialites, cultural milieus and institutions. Emotions come to live in the spaces where morality is constructed and, in this thesis, in the spaces where people make use of information, when they google their symptoms, ailments and potential diseases. Emotions drive potentiality as the social and political worlds are embodied into future-making.

Morality can also oscillate between the 'best good' for the common good of the group, but it can also refer to the individual self in how the self leads a moral life. In this thesis, my participants often had to make decisions that put the self as a locus of moral choice. As I will demonstrate, this moral self was negotiated in a space where people’s experiences and needs were not taken seriously and information needed to be managed to achieve the ‘best good’ for the self.

Chapter 2

Defining our needs

George and I sit quietly in a cafe. He is catching his breath while I look out the window.

George: I might be kind of slow answering at times, might have to take my time a bit.

Ag: Yes, you can do whatever you need.

George takes a few shallow breaths and looks out the window. I take a sip of my coffee.

Ag: I forgot cream.

George: I can get it. I'm going to pick up my cinnamon bun anyways.

He takes my coffee to the cream station and picks up his treat.

George: This [cinnamon bun] is yummy. I needed that.

In this chapter, I explore the lives and stories of my participants. Life stories and participant positionality are an important part of people's experiences. Learned knowledge can influence (and sometimes even dictate) the kinds of choices that are available for people to make. I will introduce each of my participants' struggles with chronicity. What becomes clear through their stories are the ways that they define their needs through emotions and search for ways to have them met. Navigating various forms of information and knowledge and defining needs are tools which people use to make sense of their precarity. In the second section of this chapter, I write about responsibility and provide various definitions of the term. The kind of responsibility that I present in this chapter is one that can be likened to hope and provide a distraction from the daily chronic pain. Beyond bodily pain, mental health issues also affect participants' lives as their bodies' wellbeing falls outside of their control. They are not able to enjoy the things they once enjoyed. Hope gives an ability to cope with ailments and mental health issues that my participants are experiencing. This chapter's focus is on the ways that people define their needs in times of precarity and the pragmatic means they use to feel better about their chronic affliction.

Stories

One of my main interlocutors during the summer was Christine, whom I met through another research participant, Jane. Christine was taking a summer vacation, but in between her travels, she found the time to speak with me. We first met in a coffee shop in the valley. She came in wearing sports clothes and a brace on her arm. Christine was a very energetic and confident middle-aged, middle-class woman. She had a lot to say and was happy to share her experiences with me. After about ten minutes, I realized that this coffee shop is not the best place to meet during a hot summer day because people order smoothies. Every once in a while, Christine and I had to pause our conversation and let the machine whirled noisily.

Christine is a medical professional. She has lived in the Valley for quite some time, running her private practice and raising a family. About five years ago, however, Christine's pain began. It started with a twinge in the neck, of which she didn't think much. But the neck pain progressed into something worse when she began getting migraines and tension headaches that persisted daily. She described the pain from her headaches as a "7/10, every minute of every waking day." At this point, the neck pain was nothing in comparison with the headaches. Christine, at the time working in her profession, began searching for ways to alleviate this pain and to find the cause of her headaches and neck pain. Eventually, however, she had to stop working. It took her years to search for some *reason* for the pain and a *means* of alleviating it.

Through the last five years since the debilitating headaches began, Christine saw many alternative health practitioners, therapists, and medical specialists in hopes that they had some means for alleviating pain or an explanation for her illness. She sought massage therapy, physiotherapy and acupuncture. She saw various medical specialists and received therapies, such as steroid injections and nerve ablation therapy. Christine also saw several neurologists and one with whom she built rapport. He suggested that she stop the steroid injections and instead to try various mindfulness techniques. These techniques were interesting and compelling to Christine because

> *Christine*: ... he was very much a Western medicine neurologist, a certified neurologist, but he was open to the concept of the brain's impact on pain and your psyche's impact on chronic pain.

After these conversations with her neurologist, Christine began participating in somatics therapy and the Feldenkrais Method. The method, as discussed on the International Feldenkrais Federation website, "[explores] ... the relationship between movement and consciousness."[6] It was founded by Moshe Feldenkrais, an engineer and physicist. After suffering a knee injury, he began to fuse many different disciplinary practices into a therapeutic method. The website writes that "in developing his work, Moshe Feldenkrais studied, among other things, anatomy, physiology, child development, movement science, evolution, psychology, some Eastern awareness practices and other somatic approaches." In Christine's definition of it, the method is...

> *Christine*: It's sort of a way of resetting your neuromuscular system. It's work; you constantly have to do it yourself. It's a real mindful thing. Whenever I'm walking, any activity that I'm doing, I have to be aware of how I'm moving, how I'm walking. So it's not something that is done to you, but rather it's very participatory in the whole thing, which I also like because that's actually very helpful for somebody that's in a lot of pain. *It gives you a sense of control. It's something that you can do rather than having things done to you.* That's not a nice feeling. I like to be able to participate.

Participation and a sense of control are something that Christine enjoys more than 'having things done' to her. Although Christine's desire for control can be surmised in a governmentality framework, in this thesis, I expand responsibility and control as *needs*, as my interlocutors express, that require fulfillment in their existential predicaments. I demonstrate this in the last section of this chapter.

Anna is past her middle age and lives alone in a large apartment. She welcomed me with tea and sugar cookies. She insisted I wear slippers, even though it was summer. The slippers reminded me of my own family, insisting I wear them even if my feet are hot because I might

---

[6] https://feldenkrais-method.org/archive/moshe-feldenkrais/

catch “the wolf.”[7] Anna sat across the room from me on a computer chair while I, sitting on a reading chair, tried to organize my papers and take notes. Anna did not want to be recorded, which made interviewing rather difficult. I looked at her while she spoke, noting chicken scratch by hand. I think it amused her.

Anna was a medical doctor in the Ukraine, specializing in preventative medicine, before moving to Canada. When she moved to Canada, she realized that her credentials and years of school are “useless.” Had she wanted to continue her practice, she would have had to go to school all over again and do practicums, and at that point, she felt too old to do that. She studied medicine in the ’80s in the Soviet Union, and her impressions of medical care are different than the ones that she encountered in Canada. Her first encounter with the medical system in Canada occurred when her mother got sick.

> *Anna*: They just gave her a whole lot of medications. My mother needed care, not lifelong medications. In the Ukraine, there is no long-term medication. There are breaks in medical treatment. In the Ukraine, nutrition was a huge part of my training as a doctor and things like massage to improve circulation, for example. But here in Canada, nutrition is not as important. So I just do what I know is right to do. Here people would say, what do you know? You come from an underdeveloped country. But that’s just what I know, so I do it.

When Anna got sick, it was her turn to now enter the healthcare system in Canada. Anna understood the care she received in Canada as a contrast to the care she was used to providing in the Ukraine. She felt dehumanized throughout the treatment and care process. She wasn’t treated as a person with full will and agency, but rather as a person who failed to comply with the doctor’s wishes. No one asked Anna *why* she didn’t comply or what her *needs* were. She felt that she was not heard. After some time of taking various tests to name the illness she was suffering with, she was diagnosed with an immunodeficiency condition and prescribed medications that she did not want to take long-term. Anna’s choice of not taking the prescribed medication caused tensions between her and her physician, which, once again, made her feel belittled. She had to regain control in her encounter with health providers:

---

[7] pneumonia

> *Anna*: You know, I don't like telling doctors that I am a doctor too. I don't like that, I want to be treated like a human being. But I have had to do that before. When I wasn't taking the medicines that I was prescribed, I had to tell them *that I am a specialist too* and his tone changed with me. I had to tell them, you know, I know this stuff too. What you say isn't the only way to do this.

Anna was not being taken *care* of in the same way that she was used to taking care of people. She also felt that her knowledge as a doctor was not taken seriously because she was from an "underdeveloped country." However, Anna felt that her positionality gained her some agency and control in a situation where her needs were not met. She did not like to do this, but she could bring the conversation to her side by stating that she too is a specialist. Furthermore, Anna brought research that she found on the internet to her doctor's office to challenge his judgements on her health. In this way, Anna was a responsible patient who called on her positionality to be taken seriously.

I met George through a family that I befriended in the valley. Throughout my fieldwork, I remember having to keep a lot of our meetings short, or alternate between casual conversation and the interview process because George often got tired. George is in his early 20's. He has lived on Vancouver Island all his life, moving between towns and cities in the region. In the last two years, George's ability to breathe has dissipated. When I met him, he had to take things slowly and had to ask people to slow down if he wanted to participate in social situations. Sometimes, he withdrew from group activities when he needed to take a break. Minor physical activity was straining for him, but he still insisted that he continue participating in things. George told me about the onset of his condition and his search for an answer as to what it could be.

The first issue for George was that he had trouble breathing. Breathing deeply occurred rarely, and throughout the day, he attempted to take deep breaths, usually to no avail. Beyond breathing, George saw a change in his ability to think and respond in the same way as he was used to.

> *George*: My ability to think is a lot worse. I used to have a lot easier time empathizing with people cause I could just be relaxed and then had the energy to spare like, visualize what they were explaining and think about it. But now I feel like I can easily lose people when I talk with them. Lately, I've been feeling like

> I'm not breathing much when I sleep. And then I've been having these really bad, really bad dreams. But I think they just have to do with how my body feels like it's oxygen deprived. Like a swamp, I feel like a swamp. And in that state, I dunno, dreams are kind of fucked up. I don't think my psyche has demons in it, it just comes from my physical state.

Two years ago George went travelling to the US. He noticed that he had some trouble breathing when he was en route south, but didn't pay much attention to it. By the time he got to southern states, he had said he was feeling 'overwhelmed,' and his breathing gradually got worse from then on. He continued to push through his breathing difficulties, picking up odd jobs working on farms and music festivals during the summer. At the end of the summer, he moved to a large city in B.C., and that is when his health took a turn for the worse. Since then, George has been taking things slowly with his body and trying to take care of himself

I asked George what kinds of therapies he participated in and what kinds of practitioners he saw. First, George went to his family doctor and had many tests done, such as lung x rays, heart ultrasounds, and Lyme disease tests. George seemed not to trust those tests and the results from them. When his family doctor prescribed him antidepressants, George claimed that they did not work because he did not *believe* his issue had anything to do with mental health. Then George visited a naturopath clinic in a large city on Vancouver Island where he was diagnosed with a mould allergy. According to the naturopath, his breathing problems resulted from lung damage from contact with mould. George also attempted some community acupuncture. Then he went to see an integrative medicine doctor who diagnosed him with damage from micro-toxins found predominantly in the mold. Since then, and until now, George has looked for other therapies and routes of getting better and alleviating his stressful breathing but has not yet found anything that works for him well enough to say his breathing is getting better. George needed a *means* of alleviating his inability to breathe normally. As will be seen in the next chapter, George also searched for a possible cause of his bodily misfortune. Unfortunately, he was not able to secure an answer that both made *sense* to him and aided his breathing.

Other research participants that is featured in this thesis are Jane, Christine's friend who began having issues with circulation shortly before I began my fieldwork and Ingrid, an herbal practitioner living on one of the many islands surrounding the larger Vancouver Island.

My research participants created knowledge about what it is that they wanted and needed from their health providers based on their life experiences. Knowledge is constituted through action, and it is a pragmatic inquiry about the world. However, powerful institutions and structures influence knowledge creation (Foucault 1980). I draw on practice theory of knowledge, here encompassed by embodiment literature (Kirmayer 2003, Grosz 1994, Crossley 2006, Shilling 2011, Marshand 2008), as well as pragmatic philosophy to look at knowledge constituted in action through body and experience. As Whyte (2005; 246) argues, "intelligence lies in practical engagement, through which people come to know and understand." John Dewey (see Barrow 2006) thought of knowledge as synonymous with *inquiry*. This kind of understanding of knowledge is a contrast to Western/hegemonic ideals of knowledge as a rational pursuit of 'truth' and 'fact.' However, anthropologists have examined rationality as not a solely Western concept; as Good argues (1994), assumptions behind distinguishing between "rational" and "belief" systems need to be examined to understand where they come from and what kinds of meanings they reproduce in society. E. E. Evans-Pritchard (1937) demonstrated that actions and "beliefs" follow an internal (cultural) logic and that our own (Western) "body of scientific knowledge and Logic are the sole arbiter of what are mystical, common-sense, and scientific notions" (1937; 12). Knowledge is a reference point from which we make assumptions and decisions about the world. In other words, knowledge is constituted through action that draws on lived realities, experiences and emotions and is simultaneously a facet of power.

Pragmatism is a genre of philosophy, with its roots in the works of William James (1842-1910), C.S. Peirce (1839- 1914) and John Dewey (1859-1952). Susan Reynolds Whyte (1997) does a compelling job in using this philosophy to explore how people deal with uncertainty in times of bodily, social, or economic affliction. Pragmatism posits that ideologies and knowledges are true if they work and that meaning can be found through the process of accepting or rejecting it[8]. Unlike in the 'spectator theory of knowledge' (dubbed by John Dewey [see Kulp 1986)]), where knowing is akin to seeing, in pragmatism knowledge "is the product of inquiry, a problem-solving process through which we move from doubt to belief. Inquiry, however, cannot proceed effectively unless we experiment—that is, manipulate or change reality in certain ways" (McDermid). This is an 'experimental theory of knowledge,' according to Dewey, where "the true

---

[8] https://www.iep.utm.edu/pragmati/

object of knowledge resides in the consequences of directed action, or experiment (Dewey 1984; 157). With this theoretical understanding of pragmatism, we can look at knowledge production from the purview of experimentation and problem solving from within our social experience (Whyte 1997; 20) akin to Mattingly's (2013) moral laboratory.

In the late '80s and early '90s, the social sciences went through a revolution that turned away from a Cartesian dualism of mind/body (Grosz 1994). Knowledge began to be approached through the body. The term embodiment encompasses the idea that cognition and visceral experience are interconnected, rather than separate from each other. For instance, what illness is due in part by how society views that illness, how the person afflicted experiences it, which in turn affects the visceral *experience* of this illness. Through this embodied knowledge, my participants were able to define their needs as people being touched by affliction.

