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The Information Practices of People Living with Depression: Constructing Credibility and Authority

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A thesis submitted in partial fulfillment of the requirements for the Doctor of Philosophy degree
in Library & Information Science

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**The Information Practices of People Living with Depression:
Constructing Credibility and Authority**

(Spine Title: The Information Practices of People Living with Depression)

(Thesis Format: Monograph)

by

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Faculty of Information and Media Studies

A thesis submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy

The School of Graduate and Postdoctoral Studies
University of Western Ontario
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entitled:

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is accepted in partial fulfillment of the
requirements for the degree of
Doctor of Philosophy

Date: _____

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Abstract

Depressive episodes and chronic depression often provide the impetus for both online and offline everyday life information-seeking and sharing and the seeking of support. While allopathic medication, psychiatric, and other biomedical services are the standard treatments for depression, people often use complementary and alternative medicine (CAM) to supplement or supplant biomedical treatments. Depression is a nebulous disorder with varying causes, illness trajectories, and a wide variety of potentially effective treatments. Often, treating and managing depression forms a project for life (Wikgren, 2001) where the need for information is continuous.

In the present study, I have used a constructionist, discourse analytic approach as outlined by Potter (1996) and Wooffitt (1992) to analyze the messages posted to three online newsgroups devoted to depression, CAM, and the practices of biomedicine and to analyze the transcripts from 10 semi-structured interviews with participants who self-identified as currently having depression or who have suffered from depression in the past. I have sought to understand how people justify using, or not using, CAM to treat depression. Specifically, I have investigated how people with depression use information in discourse to justify healthcare decisions and to create credible and authoritative accounts; how people with depression conceptualize CAM therapies, mainstream medicine, and depression and how these conceptualizations are represented in the discursive constructions of individuals as competent information-seekers and users; and I have investigated the information practices (e.g., everyday life information-seeking, sharing, and use) of people living with depression.

My findings show that while expert, biomedical information sources and knowledge are most often drawn upon and referred to by newsgroup posters and interviewees to warrant claims, people used a variety of discursive strategies and regular speech patterns to create credible and authoritative accounts, to portray themselves as competent information-seekers and users, to support their claims for either using or foregoing a certain treatment, and to counter the authoritative knowledge of biomedicine. In addition, my findings emphasize the importance of orienting information discussed in Savolainen's (1995) everyday life information-seeking (ELIS) model. For many people with depression, information was used to maintain a sense of coherence (related to

“mastery of life” within the ELIS model) and to create meaning in addition to solving practical problems. My findings suggest that an additional information-seeking principle to those outlined by Harris and Dewdney (1994) deserves further research attention: people seek information that is congruent with their worldview and values.

Keywords: complementary and alternative medicine, depression, discourse analysis, information practices, experiential, expert, and authoritative knowledge, cognitive authority, and credibility

Acknowledgements

If it takes a village to raise a child, it takes a community to complete a dissertation. I would first like to thank interview participants for generously giving their time and for discussing deeply personal issues openly and freely. I am indebted to my supervisor, Catherine Ross, for her wise counsel, support, and keen editorial eye. I am grateful to Lynne McKechnie for the opportunities to publish and present, the support, and the mentoring she gave to a budding scholar. A special thank-you goes to my committee member, Pam McKenzie, who not only embodies the kind of academic I'd like to emulate, but whose generous spirit, friendship, cappuccino machine, and supply of Kleenex helped me survive the joy and despair of academic life. I would like to thank other FIMS faculty, staff, and PhD students for spontaneous bop prosody at the Grad Club and other venues. It made the process much more enjoyable.

Without the adventurous spirit and love of Michael Brundin this undertaking would not have come to fruition. This accomplishment is as much his as it is mine. I officially give Michael the “P” in my PhD. I would like to thank the best out-of-laws, Bob and Gretchen Brundin, for providing me with “a room of my own,” for their guidance, kindness, and kibitzing, and for introducing me to the field of LIS. To my family—my Mom, Robyn, Jacki, Peggy, and my two dads, Don and Roy—thank-you for encouraging me and for believing in me, especially when I grappled with self-doubt. I could not have done it without you. And to Huxley, the wonder dog, thank-you for walking me when I needed it most. Unfortunately, a number of family members completed their life journey while I was completing this academic one. I dedicate this work to Don, Gwen, Kim, and my beloved grandmother, Sarah Gwendolyn Park.

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CHAPTER 1

The Problem

Contemporary healthcare is centered on self-care. Researchers estimate that between 70-90% of healthcare is undertaken by individuals without the help of healthcare professionals (Health Canada, 2004; McGowan, 2006). This proportion suggests that before people ever seek treatment from a healthcare practitioner they will try to treat the problem themselves, incorporate practices aimed at preventing or managing illness, or use other therapies in conjunction with conventional treatment. Researchers at Health Canada (2004) claim that, “Self-care is one of the pillars of health care and health reform in Canada today. Most self-care is undertaken by people independently of the involvement of health care professionals.” The emphasis on self-care coincides with the general trend in healthcare promotion discourse that documents a shift from compliance to “patient empowerment” (Wikgren, 2001). Oftentimes the “doctor-patient” relationship is described as a “partnership” where people are encouraged to take greater personal responsibility for their health and become “expert patients”—i.e., responsible for managing their own care (Lupton, 1994, 1995). However, the development of medical partnerships, patient empowerment, and effective self-care is predicated on an individual’s ability to find, make sense of, and use complex information. Using complex information is often further complicated by the dizzying array of conventional treatments offered to people, by innumerable complementary or alternative medicine (CAM) options, and by advice offered online.

For those people with depression, treatment or management of the disorder can form what Wikgren (2001) dubs a “project for life” or information project where information-seeking (both incidental and intentional) is paramount. People with depression may seek information (both online and offline) about side effects of medication, or lifestyle changes that can alleviate or regulate their disorder, or finding sources of emotional support (Brashers, Goldsmith, & Hsieh, 2002). For example, many people experience adverse side effects such as loss of libido, weight gain, and deeper depression from conventional medication. Studies have shown that antidepressants can be addictive for some people; some people experience mild to severe withdrawal upon discontinued use

(Vlaminck, Vliet, & Zitman, 2005); and individuals can become immune to their medication which results in a continuous need to experiment and a continuous need for information about possible treatments (Chur-Hansen & Zion, 2006; Olie, 2005). People often also seek out CAM practitioners or incorporate CAM treatments into their self-care routines. In addition, many people with depression seek online support and advice and they must discern the value or usefulness of information shared electronically. Consequently, treating, managing, and finding out about depression produces a complex information context that most likely requires ongoing decision-making about medication, ongoing exploration of other therapies, and ongoing information-seeking, sharing, and use.

While the rhetoric found in the consumer health information (CHI) literature describes empowered patients, wielding information and challenging the authority and expertise of medical practitioners (see Pascal, 2001, p. 1-2), medical professions ultimately retain authority over how depression is treated by providing their sanctioned interpretations concerning diagnosis, by referring the person to conventional practitioners for additional treatment, and by prescribing medicine. “Doctors thus have legitimacy and authority, based on their professional role, to exercise power and thereby also social control, deciding who is sick and who is not (Conrad, 1992; Freund & McGuire, 1999)” (qtd. in Asbring & Narvanen, p. 228).

However, people often draw upon their experiential knowledge of illness or disease to challenge or contest expert medical advice and they can also seek out CAM providers. People use CAM for myriad reasons but what is most pertinent here is that research shows many people use CAM precisely because CAM practitioners base their treatment regimens on an individual’s experiential knowledge of disease, illness, and of his or her own body. People often feel empowered and involved in decision-making with CAM practitioners; CAM offers a holistic approach that is perceived by people to foster a more in-depth explanation of illness or healing; people may have a more egalitarian relationship with their CAM practitioner; CAM practitioners tend to take more time to listen to their clients; and CAM users tend to take personal responsibility for their health and consequently they believe they know their body best and they trust their own judgement (Cartwright & Torr, 2005; Lewith, Hyland, & Shaw, 2002; Brown, Carroll, Boon, & Marmoreo, 2002; Kelner & Wellman, 1997). For many CAM practitioners the foundation

for effective care depends upon their clients' knowledge and experience with disease, illness, and healing.

In library and information science (LIS), very little research on consumer health information has explored the relationship between experiential, expert, and authoritative knowledge on the one hand, and information or information practices on the other (Carey, 2003; Kivits, 2004; McKenzie, 2001). In this study, I examine the information practices of people living with depression (and those who support them) as they assess, evaluate, justify, and make claims about depression and its treatment. I have focused this research on an understudied area in LIS: the everyday life information practices (information-seeking, sharing, and use) of ordinary people. I have used a discourse analytic approach to data analysis—a research method with much potential and promise in LIS studies—to answer the following questions:

- (1) How do people with depression conceptualize CAM therapies, mainstream medicine, and depression and how do they discursively construct themselves as competent information-seekers and users?
- (2) How do individuals use experiential and / or expert knowledge and other discursive resources to assess and evaluate the information provided by others about CAM treatments, to construct their own positions justifying CAM use or non-use, or to undermine other accounts?
- (3) What information sources do people draw upon when assessing the information provided by others and when justifying their own positions and how do they build up or undermine the value of these information sources?
- (4) What are the information practices of people with depression?

Research on how people with depression construct their illness, and whether or not they use CAM therapies, and why or why not, is important to further our understanding of

the role of information in consumer health research as individuals construct and negotiate the concepts of credibility and authority. If lay individuals are expected to provide self-care, it is incumbent upon librarians and other consumer health information providers to understand how experiential and laypersons' knowledge can supplement or supplant expert knowledge. By examining how authoritative knowledge about CAM is constructed culturally and socially and by examining how people "talk" about CAM in everyday life (both online and offline) and what information sources they draw upon in order to construct authoritative descriptions service providers can provide more useful and relevant information for their users.

In chapter two, I situate my study by providing background context about CAM and depression. Chapter three provides a review of the literature and the theory that frames this research. Chapter four outlines my data collection methods, my data sources, and my procedures for data analysis. In chapter five, I describe depression as an information-seeking context, and I explore the findings of how participants conceptualize CAM, conventional medicine, and depression, and how people with depression construct themselves as competent information-seekers and users. Chapter six outlines how newsgroup participants and interviewees construct information sources as helpful or not helpful. I also discuss various information practices such as information-seeking, information-seeking on behalf of others, question negotiation, and encountering information. Chapter seven describes the additional information practices of information sharing and information use. I conclude with a summary and discuss the implications of my findings for LIS.

CHAPTER 2

Background Context: Depression and Complementary and Alternative Medicine

2.1 Prevalence of Depression

According to the World Health Organization (WHO), depression is projected to be the leading cause of disability in developing nations by the year 2020 (Zuess, 2003). In Canada, research shows that at any given time up to 5% of the adult Canadian population suffers from major depression and that within their lifetime one in four Canadians will need treatment for depression (Centre for Addictions and Mental Health, 1999; Health Canada, 2002; Statistics Canada, 2003). Furthermore, rates of depression among Canadian youth are even higher—up to 6.5% of the population or over a quarter of a million young adults and youth from the ages of 15–24 met the diagnostic criteria for major depression in the last year. Over one million Canadians suffer from major depression with women being twice as likely as men to suffer from major depression, and two to three times more likely to suffer from dysthymia—a chronic low grade depression (Health Canada, 2002; Statistics Canada, 2003). Not only does depression permeate all sectors of society but also mood disorders have a tremendous effect on the economy. These effects are manifested through absenteeism, lost productivity, and healthcare costs. The social and financial costs of “depression (and distress)” are difficult to measure but they are estimated to be \$14.4 billion a year in Canada at minimum (Stephens & Joubert, 2001). At any given time between 5–6% of the Canadian population has depression whereas 4.5% of the population has diabetes, and 2.5% of the population has cancer. Despite a larger number of people living with depression than either diabetes or cancer, depression receives much less research attention or funding compared to either of these other two diseases.

2.2 Biomedical Aspects of Depression

Depression is increasingly viewed as a medical condition with its own aetiology, illness trajectory, impacts, risk factors, and treatments. Depression is difficult to define however, because it is a changeling—it is not restricted to a single diagnostic categorical boundary, people living with depression tend to manifest both physical and psychological symptoms, and depression can differ in appearance in the same person or from one person

to another. Peter Kramer (2005), author of *Listening to Prozac* and *Against Depression*, describes depression as “notoriously polymorphic or pleomorphic taking different forms in different people or in the same person over time” (p. 69). The umbrella term “depression” also includes a number of differentiated disorders such as major depressive disorder, dysthymic disorder, psychotic depression, postpartum depression, and seasonal affective disorder (SAD) (National Institute of Mental Health, 2007). Although depression can be treated successfully, once an individual has suffered from a depressive episode there is an increased likelihood of recurrence and depression may become chronic. Depression runs the gamut from chronic to episodic, depressive episodes can be mild to severe, and presenting symptoms can be typical or atypical (e.g., instead of feeling a stronger depression in the morning an individual may feel it at night which is atypical). The causes of depression are believed to be multifactorial: some argue that it can be caused by biology (i.e., brain function, neurotransmitters, and hormones), genetic predisposition, environment (e.g., a difficult childhood, trauma, or stress), or a medical condition (depression as a symptom of another disease), or depression can be caused by a combination of these factors. Furthermore, depression is considered both a symptom and an illness which unfortunately carries the same name.

2.3 Diagnosing and Defining Depression

Depression is identified and defined most commonly by the diagnostic criteria outlined in the DSM-IV (Diagnostic and Statistical Manual of Mental Disorder 4th edition) and by the World Health Organization’s international classification of disease (ICD-10). According to the DSM-IV, for a diagnosis of a major depression five or more of the following symptoms should be present during the same two-week period:

- Depressed mood most of the day, nearly every day as indicated by either subjective report (e.g., feels sad or empty) or observation made by others (e.g., appears tearful).
- Anhedonia: markedly diminished interest or pleasure in all, or almost all activities most of the day, nearly every day, as indicated by either subjective account of observation made by others.

- Significant weight loss when not dieting or weight gain (e.g., a change of more than five percent of body weight in a month), or decrease or increase in appetite nearly every day.
- Insomnia or hypersomnia nearly every day.
- Psychomotor agitation or retardation nearly every day. This must be observable by others, not merely subjective feelings of restlessness or of being slowed down.
- Fatigue or loss of energy nearly every day.
- Feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly every day. Not merely self-reproach or guilt about being sick.
- Diminished ability to think or concentrate, or indecisiveness, nearly every day, either by subjective account or as observed by others.
- Recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or suicide attempt or a specific plan for committing suicide (Dowrick, 2004, p. 17).

A diagnosis of mild depression is made when two to four of these symptoms are present for at least two weeks and dysthymia is diagnosed if three or four of these symptoms persist for at least two years. In addition to outlining symptoms of depression, the DSM-IV recommends an assessment that takes into account the individual's psychological, social, and physical context when diagnosing depression.

The ICD-10, on the other hand, has overlapping symptoms with the DSM-IV with one additional symptom: the loss of self-esteem or confidence. The WHO (WHO'S New Proposed Definition, 2007) also provides a definition of depression:

Depression is a common mental disorder that presents with depressed mood, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, low energy, and poor concentration. These problems can become chronic or recurrent and lead to substantial impairments in an individual's ability to take care of his or her everyday responsibilities. (para. 1)

Similarly, Canadian health-related organizations (ranging from family physician based organizations to government-sponsored organizations) that provide mental illness information and support echo the above definition and list of symptoms. For example, using a more common vernacular, the College of Family Physicians of Canada (2003) states on their Web site:

When doctors talk about depression, they usually mean major depression. Someone with major depression has symptoms like those listed nearly everyday, all day, for two weeks or longer. If you're depressed, you may also have headaches, other aches and pains, stomach or bowel problems, and problems with sex or lack of desire for sex... (para. 1)

Symptoms of depression

- No interest or pleasure in things you used to enjoy
- Feeling sad or empty
- Crying easily or crying for no reason at all
- Feeling slowed down or feeling restless and unable to sit still
- Feeling worthless or guilty
- Change in appetite, leading to weight gain or loss
- Thinking about death or suicide
- Trouble thinking, recalling things or focusing on what you're doing
- Trouble making everyday decisions
- Problems sleeping, especially in the early morning, or wanting to sleep all of the time or "hide under the covers"
- Feeling tired all of the time
- Feeling numb emotionally, perhaps even to the point of not being able to cry (para. 2)

It is apparent by the number of overlapping symptoms among the DSM-IV, ICD-10, and other health organizations that many scientists, medical practitioners, and other health professionals have reached consensus on the identification of common symptoms and the definition of depression. Not only has this definition of depression facilitated diagnosis, it has also enabled researchers to identify a group of people with depression sufficiently uniform for the purposes of research. Kramer states, "It is impossible to overstate the influence or the success of the operational definition... The altered neuroanatomy, the genetic risk, the excess disability—all are liabilities of major depression, operationally defined" (p. 159–160). An operational definition of depression has allowed medical

researchers to gain an understanding of depression's risk factors, illness trajectory, and treatment.

2.4 Risk Factors

There are four categories of risk factors associated with depression: genetic and family history, biological factors, life events or environmental stresses, and psychological vulnerability (Centre for Addictions and Mental Health, 1999). Depression is more likely to be found in people with a family history of the condition (although genetics is unlikely to be the sole cause of depression) and it is more likely to occur and last longer when it coexists with other health problems, particularly chronic illnesses, and alcohol or drug misuse (Drake, 2003). It can occur after unusual physiological changes such as childbirth. Life events that are known to be associated with depression include: childhood trauma—particularly parental indifference, loss of a parent, or abuse, loss of a family member or relationship, divorce, loss of employment, retirement, a financial crisis, family conflict, and injury or assault. George Brown from the University of London suggests that two-thirds of the population may be vulnerable to these life event factors (Brown qtd. in Solomon, 2001, p. 62). Certain types of personality, particularly those with a tendency towards neuroticism, pessimism, dependence, and perfectionism appear to be more vulnerable to depression. While depression is found in people from all economic strata, research shows that the prevalence of depression is positively correlated to low socio-economic status and low social support (Dowrick, 2004; Pilgrim & Rogers, 1999).

These vulnerabilities or predisposing factors are thought to increase both the frequency and the duration of stressful life events or difficulties. In turn, this increases the likelihood of the onset of depression (Centre for Addiction and Mental Health, 1999; Dowrick, 2004). Everyone has a certain number of these risk factors but the greater the number of risk factors and the greater the number of stressful events, the greater the chances of a depressive episode. Andrew Solomon, author of *The Noonday Demon: An Atlas of Depression* (2001), describes these risk factors as “kindling”—any one of these risk factors can be sparked into a depressive episode by a life event.

2.5 Trajectory

Many people with depression recover rapidly—over 60% recover by six months and by two years 80–95% of people with depression have been successfully treated. However, relapse is common and a significant minority of people suffering from depression are chronically depressed and remain disabled over ten years or more (Dowrick, 2004). The diagnosis of depression is also associated with an increased risk of mortality. Usually the increased risk is a result of suicide but there is also a four fold increased risk of death from heart disease associated with depression. The risk of suicide increases approximately twenty fold with a diagnosis of major depression, and about fifteen fold for those diagnosed with bipolar disorders, when compared with the general population. About one in ten people who have been admitted to hospital with diagnosed depressive disorders will subsequently commit suicide (Dowrick, 2004).

2.6 Stigma and Treatment

Research has shown how identity is tied to diagnosis (Hermans, 2003) and the conflation of personality and a diagnosis of depression is particularly acute. Kramer, for example, criticizes Western society for romanticizing depression, constructing it as an inherent part of creativity, personality, and genius (2005). These romanticized concepts and ideas about depression are reminiscent of how tuberculosis was once framed in the Victorian era (Kramer, 2005; Sontag, 1978). Kramer argues that some symptoms of depression can be “charming” especially at the onset of an episode or when depression is in its early stages. Many people with depression, for example, are socially fastidious and emotionally attuned and are consequently rewarded for being considerate of the feelings of others, for being pliant, for feeling guilty, or for being a perfectionist. Furthermore, for those with bipolar disorder mild mania can be a rewarding and productive state before the individual descends into chaos. Kay Jamison (1995), who is not only a professor of psychiatry at the Johns Hopkins University School of Medicine but also bipolar (she refers to her disorder as manic-depressive in her book), writes in her memoir:

These fiery moods... added a great deal to my professional life. Certainly, they had ignited and propelled much of my writing, research, and advocacy work. They had

driven me to try and make a difference. They had made me impatient with life as it was and made me restless for more (p. 122).

On the other hand, a diagnosis of depression is more often stigmatizing. The Canadian Medical Association (2008) found that: Canadians are much more likely to tell their co-workers or friends if a family member suffered from cancer (72%) or diabetes (68%) than mental illness (50%); the majority of Canadians (55%) would not enter a spousal relationship with someone with a mental illness, nor would they hire a lawyer with a mental illness (58%), a child care worker (58%), or a doctor (61%); and nearly half of Canadians (46%) think that people use mental illness as an excuse for bad behaviour. Gwen, an interview participant, said, “I didn’t want to go into therapy, I felt like there’s some stigma attached to it and if you don’t admit there’s anything wrong then it won’t be wrong, you’ll be fine.” The College of Family Physicians in Canada (2003) states that, “Depression isn’t caused by personal weakness, laziness, or lack of willpower. It’s a medical illness that can be treated,” emphasizing depression as pathology, not personality. Kramer (2005) argues that depression arises from, or causes, abnormalities in the brain, it progressively reduces mental functioning, shortens life, affects peripheral organs, is preventable or treatable, has genetic underpinnings, and has economic impacts, and therefore it must be classified and treated the same as any other disease. The conflation of depression and personality may partially explain why defining, diagnosing, and treating depression has been, and continues to be, notoriously difficult.

Fortunately, depression can usually be treated successfully—typical treatment involves taking antidepressant medication and undergoing psychotherapy. Despite the 85–90% treatment success rate, often people with depression do not believe that their depression is an illness in the same way that other illnesses such as diabetes are. For example, depression brought on by an unknown predilection for depression, combined with a trauma, may not be reported to a doctor or even identified by the individual themselves as depression. Sabina, a study participant who had previously made a suicide attempt, explained,

I don’t think of it [depression] as an illness but maybe I should. But I have this thing about getting help because I don’t think I would be comfortable going into a psychiatrist right now and saying, “I’ve got depression. Can I have some pills?”

While the perceived wisdom is that depression is an illness that should be treated by medication and therapy, many people do not define depression in those terms. For a variety of economic, social, or other reasons, only about one third of those with depression seek help (Statistics Canada, 2003).

2.7 Disputed Diagnoses

The risk factors, illness trajectory, biomedical aspects of depression, and characteristics and symptoms of depression outlined in the DSM-IV are based on a view of depression as a medical condition, whereas some dispute that depression is a medical condition (Dowrick, 2004; Manners, 2006). These dissidents (including some diagnosed with depression), view depression as a socially constructed concept; they question the accepted medical wisdom of depression's aetiology and they question the utility and validity of depression as a diagnostic construct. The cause or causes of depression, its definition, and its treatment continue to be contested (Moynihan & Cassels, 2005).

Manners (2006) argues that in the mid-twentieth century depression was caught between two competing theoretical discourses: the biological psychiatric discourse and the psychoanalysis view of mental illness. For some, depression was seen as a biological illness that was caused by a biological malfunction such as brain function, neurotransmitters, or hormones. Biological depression manifested itself in physical symptoms such as loss of libido and lethargy. Adherents of the competing psychoanalytic discourse viewed and treated depression as an illness that was caused by environmental factors such as inadequate parenting or personal inadequacies or flaws, and which manifested itself in psychological symptoms such as anxiety, guilt, and apathy. The biological psychiatric view of depression has gained prominence due to the support of governments, psychiatry, scientists, pharmaceutical companies, social theorists, and the public.

Manners (2006) further suggests that during the 1960s, the United States government, guided by the idea that a specific drug should treat one specific condition (the antibiotic model), was the first proponent of the biological basis of depression. The government wanted to make available to the public an antidepressant that would specifically treat depression (at the time there was no drug that targeted just depression).

Consequently, the government provided monetary support for research and drug development while the FDA (Food and Drug Administration) established the randomized control trial as the standard by which a drug's effectiveness would be tested by comparing it to a placebo. Initially, the pharmaceutical industry was against the new government regulations because randomized control trials were lengthy and expensive to execute. However, the pharmaceutical industry recognized an advantage to the new system: if psychiatry and medicine could pinpoint a solid definition of depression with a singular cause, the drug companies could develop one drug that addressed that singular, pinpointed problem. Soon the pharmaceutical companies brought to market their tricyclics, which acted on serotonin/norepinephrine reuptake mechanism (what biological scientists viewed as the cause of depression). Out of the tricyclics the SSRIs (selective serotonin reuptake inhibitors) like Prozac, Paxil, and Zoloft were developed.

In response to these developments, psychiatry began incorporating more rigorous criteria into the DSM definitions of depression. At the time the DSM was vague regarding the criteria of what constituted mental illness. If the trend was towards using one drug to treat one illness, the DSM would have to clearly delineate and define what the illnesses were that the drugs would treat. The DSM was continually edited and revised to reflect stricter criteria, and the traces of the psychological in the *Manual's* definitions of mental disorder were almost entirely erased as the DSM entries began to include more biological definitions (DSM, 1968; 1973 [revised]; 1980; 1987; 1993; 2000 [revised]).

Finally, the general public accepted the conceptualization of depression as a biological disorder or illness. In the mid-twentieth century, psychoanalysis was emphasizing the very human story of parenting, childhood, human development, and the consequences of individual choices on mental health. Because of the interpersonal nature and the societal implications of this line of inquiry, inevitably psychoanalysis was political. The anti-psychiatry movement which was led by eminent thinkers such as Foucault and R. D. Laing showed how societal values were imbedded in the social construction of mental illness and how psychiatry and medicine were used for social control. For the public, there was no comfort in thinking about depression as a consequence of parenting, childhood, or personal deficiencies. It was much easier to blame biology for causing depression and bypass feelings of guilt or personal failure.