Responsibility and Hope

Christine's section of this chapter ended with her discussing the way that she likes to feel in control and to participate in the process of making herself feel better. The two therapies that have allowed her to participate in this process are the somatic physiotherapy and Feldenkrais method. In my further conversations with Christine, I found her speaking about control and responsibility in the healing process. When I hear people speaking about control and responsibility, my mind goes directly to the governmentality framework as outlined in the literature review. However, what Christine was telling me was different from what a governmentality analysis could allow for. Through her pain and process of reorganizing the self (she was no longer able to do the things she once used to, which was difficult for her), she was starting to feel her mental health worsen. Having responsibility allowed her to feel like she is taking control of her health, her treatments, and her future.

> *Ag*: What are some other things that [keep you from delving into depression]?
>
> *Christine*: I think that my dogs, my pets had a lot to do with that. They gave me, well, maybe *personal responsibility*? I remember a long time ago when this all started, one of the specialists saying to me - because I was still working. I remember I said, I think I'm gonna have to stop working. I can't do this anymore. Because I was really struggling and feeling like I wasn't doing a good job anymore which really bothered me - And [the specialist] said to me, you know, research has shown

> that people with chronic pain who continue to work do better than people who don't. And I think that this is because that *gives people an external responsibility*. Because you start being selective with your responsibilities because there's so much that you can't do. Basically, you have fewer and fewer things that you *have* to do so for me because, working with animals, that's always been my thing and that still has stayed my thing and so that was really necessary for me. *It really is helpful to still have something that was really counting on me and that I couldn't let down, you know.*

Christine's responsibility is something different than responsibilization (Rose 1999; PAGE). Her struggle for control over her life is existential when she describes the need to be responsible for something. Good (1992; 50) argues that "work may at times be perceived by those who suffer from chronic pain as a palliative, an analgesic, a way to fend off or escape pain, and a way to maintain self-efficacy and achieve self-realization in spite of chronic pain." In the way that Christine spoke of responsibility, I see a parallel with the way the Good (1992) speaks about work. Responsibility can be "an active process of meaning-making and of self-construction, especially in the face of … 'world threatening' dimensions of pain" (*ibid*; 50). The kind of responsibility and care Christine speaks about arises both from her position as a middle-aged, middle-class woman and one that comes as a result of her profession, where she showed care and held responsibility for her patients. The above excerpt can also be read for its appeal to relational responsibility, a responsibility *for* others that gives Christine the hope and means of dealing with her daily pain. This kind of responsibility extends outside oneself and requires accountability and moral conduct with others.

Christine was not the only interlocutor who spoke about responsibility as a means of gaining control over their health. George also spoke about responsibility and how it made him feel in his body. In his case, it was responsibility gained through working, whether it consisted of odd jobs that he picked up while travelling or the work that he was doing around Comox Valley during the summer, it was work that helped him "push through" the daily pain by giving him a distraction. It was also a way in which he could prove to himself that he can do things, to participate in social life. Unfortunately, as George felt, he wasn't able to keep a job for too long, because his health got the best of him. But it was the responsibility of having something to do that felt good to him and made him feel better in his aching body. It made him feel healthier.

Often, people suffering from chronic pain also suffer from a psychological crisis. Christine felt that her mental health was overlooked during her appointments with various professionals. Sometimes the psychological care that she needed was not provided or even addressed to be an issue. Through these mental challenges, Christine's dogs were integral to her mental wellbeing because she felt a sense of responsibility that extended outside of herself (in other words, relational responsibility). Alongside support that she received from her family, friends and community, Christine was looking for responsibility beyond herself.

Responsibility in the way that my interlocutors spoke about it was a process that provided a distraction to the daily pain they were experiencing and a need that required their active fulfillment, which depended upon them to be present in the world (or, to have a reason to leave the house). As George understood it, responsibility made him feel healthier, because it allowed him to do the things that other people his age were doing that he remembers being able to do not too long ago. In this way, responsibility was a way to 'let go.' Crawford (1985) explores the ways that people approach the pursuit of health in an ambivalent way; not everyone is ready to pursue health as synonymous with self-control and self-responsibility. "Release," he posits, is a route to seeking pleasure, satisfaction, and a way to of letting go from internalized controls (Crawford 1985; 81). In this way, the responsibility that my participants spoke of was similar to a forgetting, if for a moment, that their lives were struck by pain and sickness. They sought responsibility and control to be able to 'let go' and to be able to feel like they could participate in daily life the way that they wanted to. Their entire existence would not be overcome by pain.

George had a predicament: he was not able to secure the kind of care that would help him feel better with his breathing. The fact that he could not find a route of feeling better was existentially trying and physically exhausting because of the accountability, responsibility, and self-reflection about his health that he felt was required of him. He did not want to let his friends and family down as they expected for him to be looking for ways to get better and trying new things. George told me about his decisions to stop seeing health practitioners that came from feelings of anxiety of not working hard enough.

> *George*: Hmm, I think it's really easy for me to like, get really anxious that I'm not trying hard enough. Not working enough.
>
> *Ag*: Where does this anxiety come from?

> *George*: Well it comes from inside me. But there's forces like, where I feel the pressure to do the work. So it's easy, yea, it's easy for me to - inaudible - so I go longboarding and it feels like one of the best things I can do. Working out basically. Working towards a healthy vitality. And yea for a while I stopped seeing health practitioners. I'm just kind of like, evened out. I just want to be by myself.

George went through a moral crisis where he felt affected by expectations from others and the work that he expected to do for himself. The pressure to do the work was offset by 'working out' and 'working towards' things. In this case, it did not include seeing practitioners. George was not ready for that yet. He needed to learn what his needs were and where he wanted to set his boundaries before he could make himself vulnerable in a clinical setting again. He needed to learn what it means to ask for care and balance the responsibility he felt to his family and other 'forces' and the responsibility he felt to himself and his wellbeing.

Responsibility can refer to many processes. Within the governmentality framework, self-responsibility refers to the techniques that an individual (a subject) engages in, which in turn subjugate them further. Responsibility can refer to a moral order where the responsibility of and for others creates networks of relationality. It also speaks of accountability of one's actions to the larger social, cultural and political order, once again calling upon the moral paradigm. As I have explored in this section, responsibility can also refer to an existential need that held them accountable. In this way, responsibility provided a means of 'letting go' of things that might need to be forgotten for a moment to exist in a world overcome by pain and uncertainty. Through this multifaceted understanding of responsibility we can see how we have multiple allegiances and multiple moral worlds to uphold in our daily lives. We are responsible for others, for ourselves, for securing ways to feel good and dealing with our daily existence, to our friends and family, to society and the state. The idea of responsibility oscillates between the self and others, encompassing relationality and the individual subject at the same time. It is a moral negotiation that resides between the self and others that slides the scale from individuality to relationality.

Christine and George desired support; however, it took them some time to be able to ask for what they needed from the people close to them. This process made them feel isolated and lonely:

> Christine and I were talking about illness and I asked her to think of some words to describe it.
>
> *Ag*: Illness is…
>
> *Christine*: isolating. Yes. I've actually given quite a bit of thought to that. It definitely is. It's just so easy to just tuck yourself away. Because everything is an effort, everything is an effort. And you're just tired and you don't have the energy to put yourself out there.
>
> *George*: I often feel like, I dunno, maybe lesser to some people when they - they're just so energized, so enthusiastic, just have so much to share, working on their projects. Yea. It's intense. I feel like tenuous, like a tenuous gap. As soon as I feel confident I tire really quickly.

While they were figuring out the ways that their bodies worked and looking for causes of their pain, they felt like the energy that they had to put into social situations was a lot more tiring than it was before. As George describes it, there was 'a tenuous gap' between him and others. In such a space, how are sociality and a vision of a social future restored?

When the future and the present is uncertain and isolating, when one lacks the motivation to endure another day, hope can change people's outlook on the future. Hope is a multi-faceted concept in the social sciences. Lindquist (2005; 4) briefly defines hope as "the existential and affective counterpart of agency that replaces it where channels for agency are blocked, and presence in the world becomes precarious." Hope gives the ability to imagine an alternate future, a future that has not yet occurred, but also to imagine and is reminded of what might not ever be; here hope resides in the subjunctive mood (Mattingly & Jensen 2015; 39, see also Whyte 2005). Mattingly and Jensen (2015; 39) argue that hope is linked to morality because hope imagines the 'best good' in any given situation. Drawing on Aristotle's 'virtue ethics,' they argue that from this perspective the "practical is always moral" and hope provides a practical way of dealing with and imagining a future (*ibid* 39). Jansen (2016; 448) argues that hope has two definitions; one is affect or a hopeful emotion, and the other is a hope that possesses a subject ("I hope that something/someone…"). Drawing on these definitions, I see hope as something that is *created*, searched for and researched, and something that needs to be *sustained* through socially prescribed means. Hope, in both the emoted and subject-oriented sense, is something that one finds through searching for answers, through therapies, and practitioners that can secure an idea of determinacy.

Hope is something that is created by looking for the ‘best good’ life; it gives people a sense of movement into the future and helps them manage uncertainty. Hope aided by trust can paint the hopeless and directionless days into something to look forward to. I will let Christine demonstrate:

> *Christine*: Sometimes you walk out of a clinic and you think that I don’t have the hope to keep moving forward. I think that sometimes my neurologist, *at times he gives me more hope than anything else*. I feel hope when I walk out of there, more than anything else. I would feel hope when I walked out of that room in a way that I didn’t feel with many others.

Christine found something more than a doctor in the neurologist she was seeing. She found the hope that she needed to search, to continue to look forward into the future and search for some semblance of control in her life.

George was not so fortunate. While he attended many therapy sessions with various doctors, naturopaths, and therapists, his search for a way to help himself feel better was fruitless. George lost his patience and hope in doctors. At the time of my fieldwork, George found another way to cope with his condition:

> *Ag*: So it sounds like it has been a while since you’ve been seeing these practitioners. What do you do now to deal with it? Do you see anyone?
>
> *George*: Well recently I was seeing this doctor who does integrative medicine but he’s on a break, on a sabbatical. So I was seeing him for a little bit. Mostly, consistently I was getting acupuncture. But I haven’t done that in a while. What have I been doing? Eating yummy treats. Crack food, basically. Bubble tea and treats.

Even though George is not able to secure hope through neither medical not alternative means, he searched for it in other places, in the places that were available to him. At the time of fieldwork, George defined his needs not in seeking treatment or alleviating his breathing, but in feeling good at the moment. Right now, it was ‘crack food.’ It was summer, and George went to the beach to swim, longboarded around town and visited friends and family. He did not cope with the problems that he had in any profound philosophical way, but rather, in a pragmatic release (Crawford 1985) that helped him feel better.

Responsibility and hope help us manage uncertainty. Securing hope is important for existence as it allows for future-making endeavours. I will demonstrate in Chapter 3 how uncertainty is created through illness, pain, and an inability to *trust* a diagnosis provided by doctors. Responsibility and control have helped my interlocutors deal with these existential issues. This is not to say that they created *certainty* because to say that Christine taking her dogs for a walk gave her certainty is overshooting the analysis. What it gave her was a sense of daily purpose and a daily, mundane need. Every day she knew that she would have to walk her dogs. This kind of responsibility was also a future-making endeavour.

Morality is an ordinary experience, and it is not static. It can be contained in the negotiation of personal needs in the face of uncertainty. The way to act morally and to be moral for my participants was to search for a different version of self with needs different than they were accustomed to which allowed them to be social, to be responsible, to have a purpose daily and to constitute a future for themselves. It was a way to create hope about the future, to secure the 'best good' and act on it through whichever means were available to them. This was achieved through embodied knowledge that called upon each of their positionalities and lived experiences to face the world. Using these as resources, they came to define their needs as social beings and searched for ways to have them met.

Chapter 3

Diagnosis

> George: Well, it was interesting. I definitely *believe* what the naturopath said, like that made *sense* to me. I've been exposed to mold and stuff. But my doctor, she just didn't know at all. And when I brought up mold…. I don't know, she never really, I don't think she thought about it much cause I don't think they learn about it too much. She just basically thought it was an anxiety-caused thing and she prescribed a few anti-anxiety medications. A couple of different ones... And I was definitely resistant to that because I know it's a physical thing.

This chapter's focus is on diagnosis and the ways that my participants search for answers to alleviate their painful symptoms. Each of their stories of illness is different, but in each, there is something in common: what they look for is a diagnosis that they can *trust* and which could help with their affliction. Sometimes, as I demonstrate, to name a disease or illness is not enough as it does not meet the needs or expectations of my interlocutors. My participants used various techniques to have those needs met, such as searching for new information that could help them secure a sense of certainty about their bodily pain or contesting the diagnosis that they received. They also used various therapies and techniques that, collaboratively, fulfilled their needs. I argue that what is important in the process of diagnosis is the way that it is creative of trust, the way that it meets people's needs (as described in Chapter 2), the ways that it answers to patients experiences and lived realities, and the ways that it is able to provide the *one answer* that explains causality and provides means of managing the pain and illness.

What is a diagnosis supposed to do?

In this section, I look at the diagnostic process to argue that diagnosis is different to different actors involved in the process (such as doctors and patients). Both Kleinman (1988) and Mol (2002) argue that diagnosis has different meanings and ontologies depending on *who* is interacting with it and *how* it is enacted. Diagnosis has an emotional side, as it does the work of hope in people's daily lives. However, diagnosis is not always straightforward, as the story of my participants will demonstrate. As it turns out, a diagnosis for my participants is not an end to their troubles, nor an authoritative statement delivered by a physician but is rather a journey full of contradictions, trust, and self-definition.

In the early days of medical anthropology, during the 70's symbolic turn, anthropologists often spoke of how meaning is created in illness. Diagnosis, once delivered, is understood as a process of meaning-making based on social categories that can lead to an actionable response (Kleinman 1980; 87-8; Good & Good 1981). Beyond being a meaningful explanation, diagnosis also requires discovery of diseases (Illich 1976); it requires a bodily normativity against which to define abnormality (Tishelman & Sachs 1998), it requires a classification system (Jutel & Nettleton 2011), and is a process of translation by which medical trainees can come to learn the meaning of diagnosis (Kleinman 1988; 16). In the sociology of health, diagnosis is a process contingent on larger social and historical processes that give life to illness and deviance; once labelled, illness and deviance can be controlled (Hacking 2006). Through this sociological analysis, diagnosis is seen as creative of new categories. The process of diagnosis can also become influenced by marketing forces, pharmaceutical companies and communication technologies, through, for example, monetary bonuses given to doctors for prescribing a certain kind of medication. Diagnosis is accessible via smartphones and Google searches available to a large portion of the population in North America (Barker 2011; Ebeling 2011). The process is also implicated into larger processes and institutions in the world such as companies, colleges, people who write textbooks, scientists who discover new categories of disease and physicians' own experiences. In other words, diagnosis is not isolated from the social world and is a social category. However, diagnosis is more than a network of meaning and a facet of power, and it does more than create new categories of people: it is also creative of new *realities*.

As Annemarie Mol (2002) in *The Body Multiple* illustrates, illness is something different than a diagnosable cluster of cells under a microscope. A single 'disease' has multiple beings/is multiple things through the process of *enactment*. She argues that a single disease is not just experienced differently by different actors; it *is* a different thing altogether and requires different performative and embodied measures to deal with (Mol 2002; 29-30). In this view, disease is different to people who have access to microscopes and MRI scans than it is to someone experiencing and living with this cluster of cells in their bodies. Even though the *cells* may carry the same name as the *experience*, it is the *process* of diagnosis, the *process of constructing a link between the two different things*, that conflates these two realities as one object. Furthermore, Mol argues that the practices performed in a clinical setting are

> practices in which some entity is being sliced, coloured, probed, talked about, measured, counted, cut out, countered by walking, or prevented. Which entity? A slightly different one each time. Attending to enactment rather than knowledge has an important effect: what we think of as a single object may appear to be more than one (Mol 2002; vii).

Through the process of diagnoses, an illness is enacted. In Mol's argument, through the process of enactment, different ontologies can reside within the body; hence, the title *The Body Multiple*. In this chapter, I explore the ways that the practice of diagnosis is implicated into emotional dimensions of people's lived worlds, resulting in their negotiation with what diagnosis is for them. In this chapter, I see diagnosis as a process that is negotiated through a person's personal experience of it.

Kleinman (1988) takes on the symbolic framework to look at how disease and illness constitute meaning in several different ways. With that, "illness is polysemic or multivocal" (Kleinman 1988; 8). These meanings come into being depending on experience, longevity, type of chronicity; they manage change. He argues further that "diagnosis is thoroughly a semiotic activity: an analysis of one symbol system followed by its translation into another" (*ibid*; 16). These symbolic ideas can be contrasted with Mol's (2002) ontology of disease framework, where it is not the *parsing* out of meaning but seeing how *acting* and *practice* around disease renders it different in its being. I have contrasted these two ideas in medical anthropology to draw on both of them - diagnosis is a social process that defines and names an experience. What is important here is the explanation and a cause that provides emotional engagement with a diagnosis.

A medical diagnosis is not separate from the present lived experience, nor is it separate from the beliefs and knowledge we hold as true. Our health world is intimately tied to our trust in the powerful institutions, places of knowledge production and is not separate from the larger structures that operate our lived worlds - our beliefs and ideas rely on the structures that they ultimately reproduce. Christine was given a diagnosis but hesitated to tell me about it. The diagnosis that she received did not resonate with her because, while it suggested why she might be feeling pain, it did not explain the *cause* of the pain and headaches.

Trust in a Diagnosis

> *Ag*: Have you ever received a diagnosis?
> *Christine*: No. Yes and no. I mean yes. I guess. I have what's called cerebral spondylosis so I have degenerate fisette joints in my neck. The reason I hesitate in answering your question is because it's one of those things that, like, you could do MRIs in half the population or on all of the population and only maybe half of them would show those changes but only a small percentage of people who show those changes actually have any clinical signs. But the argument in my case is that I do have clinical signs so this is the area of problem. You can get a causal area then beyond that they're like, well, we don't know what's going on, like if it's the irritation of the nerves that cause it all or is it irritation and the muscles.

Even though, after a time, Christine was able to receive a diagnosis, she didn't receive the depth of *causal* information that she wanted. What she wanted, rather than a name of an area that was affected by degeneration, was a way to tie clinical narrative into her own lived world and offer a hope that there was something that she could *do* while she went through life in pain. It was not a trustworthy diagnosis; it didn't make sense to her in the context of her pain. Intimate explanations, explanations that make sense are something important, more important than a diagnosis from a physician. She continued searching for answers and continued to get MRI scans of her neck because, just maybe, the doctors would see something new on the scan, something that they have missed before. But it wasn't just the MRI scans that she wanted to double-check. Through her research, she came across various other diseases that could be afflicting her. She wanted to test if those were possible answers for her pain.

This is the starting point of the doubt that my informants experienced with the process of diagnosis. They did not trust the diagnosis that they were given because it did not *explain* their experience of illness or provide *causality* to their suffering. The fact that they continued to search for a diagnosis and contested the diagnoses they received suggests that diagnosis has another, more emotional layer. In 2016, a conference titled *Configurations of diagnostic processes, practices, and evidence* was held in Norway. In the conference report, Brenman et al. (2016) reflected on the concept of diagnosis as it unfolded through the presentations and remarked that conference participants

> repeatedly brought up ... the affective work of a multitude of actors ... both inside and outside clinical settings. This affective work was shown to be highly generative: from enabling the emergence or contestation of new conditions, to producing diagnostic knowledge and expertise, to stabilising that which is incoherent and disorderly (Brenman et al. 2016; 8)

The affective dimensions of diagnosis connect the scientific and experiential narratives of a disease. In my research, trust is an important tool with which participants could connect their suffering to the diagnoses of the physicians.

Trust, as a concept in the social sciences, was first explored by Luhmann (1979) through three main arguments: 1) that trust is a means of control as well as a matter of dependency and cooperation - it is a social glue of sorts; 2) trust is only known to be kept or broken in retrospect; 3) trust has a temporal aspect in which it bridges the past and the future. Beckert (2005; 18 emphases added) argues that "trust can be described as the social mechanism that expresses the *shutdown of the latent uncertainty* of the trust-giver …" Here, trust is connected to certainty because to give trust in something is also simultaneously to anticipate, or hope for, a certain outcome. Luhman (emphasis added 1979; 10) argues that "to show trust is to anticipate the future. *It is to behave as though the future were certain*." Trust mediates uncertainty, and it is through an interpersonal negotiation that we can come to suspend doubt. Therefore, trust ensures that certainty can be obtained. Trust can also be given to larger systems, such as the law, the state, and the market and beyond being a mechanism for curbing uncertainty, trust is also affective in that it can connect the personal, emotional, and embodied spheres as well as larger social, cultural and political structures. Through its power to mediate uncertainty, trust is productive in instances of chronic pain and bodily suffering; I argue that this kind of trust is required because it has the potential to curb uncertainty and provide a future imaginary.

Diagnosis can upset existential realities as sometimes it is not trusted or believed. At times, it does not give the answers that we are looking for, and therefore, it fails to satisfy our needs and fails to provide hope. In the context of this research where chronic pain is something that upsets people's lived realities, the *ways* that their needs were met was crucial for their existential struggles. Furthermore, chronicity is often difficult to diagnose; the diagnostic process, in this case, is marked by uncertainty. My participants wanted to control their situations to cope with this lack they were experiencing. In the previous chapter, I looked at how responsibility and hope work together to keep Christine and George from delving into depression and other mental health problems resulting from a challenged sense of self. How do people create hope in the absence of trust in a diagnosis?

Hope and Information Management

Christine spoke of wanting to receive tests for Lyme disease, even after her diagnosis with cerebral spondylosis. Lyme disease has been controversial in the past few years in North America, particularly because of discrepancy in diagnostic methods and physicians' knowledge of these methods[9]. Lyme disease is contracted from ticks that, if left untreated, can cause a slew of problems, which often take on symptoms similar to many chronic conditions. The Canadian Lyme Disease Foundation has a section on Lyme disease diagnosis and provides the reader with a list of symptoms and a list of resources of what to do in case of Lyme disease diagnosis. The foundation quotes three reasons why Lyme disease diagnosis is difficult in Canada: symptoms are similar to other illnesses, Canadian doctors are unfamiliar with Lyme disease, and a specific type of blood test is needed to detect Lyme bacteria[10]. If left untreated, Lyme disease evolves into a chronic condition itself. Amongst the symptoms are severe headaches, skin rashes, facial paralysis, intermittent muscle, joint, tendon and bone aches, heart disorders, neurological disorders and arthritis[11].

---

[9] https://canlyme.com/just-diagnosed/

[10] https://canlyme.com/just-diagnosed/

[11] https://www.canada.ca/en/public-health/services/diseases/lyme-disease/symptoms-lyme-disease.html

Christine explored the potential of having Lyme disease. For her, the prospect of having Lyme disease was not a thought that she particularly enjoyed, but it was comforting:

> *Christine*: I would almost want to know, right, that I had Lyme disease, even though Lyme disease is not treatable, it's chronic, it's not a nice thought. *I would almost rather know that I had that*. I mean, I'm not saying I want it but I'm saying that at least I would have an answer because at least then you are able to wrap your mind around something and then more forward with it a little bit.

George also searched for various diagnoses and spoke of Lyme disease in particular. He had two tests taken for Lyme disease, but both of them came as negative:

> *George*: I had tests for Lyme, which they tested negative twice. But, I don't totally trust that.
>
> *Ag*: Why not?
>
> *George*: Cause apparently the Lyme testing in Canada isn't that definitive
>
> *Ag*: In Canada specifically?
>
> *George*: I don't know – I know there's this lab in the US you can send it to. But uh – my doctor said that if you want a Lyme diagnosis, you can get it and I was like what? Really?
>
> *Ag*: If you want a Lyme diagnosis you can get it?
>
> *George*: Yea she made it seem like, I don't know. Everyone – I didn't pursue it.

Even though George did not trust the diagnosis (or rather, lack of) that he received from his family doctor, he didn't pursue it further after having found out that a diagnosis can be as much a false negative as a false positive. George wasn't able to tell me why this was. Christine, however, had a lot to say about Lyme diagnosis and the United States:

> *Christine*: You also have to be careful because in the US a lot of healthcare is privatized. And so sometimes some of the tests that they're saying, you know, sometimes they overdiagnose and you can have false positives. So you again have to go do your research to find out what's going on. I'll often go into these crazy rampages looking at research and then I'll have a bad spell and not look at stuff for a little while and just give it a rest and when I'm feeling better it's easier. But yes [Lyme disease] is something I still consider. I haven't ruled out the possibility.

The potential of a Lyme diagnosis creates a different kind of hope from the diagnoses Christine and George have received; it provides an imagination of certainty, causality and future-making (in other words, of hope) because being able to know *what* is going on also means being able to cope with it, to manage it better. In this case, the search for answers turned away from 'truths' and 'fallacies' but to the existential *need to know* need to manage chronicity and uncertainty.

To construct hope out of their diagnostic uncertainty, my participants have had to look for it elsewhere. In this case, hope *was constructed through the process of managing information*. George did not construct his hope through this means as well as Christine did. Anna also constructed her version of hope with her navigating skills within the medical system, along with information management. She ensured *hope through control* that she gained by disclosing her identity to doctors after which she felt that medical professionals took her seriously. "I am a doctor too," she would say, after which she felt the attitude with which medical staff approached her had changed. While Anna did not contest the diagnosis that she received because she was actively involved in the process of diagnosis. Knowledge of the language, the research process, and the experiences she had in the Ukraine as a medical doctor were crucial to her being taken seriously. Anna also researched her condition and came to the doctor's office "armed" with the information and studies that she was able to access online. She was thereby ensuring hope through control and pursuit research. She illustrated that she was able to *navigate* the medical field. Anna's diagnostic process was participatory in that she could affect the kinds of tests and possibilities of treatment available to her. These ideas are elaborated on in more detail in Chapter 4.

Jane, who suffered from circulation problems, found yet other ways to create hope by delving into various documentaries to aid her in making decisions about her health and trying new things. The diagnostic process within the medical field was embarrassing and exhausting for her, as she felt that she was made to feel guilty for her past decisions and not given a proper plan of action about what she should do about her health. She watched health-related documentaries and tried what they suggested. Watching documentaries was also a learning process; she could gain management techniques to conduct her research, learn ways of speaking in the medical field and gain the confidence to advocate for herself. She could also watch things at home without anyone's judgement.

As my participants demonstrated, using various means (social, cultural, experiential and pragmatic) to *advocate* for themselves was an important part of managing illness. This was mostly achieved by managing and accessing information online. Christine was a discerning patient, learning the *reasons and arguments* as to why some treatments and diagnoses might be the right way to go or not. In this, she chose how to conduct and manage her illness through research. She was in a tension between creating hope (through wanting to know she has Lyme disease) and knowing this information could be false. Lyme disease created potential but also created doubt with its ambivalent status. For George, Lyme disease did not have an ambivalent status - he trusted the potential of Lyme disease more than he trusted his doctor.

Doubt and Mistrust

> *Ag*: How did you feel to go through these different doctors saying different things about you?
>
> *George*: Well, it was interesting. I definitely believe what the naturopath said, like that made sense to me. I've been exposed to mold and stuff. But my doctor, she just didn't know at all. And when I brought up mold…. I don't know, she never really, I don't think she thought about it much cause I don't think they learn about it too much. She just basically thought it was an anxiety-caused thing and she prescribed a few anti-anxiety medications. A couple of different ones... And I was definitely resistant to that because I know it's a physical thing.

George *knows* that whatever he has been going through for the last two years has a physical root. The medications prescribed by his physician didn't help his breathing because, as George believes, his breathing has nothing to do with anxiety. George himself acknowledges that the medication didn't work because he *believes* in it differently than his physician. He is resistant to these medications, but it does not necessarily mean that they do not work. The kind of knowledge a diagnosis inscribes in the body has to be believed and trusted. In this case, the diagnosis failed to inscribe knowledge into the body because it was not believed. There are many ways through which diagnosis can be contested and debated. People use the means of their social worlds, their lived experiences, social settings, positionality, community, and research to understand their precarity differently from the medical system.

Throughout my time spent with George, he questioned the causality of his bodily pain. He was forthright in saying that he doesn't *believe* his doctor. The problem that he was experiencing is not in mind, it is in his body, and therefore, the means of treating his issue lie in bodily treatment.

But it wasn't just this issue that made George mistrust his doctor. The doctor's interactions with him are not trustworthy; they do not create the intimacy that he is seeking. In the exchanges with his doctor, George feels that he is "forcing himself," asking for attention and care when it is not available.