Depression and unhappiness are two different things—depression is a medical disorder whereas unhappiness is not. Critics argue that an unintended consequence of treating depression as a biological disorder is that this results in the medical conflation of unhappiness and depression. Unhappiness and depression are often treated as if they are the same concept. Indeed, many people suffering from depression cannot distinguish between unhappiness and depression. If depression is defined, categorized, and treated as a biological disorder, then perhaps unhappiness can also be treated in the same manner. The conflation of human discontent and depression has resulted in the medicalization of unhappiness. If one is unhappy, according to this view, it is because something is wrong biologically, and consequently unhappiness can be treated by medication and medical professionals (Dworkin, 2001; Manners, 2006). Dworkin (2001) summarizes this view:

In the past, medical science cared for the mentally ill, while everyday unhappiness was left to religious, spiritual, or other cultural guides. Now, medical science is moving beyond its traditional border to help people who are bored, sad, or experiencing low self-esteem—in other words, people who are suffering from nothing more than life. (p. 86)

Kramer (2005) takes the implications of medicalization further. He worries “about ‘cosmetic psychopharmacology’ and, with it, the possibility that in developing medications to treat depression, we might create implicit social pressures to alter personality styles that are not sufficiently upbeat” (p. 262).

Depression estimates now are two thousand times higher than they were a half-century ago and the number of people diagnosed with depression has doubled in the last 30 years (Dworkin, 2001; Healy, 2002). “Mood disorders are now believed to be as common as dandruff” (Manners, 2006, p. 88). For some, this signals a triumph over the stigma of depression: there is no shame in the label of mental illness; the illness was merely under-diagnosed for years. Others are concerned that depression is over-diagnosed and that the spoils from triumphing over depression belong to the pharmaceutical companies who have reaped tremendous profits by medicalizing our human miseries (Moynihan & Cassels, 2005). Are more Canadians depressed now than in the past? Are doctors more aggressive in diagnosing depression? Are doctors prescribing medication for “everyday unhappiness”

and reporting it as depression? No one knows the answers to these questions but some are raising objections to what they perceive as the medicalization of the human condition. The following two messages from the newsgroup threads briefly outline a couple of points regarding this debate:

Original post:... ADs [antidepressants] are based on the dubious (and overly simplistic) neurotransmitter theories about dopamine, etc, which have since evolved into slighter more complex theories (which have the side benefit of being more convoluted to the layman i.e. take your meds and trust us).

Response: You're just SO damn brainwashed by the Man. Can't you see? You're insane! I suggest you quit all that medication and start using street drugs and alcohol. It's much safer.

Newsgroup postings

Furthermore, it is extremely difficult to disregard life circumstances or social difficulties such as abuse and poverty when diagnosing and developing a course of treatment for depression. Treating and diagnosing depression would be much easier for medical professionals and the general public if it could be demonstrated that depression is a discrete category or disease entity with a biological basis. However, this has not been proven, despite extensive and well-funded research. Not only is the biological basis of depression questioned but others question the validity of a depression diagnosis and the efficacy of antidepressants. In terms of diagnosis, major depression is a category with blurred boundaries. For example, the shared symptoms between major depression and anxiety are extensive and the medications used to treat each illness are the same and yet the two are treated as different illnesses. In addition, the diagnostic two-week time-frame of suffering from depressive symptoms is arbitrary—why not three weeks or ten days? Why four to five symptoms and not six or three? Finally, research shows that the efficacy of antidepressants is open to question as increasing evidence points to the placebo effects of drug treatments (Dowrick, 2004).

2.8 Complementary and Alternative Medicine

While the use of CAM is widespread, it is notoriously difficult to define. This is

partially due to the integration of conventional¹ Western medical practices with other medical traditions and partially because it is difficult to pinpoint and describe what CAM actually is. Among social scientists, CAM is considered a residual category—it is not defined by its internal coherence but rather by its relation to, or its exclusion from, other areas of conventional medicine (Barrett, Marchand, Scheder, Plane, Maberry, Appelbaum, 2003; Kaptchuk & Eisenberg, 2001a, 2001b; Wolpe, 2002). Ernst, Rand, and Stevinson (1998) argue that the comparison to biomedicine often results in CAM being *negatively* defined, that is, CAM is defined by what it is not. They define CAM as “a system of health care which lies for the most part outside the mainstream of conventional medicine” (p. 1026). Barrett et al. (2003) write: “The terms ‘complementary,’ ‘alternative,’ and ‘integrative’ medicine refer to an extraordinary diverse set of therapeutical modalities, most of which have little in common other than the fact that they differ from conventional Western biomedicine” (p. 938). Eisenberg et al. (1993, 1998) have previously defined CAM as those practices typically not taught in conventional medical schools or practiced by most licensed physicians. The underlying commonality among all of these definitions is that CAM is defined in terms of its separateness from conventional medicine. Saunders (2002) points out that these definitions do not adequately describe what CAM is; they are definitions of separateness, not description. Operationalizing a definition of CAM for research has been challenging.

The following two quotations illustrate attempts by researchers to define what CAM actually is rather than merely comparing it to orthodox medicine:

A more inclusive definition has been adopted by the Cochrane Collaboration: “complementary medicine is diagnosis, treatment, and/or prevention which complements mainstream medicine by contributing to a common whole, by satisfying a demand not met by orthodoxy, or by diversifying the conceptual frameworks of medicine” (Ernst, Rand, & Stevinson, 1998, p. 1026).

1. There is some debate in the literature regarding the most accurate definition of Western medicine. The three most common words used to describe Western medicine are *conventional*—formed by agreement or compact; *allopathic*—relating to or being a system of medicine that aims to combat disease by using remedies (as drugs and surgery) which produce effects that are different or incompatible with those of the disease being treated; and *orthodox*—conforming to established doctrine especially in religion (Merriam-Webster’s, 2006). I have used these terms interchangeably in order to differentiate the Western medical system from other medical systems and practices.

The National Institutes of Health Panel on Definition and Description (1997) defined CAM as “a broad domain of healing resources that encompasses all health systems, modalities, and practices and their accompanying theories and beliefs, other than those intrinsic to the politically dominant health system of a particular society or culture in a given historical period” (Saunders, 2002, p. 44–45).

A common definition of CAM remains elusive among researchers but the above two definitions clearly provide some description of what constitutes CAM. These definitions provide a much broader view of CAM because they allude to different reasons why people use CAM—reasons such as individual beliefs and the perceived deficiencies in allopathic medicine. The second quotation refers specifically to the influences of the political context and culture in which conventional medicine and CAM are practiced. This definition captures how fluid both CAM and orthodox practices can be; practices do, and will continue to, change in tandem with broader changes in society and culture.

To complicate matters further, many conventional medical doctors recognize and may advocate the use of complementary or alternative practices like meditation and acupuncture. However, this is often done out of context, that is, without the physician subscribing to the cosmology of the traditional medical system the practice is derived from. For example, a conventional medical doctor may suggest acupuncture as a possible treatment for depression without subscribing to the traditional Chinese medical system. Similarly, a conventional doctor may suggest certain nutritional treatments that come from the Ayurvedic tradition without subscribing to that medical system. The healing or medical practices that might be considered as legitimate “alternatives” to conventional, allopathic, or the orthodox medical system are those that have a different phenomenological perspective—Indigenous healing systems, Ayurvedic medicine, traditional Chinese medicine, naturopathy, and homeopathy are all examples. Practitioners of these medical systems view reality differently than orthodox practitioners do and at times they challenge or contradict orthodox medicine’s ideology or view of reality. They are complete medical systems and not merely a number of unconnected practices from which conventional doctors can pick and choose. Alternative medical systems are used with far less frequency than the orthodox system or complementary practices. Most “alternative medicine” within the realm of public awareness is, in fact, complementary to the orthodox medical system.

Two primary points are to be made here: first, Health Canada statistics show that complementary and alternative medicine is extremely popular among Canadians; for example, a 2005 study found that 71% of Canadians had used a natural health product in the last year, with 38% taking a natural health product daily. However, only 15% of Canadians use an alternative medical system, that is, a medical system with an entirely different philosophy towards illness and healing than mainstream medicine. Second, complementary and conventional practices are often not discrete or binary categories—their boundaries and borders blur—which may account for the high use of complementary therapies among the general population. For example, is a physician who recommends dietary changes and relaxation to treat stress practicing conventional or complementary medicine? Oftentimes health practices popular among laypersons become accepted by conventional practitioners and occasionally these practices are outright co-opted and incorporated into conventional medical practice.

Historically, many CAM therapies were held in low regard by the medical community, particularly in the United States where alternative medicine was viewed by the medical establishment as quackery. Despite this labelling as quackery, many Americans and Canadians used folk medicine or alternative approaches. While Starr (1982) argues that alternative medicine practitioners were not suppressed by the allopathic profession—he argues that they lost power once they shared in legal privileges of the medical profession—other scholars suggest that the rhetoric used to describe alternative medicine as quackery was merely a means for the American Medical Association and other organizations to gain power over how medicine was practiced (Crellin, Andersen, & Connor, 1997).

Today, however, the trend towards integrative medicine (using both conventional Western medicine and complementary medicine to treat people) exemplifies the growing alliance between orthodox medicine and complementary therapies (Boucher & Lenz, 1998). Some suggest that the assimilation of some CAM therapies into orthodox medicine is the means by which orthodox medicine maintains power and control over health in society (Fries, 1998). Others view the trend towards integration as a result of consumer interest in CAM practices or as a consequence of changing societal values. Barrett (2003) explains: “These trends suggest a rapprochement between previously competing or

mutually exclusive entities, perhaps resulting from a combination of consumer interest and evidence-of-effectiveness” (p. 939). A substantial body of evidence supports the idea that societal values are linked to the evolution of the conventional health care system; therefore it follows that the integration of CAM into the conventional system reflects these changing societal values (Chen & Kleinman qtd. in Barrett, 2003, p. 944). By assimilating CAM practices that are popular among laypersons, and by reflecting in practice the changing values of society, the orthodox medical system retains power and authority over how medicine is practiced.

The demand for CAM therapies has primarily been consumer driven (Eisenberg et al., 1998) and, globally, over 60 billion dollars is spent yearly on CAM therapies and products (Honore, 2004). Research has shown that people are attracted to CAM for three primary reasons:

- Patients are dissatisfied with conventional treatments because they are ineffective, produce adverse effects, are impersonal, too technologically oriented, or too costly;
- Patients seek greater “personal control” or “empowerment” over their healthcare decisions or wish to leave no option untried;
- Patients perceive alternative medicine as more compatible with their worldviews, values, or spiritual/religious philosophies, or more “natural” than conventional medicine (Astin, 1998, 2000; Caspi, Koithan, & Criddle, 2004; Kelner & Wellman, 1997; Sirois & Gick, 2002).

Keith Bakx, a medical sociologist from the United Kingdom, argues in his discussion paper on folk medicine that biomedicine has been unable to come to terms with the alienation it has created among consumers of biomedical services. Simultaneously, CAM use has increased in conjunction with broader changes in culture. The three shifts in our culture which Bakx (1991) suggests are concurrent with increased CAM use are: a rejection of authority (particularly scientific authority); an increase in consumerism; and a greater emphasis on individual responsibility for health. Other researchers concur: “our

research supports the notion that the rapid rise in CAM follows an important shift in societal values. Our respondents consistently expressed belief-centered, value-laden, and socio-cultural reasons for their use of CAM therapies” (Barrett et al., 2003, p. 942). Ray and Anderson (2000) found that the “cultural creatives”—as many as 140 million individuals in Western societies—are “disproportionately influencing society-wide practices” (p. 4). Cultural creatives tend to volunteer more, watch less TV than other groups, actively seek culture and arts, and they tend to view the body and health holistically. They are equally concerned with the body, mind, and spirit. Ray and Anderson found that the cultural creatives are the most likely segment of society to use CAM. Astin (2000) confirmed these findings: he found that identifying with the cultural creatives category is among the most significant predictors of CAM use. Throughout the United States, Canada, and Europe, the values of this segment of society have significantly influenced healthcare choices by permeating and changing the broader culture’s perceptions of healthcare and by demanding a wide variety of healthcare options (Barrett, 2003).

Not only have shifts in societal values influenced the conventional medical system, but changes in health policy have as well. The World Health Organization and UNICEF stated in 1978 that: “Health is a state of complete physical, mental and social well-being.” In 1998 this definition of health was ratified to read: “A dynamic state of complete physical, mental, spiritual and social well-being and not merely the absence of disease or infirmity” (WHO’S New Proposed Definition, 1998). Health Canada (2005) states: “Healthy living means making positive choices that enhance your personal physical, mental and spiritual health” (para. 1). Definitions of health expressed in policy tend to be holistic and the above definitions are not easily reconciled with the general disease-treating methods of allopathic medicine. A number of shifts have influenced the trend towards integrative medicine: a change in societal values, the assimilation of CAM practices into conventional medical practice, and the concomitant changes in health policy that define health more broadly than merely the absence of disease.

However, other researchers have levelled criticisms against the holistic health movement for expanding the concept of health so that it commodifies health and transforms “health” into an oppressive ideal that is unattainable, for overlooking the

environmental or social causes of disease, for often reducing complex problems and thinking to their most simplistic form, for using superficial evidence to support claims, and for its emphasis on individual responsibility for health (Alster, 1989). Coward (1989) argues that the holistic health movement's emphasis on individual responsibility for health is very much related to capitalism and to being productive. The well body is the site of productive capital and is essential for a capitalist economy.

Coward also suggests that the dichotomy many practitioners and advocates of alternative health place between "natural" medicines and "chemical" conventional medicines is precarious and dangerous. Not all natural products are pure and safe and not all chemicals are synthetic, human-made, and therefore inferior (1989). Many complementary or alternative therapies are open to criticism. Some practitioners insist that the beneficial effects of their therapies cannot be measured, thereby relieving the practitioner of the burden of proof. And for some treatments, it is simply not possible that they have the claimed effect (Murcott, 2005). Complementary therapies are not all harmless either; in fact, some can be dangerous. Taking herbs along with prescribed medication may have deleterious effects on the body for example.

Furthermore, respondents in a study done by Barrett et al. (2003) used words like "credibility," "legitimacy," "scientifically proven," "efficient," "regulated," "licensed," "based on research," and "evidence-based" to describe the strengths of biomedicine. So while CAM use has dramatically increased, its use remains somewhat controversial among some medical practitioners, government policy makers, and laypersons. A major problem for CAM researchers is providing scientific evidence that a treatment works.

2.9 Depression and Complementary and Alternative Medicine

The high personal, social, and economic costs of healthcare provision, the nature of depression, and the contested efficacy of treatment (particularly antidepressants) has resulted in the willingness of many people with depression to experiment with a variety of CAM therapies (Ernst, Rand, & Stevinson, 1998). Research shows that treating depression is one of the most common reasons people use CAM (Ernst, Rand, & Stevinson, 1998; Parslow & Jorm, 2004). Romm (2003) states, "Alternative and conventional medical practitioners are consulted for the treatment of mild to moderate and even severe

depression more often than any other mood and affective disorder” (p. 25). Some of the more common CAM therapies suggested to treat depression include: St. John’s Wort, Valerian, meditation, acupuncture, etc. (Please see Appendix E for a list of the CAM therapies mentioned on the newsgroups and during interviews).

Survey-based research has shown a relationship between CAM use and depression and anxiety (Astin, 1998; Eisenberg et al., 1998; Sparber & Wootton, 2002). In their 2002 literature review Sparber and Wootton asked: “Is CAM use a marker for mental illness...? Are anxious, depressed people more likely to seek out CAM therapies? Or do they seek CAM therapies because they become depressed and anxious about their chronic conditions, and the apparent failure of western medicine to alleviate their symptoms” (p. 93). Sparber and Wootton reviewed studies that showed the presence of mental disorders was a strong predictor of CAM use; particularly for those who suffered from chronic depression. The clear overall trend these researchers found in their review of the literature was that “All of the studies of psychiatric patients found that CAM use is positively associated with higher consumption of conventional medical care and resources” (p. 95). This finding suggests that many people living with depression take an integrated approach in treating their depression. Zuess (2003) advocates taking an integrative approach and he recommends that people with depression address all levels of the human being—the biological, psychological, social, and spiritual—in their treatment. However, still unanswered are the questions posed by Sparber and Wootton asking if CAM use is a marker for mental illness, if CAM is being sought out and used by people with depression in particular, and if conventional medicine is failing to adequately treat depression.

2.10 Operationalizing CAM

There is no clear definition of complementary and alternative medicine as many CAM treatments have moved into mainstream medical practice. For the purposes of this study, I have operationalized CAM as any practice that newsgroup participants or interview participants themselves consider a CAM therapy. In situations where it is difficult to know what participants or interviewees consider CAM, I have taken into account that large numbers of newsgroup participants regard supplementing with fish oil, Evening Primrose oil, St John’s Wort, and doing activities such as yoga as CAM.

Conversely, for the purposes of the thesis, I consider activities such as doctors or physicians prescribing allopathic medication, making referrals to psychiatrists, or performing surgery conventional Western medical practices. Although this operational definition of CAM is somewhat artificial, it allows for the inclusion of many diverse practices and treatment options and it allows for the analysis of whatever therapy the participants themselves count as CAM. Generally, and where possible, the inclusion and discussion of a CAM therapy in this study is based upon the participant's perspective. Some of these CAM therapies include: singing, dancing, meditation, writing, taking herbal supplements, and dietary changes to name but a few.

CHAPTER 3

Literature Review and Theoretical Frameworks

The literatures from a number of different disciplines are relevant to, and inform, the broad questions that frame this research. Specifically, the literature on CAM, information behaviour, constructionism (as applied in LIS), information practices, information behaviour in consumer health contexts, and laypersons', experiential, and expert knowledge were invaluable in constructing my research questions and providing concepts and framing for this research. The theoretical frameworks used in this research include the social construction of information, everyday life information-seeking (ELIS), authoritative knowledge, and cognitive authority.

3.1 CAM Research

The medical literature on CAM has various foci. One aspect focuses on the attitudes and beliefs of health practitioners towards CAM, such as nurses (Halcon, Chlan, Kreitzer, & Leonard, 2004; Joudrey, McKay, & Gough, 2004; Montbriand, 2000; Salmon, Moulton, Omer, Chace, Klassen, Talebian, et al., 2004; Tracey, Lindquist, Watanuki, Sendelbach, Kreitzer, Berman, et al., 2003), medical students (Furnham & McGill, 2003; Lie & Boker, 2004), and doctors (Botting & Cook, 2000; Dooley, Lee, & Marriott, 2004; Owen & Fang, 2003). This research makes an important contribution to the literature because the attitudes of health-care practitioners towards CAM may influence a person's decisions to use CAM or not. Furthermore, the attitudes and beliefs of health practitioners towards CAM may also partially explain why there is a dearth of systematic reviews (which can be defined as summaries of existing evidence of any empirical testing (Linde & Willich, 2003)) on many CAM therapies.

A second area of the medical literature focuses on the beliefs, attitudes, and use of CAM by patients. Much of the research on patients' use of CAM centers on demographics of various CAM user groups including older patients (Andrews, 2003; Willison & Andrews, 2004), children and adolescents (Braun, Halcon, & Bearinger, 2000; Fletcher & Clarke, 2004; Loman, 2003; Whelan & Dvorkin, 2003), and immigrants' use of CAM. Other research focuses on CAM users with specific disorders or illnesses such as people

with AIDS (Chang, van Servellen, & Lombardi, 2003; Gore-Felton, Vosvick, Power, Koopman, Ashton, Bachmann, et al., 2003), multiple sclerosis (Newland, 1999; Stuijbergen & Harrison, 2003), stroke (Blackmer & Jefromova, 2002), chronic back pain, and rheumatism (Sparber & Wootton, 2002). The use of CAM by those patients with cancer (Cassileth & Deng, 2004; Shumay, Maskarinec, Gotay, Heiby, & Kakai, 2002; Wyatt, Friedman, Given, Given, & Beckrow, 1999), and particularly those with breast cancer (Boon, Brown, Gavin, Kennard, & Stewart, 1999; Henderson & Donatelle, 2004; Simpson, 2003) are highly active research areas.

Many of these studies support Astin's (1998) findings that patients choose CAM therapies because of their philosophical and world views (Balneaves, Kristjanson, & Tataryn, 1999; Banja, 1996; Brown & Carney, 1996; Furnham & Forey, 1994; Furnham & McGill, 2003), dissatisfaction or alienation with established medical practice combined with a faith in natural remedies, and a desire for control or empowerment (Gaylord, 1999; Shumay, Maskarinec, Kakai et al., 2001; Siahpush, 1999; Truant & Bottoroff, 1999; Verhoef, Casebeer, & Hilsden, 2002; Verhoef & White, 2002). Finally, some research on CAM use by patients positions patients as consumers who make choices about their treatment (Easthope, 2004; Kelner & Wellman, 1997; White & Purtell, 2001). The globalization of medicine in terms of treatment options and medicinal products, combined with patients' growing awareness of different medical practices, has created a vast "marketplace" of possible health-care options (Janes, 2002; White & Purtell, 2001). This line of inquiry supports Bakx's view of CAM's use increasing with the permeation of postmodern values.

Research has shown that many physicians and other healthcare providers (particularly females) tend to be open-minded about CAM therapies and that they are typically not averse to recommending CAM therapies to people (Boucher & Lenz, 1998; Brems, Johnson, Warner & Roberts, 2006). Furthermore, Canadian medical students, physicians, and other medical educators have indicated that they want exposure to CAM in undergraduate medical education and continuing education. However, there is a lack of consensus among associate deans of Canada's medical schools as to what should be included in the curriculum and the additional concern that the inclusion of CAM within the Canadian undergraduate medical education curriculum will be seen as endorsement of

those CAM practices taught in the schools (Verhoef, Epstein, & Brundin-Mather, 2004). Nonetheless, many healthcare providers continue to ignore, dismiss, or simply not discuss CAM with their patients, despite the fact that patients have been the driving force behind many physicians' interest in CAM (Boucher & Lenz, 1998).

At the same time, research shows that most patients prefer to receive their health information from a doctor (Sibinga, Ottolini, Duggan & Wilson, 2004; Williamson, 1998). The most common reasons noted in the literature as to why CAM therapies are ignored by physicians and other healthcare workers are the following: CAM is not as strictly regulated as allopathic medicine; many CAM products or practices lack empirical evidence to support beneficial claims or have been shown to be ineffective in clinical trials (Dwyer, 2004; Easthope, 2004; O'Mathuna, 2000; Rogers, 2000), and physicians may be uneducated about CAM therapies and therefore uncomfortable about discussing them with patients (Tasaki, Maskarinec, Shumway, Tatsumura, & Kakai, 2002; Winslow & Shapiro, 2002). Others believe that successful treatment using CAM therapies is the result of placebo effects (Brems, 2006). While communication about CAM between healthcare providers and patients appears to be improving, much more work can be done to improve and facilitate communication.

Other studies, however, show that patients may ignore their health-care practitioner's advice. As well, patients might not inform their practitioner about CAM usage because they are concerned about a negative reaction from their practitioner, they believe the practitioner does not need to know, or the practitioner did not ask (Robinson & McGrail, 2004). Finally, the trend in health discourse towards patient empowerment, control over aspects of the decision-making process (Brown, Carroll, Boon, & Marmoreo, 2002), and self-help or self-care may affect why patients choose not to discuss CAM therapies with their practitioner. So while the trend is towards integrative medicine, CAM and allopathic medicine continue to be a contested knowledge domain.

In the health sciences literature, information and information-seeking is often contextualized as decision-making. A number of studies have examined the information-seeking behaviours of patients who are exploring or incorporating CAM into their health care or treatment programs (Montbriand, 1993; Richardson, 2002; Shen, Andersen, Albert, Wenger, Glaspy, Cole, & Shekelle, 2002). Additionally, in their doctoral dissertations two

health sciences researchers discussed how information and information-seeking is related to decision-making. Victory (1997) examined the role of information in the decision-making processes of people who chose to use CAM for their health care. Similarly, Long (2003) studied the use of CAM by women with breast cancer and the role of information-seeking as they made decisions about CAM use. Only one study (Parslow & Jorm, 2004) specifically focused on CAM use to treat depression, but this study did not address either information-seeking behaviour or decision-making processes.

3.2 Information Behaviour Research, Constructionism, and Information Practice

Trends in the information needs, seeking, and use (INSU) research show that information behaviour research in LIS has moved from a systems-centered orientation to a user-centered one (Dervin & Nilan, 1986). Information behaviour researchers have broadened their research scope from investigating the information behaviour of scientists and technologists (Bernal, 1939; Lin & Garvey, 1972) to examining other scholars and professionals (Bystrom, 1997; Cole & Kuhlthau, 2000; King, Castro, & Jones, 1994; Kirk, 1997; Leckie, Pettigrew, & Sylvain, 1996; Lomax, Lowe, Logan & Detlefsen, 1999; Loughridge, 1997; Palmer & Neumann, 2002; Stone, 1982; Sundin, 2002) to studying ordinary people (Chatman, 1992, 1996; Chu, 1999; Coles, 1999; Copher, 2002; Donat & Fisher-Pettigrew, 2002; Fisher, Marcoux, Miller, Sanchez, & Cunningham, 2004; Hersberger, 2001; Miyata, 2002; Pettigrew, 1999). Increasing research attention has been devoted to the information behaviour of ordinary people in their everyday, non-work lives (Chu, 1999; Given, 2002a, 2002b; Hartel, 2006; Hektor, 2003; Spink, 1999; Williamson, 1997) in addition to understanding information behaviour in professional or work contexts. In particular Savolainen's ELIS (everyday life information-seeking) model was instrumental in moving forward the conceptual development of everyday life information-seeking.

Concurrent with this shift in research focus from systems to user and the expansion of research scope to include everyday life activities and ordinary people, two additional developments in information behaviour (IB) research inform this study. First, IB researchers have extended the various conceptualizations of information: information has been conceptualized as a tangible commodity, as reducing uncertainty, as sense-making

and communication, as process, knowledge, and thing, as dialogically constructed, and as discursive action (Belkin, 1978; Buckland, 1991; Cole, 1994; Dervin & Nilan, 1986; McKenzie, 2003a, Talja, 1997; Tuominen & Savolainen, 1997; Wilson, 1994). The broadening of the conceptualizations of information has enabled IB researchers to utilize and apply a variety of theoretical frameworks to research—subsequently enriching scholarly understanding of information behaviour and opening up the field.

The second advancement in IB research that is pertinent to this study is the development of metatheoretical perspectives from the cognitive viewpoint to constructionist frameworks. The cognitive viewpoint as defined by Talja, Tuominen, and Savolainen (2005) is the “individual creation of knowledge structures and mental models through experience and observation” where knowledge structures are “influenced by history and social relationships” (p. 82). Although an individual’s mental models are socially and culturally influenced, the creation of knowledge takes place within an individual’s mind. The cognitive viewpoint has provided a fruitful paradigm for answering different questions posed by IB researchers such as understanding the Information Search Process (ISP) as developed by Kuhlthau, understanding task-uncertainty problems (Bystrom, 2000; Vakkari, 1999), and understanding sense-making in its earlier forms (Dervin, 1983; Dervin & Nilan, 1986). However, the cognitive viewpoint has been criticized for “mentalizing language and information.” Additionally, Hjørland (1992) argues that cognitive theories are unhelpful in solving problems of knowledge organization which are based on social discovery and knowledge construction because the cognitive viewpoint understands reality as residing within and not between individuals. Language, according to the cognitive viewpoint, is a neutral instrument. Consequently, the cognitive viewpoint may not be an appropriate paradigm for asking questions that concern cultural meanings, interpretations, or classifications.

On the other hand, the development of the metatheoretical paradigm constructionism has enabled researchers to study how information is dialogically constructed and how constructed information can be used in talk or writing, i.e., discursive action (Tuominen & Savolainen, 1997). Some LIS researchers (Frohmann, 1994; Given, 2002a; McKenzie, 2002, 2003a; 2003b; Talja, Tuominen, & Savolainen, 2005) have used a constructionist approach to show how information and knowledge is produced through

language and communication rather than within individual minds. According to this view language is not neutral; it is the site whereby information, knowledge, identity, and meaning are created or formed. “Constructionism speaks of discourses, articulations and vocabularies, and replaces the concept of cognition with conversations” (Talja, Tuominen, & Savolainen, 2005). A constructionist approach shifts attention from individual users in context to “the production of knowledge in discourses, that is, within distinct conversational traditions and communities of practice” (Tuominen, Talja, & Savolainen, 2002). In this way information is constructed through language: “this ‘information’ consists of social arguments that take part in ongoing conversations about the meaning of an issue or a phenomenon. Information is all about building credible models or versions of reality that can be defended against potential or actual criticism” (Tuominen, Talja, & Savolainen, 2002, p. 278). Constructionism has been criticized for not generating substantial empirical research programs and methodologies (Ingwersen, 1999) and for ignoring the influence of individual activities and personal histories in social interactions. Despite these criticisms, constructionism is the appropriate framework to answer the questions posed by this study because the research questions I answer focus on the social construction of information and how information is then discursively used to justify or make claims or to undermine others’ claims.

A nascent thread related to the social aspects of information and knowledge emerging in the LIS literature is the debate regarding the appropriate use of the terms “information behaviour” and “information practices.” In his article examining the historical antecedents and epistemological underpinnings of these two concepts, Savolainen (2007a) suggests that while information behaviour may be the dominant terminology used to describe this research area, the concept “information practice” provides a critical alternative. Savolainen argues that the concept “information behaviour” stems from the cognitive viewpoint—the interior site where information and knowledge is constructed via mental models, structures, and schemas. According to the cognitive viewpoint, knowledge construction occurs within an individual’s mind rendering the individual’s mental processes invisible. The invisibility of these interior processes can thus be problematic for researchers who are unable to observe the individual’s cognitive

behaviour. Savolainen suggests that researchers use the term “information behaviour” without reflecting on its epistemological significance.

Conversely, “information practice” is a concept inspired by social constructionist theory that views information needs, seeking, and use as social practices. Some scholars prefer the concept information practice over information behaviour since “the former assumes that the processes of information-seeking and use are constituted socially and dialogically, rather than based on the ideas and motives of individual actors. All human practices are social, and they originate from interactions between the members of a community” (Tuominen, Talja, & Savolainen, 2005, p. 328). In this way, the concept of practice shifts the focus away from the behaviour, action, motives, and skills of individuals: “Instead, the main attention is directed to them [individuals] as members of various groups and communities that constitute the context of their mundane activities” (Savolainen, 2007a, p.120). The social and cultural factors that influence information-seeking are central to the concept of information practice as is attention to the process of information sharing. In her study on pregnant women, McKenzie (2003c) found that “information practices” was a more suitable umbrella concept than information behaviour to describe the entire range of activities engaged in by the pregnant women, to address non-active information behaviour, and to describe information given to an individual by a third party or other agent.

However, as Savolainen (2007a) points out “information practice” is not a discrete concept and thus far researchers have not distinguished this term from others such as “information work.” The term “information work” has been characterized by Hogan and Palmer (2005) as “broader than information-seeking but narrower than information behaviour.” According to Hogan and Palmer, “Information work emerges from this framework as something essential, dynamic, ongoing and social that intermixes with, complements, supports and is supported by other kinds of work or everyday life work, for example, coping with a chronic illness” (Hogan & Palmer qtd. in Savolainen, 2007a, p. 123). Information work deals with purposive, conscious, and intended actions. “As information work covers the whole spectrum of locating, gathering, sorting, interpreting, assimilating, giving, and sharing information, it comes close to ‘information practices’

defined by McKenzie” (Savolainen, 2007a, p. 123). Consequently, the concept of information practice is most appropriate for this research project.

Savolainen (2008) suggests that LIS researchers have neglected two areas in information behaviour: information use and information sharing. “In particular, we lack qualitative research exploring how people make use of diverse information sources to further their everyday projects. However, such studies are vitally important, since information has no value in itself, information gains value when it is used...” (p. 7). On the micro level, information use is studied by determining how knowledge structures and individual cognition is changed or modified when new information is processed. On the macro level attention is paid to how people judge the relevance and value of information. Similarly, information sharing has rarely been addressed in the LIS literature. Individuals often share their stocks of knowledge with others for altruistic reasons or as participants in a community. This kind of information sharing is particularly evident on newsgroups. LIS researchers who have used a constructionist approach to frame their work, who have maintained a focus on everyday life and ordinary people, and whose work focuses on information use and sharing, are particularly relevant to this research (Given, 2002a, 2002b; McKenzie, 2001, 2002, 2003a, 2003b, 2003c; Savolainen, 2008).

3.3 Information Behaviour in Consumer Health Contexts

While researchers have investigated the information behaviour of health professionals including doctors (Coumou & Meijman, 2006; Davies, 2007; Gavvani & Mohan, 2008; McKibbin & Fridsma, 2006), nurses (Bertulis & Cheeseborough, 2008; Fourie & Claasen-Veldsrnan, 2007; Guo, Bain, & Wilier, 2008; McKnight, 2006, 2007; Nail-Chiwetalu & Barbara, 2007; Taira & Mikuni, 2007), speech pathologists (Guo, Bain, & Wilier, 2008; Nail-Chiwetalu & Barbara, 2007), nursing students (Corkett, 2007; Craig & Corral, 2007), social care workers (Jackson, Baird, Davis-Reynolds, Smith, Blackburn, & Allsebrook, 2007), scientists and science administrators (Blake & Pratt, 2006; Grefsheim & Rankin, 2007; Hemminger, Lu, Vaughan, & Adams, 2007), hospital CEOs and managers (MacDonald, Bath, & Booth, 2008; McDiarmid, Kendall, & Binns, 2007), it is the information behaviour of ordinary people, both online and offline, as it relates to consumer health that is pertinent to this study. The information behaviour studies done in

the consumer health information (CHI) area are wide-ranging. Many studies focus on women because they tend to be the gatekeepers and guardians of their family's health (Apple, 1990; Calabretta, 2002; Navarro & Wilkins, 2001; Whelehan, 1988). Bernhardt and Felter (2004) studied the online pediatric information-seeking of mothers and a number of researchers have studied the information behaviour (Szwajcer, Hiddink, Koelen, & van Woerkum, 2005) or information practices (McKenzie, 2003c) of pregnant women. Additionally, Wathen and Harris (2006) examined the health information-seeking behaviours of women living in rural Ontario and Warner and Procaccino (2004) studied health information behaviour (examining information needs, strategies, and use) by women using Kuhlthau's ISP model. Similarly, Bath and Guillame (2004) focused on the information needs of parents during a health scare to uncover what peoples' preferred information sources are. In addition, researchers have examined the information behaviour of people dealing with a specific illness, disease, or health concern such as multiple sclerosis (Baker, 1996; Baker & Pettigrew, 1999), cancer (Leydon, Boulton, Moynihan et al, 2000), HIV/AIDS (Huber & Cruz, 2000; Hogan & Painter, 2005; Veinot, 2009; Veinot, Harris, Bella, Rootman, & Krajinak, 2006), and spinal cord injury (Burkell, Wolfe, Potter, & Jutai, 2006). Baker (2004) also examined information needs at the end of life from a health perspective.

LIS researchers have applied a number of different theoretical models and frameworks to their studies of information behaviour in a consumer health context. Several studies have examined how people with health problems seek or avoid health information. Often a coping mechanism for people with health problems is avoidance or denial (Brashers, Goldsmith, & Hsieh, 2002). Brashers, Goldsmith, and Hsieh (2002) used uncertainty management theory to show how people seek or exchange health information whereas Miller's work on monitoring and blunting as a coping mechanism has been applied to health information-seeking in LIS most notably by Baker (1996, 1997, 2004, 2005; Baker & Pettigrew, 1999). Other LIS researchers have examined the role of social networks in health information-seeking, specifically using Granovetter's strength of weak ties theory (Baker & Pettigrew, 1999; Morey, 2007; Pettigrew, 2000; Savolainen, 2001). Information-seeking or information behaviour models have also been applied to consumer health research (e.g., the various models developed by Ellis, Kuhlthau, Savolainen, and

Wilson). Both Westbrook (2008) and Pálsdóttir (2008) used ELIS to frame their work, with Westbrook examining domestic violence and Palsdottir studying Icelanders' everyday health and lifestyle information behaviour. Many of these studies provide additional evidence to support Harris and Dewdney's (1994) six information-seeking principles:

- Information needs arise from the help-seekers' situation.
- The decision to seek help or not to seek help is affected by many factors.
- People tend to seek information that is most accessible.
- People tend first to seek help or information from interpersonal sources, especially from people like themselves.
- Information-seekers expect emotional support.
- People follow habitual patterns in seeking information. (p. 19-27)

Most consumer health research focuses on the information needs and seeking of individuals with specific diseases or those belonging to certain demographic or socioeconomic groups, while information use is somewhat neglected (Savolainen, 2008). This gap may be partially explained by the assumption inherent in much CHI that there is a linear relationship between acquiring information and altered behaviour. Ek and Widen-Wulff (2008) argue that

Health education programmes are generally based on the assumption that health-promoting knowledge and corresponding behaviour are automatically created as people are subjected to a rich flow of information. Improved knowledge is, however, not the same as good behaviour. Information is not synonymous with knowledge; neither is the transformation of knowledge into behaviour a simple or linear process. (p. 74)

Similarly, Sligo and Jameson (2000) point out that the knowledge-behaviour gap—what people know and how they act—may be two different things. There are a variety of reasons why people may not seek or use health information. In their study on non-seeking behaviour Ramanadhan and Viswanath (2006), for example, found that even when diagnosed with a serious disease like cancer some people do not seek or use health information beyond what their health practitioner tells them. Ramanadhan and Viswanath

found that non-seekers came from the lowest income and education groups and scored lower on attention to, and trust in, media health information. Non-seekers were also the least likely to conform to preventative health behaviours. Similarly, Lee, Hwang, Hawkins, and Pingree (2008) found that for women diagnosed with breast cancer, negative emotion was positively related to the amount of information sought by individuals with high self-efficacy, whereas among those with low self-efficacy negative emotion was negatively related to the amount of information sought. That is, negative emotion acted as either a catalyst to gathering information or as an obstacle, depending on the individual's level of self-efficacy. Additionally, the researchers found a significant increase in patients' health self-efficacy after they used health information for two months—information use was related to greater self-efficacy. This study in particular presents some intriguing findings regarding health information use.

3.3.1 Online consumer health information behaviour

The recent attention directed towards ordinary people in conjunction with the advent of the Internet has led to much research activity in online consumer health information-seeking (Abrahamson, Fisher, Turner, Durrance, & Turner, 2008; Eng, Monkman, Verhoef, Ransum, & Bradbury, 2001). The two main research streams in this area focus on information-seeking using electronic health resources and on issues arising from the use of electronic resources in disseminating health information. Much of this research focuses on the promise and perils of the Internet as a consumer health information source (Calabretta, 2002; Coggan, 2000; Detlefsen, 2004; Huntington, Nicholas, & Gunter, 2004; Klein-Fedyshin, 2002) or the virtues of using the Internet for health promotion and health information delivery (Deering & Harris, 1996; Evers, 2006; Lorence, Park, & Fox, 2006) or using online information for self-care (Nijland, van Gemert-Pijinen, Boer, Steehouder, & Seydel, 2008). Bass, Ruzek, Gordon, Fleisher, McKeon-Conn, and Moore (2006) found that Internet use among newly diagnosed cancer patients led to greater participation in treatment decisions, asking the physician more questions, and greater treatment compliance. These patients viewed the Internet as a powerful tool for both acquiring information and for enhancing confidence. Significantly, Lorence and Heeyoung (2008, 2007, 2006) found that despite policy initiatives intended to erase or bridge the gap

between those with access to digital health information and those without, differences in access persist. The links among Internet use, socioeconomic characteristics, and demographics have a direct bearing on online health seeking behaviours.

A number of studies have emerged in recent years examining electronic health resources from the information-seeking perspective of certain groups. For example, Flynn, Smith, and Freese (2006), Marschollek, Mix, Wolf, Effertz, Haux, and Steinhagen-Thiessen (2007), and Silbajoris (2000) studied older adults' use of electronic sources for health information. Another area receiving much research attention is how developing technologies support information behaviour, i.e., the information behaviour taking place in virtual communities (Liszka, Steyer, & Hueston, 2006; Tilley, Bruce, Hallam, & Hills, 2006), on portals (Rankow, 2002; Williamson & Manascewiz, 2002), and on mailing lists or e-mail (Goldner, 2006; Meier, Lyons, Rimer, Frydman, & Forlenza, 2007). These studies have shown that participation in virtual communities, portals, and mailing lists are all positively correlated to well-being, a sense of control, and making positive changes. Additionally, these studies show that online fora provide support and are generally viewed as good information sources to the people who use them. However, while there are many benefits to using online technologies, Valimaki, Nenonen, and Koivunen (2007) found that patients still like to receive healthcare information in face-to-face interactions with their healthcare providers in preference over online delivery. Finally, far fewer studies have examined how online health information is used. Only one study by Eastin and Guinsler (2006) studied if, and how, information gathered online was used—the researchers asked if individuals subsequently went to see a doctor or change their behaviour in some way as a result of acquiring information online. They found that for patients who were moderately to highly anxious about their health, seeking online health information resulted in a greater number of medical visits (although this was not a statistically significant relationship). For those patients with low health anxiety, seeking online health information resulted in fewer medical visits. The dearth of research in this area appears to support Savolainen's assertion that information use is a neglected area in LIS.

Previous research has demonstrated that those with illness use a wide range of information behaviour to satisfy information needs (including the use of online information sources and support groups) (Cytryn, 2001; Long, 2003). Eight in ten Internet users have

looked online for health information and 21% of those health information-seekers sought online information about depression, anxiety, stress, or mental health issues (Fox, 2005). It is estimated that one in four health information-seekers joins a support group (Cline & Haynes, 2001) and that many health consumers prefer to obtain their information from online support groups (Wikgren, 2001). Online support groups have been a tremendous boon for those dealing with health concerns and for those caring for someone with a health problem. Research shows that participation in online support groups is significantly correlated to increased coping skills and positive health outcomes (Agnew, 2001; Antle & Collins, 2009; Bacon, Condon, & Fernsler, 2000; Coursaris & Lui, 2009; Fingeld, 2000; Mo & Coulson, 2010; Radin, 2006). A study published by the *American Journal of Psychiatry* found that 95% of participants in online support groups for depression said communication with other patients alleviated some depression symptoms (Houston, Cooper, & Ford, 2002). Similarly, a recent study by Griffiths, Calear, and Banfield (2009) found that participation in online support groups reduced depressive symptoms. Online support groups provide peer-to-peer support (the preferred means of social support), and online support groups assist in providing empathy, information, advice, a sense of empowerment and control, humour and inspiration, and they also provide the opportunity to help others (Agnew, 2001; Bacon, Condon, & Fernsler, 2000; Fingeld, 2000; Radin, 2006; Vilhauer, 2009; Wikgren, 2001) .

Wikgren (2001) describes health discussion groups as “a type of information channel with interesting hybrid properties: they offer access to both formal and informal sources, medical facts, orienting information and emotional support, and advice and information from both known and unknown fellow participants” (p. 315). Despite a sinister side to online support groups—flaming, trolls, and malevolent lurkers—the act of sharing one’s own, and soliciting others’, advice, stories, opinions and experiences with depression suggests that there is a certain amount of trust among online users. Even while arguing different points of view, users typically have a certain level of implicit trust for others—studies have shown that the vast majority of messages posted on online support groups are positive (Coursaris & Liu, 2009; Storm & Moreggi, 1998). Additionally, other research shows the health benefits of confiding in others. Pennebaker (1990) writes, “Whereas inhibition is potentially harmful, confronting our deepest thoughts and feelings

have remarkable short- and long-term health benefits [...] Not disclosing our thoughts and feelings can be unhealthy. Divulging them can be healthy” (p. 14). While Pennebaker’s research was conducted prior to the popular use of online newsgroups, other research supports the findings that the benefits of disclosure and the act of writing online are transferable from paper to electronic mediums (Agnew, 2001; Ben-Ze’ev, 2003).

3.4 Identity, Illness Narratives, and Lay, Experiential, and Expert Knowledge

Often one’s identity is tied to diagnosis (Hermans, 2003). An excellent example of this is the Alcoholics Anonymous introduction at a meeting: “Hello, my name is Tim, and I’m an alcoholic.” In this context the illness *is* the individual’s identity. However, Dowrick (2004) suggests that a diagnosis of depression can have potentially harmful consequences for a person with depression because a diagnosis can shape both the doctor’s and the individual’s perception of the person as a “depressed” person. For the doctor the diagnosis can potentially result in unnecessary medical interventions and a solution (i.e., prescription for antidepressants) that may not address the problem or be an appropriate treatment. Ian Hacking (1999) uses the concept of classificatory looping to argue that classifying people inevitably changes the nature of the people being classified as well as changing others’ perceptions of that particular person. Gwen, an interviewee, said:

Gwen: I think one of the big problems for me is getting treated like someone who’s fragile or whose emotions aren’t reliable or something...Actually that’s something I notice a lot with my fiancé and I—if I’m upset about something it’s “Did you take your meds this morning?”...I know he means well but sometimes you just want to say, “Look, there’s more to me than just that I have depression.” And, it’s really frustrating to try and express something that you’re feeling and thinking and to have someone come back and say, “Oh, it’s just ‘cause she’s depressed.”...And if I didn’t have depression I would be happy 24 hours a day and nothing would ever bother me?...It’s unrealistic but because of this diagnosis that’s how people kind of treat you.

Some researchers claim that those suffering from mental health disorders not only grapple with illness, labelling, and identity but also undertake an integral part of the healing process when they construct an illness narrative (Carless & Douglas, 2008; Kangas, 2001; Kirkpatrick, 2008). Frank (1995) and Kleinman (1988) argue that constructing narratives are the means by which the people reclaim their body back from

medicine and make sense of the illness in their lives. The illness narrative serves as the vehicle for reflection and sense-making as it relates to the ill person's conception of themselves and their relationships with others (Adame & Knudson, 2007; Rapport, Jerzembek, Doel, Jones, Cella, & Lloyd, 2010). Kangas (2001) in her article "Making Sense of Depression" suggests that there are three conceptual aspects to making sense of an individual's illness: individual contextualization, where the individual tries to find meaning and explanation for the illness in their lives; social contextualization, where the effect and meaning of illness to the individual's social position and relationships are examined by the individual; and cultural contextualization, the use and contemplation of shared cultural knowledge about the illness. All three of these contextualizations assist in making sense of the illness and assist in developing accounts of the illness. Creating accounts is an important part of the coping process.

While the sociological meanings of "illness narrative" or "explanations of illness" are contested (Bury, 2001; Larsen, 2004), many researchers agree that when making sense of an illness laypersons typically use both expert knowledge and personal experience of illness to process and construct storylines and narratives (Bury, 2001; Kangas, 2001; Shaw, 2002). These storylines reveal that a clear-cut dualism between lay and expert knowledge no longer exists—the relationship between layperson and expert knowledge is complex, subtle, and nuanced (McClellan & Shaw, 2005). Kangas (2001) found that:

Lay perceptions of depression are made of bits and pieces taken from many sources, reflecting the fact that individual, social and cultural contextualization of depression takes place in an era of increasing reflexive practices (Giddens, 1991) and of diminishing faith in scientific and thus also in medical truths and medical authority (Kelleher et al., 1994), exposing people to a wealth of complementary and competing information from multiple sources. Lay theories, perceptions and explanations of depression are constructed and negotiated in an increasingly plural and complex environment of knowledge. (p. 89)

The proliferation and dissemination of expert knowledge, the incorporation of expert knowledge into common-sense lay discourses of health and illness, and some people's rejection of biomedical authority have blurred the boundaries between lay and expert knowledge according to the view of Kangas (2001), Bury (2001), and Larsen (2004).

Shaw (2002) takes these ideas further, and argues that through the process of proto-professionalization, people redefine their illnesses according to the stance of the profession they are interacting with. In his article “How Lay are Lay Beliefs?” Shaw (2002) draws from the work of Abram de Swaan (1990) to define proto-professionalization:

The internal process of professionalization creates external effects among ever widening circles of laymen, who adopt the basic stances and fundamental concepts of the professions as a means of orientation in their everyday life: it is a process of ‘proto-professionalization’ (qtd. in Shaw, 2002, p. 289).

Shaw argues, “Common-sense understandings are imbued with professional rationalizations, and even resistance to medical treatments are oriented around medical rationality” (p. 293). Browner and Press (1997) suggest in their research on pregnancy and childbirth that “much of prenatal care can be seen as a process of medical socialization, in which providers attempt to teach pregnant women their own interpretations of the signs and symptoms the women will experience as the pregnancy proceeds and the significance that should be attached to them” (p. 116). Similarly, Furnham (1995) found that the resemblance of layperson theories to clinical theories on the causes of mental illness may be predictive of the patient’s cooperation during the course of treatment. Starr (1982) suggests that society relies on professions to such an extent that our interpretations of the world are filtered through professional prisms. According to these researchers, lay beliefs may be influenced by medical discourses through the person’s interaction with the medical profession or consumer health information or other professional discourses.

Additionally, a study by Gill (1998) found that while laypersons may be recognized by medical practitioners as authorities of their own experience, they are not considered authorities in explaining the causes of their condition. In Gill’s study both doctors and patients exhibited great sensitivity toward social rights and entitlements during medical visits. However, laypersons downplayed their knowledge when offering explanations for their illness. In order to avoid setting themselves up for disaffiliative responses from their doctors, patients were tentative and cautious and they did not present themselves as personally committed to their positions. Laypeople did not expect doctors to recognize them as “legitimate theorists about their health problems—that is, as individuals who are

entitled to analyze the empirical facts and to arrive at explanations for the causes of their problems” (1998, p. 343). Consequently, laypersons’ recognized area of expertise is narrowly circumscribed to the domain of their own experiences. Laypeople are not entitled to share their knowledge about causation of illness or disease with their medical doctor even if they are correct. This may partially explain, for example, why physician-patient communication can be so problematic—lay understandings or theorizing about the underlying causes of illness are excluded from the dialogue (even though people living with depression tend to do a great deal of work creating narratives that would most likely be beneficial to a medical encounter).

More recently, Gill (2005), and Gill, Pomerantz, and Denvir (2010), used conversational analysis to study how people would apply subtle pressure to guide doctors to certain diagnoses. In their 2010 article, Gill, Pomerantz, and Denvir found that early in the medical visit (the information-gathering phase) people engaged in “pre-emptive resistance.” Pre-emptive resistance is a practice whereby “patients raise candidate explanations for their symptoms and then report circumstances that undermine these explanations. By raising candidate explanations on their own and providing evidence against them, patients call for doctors to restrict the range of diagnostic hypotheses they might otherwise consider” (p. 1). In this way, individuals showed that they made sense of their health problems, that they were able to interpret evidence of some possible causes of their symptoms, and consequently, they were able to manage some delicate action in the medical encounter. The practice of pre-emptive resistance allowed people to restrict the doctor’s symptom interpretation and diagnostics. However, the practice of pre-emptive resistance does not necessarily result in doctors agreeing or complying with the individual’s representations. People used information and discursive practices to legitimize the knowledge they drew upon in the layperson-practitioner encounter but doctors can view these accounts as illegitimate or disregard these accounts as “more information” and not as diagnostics.

Shaw suggests that some people, particularly those with chronic illness who have experience with the healthcare system, can utilize their experience of suffering as a way of critiquing or negotiating expert medical knowledge. During treatment of a chronic illness such as depression Shaw argues that laypeople can become experts on expert knowledge,

including medical knowledge. Researchers have found that people with chronic conditions and experience with the healthcare system are more likely to challenge their doctors (Cooper, 1997; Haug & Lavin, 1979, 1983). The person's lived experiences combined with his or her knowledge of depression can allow the person to challenge doctors', especially non-specialists', authority. Similarly, a study by Asbring and Narvanen (2004) found that, for women with chronic fatigue syndrome and fibromyalgia, knowledge and experience acted as a power resource used to persuade, resist, confront, make demands, avoid complying with doctor's orders, and to influence their interactions with healthcare providers. Many of the women in this study described themselves as experienced patients "which means that they considered themselves to be competent regarding their illness and the health care system. Experienced patients have become familiar with the arena, the system, the rules of the game, and the values, and know how they should behave to attain the best possible results for their own part" (p. 232).