> *Ag*: how did that make you feel?
>
> *George*: like not as much space was being made for me or time. Like she was kind of hasty and not nearly as open.

Why do George, Cristine and Anna show doubt in their diagnoses and medical processes? If answers to people's bodily suffering do not provide hopeful, certain, respectful, and pragmatic ways of dealing with their daily reality and if the answers downplay their embodied knowledge and experience of suffering, how can they be trusted? Pragmatic management of illness gives people a certain goal, a feeling of movement, of control that they can *do* something about their predicament in the present moment and an ability to look forward into the future in a hopeful way. They can construct trust through various means available to them. As mentioned before, those include positionality, social setting, and research, amongst others. In this chapter, I have wanted to highlight that research is creative of hope. The accessibility of the online world can produce emotion and means of fulfilling the moral 'best good' through its construction of trust. This democratic medium is a powerful agent in creating emotion and constructing moral scapes. It can also spark doubt, as Christine felt with Lyme disease (as the Canadian Lyme Disease Foundation successfully curated on their website[12]). This kind of doubt and mistrust are productive in creating the desire to search for more, different, new, certain answers.

> *Christine*: I think that you always want to have that *one answer*. You want to have a specific answer and a solution. I was a lot more frustrated with it at first, I was constantly thinking like ok, I researched all these: fibromyalgia, Lyme disease, all those different things.
>
> *Ag*: So it would be helpful to have a diagnosis?
>
> *Christine*: It would be. Psychologically, yes, no questions about it. Lyme disease is difficult to diagnose because of testing, etc, because there are so many strains of it

---

[12] https://canlyme.com/; The introductory page to the website uses phrases such as "improperly tested" and "under-reported," thereby creating doubt. Elsewhere (https://canlyme.com/just-diagnosed/), the writers of the website reinstate hope and trust through discursive practices.

> and the testing isn't definitive. There's so much information out there that it's difficult - I mean it's time-consuming to weave through all that information. And so sometimes I think to myself, maybe I should be looking back into that again.

That *one answer*, one name of an affliction, is important in a situation where one is living through uncertainty about what it is that their body is doing. This one answer ought to provide causality, explanation, potential treatment and a way to imagine and hope for the future. In the above excerpt, diagnosis is constructed as something that she needs to find herself; it is her responsibility to search for these answers herself. My interlocutors were left to search for and create this certainty themselves. As Christine notes, the search for new information, for new diagnoses is difficult because 'it's time-consuming to weave through.'

> *Ag*: Do you think it would be easier for you if you were diagnosed with something?
>
> *George*: Yes for sure. I've definitely thought of that in the past. Cause it like gives me something to focus on, Which I have kind of done that. The doctor said that it's probably mycotoxins that affected me. So that kind of helped me because that's what I'm battling. I can't let this thing take me down.
>
> *Ag*: So when there's a diagnosis it is helpful?
>
> *George*: Yea yea, it gives me hope at the time to say that it was treatable. Yea, it's helpful for the mind. It gives me a sense of direction.

Diagnosis is important, but it is not just a quest for making sense of things or meaning-making. It is a way for people to align their experiences with dominant medical narratives. At times when these things do not align narratively, my informants searched for other ways to alleviate pain. They used pragmatic means to cope with it and strategies such as information management and participation in alternative medicine. Suffering is not a profound existential idea, but a daily, hourly, minute to minute event that spills into people's lives and selves. Through the way that the diagnostic process is set up in the medical field, people find other ways to receive the hope that diagnosis is supposed to give. People come to find this hope in different ways, mainly through managing the information themselves. In the next chapter, I consider another reason for patient responsibilization through the management of information: to be taken seriously.

Chapter 4

Advocacy, Care, and the Alternative

*“*But I generally have done the research myself already to find out where I want to go.”

In Chapter 2, I wrote about Christine’s need to be an active participant in her therapeutic process. Her participation included a research process and therapeutic strategies to have her needs met. Christine employed various means and techniques to not only ensure a diagnosis that made sense to her and met her needs but also to ensure a therapeutic process that contained her moral world and curbed uncertainty. By knowing her needs, doing the research and self-managing, Christine became her advocate and an active participant in her health.

The question of advocacy in health care settings is one which has tremendous implications in terms of access to resources and success in receiving health care. In this chapter, I present the ways that my interlocutors have positioned themselves with the system they were trying to navigate. They were able to use their positionality in strategic ways to access resources. I argue that self-advocacy opens new treatments and means of receiving diagnoses and with them, new hopes. Self- advocacy leads to a pursuit of different kinds of information which can promise appealing kinds of care, diagnoses and treatments (ones that speak of folding experience and causality). Here, I argue that this need to advocate for the self in medical settings results in pragmatic use of information to feel better. Having learned what their needs are and researched information about how they may be met, patients are able to ask for care, spiritual guidance, or attention to be met through an alternative/complementary medical system.

“As soon as you get into that little niche, everything starts happening.”

The prolific use of the internet, as Seckin (2010; 36) argues, has created “successful self-health care and illness management.” Due to its accessibility, people are able to build their coping skills (for example, through curbing anxiety by conducting research online) and become empowered consumers who can manage themselves. Blogs, social media and forum spaces allow people to exchange experiential knowledge where, in the case of illness, they can share information and tips about illness management (*ibid* 37). Internet use and research of information online facilitate patient advocacy, which can work to create ‘digital biocitizens’(*ibid* 38). Seckin (2010) sees this as empowering the educated Western middle-class consumers into the ‘medical discourse’ by giving them the means to ‘arm’ themselves with research.

The self-advocacy model, as discussed in communication studies in the early ’90s, was a response to the unequal distribution of power in physician-patient interactions. The ‘participative decision making’ model designed by Deborah S. Ballard-Reisch (1990), attempted to equalize the power in the clinical setting by elevating patient agency in the decision-making process. Another model, based on self-advocacy, was created by Brashers and Klingle (1992) in which they defined self-advocacy as representing the interests of individuals seeking treatment. Unfortunately, neither of these models accounted for the use of information to manage health outcomes by patients, which, with the advent of the internet, has changed clinical interactions. Furthermore, these models failed to account for the power held in the medical institution. Lupton & Jutel (2015; 129) argue that this kind of self-advocacy, empowerment and engagement with the medical system refers “to lay people taking control over their healthcare and a personal health promotion, behaving as self-responsible, knowledgeable actors who are able to make informed, autonomous decisions and position themselves as ‘partners’ with their healthcare professionals.” Self-advocacy ties in important ways into literature about self-management and responsible patienthood.

As Redley & Weinberg (2007) argue, advocacy, and especially self-advocacy, is a mechanism through which governmentality takes shape. It is through the self that power can be managed and controlled, while within the neoliberal paradigm, the state can withdraw resources from social institutions, reifying and exacerbating the need to take care of the self. However, as scholars have noted, the self-advocacy and self-management models in the fields of disability and mental illness are rather paradoxical. Through education, it is argued, patients can gain the resources to advocate for themselves; however, the kind of education that is provided presupposes an *ability* to self-advocate (Redley & Weinberg 2007). Weiner (2011; 448) argues that the concept of self-advocacy collapses on itself because while people are *expected* to manage their illness with various educational resources, their rationality to make decisions is called into question. The question of self-advocacy can also be examined through the way that the medical system is designed, as my participants illustrate. Time allocation, the language of medicine and doctor/patient expectations may not align in the medical setting. How is advocacy navigated in these situations? What happens when people's experiences are just not listened to due to the lack of training, desire, or time?

The way that the medical system is set up was an issue for all of my interlocutors. Time and attention were both lacking in their experiences and interactions with doctors. Anna recalled how the time allotted in the clinical visit was not enough for her to make a case for herself. In these situations, Anna felt that it was the mood and judgement of the doctor that guided the kind of care she was given. George spoke about the time constraints as well as attitudes of doctors towards him:

> *George*: When I go to the family doctor I just sit there like, she talks to me for a bit, then she looks at her computer like the whole time, like chatting to me and I kind of *have to force myself upon her*.

Christine spoke of the expectations of the patient and physician. When these did not align, the patient was left to their resources:

> *Christine*: The way that it's set up is like, we've got a 10 minute slot for you and that's all the time that's given and so anything that is out of the ordinary and that doesn't respond to the treatments that it should, it's just, you're really on your own in trying to find some alternative therapy, different solutions, different routes to go down.

Time allocation in the clinic is important as it allows patients to talk about their symptoms, needs, and make a case about their health. Time and attention work together to build trust that people are looking for in their doctors. However, as the above excerpts illustrate, the system is not set up in a way as to tend to these needs. Anna spoke in nostalgic ways about the care and attention that she provided her patients in the Ukraine and contrasted that to the lack of care and humanity she was being afforded now through interactions with her physicians. “I want to be treated like a human being,” she would say when recalling the process of diagnosis and negotiation with her physician. Humanity and care were missing from these interactions. What, then, builds trust and care if the patient-doctor relationship is not designed in a way to provide the care that patients expect? My answer to this question here is that it lies in self-advocacy that affords a person the status of responsible patient gained through management of information.

Christine spent a lot of time and energy, researching various conditions online. Since the time allocated for her visit did not allow for her and her doctor to explore and elaborate on her symptoms, she did this on her own. As explored in the previous chapter, she was searching for a diagnosis, a definitive answer that would explain the cause, the location, and point to a treatment for her; she felt like it was her responsibility to find the answers herself. Christine needed access to various tests and specialists to have this work done; she needed referrals. The relationship she had with her GP was very important as it was through this relationship that she was able to open the doors to other services and diagnostic methods available through the healthcare system. She came in ‘armed with information’ to secure an open gate.

> *Christine*: The problem is that you have to be your own advocate with your GP and I think that some people would have more… well first of all it’s in the relationship with your GP and how much he or she is willing to listen to what you have to say and how far they’re willing to put - because sometimes they have to refer you to the right people. I have a GP who is really good and she’s willing to refer me to wherever I need to go. *But I generally have done the research already to find out where I want to go so that makes it a bit easier.* Not everybody’s able to do that really. It makes it easier for me to wade through what needs to be done. But that’s the thing. It takes a lot of work in just getting to the specialist sometimes... But as soon as you get into that little niche then everything starts happening.

Maintaining a good relationship with the physician is important because physicians have the power to refer, and to propel a patient deeper into the medical system. This opens possibilities for various tests, access to medical technologies and the ability to see specialists. In this case, Christine felt that her relationship with her physician was good as Christine was able to secure referrals to where she needed to go. This relationship was built on the trust that Christine is a responsible, knowledgeable, educated patient who speaks the same ‘language’ and is willing to put the work towards her health.

Anna had a similar experience. She printed the research she had done about symptoms of various autoimmune diseases and medications used for these. This information helped her to open doors to various specialists from auto immunologists to physiotherapists, who helped her manage her pain. In these situations, self-advocacy was inevitable because failure to advocate is also a failure of health, prosperity and really, a failure to the self. However, this kind of advocacy was only possible if two conditions were met: if you were able to research the ‘right’ kinds of information found online and to “speak the language” of medicine and responsibility to professionals.

> *Christine*: I do think that, as sad as that is, that when you can speak the same language as who you’re talking to, you get much more recognition and so somebody who’s just not able to advocate for themselves in a meaningful way or they don’t have the knowledge and are depressed and they get just more and more depressed then it becomes easy for them to just continue to be ignored and their needs minimised. I do think that happens a lot. I see it happening around me and I tell people you know, just educate yourself because you get much more credibility when you do that.

‘Just educate yourself’ is a far cry, when Christine, who can navigate the medical system, sees others struggling around her. However, it is not always as easy as education, and there are mental health issues (as Christine addresses) as well as systemic, institutional and intersectional obstacles in the way of gaining the status of a responsible, knowledgeable patient. Is this the kind of engagement that a person needs to be taken seriously? And what happens when they’re not taken seriously?

Care and Alternative therapies

In this section, I introduce alternative therapies and illustrate the ways that they have been used by my interlocutors and what they had to gain through their use. In the previous section, I argued that self-advocacy and self-management are exacerbated in medical settings due to the ubiquitous use of the internet and information technologies. However, the information available on the internet is not monolithic, and information management is expected of people/patients/individuals to wade through and make responsible and moral decisions based on it. My participants found themselves needing to be responsible patients and self-advocates so that they could access the system and make moral decisions based upon information available on the internet. This constituted a kind of moral order between them and the gatekeepers of the medical system. But this kind of moral engagement via information management also opened up new, pragmatic ways of dealing with affliction. In this way, people could creatively approach their futures and manage their affliction through the resources they were able to access. While, as I have argued, information management is required in the medical field to be taken seriously, it does something more. In this section, I examine the ways that people search for answers to argue that the research process opens new kinds of knowledges and ways for people to have their needs met.

I define alternative medicine by exploring how my participants have defined these practices. Christine distinguished between what she considered alternative and "Western medicine." However, the ways that she understood the different therapies seemed to oscillate between alternative and "Western medicine" depending on who was doing the therapy and what kind of certification that they had. Christine's classifications were drawn around the lines of empirical research and evidence. Also, her definitions of alternative medicine took into account the complexities of shifting/new knowledge production. In the following story, Christine speaks about how medical practices move between alternative and Mainstream Western knowledge:

> *Christine*: I found somebody called a behavioural optometrist or neuro-optometrist. It's kind of a budding field in the US where you see it a lot and you're starting to see it here. And they're working on sort of retraining the functionality of your eyes so not just the lens but a combination of how you are using your whole visual field. Like your depth perception, your ability to see 3D images, your ability to focus. They deal a lot with people who have afflicted their visual field. So I went through a 20 week eye program where it was basically just these visual exercises that I was doing. *So ya that definitely would still be considered alternative at this point. Well it would be more on the cusp now.* Because this whole field of neuroplasticity is opening all these doors of things that they didn't think or they thought were just on the fringe and was not recognised by biomedicine. But now we have this functional

> MRI and now we can scan it. So now all the life hard science people who want to see something in front of them, right, the Western medicine kind of science people they wanna see the actual proof or data that something works. Now we can see the different parts of the brain lighting up with all of these different cognitive therapies so it's pretty impressive. So I guess there's this blend now, so much more of this acknowledgement and recognition in Western medicine and I think it can only be a good thing.