A different approach was taken by Kangas (2001) who studied how lay beliefs about depression formed sense-making illness narratives, not knowledge to challenge biomedicine. However, she did find that:

'Lay' depression accounts are stories of 'normal' suffering and marginality from a perspective that is not present in expert views. Medical and other expert knowledge cannot explain illness in its social context (Radley, 1994: 5). Depression accounts differ from expert knowledge in that they are intertwined with everyday life and depression is constructed as a social and personal problem restricting and disabling the social life of the sufferers. Contextual knowledge and experience is combined with cultural resources, and making sense of illness becomes possible. (p. 303)

Kangas found that biomedical authority and discourses were not the only, nor the primary, sources for lay beliefs about depression. Lay beliefs about depression centered on psychological discourses—childhood, adolescence, misfortune; social discourses— isolation and communication problems; and holistic discourse—a combination of any of these discourses.

Moving beyond analyzing lay and expert knowledge and discourses, a number of researchers have examined the discursive practices laypersons use to present information as authoritative. Among these researchers, McKenzie's (2001, 2003b) work is particularly

relevant to this study. McKenzie uses the concepts of authoritative knowledge and cognitive authority to explore the discursive techniques that pregnant women use to justify their decisions. Other researchers such as Horton-Salway (2004) studied a chronic fatigue syndrome support group to examine how knowledge claims were locally produced. Asbring and Narvanen (2004) investigated the various discursive power strategies women suffering from chronic fatigue syndrome used to gain control over their situation and influence caregivers. These researchers show how laypersons use discursive strategies to present themselves as authoritative. While understanding what discourses people draw on (lay, experiential, expert, or a combination) when interacting with healthcare professionals or making sense of illness informs this research project, information use as it is manifested via discursive strategies is an additional and important component of this study.

3.5 Everyday Life Information-seeking and Mastery of Life

The model of everyday life information-seeking (ELIS) created by Savolainen (1995) was developed in order to facilitate our understanding of how social and cultural factors affect people's way of preferring and using information sources in everyday life (i.e., non-work contexts). Savolainen points out that everyday life information-seeking and job related information-seeking are complementary, not dichotomous. The ELIS model's central concept "way of life" is defined by Savolainen as the "order of things." "Things" refers to activities that take place in daily life such as hobbies, work, and household tasks and "order" is constructed by the individual based upon their preferences of how things are when they are perceived as "normal". Based on Bourdieu's idea of *habitus*—a socially and culturally determined system of thinking, perception, and evaluation, internalized by the individual—the order of things forms the basis on which individuals make meaningful choices in everyday life. However, the meaningful order of things may not be reproduced automatically and as a result individuals are required to take active care of it (Savolainen, 2005). This care is called "mastery of life."

Savolainen (1995) defines mastery of life as "a general preparedness approach to everyday problems in certain ways in accordance to one's values" (p. 264). Mastery of life is interpreted as "keeping things in order" and information-seeking is an integral component. Mastery of life is "associated with pragmatic problem solving, especially in

cases where the order of things has been shaken or threatened” (Savolainen, 2005, p. 144). The ELIS model suggests that way of life (“order of things”) and mastery of life (“keeping things in order”) determine each other. Individual values and stage of life along with the material, social, and cultural capital an individual has access to affects both way of life and mastery of life. Although individuals tend to prefer certain information channels, sources, and information-seeking strategies, Savolainen (2005) points out: “way of life or mastery of life does not determine how a person seeks information in individual situations” (p. 146). Savolainen calls for greater conceptual development of the ELIS model using a social constructionist framework: “how do people position themselves as information-seekers and users in discourse” (2005, p. 147). This research project attempts to address this issue.

Health information-seeking, particularly for chronic, recurring episodic conditions, or as preventative measures can form a “project of life” associated with mastery of life within the ELIS model. Patient empowerment, the expert patient, the health project, and proto-professionalization are all terms that reflect the trend towards health self-management—turning illness or a disorder into a life project where there is a need for continual information and support (Lupton, 1995; Wikgren, 2001). Furthermore, in health matters when everyday life is full of uncertainties, keeping things in order is an effective coping strategy. For example, Foote-Ardah (2003) found that among HIV patients in the U.S., management of their everyday lives as ill persons was improved when CAM practices were self-regulated because it increased the patients’ sense of control. Self-regulation was an effective coping strategy. Wikgren (2001) suggests that the health information-seeking process can be understood as a mastery of life through attempts to gain control over health-related events where the process assists the individual in coping with change.

3.6 Authoritative Knowledge in Medicine and Science

In Western societies the knowledge derived from the practices of biomedicine is the gold standard for medical knowledge. Some argue that through the processes of becoming expert patients or proto-professionals biomedical knowledge is also increasingly becoming the gold standard for lay understandings of illness as well. Consequently, the theoretical

frameworks I used for framing this research in addition to social construct of information and ELIS are authoritative knowledge and cognitive authority. Authoritative knowledge in this context must be examined on two levels—the first level being how authoritative knowledge is constructed in medicine, and the second being how authoritative knowledge is constructed by individuals within communities.

In his dissertation on contested knowledge and CAM use in Canada, Fries (1998) argues that complementary and alternative medicine will never achieve the legitimacy of biomedicine for three reasons. First, orthodox medicine retains power and authority because of the way knowledge is constructed in Western nations. Second, orthodox medicine co-opts those heterodox practices that have become popular by assimilating them, and third, orthodox medicine maintains control of medicine by controlling professionalization.

While there is a vast body of literature on the philosophy of science (Kuhn, 1962), the work of Fries (1998), Steuter (2002), and Jonas (2002) provide examples representing positions in ongoing debates about orthodox medical practice, the role of science in orthodox medical practice, and how science has replaced the church as the primary institution of social legitimation. Fries (1998) and Steuter (2002) argue that with an almost supra human approach scientists discover “the truth,” they use esoteric language that only the initiated can comprehend, and their operations are often shrouded in mystery to the laity. Science operates much as the church has operated historically—the interpretation of scripture was done by those with the correct training, i.e., the clergy. The clergy were viewed as supra human—they had a monopoly on “truth,” and the church’s operations and traditions were inscrutable to the general population which consequently excluded the laity from participating, criticizing, or analyzing those operations and traditions.

Fries argues that science has a privileged position in our society and it has enjoyed this status for centuries (again, replacing the church as the social institution for legitimation). Moreover, even though other researchers have shown that “facts” are judgements based on cultural value, that facts and science are socially constructed, and that facts sculpt science itself (Latour & Woolgar, 1986; Wolpe, 2002), appeals to science are often appeals for legitimation and ideological support. Knorr (1999) writes, “Epistemic cultures are cultures that create and warrant knowledge, and the premier knowledge

institution throughout the world is, still, science” (p. 1). Knowledge must be developed using traditional, scientific methods in order to be considered authoritative or legitimate (Grier, 1993). This requires that knowledge, as the product of intellectual activity, be validated by academic communities as well as other professional organizations and institutions. As a result, orthodox medicine utilizes science for ideological support and legitimation, which greatly increases the hegemonic control of orthodox medicine. In this way, orthodox medicine retains control of medicine and, consequently, alternative medicine is marginalized (Fries, 1998; Steuter, 2002).

Moerman (2002) suggests that

But for ordinary physicians, who have not experienced the treatments they prescribe for their patients, other devices must serve to create this assurance [of effectiveness]. In Western medicine, the primary device for achieving this end is the extraordinary romance medicine has with science. Medical students are steeped in science. Doctors routinely argue that their work is ‘scientific’. By this, they mean that it is somehow based on real scientific analysis or experiment; that is, that it’s ‘true’. Modern medical education is steeped in science – from the MCATs to the fixation on ‘data’; ‘show me the data’ is the first thing any doctor will ever ask... (p. 43)

In his chapter titled “Evidence, Ethics, and the Evaluation of Global Medicine” Jonas (2002) argues that Western medicine has “mastered the cure, but struggles with care... . Its successes and failures have arisen largely from a focus on science as defined by laboratory and experimental methods and it is empowered by technology” (p. 122). Jonas clearly illustrates the relationship of biomedicine to science in the hierarchy of evidence used by biomedical researchers (Figure 1).

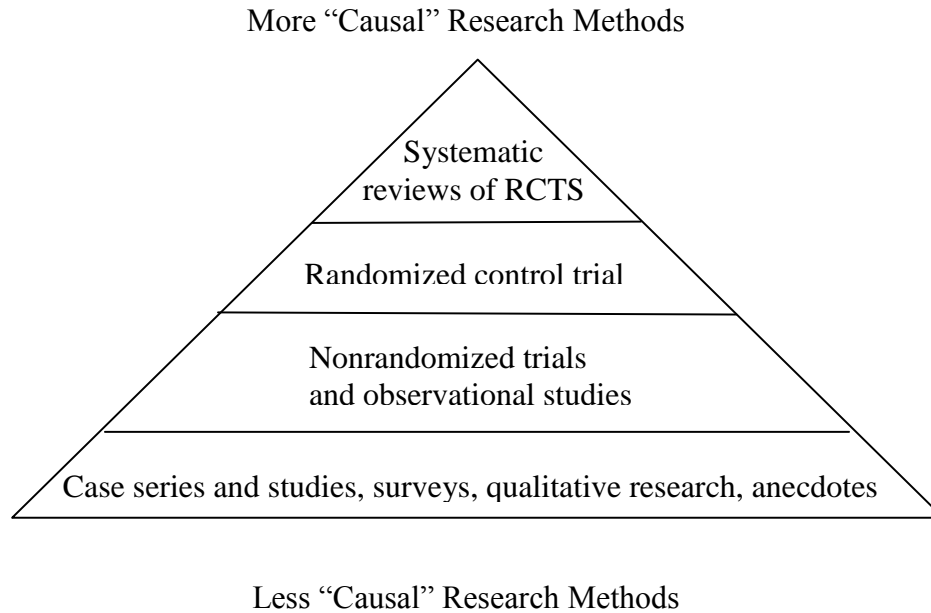


Figure 1. The Hierarchy of Evidence (Jonas in Callahan, 2002, p. 125).

The assumption underlying experimental methods is that determining cause and effect links between variables is the primary goal of biomedical research. The epistemological underpinnings of this hierarchy are universality and objectivity—and thus the research method that sits atop the pyramid, and the method that provides the “best” evidence for biomedical researchers, is systematic reviews of random controlled trials (RCTs). These research methods and their ordering within the pyramid are based upon the perception that RCTs and systematic reviews provide the best evidence for treatments, causes, effects, the establishment of facts, or other focuses of inquiry. At the bottom of the pyramid is what Jonas dubs “less causal” research methods. The location of these research methods at the bottom of the pyramid indicate that these research methods provide the least amount of evidence of causal effects for biomedical researchers—these methods focus on individual or small group interpretations and meanings of illness or disease.

This model has been successful for the last one hundred years and is particularly useful in uncovering the effectiveness of drugs and diseases of short duration. However, Jonas questions the utility of these methods in cases where illness may be chronic; he questions the use of these methods in a global context where the meanings attached to biomedicine and healing systems differ from this model and are subsequently marginalized; he questions how effective this model is in discovering how patients use the

information and treatments derived from using these methods; and he suggests that “if we make one type of evidence the ‘gold standard’...we not only assume that type of information is the only valid goal for research to pursue, we preferentially serve only a few audiences and their goals to the neglect of others” (p. 134). He proposes the following model:

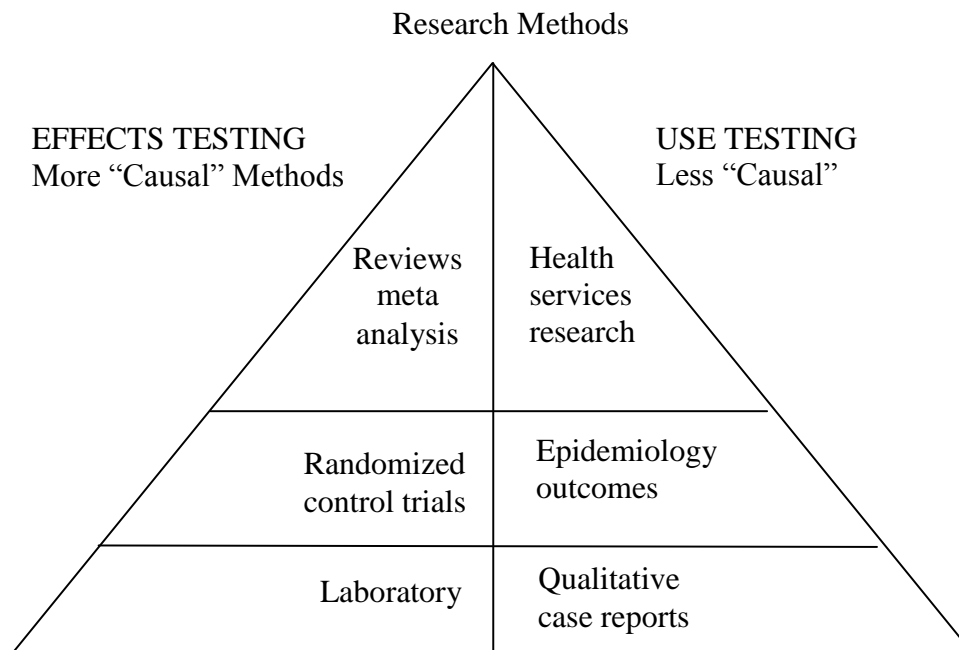


Figure 2. Balanced Evidence Hierarchy (Jonas in Callahan, 2002, p. 135).

This “balanced” model allows for input from different audiences in the construction of evidence. For example, patients, their family members, healthcare practitioners, clinical researchers, and scientists are all accommodated by this model.

A major problem for CAM researchers is providing scientific evidence that a treatment works using the types of research methods legitimized by biomedicine. A search in The Cochrane Library, a library that stores systematic reviews, in December of 2008 retrieved only 22 systematic reviews out of a possible 5,546 reviews from the search string “complementary and alternative medicine,” 50 results were retrieved from the search string “complementary therapies” (which is also the MeSH descriptor), 61 reviews were retrieved for “complementary medicine,” and 37 results were retrieved for “alternative medicine.” The vast majority of these retrieved reviews overlapped—in total 75 unique systematic

reviews were retrieved from these search strings. Of the 75 reviews retrieved, five were false drops bringing the total of systematic reviews to 70. Within the CAM community there has been a call for greater use of research methods like RCTs in building evidence for treatments but, conversely, there has been a movement towards legitimizing the results derived from qualitative research methods. Adherents to this view reject the universality of biology which “tends to blind us to the dramatic variation in the ways that people experience their own physiology based on who they are and what they know” (Moerman, 2002, p.70). Regardless, the biomedical model of disease and the knowledge derived from using these “evidence-based” research methods is so pervasive that the model is taken as reality and not merely an interpretation. In this way biomedical knowledge derived from using scientific methods retains its hegemonic position as the source of authoritative knowledge.

Finally, by controlling professionalization orthodox medicine retains control over how medicine is practiced. In the 19th century the medical marketplace in both Canada and the US was a hodgepodge of services and practices with a number of different practitioners vying for a share of the market (Crellin, Andersen, & Connor, 1997; Winnick, 2006). Scholars of professions like Abbott (1988) Freidson (1986) and Starr (1982) argue that structural arrangements and the power of formal knowledge assisted in the professionalization and eventual hegemonic control of orthodox medicine. Unorthodox medical competitors were marginalized, eliminated, or their practices were co-opted by orthodox medicine. Freidson argues that professional growth results from control over education and credentials, control of licensing and decision-making, and control over the market by excluding from the marketplace those without the formal knowledge. These advantages allowed the orthodox medical profession to achieve a medical monopoly with vast organizational power. Freidson asks, “Is professional power the special power of knowledge or merely the ordinary power of vested economic, political, and bureaucratic interest?” (p. 87).

As Winnick (2006) suggests, this marginalization of unorthodox medical practices and the hegemonic control of orthodox medicine makes the increase in CAM use all the more remarkable. It is apparent that what constitutes knowledge in medicine when distilled to practice is dialogical. While orthodox medicine maintains its monopoly over

medicine, citizens are less “mystified” by science and they are more sceptical of science, orthodox medicine, and, in the case of depression, the pharmaceutical industry. Although marginalized by the scientific community but embraced by the public, CAM challenges the way that evidence is framed and how medicine is practiced precisely because much CAM research relies on those methods that are aimed at how people use and interpret medicine—case studies, case series, surveys, qualitative data, and anecdotes.

Even within Western science, how you frame your inquiry, what you consider a worthy observation, and, once produced, how a fact is considered and framed change over time and differ between disciplines... Though studies in the sociology, history, and philosophy of science have shown repeatedly that science is, to a large degree, a cultural and social pursuit, too often in the CAM discussion science itself is rendered unproblematic. CAM opponents argue that CAM supporters are ‘antiscience’ or do not recognize the legitimacy of exploring CAM scientifically... The change in orthodox medicine’s approach to CAM is not due to new facts, but new values. (Wolpe, 2002)

However, it is through the processes of professionalization and accepting the scientific method as the “best” way to gain knowledge that makes the knowledge created through the practices of biomedicine authoritative. The following quotation taken from one of the newsgroups summarizes the tensions inherent in the conventional and CAM systems: “And what does allopathy require? It demands obedience. You must believe. You must pay with your obedience, your money, your body parts, and even your life. More like a religion. A religion based upon the lies of the great deceiver.”

3.7 Authoritative Knowledge, Cognitive Authority, and Credibility

The *Oxford English Dictionary* (2006 [*OED Online*]) defines authority in two ways: first, as the power to enforce obedience and, second, the power to influence action, opinion, or belief. These definitions highlight the relationship between authority and power—whether that power is wielded through force or perhaps more subtly, through influence. Applied to the concept of knowledge, authoritative knowledge is the knowledge that has power to influence and perhaps also the power to enforce obedience. Bridgette Jordan (1997) based her influential concept of authoritative knowledge on the central observation that for “any particular domain several knowledge systems exist, some because

they explain the state of the world better for the purposes at hand (efficacy) or because they are associated with a stronger power base (structural superiority), and usually both” (p. 56).

Authoritative knowledge is associated with power. The “correctness” or “truthfulness” of the knowledge claims being made is irrelevant because authoritative knowledge is the knowledge that “counts”; it is the knowledge that wields power and influence. While Jordan (1997) and others (Cheyney, 2008; Craven, 2005; Ellison, 2003; Fleuret, 2009; Geiger & Prothero, 2007; Hindley & Thomson, 2005; Kingfisher & Millard, 1998; Viisainen, 2000) focus on the anthropology of birth and what constitutes authoritative knowledge in pregnancy, childbirth, and parenting, an additional apt example of the close association between power and authoritative knowledge is the historical transformation of medicine in North America from pluralistic practices to biomedicine. Biomedicine is the knowledge that counts; it is the knowledge that has the power to influence (Bogdan-Lovis & Sousa, 2006; Joyce, 2005; Keefe, Lane, and Swarts, 2006). An additional aspect of authoritative knowledge is discussed by Jordan:

Authoritative knowledge is persuasive because it seems natural, reasonable, and consensually constructed. For the same reason it also carries the possibility of powerful sanctions, ranging from exclusions from the social group to physical coerciveness. Generally, however, people not only accept authoritative knowledge (which is thereby validated and reinforced) but also are actively and unselfconsciously engaged in its routine production and reproduction. (p. 57)

This quotation highlights the power of authoritative knowledge to enforce as well as to influence and its applicability to medical practice is evident. For example, some medical procedures are forced upon individuals by the courts even though these procedures violate religious beliefs. A more mundane example is the labelling of patients as “good” by medical personnel if they follow medical orders precisely or “bad” if they question medical practices and procedures or the authority of physicians or other medical personnel. Jordan goes on to define authoritative knowledge as:

the knowledge that participants agree counts in a particular situation, that *they* see as consequential, on the basis of which *they* make decisions and provide justifications for courses of action. It is the knowledge that within a community is considered legitimate, consequential, official, worthy of discussion, and appropriate

for justifying particular actions by people engaged in accomplishing the tasks at hand. (p. 58)

While Jordan's definition and concept of authoritative knowledge highlights the social aspect of authoritative knowledge, Patrick Wilson's (1983) concept of cognitive authority provides an additional complementary framework for investigating questions concerning the construction of authority. Wilson (1983) argues that all we know of the world beyond our own experience is what others tell us; it is all hearsay. Those individuals whom we count as providing reliable hearsay and whom we value for being authoritative, whom we trust as credible, and who have a valid basis for trying to influence our thinking, act as cognitive authorities. For Wilson, cognitive authority is related to trustworthiness and competence—not necessarily to expertise. One can be an expert in a field of knowledge but not have authority, or contrariwise have authority but no expertise. However, experts typically have training and certification that assists in establishing their credibility and authority. In social life we assume that friends, family, colleagues, etc., are cognitive authorities in the sphere of their own experience, but this assumption of authority of one's own experience does not necessarily mean that that individual will act as a cognitive authority for another individual. Additionally, cognitive authorities exist outside of an individual—one cannot be a cognitive authority for oneself. However, cognitive authority is not restricted only to individuals but extends to texts, institutions, organizations, and instructions (Rieh, 2005).

Cognitive authority is not static—an individual's conception of a cognitive authority can change. For example, patients can use personal experience to challenge medical authority, and the trend towards patient empowerment often blurs the distinction between lay knowledge and professional or expert forms of knowledge about illness (Banks & Prior, 2001). While experts typically have academic credentials and experience to support their authority, laypersons have to rely on other techniques to present themselves as authoritative. Oftentimes laypersons claim authority through personal experience, drawing on the expertise of authoritative sources, or by becoming "proto-professionals" themselves (Shaw, 2002). For example, Elizabeth, a study participant, explained that she trusted her doctor's expertise in prescribing medication (in this regard he acted as a cognitive authority) but that her own experience in managing depression was

valuable: “But Dr. [name] does a lot of testing, he participates in drug tests, and I really felt by that point in time that I had done most of the work that I needed to do to get healthier but he was the expert in medication.”

A final theoretical concept—credibility—is related to authority. Wilson (1983) states that:

Cognitive authority is clearly related to credibility. The authority’s influence on us is thought proper because he is thought credible, worthy of belief. The notion of credibility has two main components: competence and trustworthiness. A person is trustworthy if he is honest, careful in what he says, and disinclined to deceive. A person is competent in some area of observation or investigation if he is able to observe accurately or investigate successfully (p. 15).

Other definitions of credibility centre on ideas of believability, trustworthiness, and expertise (Fogg, 1999; Tseng & Fogg, 1999; Self, 1996). Researchers Tseng and Fogg (1999) identify four types of source credibility but the two types that are particularly relevant for this research are *reputed credibility* and *experienced credibility*. Reputed credibility “describes how much the perceiver believes someone or something because of what third parties have reported” (p. 40). Reputed credibility is concerned with source labels such as official titles (e.g., Doctor or Professor). Experienced credibility “refers to how much a person believes someone or something based on first-hand experience” (p. 40). Experienced credibility is the most complex and reliable method of making credibility judgments. In their article on factors influencing information credibility on the Web, Wathen and Burkell (2002) survey the literature and explore the concept of credibility. They found that credibility is a complex concept that is affected by the content of messages, the medium, the receiver of the message or information, and the source:

Research examining credibility...has repeatedly demonstrated that the individual or organization that is the source of the information has a great influence on the assessed credibility. Expertise, knowledge, and trustworthiness are qualities that mark credible sources of information. Users react directly to the qualities of the information source; they also utilize assumptions, reputation, and labels in their assessment of credibility. Matching the source to the audience is also important: different audiences trust different sources of information (p. 140).

Although cognitive authorities and credibility exist in relationships between two or more people, the concept of authoritative knowledge highlights the social aspects of knowledge construction. While cognitive authority and credibility has been applied in LIS by a number of researchers (Fritch & Cromwell, 2002; Rieh, 2002; Savolainen, 2007b), McKenzie (2003c) calls attention to the applicability of authoritative knowledge to LIS studies: “Jordan’s concept provides a particularly useful counterpoint to Wilson’s because it explicitly acknowledges the broader community’s role in determining what forms of knowledge (and, correspondingly, what information sources) should carry weight” (p. 264). The concept of authoritative knowledge highlights the social aspects of what kinds of knowledge are legitimate or influential in a community. Individuals produce and reproduce authoritative knowledge by drawing on those aspects of their identities and experiences that are consequential for the immediate situation, and in order to participate in the construction and discourses that count. This proposed research uses these three concepts—cognitive authority, credibility, and authoritative knowledge—to examine how people with depression justify CAM use or non-use, how people use these concepts to evaluate and assess information provided by others, and what information sources they draw from in order to justify their decisions and assessments.

CHAPTER 4

Data Sources and Collection

The researcher seeks not truth and morality, but rather, understanding

—Bogdan and Taylor

4.1 Methodology

Rather than establishing universal truths or facts, or emphasizing explanations of human behaviour (a positivist tradition), qualitative researchers aim to gain an empathetic understanding or interpretation of how some situated individuals experience the world and the meanings they associate with events, actions, structures, and claims. Qualitative research comes from an interpretivist tradition—a constructivist ontological position where individuals actively negotiate meaning (Broom, 2005). Bryman (2001) explains this position:

As ontology refers to the study of the nature of reality, a constructivist ontological view is that reality is in fact constructed rather than ‘set in stone’ or objectively measurable, and furthermore, that individuals construct their reality by associating ‘meaning’ with certain events and actions (p. 246).

With its focus on people’s lived experience, qualitative analysis is particularly well-suited to locate the meanings and interpretations people place on events, processes, actions, and structures of their lives. Qualitative research examines how people adapt, and, equally importantly, it contextualizes and connects these meanings to the social world (Rubin & Rubin, 1995; Miles & Huberman, 1994). The underlying goal of qualitative research is to understand people’s social worlds from their point of view.

Although CAM research is dominated by quantitative measurement of CAM-related practices such as prevalence of CAM use (Eisenberg et al., 1998) or the attitudes of physicians toward their patients’ use of CAM (Astin, 1998), Broom (2005) suggests that qualitative methods are particularly useful for studying CAM related research questions:

Qualitative methods...offer a potentially powerful means of uncovering the complex experiences of patients, carers, and clinicians within treatment and decision-making processes. In the complex case of complementary and alternative

medicine, qualitative...projects allow for subjectivity and complexity within human experience, making them a powerful tool for increasing our knowledge of important processes within CAM (p. 65).

A number of CAM researchers have used qualitative methods to answer their research questions (Adler, 2003; Kroesen, Baldwin, Brooks, & Bell, 2002; Verhoef, Casebeer, & Hilsden, 2002; Klein, Wilson, Sesselberg, Gray, Yussman, & West, 2005). Adler (2003) argues that qualitative methods are particularly suitable for examining the relationships between patients and healthcare professionals and for studying different CAM theories, modalities, practices, and beliefs (p. 108) while Verhoef, Casebeer, and Hilsden (2002) argue that adding qualitative research methods to the “golden standard” for evidence-based randomized control trials can greatly enhance understanding of CAM interventions. Verhoef notes that while RCTs provide important evidence about an intervention’s efficacy, they do not show why the intervention works (or does not), how people experience the intervention, or what meanings they give to their experience.

Similarly, LIS researchers began applying qualitative research methods found in other disciplines such as sociology and anthropology to LIS studies following Zweizig and Dervin’s (1977) call for librarians and LIS researchers to shift from a systems-centered approach to a user-centered one. In LIS the two different methodological approaches have been loosely characterized by a quantitative cognitive/positivist/systems-centred approach and by a qualitative constructionist/social/user-centred approach. While both quantitative and qualitative approaches have been used in LIS research, in recent years qualitative methods have become increasing more popular as many LIS researchers recognize how qualitative methods can answer important questions about information-seeking and information behaviour for example (Chatman, 1992; Given, 2002a, 2002b; McKenzie, 2001; Talja, 1999; Vakkari, 1999; Williamson, 1997). Savolainen (2005), whose mastery of life concept provides theoretical framing for this research, writes:

...qualitative methods...are most preferable since the analysis of the complex relationships between way of life, mastery of life, and information-seeking requires nuanced and context-sensitive empirical data (Savolainen in McKechnie et al., p. 147).

In order to understand how people with depression conceptualize depression, CAM, and mainstream medicine, how they assess and evaluate information provided by others, and how they use information to justify their treatment decisions qualitative methods must be used.

4.2 Research Questions

This research began with the following question: How do people with depression use information to explain or justify why they use, or do not use, CAM to treat their depression? From this initial question the following research questions emerged as I developed an interest in exploring how information and expert, lay, and experiential knowledge are used by individuals to justify, make claims, explain, and persuade. My research questions are:

- (1) How do people with depression conceptualize CAM therapies, mainstream medicine, and depression?
- (2) How do individuals use laypersons', experiential, and expert knowledge to assess and evaluate information provided by others about CAM treatments, and conversely, how do individuals construct authoritative positions justifying CAM use or non-use?
- (3) What information sources do users draw upon when assessing the information provided by others and when justifying their own positions?
- (4) What are the information practices of people with depression?

4.3 Data Sources and Data Collection Methods

In order to answer my four research questions, I used two sources to collect data: newsgroup threads and semi-structured interviews. The following sections outline the approach I used when collecting and analyzing my data. Specifically, I:

- collected and analyzed appropriate threads and messages from three online newsgroups;
- conducted semi-structured interviews which entailed transcribing, coding, and then analyzing the interview data with ten participants or until saturation was reached.

4.3.1 Pilot Study

I conducted a pilot study in which I analyzed the threads found on a depression support group. I examined the range of information behaviour found on the online newsgroup using Wilson's cognitive authority theory and Savolainen's ELIS (everyday life information-seeking) model. This study examined the information behaviour on the newsgroup as users considered, or incorporated, CAM to help regulate depression. The data came from the discussion threads and messages posted to the newsgroup and they were analyzed using discourse analytic techniques as outlined by Wetherell, Taylor, and Yates (2001). Specifically, I answered the following questions:

- (1) How is discussion about CAM therapies was discursively presented, framed, and responded to on the newsgroup;
- (2) How do individuals used experiential and expert knowledge to construct authoritative accounts justifying CAM use or non-use;
- (3) What information sources were called on in creating authoritative accounts?

I selected this particular newsgroup for my pilot study because it has been active and archived since 1995, making it the longest running and largest newsgroup on depression in terms of number of postings and number of members. It is not necessary to subscribe to the newsgroup in order to read the threads, users can post anonymously, and users occasionally e-mailed each other off-list which afforded them privacy if they chose.

I read and selectively analyzed various threads on the newsgroup that covered the years from January 1995–December 2005. The search strings I used in this pilot study were:

Table 1. Number of Records Retrieved for Search Strings

Search String	Number of Records Retrieved
<i>“Alternative and medicine”</i>	645
<i>“Alternative and treatment”</i>	615
<i>“Natural medicine”</i>	336
<i>“Alternative medicine”</i>	330
<i>“Complementary and medicine”</i>	13

I scanned all of the threads retrieved by my search strings to ensure that they met a number of criteria for inclusion in the study. First, I removed duplicate records and false drops from the study. Second, to be included in the study, the discussion thread had to include more than one posting. Third, spam (which was identified by the newsgroup users) was not included unless it provoked a relevant discussion among the newsgroup members. In total, I read and selectively analyzed 2,491 publicly available messages contained in 176 discussion threads.

A number of themes and findings emerged from the study. First, how newsgroup users constructed their depression affected their perceptions of the effectiveness of CAM and conventional medication. For example, those who constructed their depression as a chronic illness viewed allopathic medication as the most appropriate treatment and biomedical information sources as the most authoritative. Those who discussed their depression as a spiritual crisis considered both CAM and conventional medication to be effective treatments. How users introduced and framed CAM or allopathic treatment was based upon their conception of depression, which, in turn, influenced the information sources users drew upon when creating authoritative accounts. This finding is explored in greater depth in the current study. Second, expert and / or experiential knowledge was invoked by newsgroup posters as evidence to support claims. In the current study, I have expanded my analysis by examining the information sources and knowledge resources invoked by people, and by examining how people use discursive strategies and information to make and justify claims.

A final significant finding was the interesting two-fold properties of messages posted to the newsgroup in which the user directly asked for information. While asking for information from others, users would divulge their own stories, discuss the medication and treatments they were currently using to treat their depression, and provide disclosures of some kind. Information was presented via personal narratives, stories about others' experiences, or by posting newspaper articles, journal articles, or book titles or summaries. While information-seeking, these users were also sharing information. This hybrid activity supports the idea of treating depression as a life project or information project whereby information-seeking and sharing forms a part of the daily management of disease. In the current study, I expand upon this finding by analyzing newsgroup participants' and interviewees' information practices.

The main limitation in the pilot study was that the population of online users do not adequately represent all people living with depression. For example, in Canada women are treated one and a half times more often for depression than men are and they are diagnosed with depression four times as often as men (Health Canada, 2002), yet newsgroup postings, when gender was evident, had far more male authors than female authors. As a rough estimate, at least 60% of messages were written by men. Furthermore, the age range of users on this newsgroup was not representative of the general population. When age was stated or approximated (roughly 10% of messages), the eldest participant was 65 years old and the youngest was 17. Often depression occurs in the elderly—a group who are often overlooked and who may not use newsgroups as frequently as their younger counterparts. Also, depression typically first appears in late adolescence and young adulthood and younger people tend to use the Internet more often than older people do ergo, the number of younger users on the newsgroup may be overrepresented as having depression. These same limitations are applicable to the current study.

However, the study based on analyzing newsgroup postings offered the following advantages: I was able to learn more about what medication and CAM therapies people with depression might use; the postings and threads were archived since the group's inception; newsgroups grant immediate and ready access to people with depression and those who support them; the messages assisted in formulating pertinent research questions and provided additional avenues of inquiry for interviews. Most importantly, because the

newsgroup is a naturally-occurring data set, I can be confident that newsgroup users were not tailoring their posts to accommodate my reading of them for research.

4.3.2 Newsgroups

Arguably, Usenet has diminished in importance with the increased use of blogs, wikis, and portals; however, I selected newsgroups as my electronic data source for several reasons. Although there are a number of blogs and portals that deal with depression or complementary and alternative medicine, they do not generate enough traffic and discussion to adequately answer my research questions. Additionally, postings to blogs can be sporadic and the postings themselves often consist of small blurbs. While the same small-blurb style of writing can occur on a newsgroup as well, a newsgroup offers space to accommodate detailed arguments, opinions, and other types of writing. Also, the newsgroups selected for inclusion in this study have extensive archives dating back to at least the year 1996—no blog, wiki, or portal has been active for this length of time.

The postings are derived from personal participation in the support group—they are voluntary, spontaneous, and non-restrictive—and consequently, the postings are not affected by the presence of the researcher. Supplementing and complementing in-person interviews with data collected online provided a robust means to answer my research questions because I was able to take advantage of two different mediums—face-to-face communication and online interactions.

Two phases of data collection were undertaken for the current research project—analyzing newsgroup messages and conducting semi-structured interviews. For Phase I, I expanded on my pilot study to include analysis of pertinent threads from two more newsgroups in addition to the depression support newsgroup. I used the data from three newsgroups—a depression support newsgroup, a newsgroup devoted to discussing alternative health, and a biomedical newsgroup focused on discussing the practices of biomedicine. Each of these newsgroups covers an important aspect of this research project—depression, complementary and alternative medicine, and lay perspectives of biomedicine. The depression support group focuses specifically on “depression and mood disorders,” the alternative health group’s focus is on discussion about “alternative, complementary, and holistic health care,” and the biomedical group pages centres on

discussion about “medicine and its related products and regulations.” All three of these newsgroups can be found online and each group was selected based upon the large number of subscribers to the newsgroup, the longevity of the newsgroup, and the amount of activity on the newsgroup. I examined messages and threads from these three online newsgroups that were posted between the years 2002-2007.

While other search engine portals or gateways also offer access to Web groups, the newsgroups relevant to this research project (i.e., the groups where participants discuss depression, complementary and alternative medicine, and biomedicine) have far more activity than the other newsgroup hosting services. A preliminary search in the alternative health newsgroup using the search string “depression and treatment” retrieved 2,120 messages for example. Similarly, a search in the biomedical newsgroup retrieved 1,350 results using the search string “depression and treatment.” A search in the depression support group retrieves 2,310 messages using this search string. All three groups have been ranked as having high activity and a large number of subscribers—the biomedical group has 986 subscribers, the health group has 1,398 subscribers, and the depression support group has 2,265 subscribers. Throughout my findings and discussion, I have not identified what specific newsgroup the message being analyzed was derived from as the messages from each newsgroup were not sufficiently different from each other to influence my findings and warrant revealing this information.

4.3.3 Newsgroup data

The following table lists the search terms I used in the three newsgroups to retrieve relevant messages.

Table 2. Search Terms for Newsgroup Threads

Search Terms	Number of hits	Number of hits	Number of hits
	<i>depression group</i>	<i>alternative health</i>	<i>biomedical group</i>
alternative (and depression)	8,070	10,500	599
alternative and medicine (and depression)	550	3,780	324
complementary	182	238 (depression)*	59 (depression)
complementary and medicine	17	220 (depression)	32 (depression)
exercise	12,000	837 (depression)	303 (depression)
herb or herbal	1,230	730 (depression)	102 (depression)
holistic	447	319 (depression)	48 (depression)
homeopathy	190	4 (depression)	45 (depression)
meditation	2,620	204 (depression)	66 (depression)
nutrition	1,920	583 (depression)	274 (depression)
omega	1,520	378 (depression)	36 (depression)
supplements	1,210	1,120 (depression)	143 (depression)
Wort (St. John's) also "wart" due to common misspelling	5,630	694 (depression)	46 (depression)
vitamins	1,770	918 (depression)	158 (depression)
yoga	1,440	129 (depression)	40 (depression)

* In addition to searching for the singular terms listed, the search term "depression" was Boolean "and"ed in the two newsgroups that did not specifically focus on depression.

My search terms were deliberately biased toward high recall rather than precision. My goal was to retrieve as many hits as possible so that my searching would be comprehensive rather than precise; ergo, I used simple search terms. I used the same criteria for message inclusion as I did for my pilot study—I removed duplicate records, false drops, and spam (unless it provoked a relevant discussion) and the thread had to contain more than one message to be included. Ten thousand pages of newsgroup messages were whittled down to 1,941 relevant pages.

Table 3 outlines the number of relevant messages and threads retrieved from the newsgroups. In total 7,984 messages from three newsgroups in 394 threads were analyzed.

Table 3. Number of Relevant Messages and Threads from Newsgroups

depression group

<u>Number of threads</u>	<u>Number of messages</u>
2002—14	2002—94
2003—9	2003—134
2004—9	2004—159
2005—80	2005—1,328
2006—70	2006—999
Total: 182	Total: 2,714

alternative health group

<u>Number of threads</u>	<u>Number of messages</u>
2002—27	2002—484
2003—33	2003—561
2004—34	2004—714
2005—29	2005—943
2006—54	2006—1,320
Total: 177	Total: 4,022

biomedical group

<u>Number of threads</u>	<u>Number of messages</u>
2002—3	2002—264
2003—3	2003—47
2004—11	2004—147
2005—11	2005—557
2006—7	2006—233
Total: 35	Total: 1,248
Total (all): 394	Total: 7,984

4.3.4 Interviewing

I conducted ten in-depth interviews with individuals who were currently suffering from depression or who had experienced depression in the past. These semi-structured interviews provided opportunities for follow up and probing (Bates, 2004; Johnson, 2002; Lofland, 1971). The interviews ranged from 40 to 90 minutes. Six out of the ten interviews took place in the interviewee's home. Four of the interviews were conducted at restaurants chosen by the participants. All of the interviews took place face-to-face and were recorded.

Because qualitative research is inductive, a number of themes and questions used to guide my interviews were developed using the results from the newsgroup study. Additional questions were incorporated into the interview schedule based on my first interviews. (Please see Appendix A for a list of interview questions). I used a process of recording, transcribing, and open coding as recommended by Glaser and Strauss (1970) to code my interviews. I used the qualitative software Ethnograph 5.0 to analyze my newsgroup and interview data.

On a practical level, I began each interview by introducing myself, providing a written summary of the project (while giving the respondent enough time to read it) and ensuring that the participant fully understood the project prior to conducting the interview. I followed certain suggestions from Fielding (1993) about guided conversation—a method which emphasizes probing and the facilitation of conversation rather than using a more restrictive question and answer type interview. Fielding suggests that the aim of probing is to allow a participant to talk about an event or their story without directing them to any particular conclusions. The interview questions were designed according to the principles advocated by Berg (2009): they were open-ended, clear, and couched in the language levels and preferences of participants.

The process of data analysis went hand in hand with data collection. Broom (2005) suggests that analyzing data as the research progresses shapes the ongoing data collection and produces high quality data. By analyzing the data as I conducted the interviews I was able to refine my research questions, pursue emerging themes, and generate more in-depth queries for other interviews. For example, after my second interview I realized that asking participants how they deal with stress was an important question that I had omitted from

my initial interview schedule. Researchers suggest that when data collection and analysis begin at the same time and proceed concurrently the likelihood of missing significant themes is greatly reduced (Broom, 2005; Bryman & Teevan, 2005; Glaser, 1992; Lincoln & Guba, 1985; Miles & Huberman, 1994).

I read through both the interview transcripts and the newsgroup threads several times, noting ideas and emergent themes. I used open coding as described by Ezzy (2002), and Strauss and Corbin (2008). I ensured that atypical cases and conflicts with the data were noted. Following this initial analysis, I re-read the interviews looking for themes. Labelled by some as “axial coding” (Ezzy, 2002; Strauss & Corbin, 2008) this is the process of moving beyond reading and writing notes to sorting one’s observations. Within this process, once a theme was identified, I searched through the interviews for other related comments, employing “constant comparison” (Glaser & Strauss, 1970) to further develop or complicate these themes. From here, I continued to refine and develop my themes while paying attention to the nuances in the data such as the atypical cases (e.g., the sole poster who questioned the scientific method as the gold standard for creating knowledge or generating evidence). Themes were developed that specifically answered my research questions about participants’ conceptualizations of depression, CAM, and biomedicine. Additional themes were uncovered through coding related to information practices such as the act of prescribing. Developing themes and using constant comparison allowed me to organize my data and to then analyze pertinent messages and threads using discourse analysis.

4.4 Participants, Recruitment, and Gaining Access

To participate in this research, interviewees needed only to self-identify as depressed (although a clinical diagnosis of depression at some point in the participants’ lives was the ideal standard). Because mental illnesses such as depression are so complex in terms of definition and treatments, placing the requirement of a clinical diagnosis on possible participants might have created an unnecessary barrier. For example, a clinical diagnosis of depression might have been an access barrier to participants who treat their depression using only CAM therapies. Additionally, many people who suffer from depression do not get the help they require for a variety of reasons: they might not ever

receive a correct diagnosis, they might not seek help at all, or they might be in the process of being correctly diagnosed. On the other hand, despite being on the medication Paxil (an antidepressant) and being diagnosed as depressed, a potential interviewee declined to participate because she believed that she did not suffer from depression. She believed she suffered from anxiety—a disorder that she differentiated from depression. Consequently, the most important criterion in recruiting participants was their self-identification as having suffered from depression at some point during their adult lives.

Gaining access to the newsgroup threads was a straightforward process. I was familiar with online newsgroups and support groups and I was able to search group archives, gather data about numbers of subscribers, find FAQs for each group, and read examples of messages and threads. I signed up for an account and was granted access to all of the publicly available newsgroup threads.

Ten adult participants (18 and over) who self-identify as currently suffering from depression (or bipolar disorder) or who have suffered from depression (or bipolar disorder) in the past were recruited for semi-structured, in-depth interviews. Participants were recruited in two provinces in Canada via word-of-mouth or by responding to a research poster. The age of interviewees ranged from 24-78. Seven females and three males were interviewed. (Please see Appendix B for a sample recruitment letter and Appendix C for a sample recruitment poster). The following chart provides some demographic data about the participants.

Table 4. Interview Participant Data

Pseudonym	Age	Occupation
Anne	50-55	homemaker
Daniel	30-35	unemployed
Dylan	75-80	retired/former professor
Emma	50-55	teacher
Elizabeth	35-40	librarian
Gwen	20-25	graduate student
Holly	25-30	graduate student

Oscar	75-80	retired/former professor
Sabina	35-40	media worker
Teresa	35-40	researcher

Of the ten participants, four had abused or were currently abusing either alcohol or drugs. At the time of our interview Daniel had recently been released from rehab and was attending Narcotics Anonymous meetings, Dylan was a dry alcoholic, Sabina abused both alcohol and drugs in the past, and Teresa described herself as an alcoholic during our interview. Two additional participants were the adult children of one or more alcoholic parents. For one of these participants both her parents were alcoholics. I was surprised by the high number of people who suffered from both depressive episodes or chronic depression and substance abuse. Out of ten arbitrarily selected individuals, four struggled with drug and alcohol addiction and abuse and two others were directly affected by someone else's alcohol addiction which means that 60% of my interview sample was affected by drinking or drugs. While several posters to the newsgroups also mentioned a link between depression and drug and alcohol abuse, interviewing allowed me to probe this link more deeply—often treating addictions (or seeking help if interviewees were affected by someone else's addiction) provided the impetus for information or help-seeking, it affected the individual's perception of what was considered helpful information, his or her conception of treatment, how she or he defined depression, and five out of these six interviewees had attended support groups or therapy sessions (Drake, 2003).

4.5 Ethics

As the primary researcher I am ethically obligated to conduct this study in such a manner that causes no harm to the participants. I followed the guidelines for conducting research provided by Social Sciences and Humanities Research Council and the University of Western Ontario Research Ethics Board. To ensure that participation in this research involved minimal risk I: (1) provided interview participants with details outlining the study; (2) obtained informed consent prior to conducting an interview; (3) maintained confidentiality by assigning numbers to all participants' interview transcripts and using pseudonyms where necessary; and (4) informed interview participants about any possible

benefits to participation as well as any possible disadvantages. Interview participants could withdraw from the study at any time, for any reason.

Research indicates that individuals coping with mental illness (including, but not limited to, those with depression) are much better off now than a few decades ago in terms of being treated as autonomous, competent individuals. However, a number of ethical concerns continue to present themselves when studying this population. Are people with mental illness an especially vulnerable population? Are they more susceptible to exploitation? Does their illness impair their ability to give informed consent? Does discussion about personal, possibly emotional stories, experiences, and opinions asked by qualitative research questions pose any threat or harm? These are a few examples of the ethical questions I grappled with while carrying out this research program. Throughout history, persons with mental illness have been viewed as incompetent. They have been the subject of public fear and prejudice, and Eastman and Starling (2006) argue that even our labelling of mental disorders is worthy of an ethical critique—are mental disorders medical conditions, societal labels, or immature responses to life's circumstances?

The very nature of qualitative research raises a number of additional ethical concerns. For example, the use of extensive quotations in publications may identify a participant, greater engagement with participants may lead to conflicts of interest, and most importantly, ethical standards must not only be maintained, but perhaps continually revised over an extended period of time as the research and corresponding analysis progresses (Haverkamp, 2005). For example, I realized that naming the newsgroup hosting service or the newsgroups where I gathered my data would be unfair to the people who participate on the newsgroup (even though the messages are publicly available) because identifying the speaker by using the direct quotations I have analyzed would be easier. Consequently, the names of the hosting service and newsgroups have been removed. Awareness of these kinds of concerns ensured that ethical standards were maintained throughout this research project.

To address these ethical concerns I provided enough information about the study that the perceived benefits and disadvantages of participation were clear to potential participants. In turn, they could use this information to make an autonomous and voluntary decision to participate in the study or not. I also recruited participants who

tended to have viable support systems in place. I did not recruit participants who were hospitalized or institutionalized at the time of the interview. Furthermore, eight out of ten participants were not suffering from a depressive episode at the time of the interview (although seven of the ten interviewees were taking antidepressants at the time of the interview), a factor that minimized stresses associated with participation. I compiled a list of contacts for local mental health organizations and support groups in case it was needed and I ensured that all participants knew that they could drop out of the study at any time, and for any reason.

However, the intention of users writing on a newsgroup, despite the messages and threads being posted to a public forum, are to contribute to an online community; they are not intended to serve as research data. Consequently, there are ethical issues to consider when using data taken from newsgroups. On UseNet itself there are several options that newsgroup users can exercise in order to maintain confidentiality and anonymity. Newsgroup users have the option of posting to the group anonymously or using a pseudonym. Additionally, when posting a message, users can select an option that will delete their message from the newsgroup archives after it has been posted for one week. These selected messages are not archived nor are they publicly available after one week. Finally, newsgroup users are occasionally encouraged by participants to send private e-mails to each other instead of posting publicly. I have also taken two additional steps to ensure confidentiality. First, in any dissemination of my research findings (publications or conference presentations) all material taken from the newsgroups has remained anonymous. Second, for any publications or public presentations I have not, and I will not, specifically name the newsgroup hosting service or the names of the newsgroups. In addition, the messages derived from each newsgroup were not significantly different from each other to warrant identifying the newsgroup the message was taken from. I believe that all of the above options available to users on UseNet itself combined with the additional steps that I have taken to protect the anonymity of newsgroup users make this research ethically sound.

4.6 Data Analysis

4.6.1 *Discourse analysis*

A recent turn in social science research methods is toward discourse analysis—a research method that examines how language is oriented toward action and function and the construction of social reality. People use language to do things like order and request, persuade, and accuse (Elliott, 1996; Potter & Wetherell, 2001; Taylor, 2001). People’s use of language varies according to its function or purpose; people use language to construct accounts or versions of the social world.

At its most basic, the study of discourse and persons investigates how people tell stories about themselves and how they present themselves in talk. We can look at how people put together an account, the discursive practices and routines they use and the consequences of choosing one way of talking about oneself over another (Wetherell, Taylor, & Yates, 2001, p. 186).

Of the three domains of discourse analysis discussed by Wetherell, Taylor, and Yates (2001), the second domain is of particular interest for this proposed research—the study of minds, selves, and sense-making, and the construction of psychological order. Researchers using discourse analytic techniques have demonstrated how people construct identities either by their being co-constructed by selves and others or constructed through the process of story-telling, life history, or other everyday conversations.

Potter’s (1996) use of discourse analysis serves a similar function—to uncover how individuals use discourse to construct credible accounts. Discourse analysis is a research method that allows researchers to analyze how descriptions become established as solid, real, and independent of the speaker. The type of discourse analysis advocated by scholars such as Potter and Wetherell allows a researcher to focus on everyday discourse and the purpose of analysis is to understand the way that descriptions are made factual and to understand what those descriptions are used to do (social action). Rather than assess the veracity of accounts or descriptions, researchers move from studying language use as describing some objective “truth” about reality or the individual’s internal state to analyzing how people use language to construct authoritative descriptions and accomplish specific actions. This method is especially appropriate for researchers studying how

people construct accounts about controversial issues such as paranormal experiences (Wooffitt, 1992) or any other issue outside of the mainstream such as CAM use.

In her article on analyzing qualitative interviews using discourse analysis, Talja (1999) suggests that “discourse analysis studies practices of producing knowledge and meanings in concrete contexts and institutions” (p. 461). Talja argues that using discourse analysis for analyzing qualitative interviews allows a researcher to understand what discourses participants access and how they use different discourses to present various positions that have meaning for them. Using different discourses or subject positions allows individuals the flexibility to take on different identities. “The starting point of discourse analysis is that meanings, values, and ethical principles are not individual creations, but entities that people create together in communication and social action. This view of language, mind, meaning and self-hood is *dialogic*, emphasizing that we are not ‘self-contained’ selves...” (p. 470).

In recent years interest in a constructionist approach to LIS research has increased with a number of researchers either using discourse analysis as a research method or exploring its applicability to LIS (Budd & Raber, 1996; Frohmann, 1994; McKenzie, 2001, 2002, 2003a, 2003b; Talja et al., 2005; Tuominen, Talja, & Savolainen, 2002). Constructionists see knowledge as dialogically constructed through discourse and some LIS researchers take a constructionist view of information. Tuominen and Savolainen (1997), for example, view information as constructed through discourse and they view information as consisting of two almost inseparably linked phases—construction of information and using constructed information in action. McKenzie (2003b) suggests that Tuominen’s and Savolainen’s approach allows a researcher to

...develop a greater understanding of the role of information in people’s everyday lives by studying information use as discursive action: the ways that discursive constructions of previously sought or received information are put to use in talk or writing, for example, to make or justify claims (p. 267).