'Alternative' here was seen as an alternative to biomedicine specifically, rather than an alternative to Western or scientific practices and knowledge. This alternative, then, encompassed both acupuncture, the Feldenkrais method and new neurological practices. For Christine, certificates and credentials were important when choosing alternative therapies.

Anna defined alternative therapies as opposed to the lack of care she experienced in the mainstream system, therefore, care-centred. She saw the medical system in Ukraine as integrating medicine with alternative forms of care. In her view, this system did not see illness as isolated in a cluster of cells but saw the whole person being cared for, from the mental, physical, and societal aspects of personhood. George, on the other hand, called each practitioner a 'doctor'. He did not discern the different practitioners until pressed by the anthropologist to explain what their specialty was. To a certain extent, I created categories of alterity through my fieldwork and reified them where they may not have been before, especially when speaking with George. However, George did distinguish between his family doctor and other practitioners he went to see. George spoke of the medical system as a gatekeeping tool. Overall, George's concern was not with distinguishing the kinds of care he could expect to receive through different means (as Christine and Anna discerned), but rather, I saw his concern with using multiple means to gain some ability to get better, to alleviate his symptoms, regardless of what a practitioner was 'classified' as.

The way that "alternative" is defined by different people allows us to see what 'alternative' is alternative to. Here is it biomedicine and lack of care in the medical system. Once the mainstream and alternative is established, we can see how people's experiences influence and define their needs in regards to these systems.

'Alternative' is difficult to define and sometimes to define it takes away from the things that it *does* for people who use it. Through my participants' stories, I identified two reasons that they chose alternative therapies: trust and care. As explored in Chapter 2, my participants defined their needs through their experiences. Their use of alternative therapies allowed them to approach their needs, their pain and relations with physicians and sources of care creatively.

In feminist literature, care is an important concept. Care is laborious and often invisible. This labour of care has been explored at length in psychology, history, social theory, health and disability studies. For Joan Tronto (1993; 103), care includes everything that we do to live in the world interwoven with ourselves, our bodies, and everything around us. Care holds a political significance because it encompasses everything we do. Maria Puig de la Bellacasa (2017; 4) argues that "politics of care engages much more than a moral stance; it involves affective, ethical, and hands-on agencies of practical and material consequence." Furthermore, care is a selective mode of attention and practice with asymmetrical power relations; through care, people can be subjected to power and governed (Martin et al. 2015). de la Bellacasa (2011; 5) conceptualizes care as a labour of maintenance of life and things "with ethical and affective implications." It is essential to understand the politics of life in a world that is interdependent. Linkages and dependencies are laborious, affective, emotional and, approached through an ethic of care, hold potential for a robust analysis of power and knowledge politics (de la Bellacasa 2011).

What is the relationship between care and advocacy? I draw on some excerpts from my participants and various practitioners to illustrate that control and responsibility on the one hand, and trust and care on the other, constitute each other into a caring space. Advocacy has to do with being taken seriously, having one's experiences acknowledged and being able to experiment with new ways and information to feel better. This is what draws people to engage with alternative therapies.

Ingrid is a holistic practitioner and clinical herbalist, holding different licenses which provides many kinds of therapies to her clients. She understands health to be constituted socially, mentally and physically. Because of the social aspects of health, Ingrid maintains accessibility in her practice. Every week she volunteers at a local center where people can access alternative therapies for free. Through her work with low-income families in the Vancouver Island and Vancouver areas, she sees how poverty and the environment affect people's health in negative ways, and she makes sure that she touches upon those issues in her consultation process. The initial consultation lasts around an hour during which she and her clients interview each other. Some of the topics that the initial consultation touches upon are medical history, family history, family situation, emotional space, medications, diet, concerns and hopes. She also consults on any difficulties that the patient may have in their lives beyond their physical or mental health. This process is important for Ingrid because it builds trust between her and her participants. Furthermore, this process allows her to discern what her clients want or need from treatment, and she addresses those needs in the treatment she procures. Sometimes people are not responsive to certain treatments, and she tries to "attune [herself] to that." For example, if the person is not responsive to the treatment, she will suggest other ways of meeting the needs of the client.

Ingrid brought up the idea healing is a process that is 'wrapped up' in our lives, desires, and anxieties in very intimate ways. In the doctor's office, those desires and anxieties are not always acknowledged due to systemic constraints. Ingrid saw herself as a secondary option operating next to the medical system. The people who came to see her already know what their needs were. Frequently, they have already researched her practice and her field to know what to expect. They want guidance from her, attention, and the ability to discuss choices and learn self-advocacy. A lot of the time, says Ingrid, "they already know what they want. I just listen."

Participants of alternative therapies could expect and ask for different things of their practitioners. As mentioned in Chapter 2, Christine participated in the Feldenkrais method because she wanted to feel included in the treatment she was undergoing. These therapies were participatory and allowed her to practice mindfulness. For Anna, the reason for searching for wellbeing outside of the mainstream medical system was different than Christine's:

> *Anna*: I went to a massage therapist and then to acupuncture. It was great food for thought for me. I could observe my body and the emotions that these things stirred up. I become more aware of the pain in a way. I did some soul digging at that time.

Anna wanted to "observe" and "become aware" of herself. She also found the care she received in alternative therapies to be "incomparable" to the one in the medical system. Paying for care was something that she wanted to do because it allowed her to express herself and be listened to. In this way, she had her needs met in a different way than in the clinic or with her physician. She was humanized, things were slowed down for her, and her choices and decisions were taken seriously.

George, whose need was to alleviate his inability to breathe fully and the pain it caused in his body, found that some therapies were better than others. Even though he wanted a diagnosis, what he wanted more was a method for managing his breathing:

> Ag: And how do they explain what your disease is?

> George: They didn't really explain, they just were trying to help me out. Like I would tell them I need some help breathing - I have difficulty breathing and they would give points [acupuncture] for that they just wanted to help.

As mentioned throughout this thesis, an ethic of care is what George was after. A naturopath showed concern for the way that George was breathing by asking questions, suggesting and trying different kinds of remedies, and giving George massages. Even though there was no talk of *truth* in this setting, *trust* and *belief* were created that allowed George to alleviate uncertainty through care.

In these encounters with practitioners and clients, trust was created through the exchange of ideas, emotions, concerns, hopes, and money. This was a relationship of trust that was constituted within the market. However, beyond responsible consumers who knew where to get their needs met, my interlocutors were creative of a world in which they could explore and imagine different needs and hopes they wanted to address. They were able to receive the labour of care that the medical health care system did not provide.

Diagnosis and advocacy rely on emotional dimensions based on trust and belief to transform information into knowledge and experience. In the face of existential crises, people use pragmatic means to deal with their afflictions; care is integral to this process. Through personal agency, my participants were able to create their dimensions of care by defining their needs, searching for information, pragmatically trying new things and at times by adhering to the moral, responsible patient paradigm. They also failed and refused to be responsible patients (in the governmentality framework) at times appealing rather to other kinds of responsibilities and allegiances they had. George illustrated that with his choice to stop seeing practitioners (as illustrated in Chapter 2). This decision stemmed from a commitment to ensuring the 'best good' in life and negotiating what it means in life at any given time.

This chapter illustrated how we are compelled to be responsible patients. My interlocutors, to make sense of their affliction in a way that made sense to them. They had to decide *how* to participate, or not participate, and in what. Trust was an important facet of this choice, as were the pragmatic management techniques that my interlocutors learned. These issues were constructive of a moral order in which, to gain access to help, alleviation of symptoms, or be taken seriously, the patient *needed to make themselves responsible*. Standing up for oneself and making choices when there is something at stake (such as one's bodily existence) is constructive of morality, of a way to be in the world that ensures the 'best good.' Morality is also tied to the larger structures that dictate the 'right' way to be. Self-advocacy becomes both a moral quest for self-maintenance and a reproduction of the neoliberal citizen. This process is exacerbated by alternative medicines, where the responsible patient looks outside the medical system to have their needs met. In this way, the alternative therapeutic system works to reify and reproduces the moral framework of neoliberal society while simultaneously reproducing a sense of morality and care within people's struggle to attain health. The next chapter will ask how this moral framework is maintained through online sources and how doubt and trust are created through information technologies.

Chapter 5

Information technology and its management

Health is becoming datafied due to the ubiquitous use of information technology. Smartwatches and fitbits, applications and websites that provide online diagnoses, pacemakers and insulin dispensers have all contributed to the datafication of everyday health. As I illustrated in Chapter 4, systemic medical constraints, where trust is not secured in the doctor-patient relationship and where patient's experiences are not taken seriously, datafication (or, the use of data in the context of everyday health) can secure trust and hope. In this chapter, I aim to add to these conversations about 'datafication' of health by examining popular discourses about health, access to information, and self-diagnosis to argue that these processes create new moralities and relationalities. In this thesis, I have argued that we are morally obligated to access information, to advocate for ourselves to ensure the best care for ourselves. However, as I will demonstrate in this chapter, the gateway to this enactment of morality is, in part, encompassed in the use of information technologies and their management. These technologies also require moral engagement and an ability to discern 'right' and 'wrong' arguments and information. While information and data are often conceptualized as being value-free, I view values as being constituted through human engagement; information and data are affective, productive of trust, moral orientations, power and emotion. Information technology creates morality through people's engagement with it. Furthermore, information and new technologies are also creative of needs (as encompassed in larger processes through structures, politics, cosmologies and positionalities), self-definition, identity formation (in the context of health), can work to structure experiences and compel us into acting as responsible, self-caring citizens. Information management is, therefore, another form of responsibility that constitutes people as moral actors in the world.

Within the governmentality framework, datafication of health is a result of ‘datafied power,’ where there are “asymmetric relations between those who collect, store, and mine large quantities of data and those whom data collection targets” (Ruckenstein & Schull 2017; 261). In this framework, big companies have more access to data and can mine the information provided by data users. Consumers of these technologies also perform “digital labour,” which feeds the algorithms necessary to perform functions for the consumer and gather data. This results in increased surveillance from private companies who may also participate in data sharing with other companies; this asymmetry in access to data is exploitative (Lupton 2016; Till 2014; Rabinow & Rose 2006). “Dataveillance,” a term used to describe the increased surveillance through data, “is distributed across multiple interested parties - in the case of heath, including caregivers, insurance payers, pharmacies, data aggregator and analytics companies, and individuals who provide information” (Ruckenstein & Schull 2017; 264). Reminiscent of Hacking’s ‘making people up’ paradigm, Barker (2011) looks at how Lyrica, a drug for fibromyalgia, can confirm the existence of a biomedically ambiguous illness, even as many doctors and scientists are skeptical of a fibromyalgia diagnosis. Technological health products and applications are popularized through marketing and increasingly used in workplaces. Corporations provide incentives such as bonuses and insurance premiums for their employees to participate in tech-mediated wellness programs that engage self-tracking activities (*ibid* 264; see also Hull & Pasquale 2017; Till 2017). The ‘datafied’ power paradigm is important in that it observes how power is reproduced through new technologies.

Technologies also produce new means for people to relate to themselves, their biographies and the ability to approach politics of resistance in new ways. As Ruckenstein & Schull (2017; 266) argue, “ethnographers have observed that engagements with personal data and its technologies enable individuals to make meaning of their life experiences and relate to their bodies and selves.” Nick Fox (2017; 136) argues that personal health technologies (in this instance, wearable technological devices) have the potential to foster subversive micropolitics of “resisting citizen health.” Fainzang (2013) examines self-medication, an act which has largely become mediated by the use of internet research, as encompassing not just the individual and the power structure of medicine, but the whole of the person's life, such as their relationships, past experiences, and general beliefs. She argues that

> self-medicalization is not always a question of the internalization of medical and therapeutic perspectives leading to a decision to make one’s body dependent on drugs, but may also be the affirmation of a personal judgement - although still socially constructed - concerning the social causes of one’s illness and therefore the accomplishment of a political act (Fainzang 2013; 502).

In Fainzang and Fox’s views, health technologies have political potential, and the ways that people interact with these technologies need to be more closely examined. Lupton and Jutel (2015; 133) argue that through the use of applications for self-diagnosis a ‘dispersal/fragmentation of authority’ occurs. The apps themselves do not claim to replace authority, only to empower the patients to seek professional help. They steer the authority back to the traditional power structure of health: the medical authority. However, to access this medical help, patients have had to already diagnose themselves. Therefore, apps play their credibility to different types of authority: the patient’s own, traditional medical and algorithmic authority, thereby creating an ambivalent place of trust and locus of authority.

Beyond power analysis of data and technology, scholars have also looked at the affective ways that people engage with data and their health. Ruckenstein & Schull (2017) argues that people’s approach to health technologies is ambivalent because people can refuse to give companies access to their self-tracking data while simultaneously experience care and build affective bonds with their technological devices. Likewise, my interlocutors spoke of a sense of control that stemmed from their use of research online. Their use of this method had real-life consequences because they were taken seriously by their doctors, and they could access the resources that they needed. However, they did not always trust the data and needed to learn how to manage it. The use of technology in the area of health sparks new discussions about self-advocacy, self-medication and medicalization, self-management and finally, self-diagnosis. These self-oriented acts can be accomplished through the management of information.

Self-diagnosis and access

Online resources and apps have increasing diagnostic potential. Technologically assisted self-diagnosis is a complex issue because it encompasses many actors, amongst them software engineers, app developers, health professionals, market forces and finally, and the people using these new technologies. I have examined existential dilemmas that people experience when they self diagnose. In social science literature, self-diagnosis has been approached through a governmentality paradigm, examining how responsible patients enact the field of power onto themselves. In a neoliberal world, this means that the labour and time that physicians and doctors would need to give to the patient is done by the patient themselves, allowing resources to be withdrawn from social services that manage health.

Self-diagnosis through online information also opens up questions of accessibility; it is these questions I turn to now by examining a discussion on a social media platform. On the one hand, self-diagnosis is discussed as departing from medical truth and surrendering to irrational thought. On the other hand, and especially in regards to mental illness and neurological disorders, self-diagnosis is framed as a way for people who are not in a position to self-advocate to be able to have a voice and to make sense of their precarity, in similar ways that I have explored throughout this thesis.