For this proposed research, discourse analysis, and particularly the psychological order of minds, selves, and sense-making is pertinent to exploring how individuals construct their depression and how they discursively justify CAM use or non-use to treat or

manage their depression. Researchers have shown how the relationship between depression, creativity, personality, and self-identity (including the organization and reorganization of the self as an individual moves through depression) is socially constructed (Dowrick, 2004; Hermans, 2003; Kramer, 2005; Manners, 2006). Additionally, ideas about diagnosis, treatment, or management of depression are also socially constructed, making discourse analysis a useful analytical tool. Similarly, discourse analysis allows a researcher to uncover how individuals construct authoritative accounts justifying CAM use or non-use. As Potter (1996) outlines, this kind of discourse analysis does not focus on the accuracy or veracity of claims but rather on how cases are discursively constructed to appear authoritative. The last stage of my analysis is to examine information use as discursive action following a similar approach as McKenzie (2001, 2002) to answer the question: How do individuals apply discursive constructions of previously received information to justify or make claims?

I analyzed the selected threads of three newsgroups and my interview transcripts using discourse analytic techniques, specifically focusing on the discourse domain of minds, selves, sense-making, and psychological order.

4.7 Trustworthiness

Researchers have argued that applying the concepts of reliability and validity to qualitative research is inappropriate (Bryman & Teevan, 2005; Lincoln & Guba, 1985). In lieu of reliability and validity, Lincoln and Guba proposed the concept of *trustworthiness* as a criterion to gauge the “goodness” of a qualitative study. The concept of trustworthiness includes four criteria: credibility, transferability, dependability, and confirmability. This research meets these criteria in the following ways:

Credibility was achieved by using triangulation. I used different data sources—interviews and newsgroup messages and I used different data collection methods: interviews and document analysis. During my analysis it became apparent that my two data sources were particularly strong for answering different research questions. For example, interviewing people who have been living with depression allowed me to probe questions regarding how they conceptualized depression, CAM, and biomedicine in ways I was unable to do on the newsgroups. On the other hand, the online newsgroup messages

and threads provide robust data for answering questions regarding how people justified their arguments and made claims.

Transferability—because qualitative research typically entails an in-depth, intensive study of a small group or individuals, researchers are encouraged to produce thick description, that is, rich accounts and details that are not typically generalizable but that might be applicable to other contexts. Thick descriptions of the newsgroups messages and the structure and content of the newsgroups themselves establish transferability. Also, I have endeavoured to produce thick descriptions in my interview data.

I have kept records of each stage of the research process. Potter (1996) argues that the nature of discourse analysis itself provides trustworthiness because the reader can read the data and decide for him or herself how well the data have been analyzed. “If we have a transcribed record of discourse, rather than a set of formulations in note form, it places the reader of the research in a much stronger position to evaluate the claims and interpretations” (p. 105-106). Developing inter-coder reliability tests would not have been useful or realistic for this research project.

Finally, Haverkamp (2005) discusses “trustworthiness” in qualitative research; using the concept to describe the relationship between the researcher and participants. She writes:

If we accept that the qualitative research enterprise is fundamentally relational, we must consider how we, as researchers, assume a fiduciary role in reference to our research participants. A fiduciary relationship is one of trust, in which one party with greater power or influence accepts responsibility to act in the other’s interest (p. 151).

This is a guiding principle I followed while carrying out this research project—I have attempted to act in the interest of any participants that volunteered for this research and for posters to the newsgroups. In addition to disseminating the research findings to the academic community, I have offered to share my research findings with any or all participants who are interested.

4.8 Reciprocity and Rapport

While I did not formally offer any compensation (other than active listening) for participating in this study I did purchase various thank-you gifts such as sending a thank-you card with a small box of chocolates or in one case I purchased two packages of cigarettes for an interviewee. Four of my interviewees chose to be interviewed in a public restaurant. In these four instances I paid the bill each time. My purchases consisted of one lunch, one dinner, and twice I paid for coffee and dessert. I have offered to share my research findings with my interview participants but thus far no one has accepted my offer. I did not post the same offer on any of the newsgroups.

I did not have to consult any mental health organizations or other health professionals or act as an advocate for any of my interviewees. Five of the ten interviewees were curious about what subject area I was doing this research for and each of them were surprised that this research project related to library science. Two interviews were particularly emotional—at various points both I and the interviewee were crying but we were in the comfort of the participant's own home and neither situation was an alarming one. One of the emotional interviewees told me after the interview that “it was good to cry. It was like therapy.”

CHAPTER 5

Depression as an Information Project: Discursive Constructions of Depression and Individuals as Information-seekers

Response: Anyway, there certainly *is* something wrong with being a nutcase, or whatever more dignified term you'd prefer. We're not, after all, here to celebrate depression, or bipolarity, or whatever else we have to deal with, in spite of the occasional blather about how much more insightful and sensitive the mentally ill are and how shallow and one-dimensional the 'normies'... are. Mental illness sucks. Depression sucks. Being a fucking nutcase sucks.

Newsgroup posting

(All newsgroup postings are reproduced in the original including spelling, grammar, and punctuation).

5.1 Introduction and Overview

Conceptualizations about depression and the subsequent use of CAM and / or biomedical healthcare services to treat it are formed through culture, definitions, and experience. The above quotation alludes to some of the culturally circulated understandings of depression. At one extreme, people with depression are perceived as having heightened "insight and sensitivity" and, at the other extreme, they are labelled pejoratively as "nutcases." Our cultural messages about depression range from celebrating the "mad" genius of Virginia Woolf to admonishing those with depression to "snap out of it." Our cultural messages, definitions, and experiences of depression are variable because depression is a highly individualized disorder. Cultural and social factors such as age, ethnicity, gender, socioeconomic status, and sexual orientation, as well as an individual's definition of what depression is, all influence how an individual experiences depression and how he or she decides to treat his or her disorder.

Individuals conceptualize and experience both depression and healthcare services in different ways and therefore they subsequently make different treatment and healthcare decisions (Brown, Dunbar-Jacob, Palenchar, Kelleher, Bruehlman, & Sereika, 2001). How individuals conceptualize depression and various healthcare options inform information practices in terms of what information the individual perceives as valid and credible;

conceptualizations determine what kind of knowledge (i.e., lay, expert, or experiential) individuals draw from in order to present themselves as authoritative; and conceptions influence what information sources individuals invoke to justify or undermine claims. An individual's conceptions about, or definition of, depression is the point from which all other treatment activity stems. Conceptualizations about depression affect treatment decisions, an individual's receptivity to CAM, and his or her use of medication and / or other biomedical services.

Not only is there great variation in conceptualizations about depression, these conceptualizations often change over time (Brown et al., 2001). Therefore, people with depression often have to be aware of new and potentially controversial treatments. To act manage or treat depression, people living with depression are required to continuously seek information—a process Wikgren (2001) dubs an “information project.” An information project is a concept associated with Savolainen's (1995) “mastery of life” within the ELIS model. While Wikgren's conception of an information project focuses solely on information-seeking, throughout this work I have expanded this idea to include information practices such as information-seeking, encountering, sharing, and use. Newsgroup participants and interviewees continually experimented with various treatments offered by both orthodox and / or complementary practitioners; they continually negotiated and navigated their way through a tremendous amount of information on topics that ranged from coping and stress relief to discussing the advantages and disadvantages of practices such as electroconvulsive therapy; and they continually considered and / or incorporated new information about management and treatment into their healthcare regimens. To further their information projects and to justify their claims, newsgroup posters and interviewees would often portray themselves as competent information-seekers, evaluators, and users.

In this chapter I present the findings that answer my first research question: How do people with depression conceptualize depression, and how do these conceptualizations inform the construction of depression as an information project and the construction of individuals as information-seekers? I begin the chapter by delineating my analysis of the various conceptualizations people had regarding depression, biomedicine, and CAM and I discuss how these ideas relate to authoritative knowledge. I then highlight and explore a

single important aspect of depression as an information-seeking context—how people act as prosumers (both producers and consumers of content) in support groups and self-help groups. Following this brief discussion, I introduce the discursive strategies people employed to justify or undermine claims, and, finally, I show how people discursively constructed themselves as competent information-seekers and users.

5.2 Conceptualizing Depression

As discussed previously in Chapter 2, depression is difficult to define despite the fairly uniform diagnostic criteria laid out in the DSM-IV, the World Health Organization's international classification of disease (ICD-10), and by Canadian mental health organizations and professionals. Defining depression is problematic because depression manifests itself in a myriad of forms, depression develops under many different conditions and situations, and often a diagnosis of depression is given because of the manifestations of symptoms, and not necessarily because an individual suffers from a condition called “depression” (unlike individuals diagnosed with high blood pressure or cancer, for example).

Because depression is highly ambiguous in terms of its aetiology, manifestation of symptoms, and diagnosis, people often struggle with defining and categorizing depression or determining the “root cause” or causes of their depression. While posting on the newsgroups and during interviews, individuals discussed a variety of definitions of depression that ranged from the biomedical to the spiritual. These definitions reflect the arguments and debates about diagnosing depression raised in Chapter 2—for some depression was considered a biological illness, for others depression was a condition brought on by life circumstances or traumas or a combination of biological and social factors such as an individual's lifestyle, poverty, or addiction, and, for many, depression was both a medical concept as well as a personal problem. Consequently, information needs, seeking, sharing, and use were highly variable among newsgroup participants and interviewees.

5.3 Biomedical Constructions of Depression

Many newsgroup participants and interviewees experience depression, or some aspect of depression, medically. That is, these people with depression experience depression as a medical problem whereby they interact with doctors, nurses, psychiatrists, or other healthcare practitioners or seek medication or other orthodox therapies. Even for those who did not interact with the biomedical system, depression was often conceptualized using concepts, ideas, and the language of biomedicine, and by drawing upon expert, biomedical information. Some persons with depression experience depression only as a medical problem: To treat depression one takes prescribed medication, visits a psychiatrist or engages in some psychological counselling, and follows advice prescribed by medical professionals. According to this view, depression is a disorder like many other medical conditions—treating or managing depression requires medication, attention, and action.

5.3.1 *Biomedical definitions of depression*

Response: If brain chemistry can make you hear voices, experience manias followed by crashing lows, then why can't they be responsible for persistent depression 'for no reason' - which is just one of many functions controlled by the chemical soup that regulates our brain.

Newsgroup posting

Medically sanctioned ideas about the symptoms and definitions of depression were considered by some newsgroup participants and interviewees as the most authoritative. Individuals turned to expert definitions and categorizations to define the kind of depression they suffered from and to determine if they, or others, suffered from depression at all. A number of information sources based upon, or associated with, a biomedical approach were accepted by individuals as authoritative including: completing depression tests or inventories (created by health professionals) that indicated an individual might be suffering from depression; manifestation of depressive symptoms that map onto symptoms described in popular medical literature; defining depression as a “brain chemistry” or a biological disorder (using the language and terms of biomedicine); and a diagnosis from a medical

professional. The act of labelling and treating depression as an illness by the medical establishment was a reassuring indication for some individuals that they did indeed suffer from depression. Three newsgroup posters indicated that they were depressed simply because their doctor prescribed an antidepressant. For these individuals professional or expert epidemiological definitions of depression and biomedical information sources were the most legitimate. In the process of formulating discursive conceptualizations about depression most newsgroup posters and interviewees drew upon evaluated, biomedical information sources and the authoritative knowledge of conventional medicine.

Biomedical definitions of depression coalesce around the manifestation of symptoms as described, for example, in the DSM-IV and other trustworthy sources. This understanding of depression was reflected in newsgroup messages and interview transcripts. A message posted to a newsgroup read:

Response: If a person satisfies the DSM criteria for depression, I'd say there's a 99.5% chance that the person has the same disease as those people who are diagnosed with 'depression.' Part of the diagnostic criteria is that the symptoms are not better accounted for by a general medical illness, or by another psychiatric illness.

Newsgroup posting

When asked the questions: "What is depression? Could you (briefly) describe yours?" a newsgroup poster responded with the following excerpt from Wikipedia:

Response: Clinical depression is a condition that meets specific criteria.
 From: <http://en.wikipedia.org/wiki/Clinical>
 According to the DSM-IV-TR criteria for diagnosing a major depressive disorder <http://www.behavenet.com/capsules/disorders/mjrdepd.htm> (see also: DSM cautionary statement) one or both of the following two required elements need to be present: Depressed mood, or Loss of interest or pleasure. It is sufficient to have either of these symptoms in conjunction with four of a list of other symptoms, these include:

- Feelings of overwhelming sadness or fear, or seeming inability to feel emotion.
- Marked decrease of interest in pleasurable activities.
- Changing appetite and marked weight gain or weight loss.
- Disturbed sleep patterns, either insomnia or sleeping more than normal.
- Changes in activity levels, restless or moving significantly slower than normal.
- Fatigue, both mental and physical.

- Feelings of guilt, helplessness, anxiety, and/or fear.
- Lowered self-esteem.
- Decreased ability to concentrate or make decisions.
- Thinking about death or suicide.

For me, there isn't much more to describe than that.

Newsgroup posting

Additionally, many people described their depression as a biochemical problem that needed to be managed. Elizabeth stated, "I think of it [depression] as something that is just chemical but manifests physically and emotionally and is also something which needs to be medically treated but also needs a certain amount of action by the person who's suffering it." Another interviewee, Emma, concurred: "Well, it's [depression] something that has to be managed. Like I still have it. It's something that has to be managed and lots of times now when I think about it I think well, I need to take ten milligrams more of this or ten milligrams less of this because mine seems to be for the most part chemically reacting to things... ."

Biomedical definitions of depression can fulfill an extremely important function for people living with depression because they can form the basis for diagnosis and treatment. A diagnosis often assists in making sense of the chaos of mental illness by conferring a number of benefits for persons with depression such as explaining the genesis or causes of depression as defined by the medical model (i.e., biology, chemistry, co-morbidity, etc.); it can assuage concerns about what kind of depression a person suffers from (bi-polar disorder, dysthymia, clinical depression, or seasonal affective disorder); it can help those with depression to distinguish between states of "normal" and "ill"; it labels and categorizes depression as a legitimate illness that requires attention; it can validate an individual's experience of depression; a diagnosis can set parameters around the experience of depression in terms of what symptoms may be present as well as providing an illness trajectory; and a diagnosis is a pre-requisite for accessing publicly funded medical and healthcare services (in Canada, the United Kingdom, and Australia). A diagnosis was viewed by some as an essential starting point for treatment.

A diagnosis introduces people with depression to scientifically vetted treatment options via medical professionals who have training in dealing with mental illness, and

this, in turn, typically assists with decision-making and developing coping strategies. As one newsgroup poster advised: “For a start, GPs [general practitioners] are in the best possible position to make, or get, a reliable diagnosis - your symptoms might be (partly or wholly) down to something that isn’t ‘Depression.’” This poster alludes to another important reason why people seek medical attention for depression—to rule out other possible causes of depression. For example, depression can be a symptom resulting from a different problem such as low blood sugar or effects from other medication. A professional diagnosis often provides a sense of security, comfort, or control which can normalize the experience of depression. Most importantly, a diagnosis was a means by which individuals could draw upon the authoritative knowledge of biomedicine to justify to others and to themselves that they have a disorder that requires medical attention. Whether this authoritative knowledge is “correct” does not matter (e.g., the individual may suffer from depression due to poverty or life circumstances rather than from a biochemical problem); it is the knowledge that counts in depression treatment (Browner & Press, 1996).

5.3.2 *Medication and depression*

Many newsgroup members and interviewees accepted as authoritative the recommended biomedical treatment of taking antidepressants because they believed that depression cannot be treated or managed without prescribed antidepressants despite their many drawbacks. A common discursive strategy used to justify taking medication was to liken depression to diabetes or to taking antibiotics for an infection. One simply needs to take allopathic medication to regulate one’s disorder.

Response: I admit I do not understand this at all. Why do so many depressives approach the treatment of mental illness as being different from physical illness? I suffer from bipolar disorder and because my illness is managed but not cured I will have to take medication for the rest of my life... I would be no more inclined to stop my meds thinking I must be better than I would stop taking insulin to see if my diabetes was better if I were diabetic. It seems to centre around the concept that physical illness is acceptable while mental illness is a personal flaw and we are somehow responsible and inadequate for not being able to make ourselves well.

Newsgroup posting

For those who perceived their depression as a chemical imbalance or as a chronic condition, for example, antidepressants were necessary for treatment or regulation of depression and these individuals tended to adhere to treatments offered via mainstream medicine and they tended to consider these treatments authoritative. “It’s [depression is] brain chemistry, it either works or it doesn’t, if it doesn’t then it’s the wrong drug” (newsgroup poster). Antidepressants were preferred over other conventional treatments such as therapy, particularly when depression was understood as a chemical problem, “Behavioral strategies will not fix neurochemical problems. Medical treatment may make all the difference in the world, and open up a much better world for you” (newsgroup poster).

Even when medication was not perceived as a complete treatment solution, some users justified using antidepressants because they “allow you to level out so that you can take on more and more responsibilities” (newsgroup posting). For some, taking medication was not considered a panacea, but rather the purpose of using medication was to give individuals enough equilibrium so that they could resume or assume day-to-day activities and responsibilities. This is an important reason why people justified taking their medication; it served as a coping strategy.

However, studies show that many patients experience adverse side effects such as loss of libido, weight gain, and deeper depression from allopathic medication. Moreover, antidepressants can be addictive (Vlaminck, Vliet, & Zitman, 2005), people with depression can become immune to their medication which causes them to continually experiment, not all medications treat all kinds of depression, and people often stop and start their medication which reduces its efficacy. Sometimes medication exacerbated depression. For some it did take, or it might take, years before an effective combination of medication was found. Antidepressant use could be problematic for a variety of reasons: apprehension about a pill controlling mood, concerns over supporting the pharmaceutical industry and the perceived collusion between doctors, researchers, and big pharma, concerns over ingesting “chemicals” or what are deemed “unnatural” substances. Some believed that their depression was not a chemical problem and that it did not require medication. For many newsgroup participants and interviewees the decision to use, or not use, antidepressants was ongoing and required continual monitoring, seeking and use of

information in addition to negotiating authoritative knowledge. An example of negotiating these tensions is outlined below:

Original post: I got my doctor to change my prescription to Wellbutrin...I wonder if I really even need it. I never have felt the need for an antidepressant, sure I have had some down times but I've been able to deal with them. My question is how do I know if I need this medication or not. I do notice one difference. When my principal acts like a fool, I don't get as upset as I once did. Is this part of the cure. If it is, I will stay on the medicine. Here's how I feel. Although I don't get as annoyed over things, I am not feeling the same intense feelings I once felt while looking at the colorful changing leaves of autumn, and the orange glowing Halloween lights...i don't want to be numb to life.

Newsgroup posting

5.3.3 *The biomedical system*

Users had much to say about the biomedical system (including supporting industries such as the pharmaceutical industry), the efficacy of treatments for depression that are derived from the knowledge produced by the biomedical system, and the professional knowledge of people who populate the biomedical system and serve the public—doctors, psychologists, psychiatrists, and other professional therapists. For good or for ill, doctors were the health professional people interacted with most often to treat depression. In order to receive a diagnosis, access medication, or obtain a referral to other healthcare professionals such as therapists, psychiatrists, or pharmacists, people had to consult doctors. Doctors served as the primary source for treatment but they also acted as gate-keepers to other medical services. They were the most important professional for treating depression and people relied on them for their expertise particularly when it came to their knowledge of medication. I will be discussing the value of doctors and other healthcare professionals as information sources in following chapters.

There was much discussion about the healthcare system and related industries. Freidson (1986) points out that medicine has pursued a systematic connection with science and technology and newsgroup participants and interviewees were keenly aware of these connections. Where nationality was stated, most newsgroup posters were from the United States. Other newsgroup posters identified themselves as Canadian, British, and

Australian. The differences between the publicly funded healthcare systems found in Canada, Britain, and Australia compared to the healthcare system in the United States were often distinct—for example, several American newsgroup posters wrote about trying to get treatment from a doctor but they did not have insurance and they were unable to pay for antidepressants or medical treatment or they had inadequate healthcare insurance that provided intermittent coverage. However, there were underlying commonalities and shared ideas among other newsgroup posters who identified themselves as Canadian, American, British, and Australian newsgroup posters in terms of skepticism about the role of the pharmaceutical industry in treating depression, the role of government organizations such as the Food and Drug Administration (FDA), and the role of medical research. Users were aware of the various actors, professionals, organizations, and the different disciplines that typically comprise the West's complex medical system and the knowledge derived from that system.

The capitalist system that supports the outrageously profitable pharmaceutical industry was critiqued by people who had strong opinions and beliefs about the biomedical system and the knowledge derived from this system. Users were wary of the profits made by pharmaceutical companies. “The fact of the matter is the pharmaceutical companies do not want people using safe natural remedies because there is no profit in it for them. Instead they will have their minions of psychiatric pushers push off expensive poison pharmaceuticals” (newsgroup posting).

Others argued that despite flaws in the system, the FDA, the pharmaceutical industry, medical researchers, and conventional practitioners greatly improved the quality of life and, in some cases, saved lives of people with depression. The biomedical system was typically understood as a valid, authoritative medical system despite the many drawbacks or bad experiences emanating from interactions with healthcare providers, the often uninviting physical infrastructure of medical facilities, and the profit and / or political motives of the medical profession and supporting industries. Gaining access to, and using, the conventional system was a priority even if people were dissatisfied with certain aspects of the system. For most newsgroup participants and interviewees the knowledge derived from the biomedical system was authoritative as were biomedical information sources.

Conceptualizing depression by drawing upon biomedical definitions of depression was a double-edged sword. On the one hand, by drawing on the authoritative knowledge of biomedicine, newsgroup posters and interviewees were able to attend to, and treat, their depressive symptoms in ways that allowed them to make their health a priority by, for example, taking antidepressants, dropping or negotiating obligations, or taking time off from work. Conversely, by invoking biomedical definitions and conceptualizations of depression, some newsgroup posters and interviewees are actively engaged in reproducing the authoritative knowledge of biomedicine and thereby contributing to the further consolidation of biomedical explanations of depression at the expense and marginalization of other explanations such as life circumstances, spiritual malaise, or environmental factors (Geiger & Prothero, 2007). It is these other conceptions of depression I discuss in the following sections.

5.4 CAM Constructions of Depression

Biomedical definitions of depression were useful (even if they were challenged) and they often provided the starting point for thinking about depression and treatment options. However, biomedical definitions did not account for an individual's context and many persons with depression defined their depression according to their personal life circumstances and belief systems thereby individually negotiating the authoritative knowledge of biomedicine. Consequently, many posters and interviewees used both conventional and alternative practices to treat or manage their depression. Even for those who defined depression in biomedical terms and treated the disorder with medication and / or therapy, CAM therapies were not entirely excluded. Many individuals used an array of CAM therapies (that they described as CAM or the CAM activities were outside the domain of prescribing medication, making referrals to other biomedical practitioners, or performing surgery. Section 2.10 outlines the operationalization of CAM in this study) including reiki, acupuncture, exercising, taking supplements such as vitamin B, journaling, following special diets, reading as "therapy," doing yoga and / or meditation, or following spiritual practices, etc., in addition to taking allopathic medication (i.e., antidepressants). Those who described their depression in non-medical terms (e.g., a spiritual crisis) were more likely to use CAM therapies to treat their depression and they were more likely to

invoke other ways of knowing (e.g., experiential knowledge) and a diverse array of information sources to justify their claims.

Much of what can be considered CAM can also be considered self-care. Rogers (2000) has defined self-care as “consumers taking responsibility for their health” (p. 544). If conceptualized in this way it is not difficult to understand why CAM is so popular—people engage in everyday activities like exercising, eating well, relaxing, and taking supplements to maintain health or to aid in treating certain ailments. Interviewees and newsgroup participants cited playing music, singing, writing, and creating art as therapeutic and healing activities that assisted with coping. Interviewees and newsgroup participants often described these activities as treatments that helped with self-care and as treatments they engaged in, in addition to what their healthcare practitioner advised. CAM therapies often provide a wider range of treatment options than orthodox medicine and many CAM practices include additional physical, psychological, and spiritual strategies for coping with depression.

A component to self-care and a common discourse invoked to justify using CAM can be described as “try it and see if it works.” The rationale provided by some people for using CAM is that there is nothing lost by trying a CAM therapy; if it works, great and if it does not, it was worth a try:

Original post: [name] i am between jobs and made some cutbacks on foods and nutrition supplements. i used to take multivitamin + meds + B complex + fish oil. i'm not sure if fish oil helps me or not (it can't hurt!). my ideal diet would have less carbs and more fish.

Newsgroup posting

The “it’s worth a try” discourse was often linked to another discourse about CAM—that “it’s harmless” or “it can’t hurt” as seen in the example above. However, some CAM therapies can negatively interact with allopathic medications. Despite this, the prevailing perception among many newsgroup users and interviewees was that CAM was harmless and / or worth a try.

In addition, perceptions about the efficacy of prescribed medication (i.e., antidepressants) were contested. Many people with depression posting on the newsgroups

and five out of ten interviewees did not want to take prescribed medication (even if they were currently taking it) and occasionally they would experiment with discontinuing allopathic medication altogether and try complementary or alternative treatments. These individuals would draw on “drug-free,” “natural,” or “harmless” discourses in an attempt to justify their conceptualizations of CAM as a superior alternative to medication and to challenge the authoritative knowledge of biomedicine.

Often newsgroup posters who experimented with quitting their prescribed antidepressants described CAM therapies such as St. John’s Wort as “natural” and the implication was that they were superior to synthetic allopathic medications. This supports other findings of why people choose CAM—they perceive them as more natural, they do not have as many adverse side effects, and they are more compatible with the patients’ worldviews (Astin, 1998):

Original post: I have been taking prozac for a few years for anxiety and depression, while it has been a good drug, I feel like I want to try to get off it and see if a full recovery is possible. Has anyone been able to successfully slowly stop taking their meds in favor of more natural remedies (ex. st. johns wort, nutrition, exercise)?