Below is an excerpt from such a debate. The post accessed on Instagram on March 20, 2019, illustrates the way that a moral right and wrong is constructed through a discussion about self-diagnosis:

> *Post 1*: Please stop self diagnosing. I don't care how much research you've done. You need to get officially diagnosed before you say that you have any disorder that requires a medical diagnosis!!!!!!!!! You don't have the education. You know so little. If you are showing symptoms, ask a professional! Seriously stop. I don't care about how many online tests you've taken. They can help you! Pls take care of yourself! If you're not diagnosed with ocd, don't say you have ocd. If you're not diagnosed with depression, do not tell ppl you have depression. I'm not saying you're lying about showing symptoms!!!! Your struggles are 100% valid. But you're not a doctor. If you're not diagnosed with social anxiety, you can't tell people you have social anxiety!!!!!! If you're not diagnosed with autism, PLEASE don't call yourself autistic. That one is even worse because it's neurological and not mental. If for some reason you're unable to get diagnosed: I'm sorry that's really rough :(but you can't self diagnose. I'm sorry this rant is vague but this subject makes me very heated.

I want to highlight a few responses in the comments:

> *Respondent 1*: Thankyou so so much for making this people NEED to see this! The amount of BS I see on snapchat of people putting depression tweets and then with the caption ‘hits hard’ like you haven’t been diagnosed!! Stop!!!
>
> *Respondent 2*: You’re such a rude person for saying “sorry that’s rough” to people not being able to afford a diagnosis. “You still can’t self diagnose” you can’t tell people what to do sweetie. Stop thinking that only people who can afford nice things should get special treatment…
>
> *Reply to Respondent 2*: Yea I agree but we still need to teach people what’s right and wrong and not reward them with sympathy for being in the wrong if they know they are.
>
> *Respondent 3*: The only mental illnesses that I believe are self diagnosable are the ones that are extremely obvious, like eating disorders and gender dysphoria. Also some kids do not have parents that will take them to a professional for either financial reasons or just not believing that there is something wrong with their child so they dont have any other choice but to self diagnose. The only people I don’t believe should diagnose are the idiots who get sad once and sAy tHeY aRe dEpReSsEd, the people who forget to eat 16 hours and sAy tHeY aRe AnoRexIc, and other people like that.
>
> *Respondent 4*: I’m generally against self-diagnosing because people can’t diagnose themselves… not even professionals. Your view of yourself is biased and distorted, it’s impossible to be objective about yourself. But I don’t shame people for doing that because it’s none of my business anyway. Tbh I don’t get the point of self diagnosing. What’s the point of putting a label on yourself (which you’re not even sure of)? Someone enlighten me please.

Although the above posts are referring to a specific phenomenon, where people self-diagnosing with mental illness are perceived as ingenuine, these responses illustrate the issues with self-diagnosis by drawing a line between the ‘right’ and ‘wrong’ way of diagnosing oneself. Even though self-diagnosis is constructed as immoral in the initial post, the responses attempt at distinguishing between the *kinds* of self-diagnoses that are ‘right’ and ‘wrong.’ Respondent 3 uses belief to parse out the moral code for this situation by bringing up eating disorders and gender dysphoria and using them to complicate the binaries of ‘right’ and ‘wrong.’ For instance, gender dysphoria *can* be self-diagnosed because the individual can be trusted to know what kind of relationship they have to their bodies and socially constructed ways of embodying social conduct. However, mental disorders, like depression, and especially neural disorders such as autism, are ‘wrong’ to self diagnose. In these cases, whoever is reading this post can situate themselves into this moral continuum of the ‘right’ and ‘wrong’ of self-diagnosis.

Examples such as gender dysphoria and eating disorders point to the history of medicalization and the construction of normative categories. They also open conversations of systemic challenges which occur through the clinic but are implicated into policy, insurance, and political atmospheres. Mental health and neurological disorders are important to the above conversation: how does one access a resource in a field where self-advocacy is extremely important, but where mental health and neurological disorders prevent you from being able to advocate for yourself (Weiner 2011)? The account pro_choice on Instagram had this to say:

> *Pro_choice*: Self diagnosis is valid. Not everyone can access healthcare. Not everyone is taken seriously by medical professionals (google racism and sexism in medical fields). Attitudes like these are why some of us continue to be disregarded and ignored, or are too afraid to come forward and talk about our mental illness/physical illnesses. We live with our conditions everyday of our lives. We live with our pain. And I’m tired of people telling us it’s not valid until I have a fancy diagnosis from a doctor.

‘Get educated’ as mentioned in Chapter 4, is a far cry to someone who has access to education in ways that others do not. However, this kind of call for education was also seen in the above conversations on social media: “you don’t have the education. You know so little” and “google racism and sexism in the medical fields.” Here, education (and lack of it) painted conduct that could alleviate doubt, create certainty and construct a moral/ethical orientation of the person reading it.

The Informational Idiom

The final concept that I bring up in this thesis is the ‘informational idiom,’ which, according to Corsin Jimenez (2010; 184), is the “latest idiom of ‘self-awareness’.” Corsin Jimenez writes about trust as it connects to knowledge, morality, and information. The current basis for moral trust, he argues, is that of 'robust information' which renders a system morally robust, and therefore, trustworthy. He argues that "morality emerges thus not as an aspect of human relationships but as a feature of the infrastructure of information, where robustness of information is achieved through research, education and the process of googling information. If we make our information more robust, we strengthen our morality" (*ibid* 180). In this view, morality becomes a feature of the infrastructure of information. However, this kind of robustness conflates information and knowledge where "if information stands for society; then our informational base stands for our moral choices. We are our information, which is why our information needs to be unbiased, pure, elemental" (*ibid,* 184). We make our choices and decisions based on information, and these choices have to be unbiased, pure, and elemental; in other words, moral.

It is with the 'information idiom,' where value-free information requires proper management that we are compelled to act morally. By compelled to act morally, I mean to act according to information which is available to sift through and based on which decisions can be made and moral positioning is achieved. Corsin Jimenez (2010; 180) also compares the distribution of responsibility, arguing that, rather than responsibility being dispersed through relationships (relational), it is based on the availability of information. Here, responsibility, like morality, does not relate to human relationships but the availability and dissemination of information. As I have demonstrated in this thesis, the morality that my participants were compelled towards was constituted partly through their management of information. Unlike Corsin Jimenez, I do not argue that information is value-free, rather, as I have illustrated, people are affected by and in turn, affect the information that they come across. This is because people's lives are folded into the process of information management, and life is not a value-free process. We expect information to be value-free, that it will not obstruct morality with values and beliefs. However, my interlocutors emoted to the information they gathered online. They folded their past, present, and a potential, hopeful future into their online research. Information management was never value-free. As they navigated the online world, from blogs to forum boards to memes on social media platforms, they were faced with moral decisions; what do I think of self-diagnosis? Is Lyme disease diagnosis something I should be looking for? Should I see an herbalist for this depression issue?

This informational morality becomes apparent in the ways that people are expected to, and expect of themselves, to manage information. I have explored the ways that people use information to make decisions about health. Engagement with information was important as it provided existential answers and coping strategies for people suffering from chronic conditions. It made them responsible and in control of their health. In the eyes of physicians and the medical system, they were moral patients because they managed, approached, and worked towards attaining 'robust information.' These patients, especially Christine and Anna, could be trusted. Trust was constituted between the management of information, management of uncertainty, and powerful institutions.

It is the belief in value-free information that renders the management of information constitutive of morality. However, value-free information does not exist, as structures, emotions, trust, doubt and appeals to different kinds of authority (and morality) obscure the idea of objectivity. The debates that occur online, blogs and forums, along with the ways that websites are constructed and designed provide perspectives from which people are compelled to take a position within them. They position themselves on the spectrum of information and data that appeals to different kinds of knowledges, positionalities and beliefs. Information found online is not value-free but is mediated through human emotion. Information management points to a moral engagement with ideas of value-free information and can be understood as a belief in the objectivity of information. As I have illustrated in the previous chapters, people dealing with uncertain afflictions, in this case, chronic illness, want to create certainty in their lives through the management of information to fulfill existential goals and more pragmatic goals of being taken seriously and receiving care. This management can be done while searching for a diagnosis that makes sense in their lives and bodies, and while constituting a trust with their health providers that they are indeed knowledgeable patients who want to heal. They do this by gathering data. In this way, making a better, a 'best good' life possible for themselves is also the making of a moral life chosen in part by gathering information online.

Conclusion

Resources available online ranging from websites and apps (such as WebMD) to blogs and forums (Reddit; https://patient.info/forums), social media, and bite-sized arguments delivered in the form of memes operate in social/cultural/political scapes. They craft morality and certainty about a precarious future. I examined the role that emotion, belief, and trust play in the process of health attainment and argued that our existential precarity is the reason we look to alleviate it. It would not make emotional, ethical, or moral sense not to act in this way. Moral lives are constituted via allegiances and responsibilities that create the 'best good' but also through people's values, decisions about what is right and wrong, through inquiry and making use of experience and positionality. Furthermore, powerful institutions, beliefs, structures, politics, and forces within a person's milieu contribute to how these moral lives are constituted. Information found online appeals to authority (whether religious, political, scientific or social) and to be parsed out it needs to make sense in the context of people's lives, cosmologies and allegiances. Online, authoritative allegiances can take the form of textual, sensory, discursive and emotional bias. As websites blogs and forums often rely on revenue to maintain themselves, they may operate in the form of click-bait articles. These multifaceted issues bring up many moral question and conundrums.

In this thesis, I have explored four main concepts: responsibility, hope, morality, uncertainty. I examined responsibility as a distraction from pain as it oscillates between the self and others, encompassing relationality and the individual subject at the same time, turning moral and ethical allegiances into the complex lives of my participants. I argued that online information management requires moral responsibility to manage information ethically. The second concept, hope, is created, searched for, sustained through socially prescribed means and has the potential of securing determinacy. It also has a moral dimension due to its future-making orientation. Through the concept of morality, I examined how the 'best good' for the self is constituted through information management. Finally, uncertainty is the starting point of this complex process because people use whatever means available to alleviate the indeterminate future and imagine it morally.

In this thesis, I have argued that people suffering from chronic conditions feel compelled to use online information when searching for diagnoses and therapies to secure the best outcome for their health. I have looked at how the process of research relies on several factors such as life experiences, motivations, needs, and positionally and how trust and hope are important in the process of health attainment. Through the use of online information, morality is produced, maintained, and managed.

In Chapter 1, I outlined my theoretical framework by examining the moral dimension of future-management. In Chapter 2, I examined how people define their needs and the pragmatic means they use to feel better about their chronic affliction. I argued that emotional adjustments, which create hope and give a sense of responsibility, are important for people's management of illness. In Chapter 3, I looked at the process of diagnosis to argue that diagnosis relies on the creation of trust to answer to patient experiences and lived realities. In Chapter 4, I argued that self-advocacy ensures pragmatic engagement with information, thereby, leading to a pursuit of new kinds of treatments, care, and diagnoses. In Chapter 5, I examine how the datafication of health, access to information and self-diagnosis create new moralities, responsibilities and relationalities.

This project has its limitations and does not attempt to provide answers that are universally applicable. To begin, the focus of this research was on participants whose chronic pain and life experiences related them to information online in an intimate way. However, such engagement informational morality could differ depending on context, disease and affliction (such as a cancer diagnosis, HIV infections, communicable diseases and mental health). The types of experiences people have with health professionals may be different according to different factors, including positionality. This brings me to the second limitation: my participants were largely white, middle-class populations. These experiences are different in populations who lack choice, whose lives are surveilled by the state (as opposed to individuals practicing self-surveillance) and whose lives are structurally vulnerable. Given more time, I would have paid more attention to the positionality of participants in the recruitment process. Thirdly, this research project was limited by time and funding available for me to stay in the field. Given this issue, if I could change something about this research project, it would be the initial research question. While the question allowed an openness in the field that is important in anthropology (as it allows research participants to interpret the questions in their way), it was too broad in light of logistical limitations.

Some important questions open this research to the larger issues in the world and current events: What does it mean to morally deal with information?? What happens when a person does not have the means to have their needs met through alternative therapies nor the medical system? What happens when people try to create trust and hope with the means that they have available to them? Whose authority is appealed to when health decisions are made? What is the relationship between information management, the market and politics?

In the spring of 2016, a southern Alberta couple, David and Collet Stephan, was convicted for the death of their child, who died of meningitis because the couple "failed to provide the necessities of life" (CBC News Calgary). The couple was found to be "purposely withholding medication that they knew would assist the child," Shannon Prithipaul, the past president of the Criminal Trial Lawyers Association, told the CBC. The couple is part of a Mormon community that is skeptical of mainstream medicine (Gerson 2016). David's father, Anthony Stephan, is the CEO and co-founder of "True Hope," a chain of nutritional supplements that claim to cure ADHD, anxiety, autism, bipolar disorder, depression, fatigue and stress (True Hope Mental and Physical Wellbeing). On the company website, Anthony Stephan reflects on faith and hope in God:

> Hundreds of participants have borne that same witness and acknowledged the hand of God in bringing restoration to their life or that of a loved one. Hence, we have named this web site "TRUEHOPE" because we believe that true hope can only be found in the healing sustenance that God has provided for us. No man or company or science can ever replicate or replace that which our Creator has provided for us… (True Hope Mental and Physical Wellbeing)

The website appeals to religious authority (in the context of the mormon community residing in southern Alberta), as illustrated in the quote above, experience, and scientific authority (pdf are provided on the website for various studies on psychiatric conditions and nutritional supplements). What kinds of morality does appealing to different authorities hold? What happens when religious (or spiritual) authority is instrumentalized into a capitalist system? This story reminds me of a plethora of online self-help websites and ads that provide information to better the self through a miracle cure, diet or therapy. What is the role of self-responsibilization (the neoliberal framework of governance) in an authoritatively fragmented world?

I fucking hate pseudoscience
May 1 at 10:49 AM ·

Pro-vaccine **Anti-vaccine**

Anti-vaxxers don't work with sick children.
Safe at home, they spread lies about
vaccines, utterly blind to the consequences.
Others must remedy the suffering they cause.

(Pro-vaccine/Anti-vaccine)

On February 28, 1998, Dr. Andrew Wakefield published an article in *The Lancet*, which began the latest vaccine controversy, now lasting over 21 years. In the article, Wakefield (since discredited as a doctor) links the MMR (measles, mumps, rubella) vaccine to autism (Quick & Larson 2018). From this article, the 'anti-vaxx' movement has grown. Opinions about the movement are polarized. I included a meme from a social media site which illustrates how this debate is morally polarized, where smiling women, dressed in white lab coats holding a smiling child, presumably doctors or nurses, stand opposed to a woman hunched over a laptop with a skeleton on the screen. This meme presents a binary of good and bad, presenting the perspectives (either the 'pro' or 'anti') as a moral choice.