However, “natural” and “drug-free” discourses about CAM were often contested by invoking biomedical information sources. In the following message the poster hints at the lack of scientific evidence, and the prevalence of pseudo-science, used to support claims about the efficacy of CAM remedies.

Response: Anyway, it’s just the “natural” thing as a marketing ploy, coupled with the lack of any credible scientific evidence that it actually works, coupled with a lot of scientific theory that I call “the science of silkyence” (a shampoo company used to sell shampoo with the idea that it worked because their company knows a lot about the science of getting your hair silky looking).

Newsgroup posting

For many newsgroup users, deciding whether or not to take medication or to use CAM is reflective of how they personally construct the disorder of depression and what meaning, if any, they find in their depression. In turn, these constructions of depression

are often related to how authoritative the individual perceives the underlying knowledge systems and associated information sources of biomedicine and CAM.

5.4.1 Beyond biomedicine: Other definitions of depression

Professionals emphasize diagnostic categories (like depression) based upon a symptom approach to presenting problems. By contrast, patients themselves understand their problems within a unique biographical context situated in time and place (Pilgrim & Rogers, 1999, p. 36-37).

For some newsgroup participants depression was defined as cause and effect (depression was caused by a certain circumstance or circumstances and depression was the effect of these circumstances): anxiety, sadness, and worry, weeks on end feeling blue, a normal reaction to life circumstances, an incessant, emotional weight, a way for the mind to protect itself, out of control emotions, or a spiritual issue. These definitions and descriptions are highly individualized as they are based on the individual's context and situation. Consequently, biomedical information sources that were not congruent with, or supportive of, these definitions were occasionally challenged.

Some people living with depression contested medical diagnoses and, rather than framing their depression using medical concepts, they framed their definitions of depression in terms of life challenges or in terms of the kind of person they wanted to be or they challenged medical concepts of depression for no particular reason.

Original post: I have a lot of the symptoms of depression—weight gain, tendency to sleep a lot (but not much at night), inability to do anything I don't absolutely have to... But maybe I'm not depressed. Maybe I'm just a lazy, bitter, pig. Maybe having a diagnosis of depression is just an excuse to not be the person I'd like to be, not to have to do anything.

Original post: Hello everyone, I have always felt myself to be 'somewhat depressed' or 'mildly depressed' or perhaps 'not a very happy person.' But even with a diagnosis of depression from a psychologist, I find myself resisting the idea that I'm actually depressed. I'm not sure why.

Newsgroup postings

Despite having a medical diagnosis of depression, these individuals question the applicability of biomedical knowledge in defining depression in a way that is meaningful to them. The above posters continue to grapple with what depression is, what it means in terms of self-perception, and they continue to deal with the effects depression has on their lives. For some, depression is a crisis of meaning as they navigate and negotiate a world that is not of their own making and biomedical information sources, and biomedical authoritative knowledge, do not adequately address these issues.

Interviewees provided a wide range of descriptions to describe their depression. Daniel, an interviewee who also struggled with drug and alcohol addiction, likened his depression to an addiction: “Yeah, you never know like it’s [depression] always there, it’s just like an addiction really. It can show up at any time, unexpected. You know it bothers me. It follows you around everywhere. Sometimes it’s inactive, sometimes it’s not; don’t know from day to day.” Gwen described her depression as “a demon. The idea of being possessed; the idea of not having control over your thoughts, over your life.” For Oscar depression was:

Oscar: Lack of, or let’s say not enough joy in my life. Gloominess, annoyance with the world... There’s another little interesting tidbit on my depression and that is I get along fabulously with people who do not think the world is alright. I don’t like people who say, ‘Oh, hello there and we’re having so much fun’ it just drives me bonkers... I don’t get along with pollyannas. I like people to have some kind of sense that this is not the best of all possible worlds.

Andrew Solomon (2001) argues that human consciousness is comprised of three parts: the psychological, the biological, and the theological (belief systems) and that depression can affect any, or all, of these three parts. Consequently, it is not surprising that, for some, depression was defined as a spiritual issue.

Response: This [depression] feels like more of a ‘spiritual’ issue. Although I’ve always believed that the ‘spirit’ was simply a function of the brain, at this point I’m willing to try anything. My mom is a devout Catholic, she wants me to talk to a priest, and go to a ‘healing mass.’ I’m as anti-religion as they come, but I may be willing to do it.

Newsgroup posting

Solomon goes on to state: "...religious belief is one of the primary ways that people accommodate depression... It cannot usually pull people out of depression... It can, however, defend against the complaint, and it can help people survive depressive episodes" (130). For this particular poster defining and treating depression as a spiritual issue presented a range of additional treatment options and broadened his conception of what information might be considered authoritative. For many newsgroup posters and interviewees, biomedical explanations of depression were not comprehensive in their scope which led many to seek additional information about various ways to treat and to think about depression as they negotiated authoritative knowledge.

5.4.2 *The CAM system*

Charges levied at the perceived weaknesses of the conventional medical system were also applied to CAM practitioners and systems. Naturopaths and other CAM practitioners also work for profit, and it is quite common to find pharmaceutical companies in the supplement marketplace. People experience adverse reactions and side effects from CAM therapies and in some cases these side effects were quite serious or interfered with conventional medication. In addition, some pointed out disadvantages that were endogenous to CAM. For example, the following poster argues that the conventional system gave individuals greater recourse for action than the unregulated CAM system:

Response: Is anyone legally obligated to report adverse reactions to taking Dr. [name]'s advice?? That could possibly be why there are so few reported adverse reactions... Along with a slight difference in the number of people taking the respective treatments. But Dr. [name] says there aren't any adverse reactions because it's "natural." Know what. Water is natural too. But I can think of some adverse reactions to water - like drowning. Everything is dose dependent.

Newsgroup posting

Many individuals questioned the value and safety of CAM therapies that have not been clinically tested.

For some, CAM was understood as counterknowledge—"propositions that fail basic empirical tests. The essence of counterknowledge is that it purports to be knowledge

but is not knowledge. Its claims can be shown to be untrue, either because there are facts that contradict them or because there is no evidence to support them” (Thompson, 2008, p. 2). One poster wrote: “alternative medicine for alternative depression” implying that depression cannot be treated using CAM therapies because there is no scientific evidence that CAM can treat “real” depression. Conversely, others on the newsgroups are purveyors of CAM counterknowledge and they often see themselves as keepers of special knowledge that only they themselves and a select few others have and they often see themselves as independent thinkers who are skeptical (occasionally to the point of believing conspiracy theories) of authority figures such as doctors and authoritative organizations like the FDA.

For a variety of reasons many people are alienated from the biomedical system and CAM was viewed as offering some legitimate therapies to assist in treating, managing, and coping with depression. Among CAM users the most prevalent conceptions of CAM practices were that they were less invasive and less expensive than biomedical treatment, CAM treatments were readily available without a prescription, and some CAM therapies were designed to treat not only the biological aspects of depression but also the spiritual and psychological. CAM users often drew on “natural,” “harmless,” and “give it a try” discourses to justify their CAM use. When some newsgroup participants and interviewees used CAM therapies, they would draw upon different sources of authoritative knowledge (sometimes including biomedical sources). What information sources were deemed credible and what knowledge was considered authoritative (biomedical and / or other ways of knowing) to both interviewees and newsgroup participants, depended upon how an individual conceptualized his or her depression. How individuals discursively undermined or justified biomedical knowledge or other ways of knowing is the subject of the next two chapters. In the following sections I examine the “prosumption” aspect of support groups and self-help and I examine how individuals constructed themselves as competent information users and seekers.

5.5 Information-seeking Context—Self-help, Support Groups, and Prosumption

While treating, managing, conceptualizing, or finding out about depression all provide context for information-seeking, presently, I focus on one specific aspect of depression as an information-seeking context: prosumption. The format and structure of

the newsgroups influenced the information-seeking, sharing, and use that occurred online by providing the opportunity for newsgroup participants to act as “prosumers” Toffler (1980). “We invented the word prosumer for those of us who create goods, services or experiences for our own use or satisfaction, rather than for sale or exchange” (Toffler, & Toffler, 2006, p. 153). The very existence of online support groups is predicated on individuals simultaneously producing and consuming services outside the confines of a monetary economy. Borkman (1990) notes that prosumption expands the possibilities of, and exploration of, non-traditional roles in self-help and support groups. “In being both consumer/provider, a different role relationship emerges from that of the professional/client role relationship. The mutual aid self-help role is nonhierarchical since both parties are peers facing the same problem receiving from/giving to the other” (p. 3).

Additionally, four out of ten interviewees had experience with Alcoholics Anonymous or Al-Anon—face-to-face support groups that share the same nonhierarchical relationships found on the newsgroups (i.e., high socioeconomic status or other traditional measures of status do not necessarily confer authority). A fifth interviewee participated in group therapy. In total, five out of ten interviewees participated in some kind of 12-step program or group therapy where they acted as prosumers—simultaneously producing and consuming therapy and support.

The format of the newsgroups and self-help groups encourage information-seeking, use, sharing, and exchange. People often participate in these forums to glean information and to receive support but they also exchange information as a service for others and for personal satisfaction (Burrows, Nettleton, Pleace, Loader, & Muncer, 2000; Hardey, 2001; van Uden-Kraan, Drossaert, Taal, Shaw, Seydel, & van de Laar, 2008). Newsgroups and face-to-face support groups work because their structure is based on prosumption and because their structure is nonhierarchical. In a nonhierarchical environment, however, the quality, veracity, and accuracy of the information, advice, and opinions shared varies and consequently, establishing credibility and authority and assessing and evaluating information are ongoing, complicated concerns. In addition, the simultaneous act of producing and consuming information or help required many newsgroup members and interviewees to portray themselves as competent information-seekers and users in order to build up their accounts and justify their decisions.

5.6 Discourse Analysis and Information

I have examined the discursive strategies people use to build up factual accounts and descriptions using the analytic tools developed by Edwards and Potter (1992); Potter (1996); Potter and Wetherell (1987); Wooffitt (1992); and Wetherell, Taylor, and Yates (2001). In 1997, Tuominen and Savolainen suggested that studying the discursive use of information would be fruitful for LIS researchers. This approach has been utilized most prominently by McKenzie (2001, 2002, 2003, 2004, 2009, 2010) in her studies of the information practices of pregnant women and by Johannisson and Sundin (2007) in their study of the information practices of professional nurses. The application of discourse analytic techniques in LIS research can provide an apt prism by which researchers can study concepts such as credibility, cognitive authority, sense-making, information sharing, and information use.

In his seminal work *Representing Reality* (1996) Potter examines how individuals use a variety of discursive strategies in order to present an account as factual. He argues that in almost every situation from police reports, to courtroom proceedings, to mundane arguments between couples about whose turn it is to do the dishes, humans construct accounts that appeal to the facts, to describe what really happened, and to establish authority. Potter outlines the characteristics of factual discourse: it is finely organized, subtle, and powerful; there are standard procedures that are drawn upon when working up a factual description; individual skill at creating factual accounts varies from those who do it well to those who do it poorly; people produce descriptions because of what such descriptions can do in some activity whether it is a conversation, a report, entertainment, or a posting on a newsgroup; and factual accounts can be undermined using the same standard discursive procedures used to build an account.

Potter writes:

... how are descriptions produced so they will be treated as factual? That is, how are they made to appear solid, neutral, independent of the speaker, and to be merely mirroring some aspect of the world? How can a factual description be undermined? And what makes a description difficult to undermine? Second, how are these factual descriptions put together in ways that allow them to perform particular actions? (p. 1).

Potter's discussion of descriptions focus on two important points: descriptions are selective; they relate to both what is described and what is left out; and they are built-up for what they can accomplish during a course of action.

Potter suggests that factual accounts have a double orientation—an *action orientation* and an *epistemological orientation*.

On the one hand, a description will be orientated to action. That is, it will be used to accomplish an action, and it can be analysed to see how it is constructed so as to accomplish that action. On the other, a description will build its own status as a factual version. For the most part, the concern is to produce descriptions which will be treated as mere descriptions, reports which tell it how it is. It is important to emphasize that the perspective developed here treats the epistemological orientation of accounts as *itself* a form of action; it is something built by speakers or writers—although it does not assume that this building is necessarily, even often, conscious or strategic... (p. 108).

Potter describes the distinction between action and epistemological orientation of descriptions as “more heuristic than actual” as the two are often entwined in practice.

Potter identifies a number of discursive strategies or techniques people use to create factual accounts. The following strategies were evident as newsgroup participants and interviewees constructed their conceptualizations of depression, when they made claims or undermined others' claims, and when they were assessing or evaluating information sources:

- Interests and category entitlements—people would manage stake and interest, category entitlement, and footing.
- Constructing out-there-ness—people would draw on empiricist discourse, consensus and corroboration, and detail and narrative strategies.
- Working up representations—people would draw on the techniques of extrematization and minimization and normalization and abnormalization.

In the remainder of this chapter, I examine how individuals use certain discursive strategies in order to construct themselves as competent information-seekers and users.

5.6.1 *Construction of individuals as competent information-seekers*

To strengthen their claims, credibility, and authority interviewees and newsgroup posters typically portrayed themselves as active and effective information-seekers. Posters to the newsgroups, in particular, had to depict themselves as competent information-seekers and capable information evaluators because other posters could challenge their claims and the validity of the evidentiary sources they used as the basis of their claims. Furthermore, posters could be accused of having a stake or vested interest in what they claim and / or they could be perceived by others as not being entitled to the category of knowledge they based their claims upon. Potter (1996) defines category entitlement as "... the idea that certain categories of people, in certain contexts, are treated as knowledgeable. ...category entitlement obviates the need to ask how the person knows; instead, simply being a member of some category...is treated as sufficient to account for, and warrant, their knowledge of a specific domain" (p. 133). Category entitlement must be built-up, however, and the following posts exemplify how some people would use information to work up their entitlement to speak about depression treatment while simultaneously constructing themselves as competent information-seekers.

Original post: ... I've done alot of research on what's called Omega-3's. You may have heard of them... They're promising in the field of depression treatment...

Original post: ... Finally, about 5 months ago I went on an all out internet search. I looked for everything: meds, supplements, electro cranial massage. I wanted SOMETHING to help... Anyway, I start reading about fish oil, and figure what the hell...

Original post: ... All during this time, I was continually in one-on-one therapy and group therapy, and I read countless self-help books...

Newsgroup postings

In the above examples, statements such as "I've done a lot of research," "I went on an all out internet search. I looked for everything," "I start reading about fish oil," "I read countless self-help books" all serve to strengthen the poster's self-characterization as a competent information seeker and user who can be trusted to present the "facts" derived

from his or her reading and understanding of information. The first poster goes a step further by implying that he is familiar with the biomedical research literature on depression when he states, “They’re promising in the field of depression treatment.” By drawing on their expertise in finding, understanding, and using information, posters would build their category entitlement thereby warranting their claims and supporting their recommended treatments for depression.

However, there were occasionally challenges to a poster’s status as a competent and trustworthy information seeker as some questioned the quality of the information posted (such as examples of counterknowledge) or the poster had a reputation for being incompetent or unbiased. One newsgroup poster in particular was a poor fact constructor and debater and she was also perceived as biased. Consequently, most of her posts were vociferously challenged or dismissed as in the following brief message:

Response: The information is vital, but it is not news. [name] posted it because she hates conventional medicine, even to the point of accepting the lies of the Cult of Scientology.

Newsgroup posting

Because the poster being responded to was perceived as being radically anti-biomedicine and hence impartial, her status as a competent information user was undermined. The “information” that the original poster posted to the newsgroup was an article published by Reuters. The article was titled: *Warning-Antidepressant Patients Need Watching* and the reporter explored the link between taking antidepressants and the increased risk of suicide. Interestingly, even though the information this poster was sharing was credible and trustworthy, the messenger herself was not considered credible or trustworthy or entitled to act as a cognitive authority.

Similarly, the following messages were posted in response to an original message questioning the abilities and value of medical professionals. Other newsgroup posters challenged the original poster’s status as a competent information user based upon her claim that doctors are “quacks.”

Original post: ...in fact they [doctors] are quacks and charlatans themselves as is obvious from their total lack of the most vital knowledge and skill of their profession.

Response 1: Bullshit. Self diagnoses are usually wrong. Even the doctor will not attempt a diagnosis in many cases without laboratory tests and imaging studies ... But even when self diagnosis is correct, it is usually not likely that the patient will know more than the doctor about treatment options, even after hours of internet research.

Doctors don't know everything, but you don't know shit.

Response 2: a) how on earth would you even know the first F'IN thing about the "most vital knowledge" of a profession, of which you are not a part? I'll just go ahead and answer my own rhetoric - YOU WOULDN'T.

b) Knowledge is not ever completely obvious. Therefore a statement like that doesn't even deserve the term "specious", because it's SO absurd, it's not even slightly seductive, even to the most moronic of readers...

c) The obvious truth is simple: Some doctors are good, some are mediocre, some are bad, and there are probably many layers on a continuum in between these extremes...

Response 3: Doctors are useful for a diagnosis. But if a person has looked into their health for a long time, and thought about it and tried different things, they eventually begin to see what can make them healthy. Most people have been dumbed down to a considerable degree, by the mass media and the education system, and they think that the official health system is the best because it is scientifically proven.

However, if you look into the words "scientifically proven" you will usually find that it means manipulation and half truths, all in the cause of propping up the business with disease (pharmaceutical cartel), who are in business to make money - simple as that. They claim they are concerned with people's health, but they have to say that otherwise everybody would be onto them.

Newsgroup postings

Respondents one and two vigorously challenge both the original poster's category entitlement to make the claim that doctors are "quacks" and the original poster's claims

undermining the authoritative knowledge of conventional medicine. While the third poster acknowledges the value of doctors, he suggests that those with experiential knowledge have some expertise in knowing what treatments work for them. The third poster argues that most people are ill-equipped to think about, and make good decisions about, their health due to a poor educational system, mass media, and a medical system based on for-profit research and not because people are inherently poor information users. The third poster suggests that most people who have been proactive about taking care of their health and who have acquired experiential knowledge are capable information users and consequently capable of negotiating biomedical knowledge.

Interviewees also portrayed themselves as knowledgeable information-seekers and evaluators, as exemplified by Anne in the passage below:

Tami: Well, it sounds also that you've done a lot of reading about depression

Anne: Yeah, magazines. Very seldom will I read a book. When [name] was here we did have the Internet. I read a lot... for a person who doesn't read books I am a knowledge seeker. I'm a magazine junkie. If there's an article that catches my interest I'll read it but to sit down and read a whole book, no. But different articles and things like that I will read.

Tami: And so have you generally found that most of this information has been helpful to you?

Anne: Yeah, because I think maybe I'm intelligent enough to sort out what is garbage and what isn't, you know. There is no little magic pill. And then other things you think may be feasible but you'd have to look into it and then other things which you know would totally work for you. It's just like de-stressing yourself by taking a walk or having a bath. I mean I've had more baths in the last six months than I've probably had in the last ten years because I found out it can relax me.

Tami: So how do you decide what information is helpful to you. Like if you read a personal story does that give it [the information] more credence or credibility?

Anne: I think so if it comes from somebody credible that you know has written to help or you know to either heal or help yeah, it does. And personal stories, one-to-one personal stories you know friends, family, acquaintances talking I take that with a lot more weight than I would just somebody on the TV doing an infomercial about something.

Anne's information-seeking and evaluating skills and her experiential knowledge of depression enable her to characterize herself as a "knowledge seeker," a competent information user, and as someone who is able to discern what information is credible.

In the excerpt below Dylan drew on his lived experience and expert sources when explaining what kind of information was useful to him:

Tami: Do you trust your own knowledge and experience more than what experts or friends and family might suggest?

Dylan: I would say that you can look at that two ways. I trust my own knowledge in knowing what's going to work with me because I think I know myself [both laugh] pretty well at this point. And having been through all this. I know maybe what's going to be best for me. For example, I know I don't want to go into Tai Chi because I know I wouldn't like it. But I would have to give equal to both because I do trust what counselors tell me too. But I think if a counselor told me to do something I thought maybe wasn't going to work with me I'd question it.

Tami: Right.

Dylan: But I rely a lot on talking with other people. Yes. Particularly people who have been through the same thing. And lots of people in AA have depression and anxiety problems. I would say almost half of them because the whole thing gets tied together.

Like Anne, Dylan perceived himself as a competent information user and evaluator who could judge the value of information, whether the source was from a lay or expert perspective. To build authoritative accounts or to justify CAM use or non-use newsgroup posters and interviewees often demonstrated that they understood the information they acquired, that they were capable searchers, and that they could critically evaluate and assess the information that was shared, referred to, challenged, or encountered.

Information and / or personal experience was used to build up a poster's or an interviewee's category entitlement justifying why he or she chose certain treatments over others and information and / or personal experience was also used to challenge, build up, or negotiate biomedical authoritative knowledge or to build up and / or challenge other knowledge.

5.7 Conclusion

Many newsgroup posters and interviewees' conceptualizations of depression were shaped by illness narratives—a core explanation of the individual aetiology of depression. Kangas (2001) writes: “The importance of illness narratives lies in the fact that they are a vehicle for reflection and expression in a process where the individual searches for explanations and constructs understanding of the illness experience in relation to self and others” (p. 76). For some newsgroup posters and interviewees these conceptualizations or narratives were centered upon biomedical understandings of depression. For others, CAM understandings of depression were preferred, particularly when newsgroup members or interviewees contextualized depression in terms of their life journey or inherent personality traits. CAM conceptions of depression offered a broader context for understanding and treating depression than biomedicine. However, most posters and interviewees used both CAM and biomedical treatments to treat or manage their depression as exemplified by the following post:

Response: Depression is best treated by multiple means. Drugs and therapy are only two of six known means, the other four are: diet, exercise, meditation and social activity...

Newsgroup posting

Depression is unusual in that depression caused by, or exacerbated by, unfortunate life or socioeconomic circumstances, for example, cannot be treated by any medical system. In addition, treatments that were repeatedly recommended as an effective means of managing depression such as developing self-discipline and routines, “trying” to change mental and behavioural patterns, and changing habits cannot be claimed as treatments developed by any one medical system.

However, the underlying knowledge system of biomedicine was the most authoritative for all interviewees and the vast majority of newsgroup posters. Only one individual questioned the validity of the scientific method: “I hate life, but I don't believe in ‘depression’. That's a long conversation--I don't subscribe to the medical model of things as being ‘the truth,’ etc. However, the point is that things were much, much easier

when I took drugs...and I have chosen to not. I am determined to not take meds again” (newsgroup posting).

The conceptualizations and meanings of depression underpin the information practices of newsgroup participants and interviewees. The findings presented in this chapter show how treating and managing depression often forms an information project or life management project. Treating depression often requires individuals to continuously experiment with different CAM and / or biomedical treatments. This, in turn, often requires individuals to evaluate and navigate their way through a tremendous amount of information, to interact with a wide variety of information sources (including people), and to negotiate biomedical authoritative knowledge.

In order to lend their claims greater authority, newsgroup posters and interviewees would use discursive devices to portray themselves as capable information-seekers and users. Many drew upon their experiential knowledge of depression (category entitlement) and they referred to “research,” “reading,” “searching the Internet,” “scientific literature,” and other information-seeking / encountering activities to discursively construct themselves as competent information evaluators and users.

How people seek, share, and use information when dealing with depression (or someone they know who is depressed) is the subject of the next two chapters. More specifically, I examine how people use different discursive strategies and draw upon different kinds of knowledge, i.e., laypersons’, experiential, and expert knowledge to assess and evaluate information given by others, to justify their own positions, to assess the credibility of the information shared, and to counter or negotiate biomedical authoritative knowledge or to build up other ways of knowing.

CHAPTER 6

Information Practices and the Discursive Construction of Information Sources

Subject: My wife might be depressed

Hello, I thought I'd gather some information from a variety of sources prior to taking any kind of action, I realize that Usenet isn't the best source but maybe I'll get some more ideas.

Newsgroup posting

6.1 Overview

In this chapter I examine how interviewees and newsgroup participants discursively construct information sources as helpful or not helpful by analyzing how people work up or undermine accounts. I also analyse the information practices of information-seeking (both for oneself and on behalf of others) and information encountering of newsgroup participants and interviewees. I examine the barriers they encountered when seeking information and how information-seekers and respondents negotiate questions. First, I discuss the differences between practical and orienting information in order to situate my analysis.

6.2 Practical and Orienting Information

Interviewees and newsgroup subscribers sought both practical and orienting information (Savolainen, 2008). One of the most important functions of a newsgroup is to provide a forum for information-seeking and sharing (Burrows, Nettleton, Pleace, et al., 2000; van Uden-Kraan et al., 2008; Wikgren, 2001). Some claimed that the information shared on the newsgroups was more detailed and varied (even if that information was incorrect) than the information given by professionals during face-to-face visits. For newsgroup users, information-seeking and sharing involved sharing experiences and asking others for problem-solving information (practical information) about CAM, biomedical treatments, depression, and coping (Wikgren, 2001). Orienting information such as online news articles, biomedical information, and book recommendations were often acquired on the newsgroups as well. Similarly, many interviewees sought and shared practical information via face-to-face therapy or support groups, and interactions with

family members, friends, and healthcare professionals (Harris & Dewdney, 1994).

Interviewees also used a variety of orienting information sources.

Savolainen (2008) defines practical information as problem-solving information. When posting to the newsgroups, some speakers provided background context in their messages depicting their experiences with depression, symptoms, or treatments tried. Posted messages would often describe a problem or relay a direct question actively soliciting advice, help, or stories (which were considered a form of help by both interviewees and newsgroup participants). The following messages demonstrate how sharing information and providing background context assist in posing a question in a manner that guides the kind of information the poster wants to obtain from respondents—in these examples, problem-solving information:

Original post: I have been living with depression for about 8 years and recently started using...(Prozac). Unfortunately, even after 8 months it is still ineffective, so I have been trying some alternative remedies (with no success yet). They are:

1. Saint John's Wort (3,000 milligrams a day)
2. Gingko Biloba (100 milligrams a day)
3. 5-HTP (50 milligrams a day)

Does anyone know of any other alternative antidepressants?

Original post: I've been trying some alternative medicine for bi-polar and have gone off my meds to find out if it has worked. 2 months without Lithium or Prozac ... I feel Ok except for a couple of hours of apprehension now and again but no mania or depression that I recognise... Has anyone else gone this route? And how long do I need to be off my meds to know if I'm cured. Anyone have any thoughts?