Gabriela Capurro et al. (2015) examines the ways that anti-vaxxers are formed as "central characters in the in the [measles] outbreak's unfolding narrative which came to represent a threat to public health and moral order" (Capurro et al. 2015; 25). In their analysis, Capurro et al. (2015) state that only a small percentage of people constitute an *anti*-vaccination attitude; rather, people's positions of vaccines vary from hesitancy to skepticism to refusal. Through a Canadian news media analysis, they found that moral panic (constructing anti-vaxxers as "criminals," unintelligent, likened to terrorists, etc.) and moral responsibility (to both children and the wellbeing of the state) were elicited through the different news stories. The conversation on public news media was therefore constitutive of a morality and a moral conduct with regards to vaccines, public life and information itself.

What is interesting in this discussion is the way that the movement has "grown into a libertarian political rebellion that is drawing in state Republican officials who distrust government medical mandates" in the United States (Arthur 2019). Arthur Allen argues that this movement had clung to the idea of freedom for parents to choose whether or not to vaccinate their kids. With that comes the political dimension of information management. Vaccinations and questions of freedom of choice are now implicated into another layer of moral questions: who do you stand with and why? Which political party do you support? What is your definition of freedom to choose and for whom?

There are many examples like this in North America, and the conversation is not just limited to nutritional pills and vaccines; vegan diets for newborns, new health food trends, diets and diet pills, health tourism and cultural appropriation of health are just some things that pose pressing questions about moral conduct. However, the concept of information management can stretch beyond health to other conversations pertinent in the world right now. Fake news and misinformation, global warming and migration are just some topics that are hotly debated and whose actors accuse each other of mismanagement of information. Therein lies the responsibility of online moral conduct in the modern world. Finally, an interesting question that stemmed from this research is about immorality: what does it mean to be immoral? What does it mean not to enact the best good, to not be affected morally? What does it mean to be immoral in the context of information management?

I also want to tie these conversations to work currently being done in the social sciences. As I have explored in my literature review, consuming lifestyles can constitute identities and self-responsibility. Paired with information technology, this engagement becomes more susceptible to surveillance, data mining, and political influence (for example, political movements aligning themselves within moral conversations that stem online). An important question here is how are (political) identities built by consuming information? Along the lines of consumption, the self-help genre constructs morality through the creation of lifestyles and behaviours (de Courville Nicol). How is online information (in the form of blogs and YouTube videos) creative of self-help lifestyles? What are influencers selling and why? How do they use their followers in this interactive economy (Andrejevic 2002)? And how do people interact with this online lifestyle consumption (see Miller 2012)?

In a world saturated with various information technologies, it is impossible not to think of humans as cyborgs whose lives are intimately linked to systems and networks. From a posthumanist and STS perspective, the questions that this research can pose further are: how are different actors constituting the online space? Algorithms and Google searches have their agencies which incorporate several actors. How are algorithms different from the different actors involved in their creation? How are algorithms experienced and through which technological means (Berg 2017)? Is the online world experienced as a magical/oracular space?

Finally, the question of power is important for this research. Building/designing of online data and the emotional dimensions of new technologies are important dimensions of this research. From the perspective of sensory studies, how are sensory worlds built digitally (see Lupton 2017a and Urban 2017) and how do they appeal to different kinds of authority? How are affective, emotional and sensory spaces created through digital technologies (Lupton 2017b)? If affect can provide us with new ways of examining politics and power, what does it tell us about power, virtuality and digital technologies? Technology, after all, is not value-free and technological engagement is personal and emotional, and with that, it is useful to examine how new technologies are emotive and productive of new forms of power.

We cannot, however, forget the personal, ordinary experiences of online data, information and technology. As Christine has shown, information can be used to ensure certainty to the constant state of precarity and pain brought on by her headaches. Christine and Anna learned to use certain kinds of information in contexts that allowed them to be seen as moral individuals and responsible patients, but that simultaneously allowed them to have their needs met, as they defined them from within their positionality. They did this to ensure the ‘best good,’ however, they defined it. George also ensured the best good for himself by being involved in his search for health. As I illustrated, at the moment of fieldwork, it included *not* pursuing health and taking a break from the constant responsibility and accountability that he felt he needed to maintain.

As I was writing this thesis, I went to my doctor for a regular checkup. I told her that I want to quit smoking, and I want to have a prescription for nicotine gum. She was reluctant to write a prescription but eventually agreed. She also suggested that I go to a smoking clinic, held once a month by nurses at my university, to learn about how smoking is more psychological than physiological.

Doctor: Let's look for a resource for you

I move my chair over to her desk so that I can see the computer.

- *Smoking cessation resources* - she types into the Google search box.

Doctor: Hmm…

She scrolls through the search results

Ag: This one looks good.

I say as I point at the screen

Doctor: Yes, let's try it.

The result produces a pdf document that contains information and tactics for quitting smoking.

Doctor: This looks like a good one. I'll email it to you so you can read it at home. But there's plenty of stuff like this online (she presses the back button and the Google search page reloads). You can look it up at home.

APPENDIX A

CONSENT FORM TO PARTICIPATE IN INTERVIEWS

Study Title: "'Participation in Complementary and Alternative Medicine: How people choose and interact with CAM practices.'"
Researcher: Agnieszka Bill-Duda
Researcher Contact Information: email: billduda@ualberta.ca; or phone: 514-746-9939
Faculty Supervisor: David Howes PhD
Faculty Supervisor Contact information: email: david.howes@concordia.ca; or phone: 514 848-2424 ex 2852.

You are being invited to participate in the research study mentioned above. This form provides information about what participating would mean. Please read it carefully before deciding if you want to participate or not. If there is anything you do not understand, or if you want more information, please ask the researcher.

A) PURPOSE

The purpose of research is to examine ways in which people interact with complementary and alternative medicine. Participants will be asked about their experiences in interacting with environments and practices of these medicines. Participants may be asked to reflect on past experiences and to interact with the data thus far collected by the researcher.

B) PROCEDURES

After signing the consent form, you will be asked a series of questions having to do with your experience and participation in complementary and alternative medicine. The interview may last from 15 minutes to an hour and will be recorded. You can withdraw from answering any questions you feel uncomfortable with and/or fully withdraw from the research study at any time during or after the interview.

C) RISKS AND BENEFITS

The researcher will ensure that risks resulting from the interview process are minimal. No information will be disclosed; data collected from interviews will be stored in a locked location accessible only to the researcher. Participants are reminded that withdrawal from the study at any time is possible without negative consequences. No direct enticements will be provided to participants. Personal benefit of the interview to participants is reflection on their practice and participation in complementary and alternative medicine.

D) CONFIDENTIALITY

The information gathered during the interview will include reflections on participation in health-related practices, the content of participation, feeling of community, and content of alternative medicinal environments. No information gathered during the interviews will be disclosed to third parties and identity of participants will remain anonymous. Research findings will be published, however, it will not be possible to identify you in the published results. Data collected from the interviews will be written in a journal which will be kept in a locked storage by the researcher and destroyed five years following the project's completion. Your participation in this study is CONFIDENTIAL; the researcher will know but will not disclose your identity.

E) CONDITIONS OF PARTICIPATION

You do not have to participate in this research. It is purely your decision. If you do participate, you can stop at any time. You can also ask that the information you provided not be used, and your choice will be respected. You can withdraw your consent at any point during and/or after the interview without any negative consequences. You also have the freedom to avoid topics I feel uncomfortable with. The data obtained in this study is for the purpose of a Master's thesis and may be published; your identity will remain anonymous throughout.

6) PARTICIPANT'S DECLARATION

I HAVE CAREFULLY STUDIED THE ABOVE INFORMATION AND UNDERSTAND THE CONTENTS OF THIS AGREEMENT. I HAVE HAD THE OPPORTUNITY TO ASK

QUESTIONS HAVE RECEIVED SATISFACTORY ANSWERS. I FREELY CONSENT AND VOLUNTARILY AGREE TO PARTICIPATE IN THIS STUDY UNDER THE CONDITIONS DESCRIBED.

Name: ______________________________________

Signature: ____________________________________

Date: ____

If you have questions about the scientific or scholarly aspects of this research, please contact the researcher. Their contact information is on page 1. You may also contact their faculty supervisor.

If you have concerns about ethical issues in this research, please contact the Manager, Research Ethics, Concordia University, 514.848.2424 ex. 7481 or oor.ethics@concordia.ca.

Bibliography

Ahmed, Sara. 2004. The cultural politics of emotion.

Allen, Arthur. 2019. "How the anti-vaccine movement crept into the GOP mainstream" Politico. May 27, 2019. Accessed on May 29, 2019 <https://www.politico.com/story/2019/05/27/anti-vaccine-republican-mainstream-1344955>

Andrejevic, Mark. 2002. "The kinder, gentler gaze of Big Brother: Reality TV in the era of digital capitalism" *new media & society* 4(2):251–270.

Archambault, Julie Soleil. 2018. "Taking love seriously in human-plant relations in Mozambique: Toward an Anthropology of Affective Encounters" Cultural Anthropology. 31:2, 244-271.

Ballard-Reisch, D. S. 1990. A model of participative decision making for physician-patient interaction. Health Communication, 2(2), 91-104.

Barcan, Ruth. 2011. Complementary and Alternative Medicine: Bodies, Therapies, Senses.

Barker, Kirstin K. 2011 "Listening to Lyrica: contested illness and pharmaceutical determinism" Social Science & Medicine. Vol. 73. 833-842.

Barrow, Lloyd H. 2006. "A brief history of inquiry: From Dewey to standards." Journal of Science Teacher Education 17, no. 3: 265-278

Beckert, Jens. 2005. "Trust and the Performative Construction of Markets"

Berg, Martin. 2017. “Making sense with sensors: Self-tracking and the temporalities of wellbeing” *Digital Health*. 3: 1-11.

Brashers, D. E., Haas, S. M., & Neidig, J. L. 1999. The patient self-advocacy scale: Measuring patient involvement in health care decision-making interactions. Health Communication, 11(2), 97-121.

Brenman, Natassia, Anna Witeska-Młynarczyk, Nina Nissen and Mette Bech Risor. 2016. “Configurations of diagnostic processes, practices, and evidence: a conference report” Somatosphere: Science, Medicine, and Anthropology. Accessed March 19, 2019. <http://somatosphere.net/2016/11/configurations-of-diagnostic-processes-practices-and-evidence-a-conference-report.html>

Busby, Colin. Jacobs, Aaron. and Ramya Muthukumaran. 2017. “In Need of a Booster: How to Improve Childhood Vaccination Coverage in Canada” *Institute C.D. Howe*. Commentary No. 447. <https://www.cdhowe.org/sites/default/files/attachments/research_papers/mixed/Commentary_477.pdf>

Butler, Judith. 2005. “Giving an Account of Oneself” Diacritics Vol. 31, No. 22-40

Caliandro, Alessandro. 2018. "Digital methods for ethnography: Analytical concepts for ethnographers exploring social media environments." Journal of Contemporary Ethnography 47, no. 5: 551-578

CBC News Calgary. 2016. Alberta parents convicted in toddler's meningitis death” April 26, 2016. Accessed on May 27th 2019. https://www.cbc.ca/news/canada/calgary/meningitis-trial-verdict-1.3552941

Corsín Jiménez, Alberto. 2011. “Trust in Anthropology.” Anthropological Theory 11, no. 2: 177–96.

Coulter, Ian and Evan Willis. 2007. “Explaining the growth of complementary and alternative medicine” Health Sociology Review. 16. 3-4. 214-225

Crawford, Robert. 1985. “A cultural account of 'health': control, release and the social body” in ED McKinlay, J B. Issues in the political economy of health care. Travistock Publications.

Crawford, Robert. 2006. “Health as a meaningful social practice” health. Vol 10. No. 4. 401-420.

Crossley, Nick. 2006. *Reflexive Embodiment in Contemporary Society.* Open University Press:

Das, Veena. 2006. *Life Worlds: Violence and Descent into the Ordinary*. University of California Press.

De Courville Nicol, Valerie. 2011. “The Anxious Self in Contemporary Self-Help Literature” Fear, Terror, Horror At The Interface. Accessed on <https://concordia.academia.edu/Val%C3%A9riedeCourvilleNicol>

de La Bellacasa, Maria Puig. 2011. "Matters of care in technoscience: Assembling neglected things." Social studies of science 41, no. 1: 85-106

de La Bellacasa, María Puig. Matters of care: Speculative ethics in more than human worlds. Vol. 41. U of Minnesota Press, 2017

Deleuze, Gilles, and Félix Guattari. "A thousand plateaus, trans. Brian Massumi." (1987).

Dewey, John. "The quest for certainty." (1929).

Dubé, Dani-Elle “Who’s really to blame for Canada’s falling vaccination rates? It’s not just anti-vaxxers, report says” Global News. April 27, 2017. Accessed on May 28, 2019. <https://globalnews.ca/news/3409038/whos-really-to-blame-for-canadas-falling-vaccination-rates-its-not-only-anti-vaxxers-report-says/>

Durkheim, Emile. "The determination of moral facts." Sociology and philosophy (1953): 35-62.

Ebeling, Mary (2011) “‘Get with the Program!’: Pharmaceutical marketing, symptom checklists and self-diagnosis” Social Science & Medicine. Vol. 73. 825-832.

Evans-Pritchard, Edward E. Witchcraft, oracles and magic among the Azande. London: Oxford, 1937.

Fainzang, Sylvie. "The other side of medicalization: self-medicalization and self-medication." Culture, Medicine, and Psychiatry 37, no. 3 (2013): 488-504.

Foucault, Michel. "Discipline and punish: The birth of the prison, trans. Alan Sheridan." (1977).

Foucault, Michel. “Power/knowledge: Selected interviews and other writings” 1972-1977. Pantheon, 1980.

Fox, Nick J. "Personal health technologies, micropolitics and resistance: A new materialist analysis." Health: 21, no. 2 (2017): 136-153.

Fox, Nick, and Katie Ward. "Health identities: from expert patient to resisting consumer." Health: 10, no. 4 (2006): 461-479.

Fries, Christopher J. (2008) “Governing the health of the hybrid self: Integrative medicine, neoliberalism, and the shifting biopolitics of subjectivity” Health Sociology Review. 17:4. 353-367.

Fries, Christopher J. (2013) “Self-care and complementary and alternative medicine as care for the self: An embodied basis for distinction” Health Sociology Review. 22:1. 37-51.

Geertz (1998) “Deep Hanging Out” New York Review of Books. October 1988. Accessed May 15, 2019 <https://www.nybooks.com/articles/1998/10/22/deep-hanging-out/>.

Gerson, Jen. “The story of the tragic death of Ezekiel Stephan in 2012 begins with the tragic death of his grandmother in 1994” The National Post. June 10, 2016. Accessed on May 27, 2019 <https://nationalpost.com/news/canada/different-spin-on-health-inside-tragic-death-ezekiel-stephan>

Giddens, Anthony (1991) Modernity and self-identity: self and society in the late modern age. Stanford, Calif: Stanford University Press.

Gluckman, Max, ed. The allocation of responsibility. Manchester University Press, 1972.

1994. Good, Byron J. Medicine, Rationality and Experience: An Anthropological Perspective. Cambridge: Cambridge University Press

Good, Byron and Mary Jo DelVecchio Good (1981) “The Meaning of Symptoms: A Cultural Hermeneutic Model of Clinical Practice” In L. Eisenberg and A. Kleinman (ed.), The Relevance of Social Science for Medicine. Dordrecht, Holland: D. Reidel Publishing Company.

Good, Mary-Jo DelVecchio, Paul Brodwin, Byron Good, and Arthur Kleinman, eds. Pain as human experience: An anthropological perspective. No. 31. Univ of California Press, 1992

Grosz, Elizabeth A. Volatile bodies: Toward a corporeal feminism. Indiana University Press, 1994.

Hacking, Ian (1986) “Making Up People” In Reconstructing Individualism: Autonomy, Individuality and the Self in Western Thought.

Hacking, Ian (2006) “Making up people” London Review of Books. Vol. 28 No. 16. 23-26

Haraway, Donna. "A manifesto for cyborgs: Science, technology, and socialist feminism in the 1980s." The postmodern turn: New perspectives on social theory (1994): 82-115

Haraway, Donna"When species meet." (2008).

Hull, Gordon, and Frank Pasquale. "Toward a critical theory of corporate wellness." BioSocieties 13, no. 1 (2018): 190-212

Illich, Ivan (1976) Limits To Medicine: Medical Nemesis: The Exploration of Health. Harmondsworth: Penguin.

Jutel, Annemarie & Sarah Nettleton (2011) “Introduction: Towards a sociology of diagnosis: reflections and opportunities” Social Science & Medicine. Vol. 73. 793-800.

Jutel, Annemarie, and Deborah Lupton. "Digitizing diagnosis: a review of mobile applications in the diagnostic process." Diagnosis 2, no. 2 (2015): 89-96

Kirmayer, Laurence J. "Reflections on embodiment." Social and cultural lives of immune systems (2003): 282-302

Kleinman, Arthur (1980) Patients, Healers, and the Context of Culture: An Exploration of the Borderland Between Anthropology, Medicine, and Psychiatry. Berkeley: University of California Press.

Kleinman, Arthur (1988) The Illness Narratives: Suffering, Healing and the Human Condition. United States of America: Basic Books.

Kleinman, Arthur. What really matters: Living a moral life amidst uncertainty and danger. Oxford University Press, 2007

Kleinman, Arthur, and Joan Kleinman. "Suffering and its professional transformation: Toward an ethnography of interpersonal experience." Culture, medicine and psychiatry 15, no. 3 (1991): 275-275

Kleinman, Arthur, and Joan Kleinman. "The appeal of experience; the dismay of images: cultural appropriations of suffering in our times." Daedalus 125, no. 1 (1996): 1-23

Leder, Drew. The absent body. University of Chicago Press, 1990

Leder, Drew, and Mitchell W. Krucoff. "The touch that heals: the uses and meanings of touch in the clinical encounter." The Journal of Alternative and Complementary Medicine 14, no. 3 (2008): 321-327

Lindquist, Galina. Conjuring hope: Healing and magic in contemporary Russia. Vol. 1. Berghahn books, 2005

Luhmann, Niklas. "The morality of risk and the risk of morality." International Review of sociology 1, no. 3 (1987): 87-101

Luhmann, Niklas. Trust and power. John Wiley & Sons, 2018.

Lupton, Deborah, ed. Risk and sociocultural theory: New directions and perspectives. Cambridge University Press, 1999

Lupton, Deborah. "Consumerism, reflexivity and the medical encounter." Social science & medicine 45, no. 3 (1997): 373-381

Lupton, Deborah. "Towards critical digital health studies: Reflections on two decades of research in health and the way forward." Health: 20, no. 1 (2016): 49-61

Lupton, Deborah. a. “Editorial: Towards sensory studies of digital health” *Digital Health*. 3: 1-6. 2017.

Lupton, Deborah. B. “How does health feel? Towards research on the affective atmospheres of digital health” *Digital Health*. 3: 1-11. 2017.

Lupton, Deborah, and Annemarie Jutel. "‘It's like having a physician in your pocket!’A critical analysis of self-diagnosis smartphone apps." Social Science & Medicine 133 (2015): 128-135

Manderson, Lenore & Carolyn Smith-Morris (2010) “Introduction: Chronicity and the Experience of Illness” in Chronic Conditions, Fluid States: Chronicity and the Anthropology of Illness. ED. Lenore Manderson and Carolyn Smith-Morris. New Brunswick: Rutgers University Press. 1-18.

Massumi, Brian. Parables for the Virtual. Duke University Press, 2002

Marchand, Trevor HJ. "Muscles, morals and mind: Craft apprenticeship and the formation of person." British Journal of Educational Studies 56, no. 3 (2008): 245-271

Martin, Aryn, Natasha Myers, and Ana Viseu. "The politics of care in technoscience." Social Studies of Science 45, no. 5 (2015): 625-641

Mattingly, Cheryl. Healing dramas and clinical plots: The narrative structure of experience. Vol. 7. Cambridge University Press, 1998

Mattingly, Cheryl. "Moral selves and moral scenes: narrative experiments in everyday life." Ethnos 78, no. 3 (2013): 301-327

Mattingly, Cheryl & Jensen, Uffe Juul “What Can We Hope For? An Exploration in Cosmopolitan Philosophical Anthropology” Liisberg, Sune, Esther Oluffa Pedersen, and Anne Line Dalsgård, eds. Anthropology and philosophy: Dialogues on trust and hope. Vol. 4. Berghahn Books, 2015

Mattingly, Cheryl, and Jason Throop. "The anthropology of ethics and morality." Annual Review of Anthropology 47 (2018): 475-492

Maturo, Antonio. "Medicalization: current concept and future directions in a bionic society." Mens sana monographs 10, no. 1 (2012): 122

McDermid Internet Encyclopedia of Philosophy Online ed. “Pragmatism” Accessed on February 15, 2019 <https://www.iep.utm.edu/pragmati/>

Merrild, Camilla Hoffmann, Mette Bech Risør, Peter Vedsted, and Rikke Sand Andersen. "Class, social suffering, and health consumerism." Medical anthropology 35, no. 6 (2016): 517-528

McGuire, Meredith B. "Religion and healing the mind/body/self." Social Compass 43, no. 1 (1996): 101-116

Miller, Daniel. 2012. Consumption and its consequences. Polity, 2012

Mirk, Sarah. “Audre Lorde Thought Of Self-Care as an “Act Of Political Warfare”” Bitch Media www.bitchmedia.org. February 18, 2016. Accessed on May 28th 2019. <https://www.bitchmedia.org/article/audre-lorde-thought-self-care-act-political-warfare>

Mol, Annemarie (2002) The Body Multiple. N.C: Duke University Press.

Mudge, Stephanie Lee. "What is neo-liberalism?." Socio-economic review 6, no. 4 (2008): 703-731

Navaro-Yashin, Yael. Faces of the state: Secularism and public life in Turkey. Princeton University Press, 2002

Navaro-Yashin, Yael. "Affective spaces, melancholic objects: ruination and the production of anthropological knowledge." Journal of the Royal Anthropological Institute 15, no. 1 (2009): 1-18

O’Malley, Pat. “Uncertainty Makes us Free: Insurance and Liberal Rationality” in Samimian-Darash, Limor, and Paul Rabinow, eds. Modes of uncertainty: Anthropological cases. University of Chicago Press, 2015

Orwell, George. "Nineteen eighty-four: A novel." London: Secker & Warburg (1949)

Pro-vaccine/Anti-vaccine. Facebook.com. I fucking hate pseudoscience. https://www.facebook.com/hatepseudoscience/ accessed on May 27, 2019.

Quick, Jonathan D. and Heidi Larson “The Vaccine-Autism Myth Started 20 Years Ago. Here's Why It Still Endures Today” Time. February 28, 2019 accessed on May 27, 2019. <http://time.com/5175704/andrew-wakefield-vaccine-autism/>

Rabinow, Paul, and Nikolas Rose. "Biopower today." BioSocieties 1, no. 2 (2006): 195-217

Redley, Marcus, and Darin Weinberg. "Learning disability and the limits of liberal citizenship: interactional impediments to political empowerment." Sociology of Health & Illness 29, no. 5 (2007): 767-786

Reith, Gerda. “Uncertain Times: The Notion of ‘Risk’ and the Development of Modernity.” Time & Society 13, no. 2–3 (September 2004): 383–402.

Rose, Nikolas (1999) Powers of Freedom: Reframing Political Thought. Cambridge: Cambridge University Press.

Rose, Nikolas. Molecular Biopolitics, Somatic Ethics and the Spirit of Biocapital Social Theory and Health, 2007, 5 (1): 3-29

Ruckenstein, Minna, and Natasha Dow Schüll. "The datafication of health." Annual Review of Anthropology 46 (2017): 261-278

Rutherford, Danilyn. "Affect theory and the empirical." Annual Review of Anthropology 45 (2016): 285-300

Samimian-Darash, Limor, and Paul Rabinow, eds. Modes of uncertainty: Anthropological cases. University of Chicago Press, 2015

Scheper-Hughes, Nancy, and Margaret M. Lock. "The mindful body: A prolegomenon to future work in medical anthropology." Medical anthropology quarterly 1, no. 1 (1987): 6-41

Seçkin, Gül. "Cyber patients surfing the medical web: Computer-mediated medical knowledge and perceived benefits." Computers in Human Behavior 26, no. 6 (2010): 1694-1700

Shilling, Chris. "Embodiment, experience and theory: in defence of the sociological tradition." The sociological review 49, no. 3 (2001): 327-344.

Shilling, Chris. The body and social theory. Sage, 2012.

Skoggard, Ian, and Alisse Waterston. "Introduction: toward an anthropology of affect and evocative ethnography." Anthropology of Consciousness 26, no. 2 (2015): 109-120

Sointu, Eeva (2012) Theorizing Complementary and Alternative Medicines: Wellbeing, Self, Gender, Class. London: Palgrave Macmillan.

Sointu, Eeva (2013) “Complementary and alternative medicines, embodied subjectivity and experiences of healing” Health. 17:5. 530-545.

Stewart, Kathleen. Ordinary affects. Duke University Press, 2007.

Strathern, Marilyn (2014) “Reading relations backwards” Journal of the Royal Anthropological Institute. Vol 20. 3-19.

Taussig, Karen-Sue, Klaus Hoeyer, and Stefan Helmreich. "The anthropology of potentiality in biomedicine: an introduction to supplement 7." (2013): S3-S14

Till, Chris. "Exercise as labour: Quantified self and the transformation of exercise into labour." Societies 4, no. 3 (2014): 446-462

Till, Chris. "Commercialising bodies: the new corporate health ethic of philanthrocapitalism." Quantified Lives and Vital Data(2017)

Tishelman, Carol & Lisabeth Sachs (1998) “The Diagnostic Process and Boundaries of Normality” Qualitative Health Research. Vol. No. 1. 48-60.

Throop, C. Jason. "Moral moods." Ethos 42, no. 1 (2014): 65-83.

Tronto, Joan C. Moral boundaries: A political argument for an ethic of care. Psychology Press, 1993.

True Hope Mental and Physical Wellbeing "Revolutionizing Mind and Body Health" truehope.com Accessed on May 27th, 2019 <https://www.truehope.com>

True Hope Mental and Physical Wellbeing "True Hope Story" truehope.com Accessed on May 27, 2019 <https://www.truehope.com/about/the-truehope-story>

Tsing, Anna Lowenhaupt. The mushroom at the end of the world: On the possibility of life in capitalist ruins. Princeton University Press, 2015.

Urban, Monika. "This really takes it out of you!' the senses and emotions in digital health practices of the elderly." *Digital Health*. 3: 1-11. 2017.

Vanderslott, Samantha "Anti-vaxxer effect on vaccination rates is exaggerated" The Conversation. March 13, 2018 Accessed on May 29, 2019. <https://theconversation.com/anti-vaxxer-effect-on-vaccination-rates-is-exaggerated-92630>

Weiner, Talia. "The (un) managed self: paradoxical forms of agency in self-management of bipolar disorder." Culture, Medicine, and Psychiatry 35, no. 4 (2011): 448

Whyte, Susan Reynolds. Questioning Misfortune: the pragmatics of uncertainty in eastern Uganda. Vol. 4. Cambridge University Press, 1997

Whyte, Susan Reynolds. "Uncertain undertakings : Practicing health care in the subjunctive mood" in ed. / Vibeke Steffen; Richard Jenkins; Hanne Jessen. København. Managing Uncertainty: Ethnographic studies of illness, risk and the struggles for control. Museum Tusculanum, 2005. p. 245-264.

Wiles, Janine, and Mark W. Rosenberg. "'Gentle caring experience': Seeking alternative health care in Canada." Health & Place 7, no. 3 (2001): 209-224

Zinn, Jens, ed. Social theories of risk and uncertainty: an introduction. Blackwell Pub., 2008.

Zigon, Jarrett, and C. Jason Throop. "Moral experience: introduction." Ethos 42, no. 1 (2014): 1-15.