Original post: Does anyone here have a clue? I have changed my diet, increased my exercise. I tried some natural therapy but unfortunately they interacted with my anti-d's. I am *never* well... I just don't think I can take much more of this shit.

Newsgroup postings

Seventy-five newsgroup threads began with a message similar to the ones above: the poster described his or her situational context; the poster simultaneously seeks and shares

information; and, importantly, the poster poses the question in a way that subtly guides respondents to the kind of information that he or she wants to obtain. In this way, people sought and shared information that was problem-solving and that often came from a certain perspective.

The act of soliciting advice, stories, and others' opinions and experiences with depression shows that there is a certain amount of trust and credibility given to other newsgroup members' experiences. Indeed, many newsgroup users treated the information gleaned from the newsgroups as credible because it was taken for granted or assumed that individuals responding to questions participated on the newsgroup because they had experienced depression or supported someone who suffered from depression. This process is much like the credentializing that AA and Al Anon participants perform at the beginning of meetings which warrants subsequent stories or information as coming from a source with first-hand experience.

Savolainen (2008) describes orienting information as the information sought to monitor daily concerns. "The practice of seeking orienting information may be exemplified by daily media habits such as reading the newspaper before leaving for work, listening to the radio news while driving home... The monitoring of everyday-life events can be conceived of as a generic longtime project that is focused on the care of everyday matters" (p. 83). At various times throughout a depressive episode (or habitually for those with chronic depression), people would access different orienting information sources such as online and offline news sources, consumer health Web sites, magazines, books, and for some, a newsgroup. The newsgroups used for this study are themselves a source of orienting information for a few participants who regularly post and read different messages. One poster indicated that he visited a particular newsgroup everyday. For some, the newsgroup was an important orienting information source and an important source of support. However, most posters participate in newsgroups irregularly (Burrows, Nettleton, Pleace, et al., 2000) and, because I did not interview any newsgroup participant, I cannot assess the value of newsgroups as orienting information sources from the perspective of newsgroup posters.

Newsgroup posters did, however, use a variety of orienting information sources when posting on the newsgroups. For example, newspaper articles, scholarly articles, and

recommended Web sites and books were mentioned or posted to the newsgroup to provoke general discussion and to provide support for arguments. While I cannot state unequivocally that the online newsgroups themselves served as an orienting information source for all newsgroup users, other orienting information sources from a wide variety of media were shared on the newsgroups.

Interviewees also used a variety of orienting information sources. Most people living with depression (including both newsgroup posters and interviewees) monitored their physical, emotional, and mental states and they frequently assessed and evaluated their condition based on this embodied information (Brown et al., 2001; Browner & Press, 1996). Additionally, nine out of 10 interviewees paid attention to articles, reports, magazines, and other health-related media as part of their orienting information practices and in this way acted much like posters to the newsgroups. For example, Dylan visited the Web site, Ask the Patient, for specific health orienting information. People also acted as orienting information sources for interviewees.

No interview participant mentioned reading specific blogs or subscribing to newsgroups or listservs as part of their orienting information practices and two interviewees stated that they specifically avoided online or offline orienting information sources like support groups. Gwen avoided newsgroups and online forums because

what I find is a lot of people talking about their problems and just going on and on about what's going on in their lives, and I find if they are worse off than you than you feel guilty, because where do I get off being depressed? My life's not that bad. And if they're better off than you, well, what have you got to be depressed about, listen to this. And it's just not very productive I think to compare myself to others.

Similarly, Anne avoided face-to-face support groups:

Anne: I have no desire or want or think that it [participating in a support group] would help me at all because yes, other people's stories I do take into consideration and they do give me information but I don't think that just going around and sitting in a group situation and talking about ... my pain and your pain is really gonna help me... I'm not a, I'm not a person to sit in a group and discuss my woes.

Sources of both practical and orienting information were important to newsgroup users and interviewees.

6.3 Discursive Construction of Information Sources

To justify or build up claims about using CAM or biomedicine, individuals demonstrated that the information sources they drew upon were not only unbiased (or the individual explicitly stated his or her bias and provided a clear rationale for it) but also authoritative, credible, and trustworthy. Many posters and interviewees made use of their experiential knowledge to build up their category entitlement or they invoked experts or a combination of these knowledge resources to work up credible, factual accounts. The following sections explore how individuals use discursive strategies, and expert and / or experiential knowledge to assess and evaluate or to justify or undermine the value of information sources.

6.3.1 Experiential, lay, and expert knowledge

In healthcare, expert, lay, and experiential knowledge all play important, but different, roles. Borkman (1990) defines experiential knowledge as the knowledge that is derived from personal, lived experience. Experiential knowledge is considered concrete and pragmatic and it is grounded in the reflections of those who are living with, or resolving, a problem. Professional or expert knowledge, according to Borkman, is analytical, research-based, founded on scientific principles, and derived from a body of knowledge or skill that is transmitted by specialists. Lay knowledge is defined "... according to the definition used by sociologists and anthropologists, who refer to it as 'recipe knowledge' (Berger & Luckmann, 1967), folk information, common sense of the person on the street (Holzer & Marx, 1979), or information transmitted from one generation to the next. It also includes information gleaned by bystanders from the mass media or from scientists or professionals" (qtd. in Borkman, 1990, p. 5).

Borkman argues that the perspective and the knowledge base of individuals is very different depending on whether they have gained their knowledge from living and coping with a disease (experiential knowledge), or if they have studied, practiced, or apprenticed with a specialist (expert knowledge), or if they have recently been diagnosed and are

beginning to learn how to live with the disease, or if they are a layperson who does not suffer from the disease but may know someone who does, or if they are a layperson who may have read articles, books, or stories about the disease (lay knowledge). Although the expert, lay, and experiential knowledge domains are often fluid, and frequently overlap, Borkman (1990) argues that generally in healthcare experts are relied upon for developing new treatments and for performing procedures whereas experientialists and laypeople (family and friends) are relied upon for more emotional support and coping skills.

Wilcox (2010, in press), however, argues that there is middle ground between expertise and lay knowledge:

While some lay people do acquire specialised knowledge or participate in research in ways that are recognised by professionals, support groups and social movements can also transform direct experience into collective knowledge and provide access to specialised ideas, while many patients and caregivers remain isolated and uninvolved in the production of knowledge (n.p.).

Furthermore, Wilcox suggests that expertise and the production of knowledge are social phenomena and questions about who is recognized as an expert, when, why, and how is socially negotiated. While a doctor or a CAM practitioner such as a naturopath might be credentialed and recognized as an expert in his or her respective fields, their specialized knowledge might not be recognized as authoritative in another social context. McKenzie (2001, 2002, 2003a, 2003b, 2003c) and Browner and Press (1996) have shown, for example, that individuals often negotiate, incorporate, ignore, or undermine biomedical information regardless of source credentials or expertise. How people use lay, experiential, and expert knowledge to construct the usefulness and / or authority of information sources (or to undermine information sources) and to negotiate what authoritative knowledge is applicable to their situation is the subject of the following sections.

6.3.2 Professionals in the healthcare sector as information sources

Physicians or doctors are the most often cited source for patients wanting health information (Carey, 2003; Warner & Procaccino, 2004). Additionally, physicians have been the primary focus of research investigating patient-medical provider communication

(McKenzie, 2004). For people living with depression to receive a diagnosis, to access medication, or to obtain a referral to other healthcare professionals such as therapists, psychiatrists, or pharmacists, they must consult physicians. Physicians served as the primary source for treatment and they often acted as gate-keepers to other medical services and to medical information. They were the most important professional for treating depression and both newsgroup participants and interviewees relied on them for their expertise; particularly when it came to their knowledge of medication. In response to posts on the newsgroup soliciting advice about depression, the first bit of advice typically offered was to consult a physician or doctor. Sabina, who cited the BBC Web site as a valuable, credible information source when she was searching for information about depression, said "...the BBC Web site is very much like, 'Go see your doctor.'... I have total respect for doctors." Even when people were not happy with the care they received from their physicians they continued to rely on them and had little to no choice about interacting with them.

Physicians were one of the most authoritative sources invoked to justify using, or not using, CAM (CAM is operationalized as recommendations other than prescribing medication, performing surgery, or making referrals to other orthodox practitioners).

Response: My new doctor is fairly convinced by some of the research into fish oil and Evening Primrose Oil and similar food supplements, I'm encouraged that they seem to be helping... Don't expect any overnight success tho, it's more a slow buildup over months. Definitely not snake oil but certainly not a "cure", IMO anything that helps helps.

Response: My pdoc [prescribing doctor] has just put a whole new twist to this argument. She is becoming a staunch advocate of alternative remedies and nutrition. I said in reply to the OP [outpatient pharmacy] that I have an inherited predisposition, which my pdoc accepts. But, she asks, WHAT DOES THIS MEAN? ... Saying that I am predisposed may simply mean that I have an inherited glitch... She has advised me to be assessed by a naturopath.

She is in favour of everything that [name] says... She has given me some stuff to read, and I will come back when I have read it. As for all the statistics, if I find something that works for me, I won't be interested in the "why."

Each of the above posters uses a discursive technique—what Potter calls “out-there-ness”—to construct his or her account as independent and factual and as something that exists outside of him- or herself. The posters accomplish this action by changing footing. Erving Goffman (1979, 1981) discussed the different roles participants involved in speech can play; such as the principal, author, animator, addressed recipient, over-hearer, and eavesdropper. In the above messages, for example, both speakers construct themselves as the animator, the person who says the words, and they construct their doctors as the principal, the person whose speech is represented. The statements “My new doctor is fairly convinced by some of the research into fish oil and Evening Primrose Oil...” and “My pdoc has just put a whole new twist to this argument...” allows each speaker to change footing in order to make claims that can be verified by credible information sources external to him- or herself. This discursive move allows these two speakers to transfer agency and responsibility for the argument onto an external source. The posters are merely relaying the information they received from an expert which de-personalizes their claims and also makes their version of events much more difficult to undermine.

In the above messages, both posters drew on the expert knowledge of their doctors to justify why they were using or investigating some CAM treatments. The doctor in the first message referred to “research” (externalizing to a source other than him- or herself) as convincing evidence for recommending that this particular patient try fish oil and evening primrose oil. In this instance, the doctor draws upon his or her expertise as well as the expertise of other sources to construct a credible argument for suggesting fish or evening primrose oil. The prescribing doctor in the second message relies on her expert training by describing a possible cause for this person’s depression and by discussing possible treatments—“she is becoming a staunch advocate of alternative remedies and nutrition.” In the second message, the doctor’s bias is evident (she is “becoming a staunch advocate”) but this poster is receptive to both the doctor’s referral to a naturopath and her recommended reading because the poster thinks this doctor is sharing credible information and, therefore, the poster believes that doctor is also an authoritative information source.

Both posters are building a sensitive case justifying CAM use and therefore they portray themselves as skeptical and cautious of CAM, but open to new ideas: “Definitely

not snake oil but certainly not a ‘cure’, IMO anything that helps helps” and “As for the statistics, if I find something that works for me, I won’t be interested in the ‘why’.” The posters’ skepticism also serves to highlight their competency as information users and evaluators—they do not believe what anyone tells them, even experts. However, the posters’ successful experiences with the CAM treatments support their doctors’ claims and expert knowledge in a process that comes full circle: first the doctor recommends the CAM treatments and then the success of the recommended treatment bolsters the expertise of the doctors from their patients’ point of view.

Doctors were often referred to as expert information sources and people frequently acted as the animator of their doctor’s words in order to justify their treatment decisions. In the following example, Dylan justifies taking what he describes as a “miniscule amount” (10 milligrams) of an antidepressant (Altase) because his doctor reassures him that it is not doing him any harm.

Dylan: And my family doctor tells me that at my age it doesn’t really matter. I’m taking a small enough amount that it’s not doing me any harm. And what’s the purpose of fiddling with it?

Dylan uses the information provided by his doctor (expertise) to justify taking a small dose of an antidepressant, despite having previously been addicted to Valium and alcohol. In addition, in managing his addictions Dylan avoided taking drugs of any kind (for example, he refused anaesthetic for a minor surgical procedure). By drawing on the expertise of the doctor Dylan accomplishes sensitive action justifying his use of antidepressants despite his previous history of addiction and his avoidance of drugs and alcohol. Interestingly, according to Dylan, the doctor invoked the “harmless” rhetoric commonly found in CAM discourses to justify using an allopathic medication.

Similarly, in the following message, the original poster draws on his psychiatrist’s expertise to rebut other newsgroup participants’ advice to take the medication Selegiline (which is used to treat early Parkinson’s disease, senile dementia, and depression):

Original post: Just back from my psychiatrists office this afternoon. And I told him about your suggestions, and he said that these drugs can lead to manic psychotic behaviour...

I would ignore he's advice, and just buy Selegiline from an online pharmacy, but the psychiatrist seems so convinced that dopamine agonists are not a good idea, and who am I, with no medical training at all, to disagree with he's advice?

... Does anyone know of any good smart drugs for anhedonic depression?

This poster has to carry out delicate social action. He has to balance a conflict between information gleaned from newsgroup members with information given to him by his psychiatrist. The poster presented information he received from newsgroup members to his psychiatrist who then challenged the value of that information. The psychiatrist encouraged the patient to continue taking the medication that he has prescribed. The poster has to justify two things in his message: first, he must account for why he has decided to follow his psychiatrist's orders rather than follow the collective advice he has received from newsgroup members about drug treatment, and second, why he is continuing a course of antidepressants that are evidently problematic.

In order to accomplish this action the poster changes footing by animating his psychiatrist's words. This discursive move allows the poster to present potentially problematic information neutrally—he is not the author of the words and subsequently the words do not necessarily represent his opinion. Ergo, the conflicting opinion between some newsgroup members and the psychiatrist about the helpfulness of the drug Selegiline does not necessarily represent the poster's view on the matter. The poster then justifies heeding his psychiatrist's advice over the other newsgroup posters' advice by personalizing and emphasizing *his* lack of expertise, not the lack of expertise found among newsgroup members who gave him the advice in the first place, "...who am I, with no medical training at all, to disagree with he's advice?" The poster invokes his doctor's expertise to justify why he is not following the advice he received from other newsgroup members. By using these discursive strategies in this way, the poster can maintain good relations with other newsgroup members. These discursive moves allow the poster to follow his psychiatrist's recommendations while continuing to seek help from other newsgroup members.

Similarly, in the message below the poster animates his psychologist's words—invoking an expert source—to support his claims about the genesis of his depression.

Original post: I saw a psychologist a few days ago and he doesn't like antidepressants. He says they barely work and never address the roots of the problem. He says that with what my life has been like it's no wonder and perfectly normal for me to be depressed. It was the only validation I can remember for a long time. I'm tending to agree with him.

Newsgroup posting

For many persons with depression validation from a healthcare professional was extremely important because it allowed them to justify to themselves and to others that there were reasons why they were depressed and that depression was not a personal fault. The above message provides another example of expertise coming full circle: the psychologist does not like antidepressants and, by suggesting and then validating a different cause for this person's depression, the psychologist becomes even more worthy of the patient's trust and respect. In turn, support from a professional provides credible evidence that allows this poster to justify why he was not pursuing allopathic treatment.

Medical professionals were cited by newsgroup members and interviewees as the expert sources people most often interacted with to treat their depression. People would invoke their healthcare practitioners' expertise in order to discursively construct these information sources as authoritative and credible.

6.3.3 *Cognitive authorities and other experts*

On the newsgroups it was evident that there were a few posters who acted as both gatekeepers (Metoyer-Duran, 1993) and cognitive authorities. One individual in particular was a highly regarded and fairly active participant on the depression support newsgroup. He has a PhD (though the subject area of his expertise was never explicitly stated) and he was perceived as a valuable source of information and support. Other newsgroup members posted the following about him:

Response: [name] ... wrote a great guide on medication.

Original post: I love it when [name] posts. Truly a stable presence in an unstable environment.

Original post: you might want to check out: [name of Guide]: [url] it was written by someone who posts here... can be very helpful in understanding these meds.

Original post: One of the occasional posters, has written up a good guide on all this. He's gone beyond what I did...in that he researched a lot of drugs and I only look into the ones I've taken/taking... [name] even turned me on to a pretty interesting antidepressant that is only now getting publicity again because it's available in a PATCH...woo!

Newsgroup postings

This poster was a trusted, credible information source for many newsgroup members. Even though this poster's PhD was not in medicine and he was not a healthcare professional, his experiential knowledge of depression and expert qualification (e.g., the PhD) combined with his having a valid reason for trying to influence other newsgroup posters' thinking made him a cognitive authority for others on the newsgroup.

Expertise in an area of specialization outside of medicine was also perceived as useful if that expertise assisted with coping. In the following excerpt Dylan recalls an Anglican priest who had a double qualification for helpfulness—he was both an expert at helping people in his role as priest and he was also an AA member with personal knowledge of the twelve steps.

Dylan: I would say discussions that I have, particularly in the framework of AA meetings, is most helpful...

I used to deal with an Anglican priest; I did about three step fives with him over the years at least [part of the AA 12-steps—admit to God, to ourselves, and to another human being the exact nature of our wrongs]. He is an Anglican priest, he's retired now, he's about the same age I am; he is also a member of AA. He's a person who had alcohol problems and was in AA but he's an Anglican priest so there's a double thing there. He's a clergy person who's used to dealing with people and their problems but he's also a member of AA so he knows; he also does step fives with people. So that's been beneficial to me. When I do it again I think I'll do it with our minister at the Unitarian church, at the Unitarian church because although he isn't, is not himself an alcoholic being a minister he deals with those things and also his wife is a member of the program because she's a drug, recovering drug person. So he's quite knowledgeable himself and I think I'll try it with him.

Similarly, for the following poster medical experts were not necessarily the only, nor the primary, source of expertise and information for people with depression.

Original post: [name], ... If you're talking about the treatment and diagnoses of depression, I don't know if it takes a psychiatrist/therapist to be the only specialist considered... If someone is depressed, they may or may not go to a psychiatrist/therapist. They may go to their clergyman, friends, a spiritual healer, their general physician for meds, a support group, a 12-step group, a holistic medicine clinic, etcetera instead. In other words, there are many routes in the treatment of depression and pdocs/therps are but one.

Newsgroup posting

The help that other experts can provide can be equally as important and useful as the help offered by healthcare professionals.

Family members, friends, and other personal contacts often acted as expert information sources in that they had "expertise" in knowing what was "normal" behaviour or typical behaviour for an individual. In the message below, respondent 1 invokes her family as a credible, unbiased information source. The message was written in response to the following post about an article in a May issue of *Discover Magazine*:

Original poster: > Article in the May issue of Discover Magazine suggests nutritional > treatment for Depression, et al. > they might be onto something, maybe not.

Response 1: Oh, I think they very well might be. I know my depressive symptoms have decreased greatly in the past few months from aggressive nutritional therapy... along with diet and exercise. My family says they've never known me to be functioning so well mentally and emotionally as I have been of late. I think this idea deserves further study.

Respondent 1 draws on her experience to construct a credible explanation of her recent success coping with depression but she also draws on her family's evaluation of her mental state as an authoritative information source that bolsters her claims about nutritional

therapy. The poster invokes family members as reliable information sources who can confirm the positive effects of following a diet and exercise plan to treat depression.

Similarly, in the following message, it was the poster's family, friends, and boss who alerted her to the possibility she might suffer from depression which, in turn, prompted information-seeking on the newsgroup.

Original post: Hello, I've been having some pretty bad problems with depression... My family and friends want me to get some help. I tried talking to my doctor but he didn't seem interested. What can I do to see about getting some help? Do I need to seek out a "therapist"? Should I ask for medication? ... Like I said, my family and friends came to me. My boss at work even mentioned something. I didn't even realize I was showing my emotions.

In this message the poster reports what her family, friends, and boss have said to her about getting help for treating depression. She invokes these people as unbiased information sources who support her claim that she actually has depression and that she needs to get help because the expert source, her doctor, did not validate her suspicions that she suffered from depression. Posters who claimed to suffer from depression but did not receive a diagnosis from a doctor or other healthcare professional often drew on outside sources to provide confirmation that they did actually suffer from depression. Other newsgroup posters, for example, would report the results of their online quizzes or refer to interpersonal sources as evidence confirming that they did suffer from depression.

A final example shows how institutions were constructed as expert sources:

Response: Anyone promoting something that cannot be backed up by scientific tests as rigid as the FDA requires should really be at some new age site, not here where someone who is desparate might latch onto this and the[n] die because they didn't get the medical help they needed.

BTW [by the way] - I and my two children are alive only due to the medicines you reject.

Newsgroup posting

In this case, the speaker is using the FDA as an authoritative, expert information source and as the gold standard for scientific testing and evidence. She disparagingly refers to

alternative medicine as “new age” and implies that alternative medicine is ineffective and potentially dangerous, particularly when used in lieu of conventional medical treatment. However, she does not discuss complementary medicine but rather places alternative medicine and allopathic medicine in opposing categories. This poster is using experiential knowledge acquired through the lived experience of herself and her two children to justify her use of allopathic medication. Although the statement “BTW – I and my two children are alive only due to the medicine you reject” is ambiguous—the poster might be suggesting that medication prevented her and her children from committing suicide or medication prevented her from harming her children—she uses extreme-case formulations by positioning her decision to take medication as a matter of life or death (extrematization). She uses expert and experiential knowledge to strengthen her claims.

Although expert sources were frequently invoked by speakers building credible accounts, experiential and expert knowledge were often used together to further justify claims. Furthermore, biomedical sources and other expert information sources could be countered and undermined. People would contest expert sources when the information they were given conflicted with their experience, beliefs, or other information sources they trusted more. People would frequently draw upon their experiential knowledge and different expert sources to undermine biomedical information sources.

6.3.4 Undermining expert sources

Despite serving as cognitive authorities and being considered a highly valuable information source for many people, doctors’ expertise was not always viewed as credible and occasionally doctors were viewed as barriers to obtaining the information people wanted. “My doctor is just a regular MD that I have been going to for years. He will try and refer me somewhere else if I get too questiony on him and on my horrid teacher’s insurance I just can’t afford all that” (newsgroup poster). This quotation alludes to an important problem lay people might encounter if they happen to disagree with the prescribed treatment or management of their health by powerful healthcare professionals—they have little recourse. As Freidson (1986) has noted in his seminal work on professions:

The medical system like many another professional system, is one predicated on the view that the layman is unable to evaluate his own problem and the proper way in which it may be managed: this justifies the imposition by the profession of its own conception of problem management. The client's rights are specified simply as the right to choose or to refuse professional ministrations... Once engaged in a service, its terms are largely not a matter of choice, the client's position being similar to that of a child in juvenile courts... This, I believe, is improper (p. 352).

Not only does the medical professional continue to hold a powerful place in society, the knowledge derived from the biomedical system is considered the gold standard for evidence and biomedical knowledge is authoritative knowledge.

However, speakers often undermined medical information by invoking their experience as an embodied information source.

Dylan: Well, I'm not sure it was the right kind of help. Our family doctor at that time, and that's many years ago now, prescribed Valium for me which I don't think was a good thing looking back because, being of an addictive personality, which he knew, I don't think that was the right thing to prescribe for me and I managed then to become at least if not physically, I became mentally addicted to having... Valium.

Although Dylan followed his doctor's orders, in hindsight Dylan believes that his doctor should have given his experience with addiction greater consideration before suggesting Valium as a treatment for depression and anxiety. Dylan questions his doctor's expert knowledge by invoking his own experience (i.e., category entitlement) and embodied knowledge with addiction.

In the following interview excerpt Anne drew on new and previously sought information as well as advice from friends and relatives to challenge her doctor's expertise about treatments.

Anne: You just take it for granted that the doctors, that you gotta listen to the doctor. He knows what to give you and you gotta do it otherwise...

Tami: ... did you go searching for information to find out about side effects [of treatment]?

Anne: Yes, I did because that was one of the things when I went into the doctor and said, “No I’m not having this because I did some research on it and this, this, and this can happen to me” and you know he just blew up.

Tami: Really?

Anne: He blew up. “Like if you’re gonna listen to your friends or listen to what you read rather than your doctor than you can’t be my patient.” It’s like no, you can’t be my doctor. You know so I just said no. First time in my life I said no to a doctor.

Anne’s encounter with her doctor is complex in that it is evident that the doctor and Anne contested each other’s claims about what constitutes effective treatments. Whereas Anne drew on information and advice from sources that she trusted (i.e., research, friends, and “reading”) to challenge the doctor’s claims, the doctor drew on his professional knowledge to counter the information Anne presented (and that he perceived as non-authoritative). It is apparent that there was a power struggle between Anne and the doctor and that Anne had little recourse when she challenged the doctor. This example shows that while experience was an important resource for undermining expert accounts, other discursive resources were used by speakers to undermine expertise including invoking previously sought information, “I did some research on it and this, this, and this can happen to me.” This excerpt also highlights how interpersonal information sources can be perceived as more credible and trustworthy than expert sources even when it might be detrimental to the person to invoke them: “if you’re gonna listen to your friends...than you can’t be my patient.”

6.3.5 Experiential and expert knowledge

People often drew on both experiential and expert knowledge to justify and make claims for their positions. In the following example, Dylan distinguishes between information sources that are the most helpful with coping and expert medical information about the condition of depression. Dylan wants information that he considers “helpful” as well as factual information.

Tami: So what would you say if you had to pick one or two information sources

that were the most helpful?

Dylan: I'd say reading and books. Do you mean help in finding out about the condition or dealing with it?

Tami: The condition, about dealing with it, about accurate information

Dylan: Yeah, I would say reading in the spiritual area has been most helpful and also reading. Well the Internet is particularly useful in terms of finding out about the advisability of different medications. There's the Web site called Ask the Patient that's useful but I would say the main thing has been reading and books and articles, and talking with other people.

Dylan, like other interviewees and newsgroup members, categorizes what kind of knowledge and information is best suited to solving particular problems. Some considered expert knowledge the most appropriate regarding matters of medication and diagnosis and they considered experiential knowledge as useful for providing support. These findings support Borkman's (1990) conclusions.

In the following message, the poster draws on his experience and the experience of his friends to undermine and challenge the knowledge claims of prescribing doctors (as a group) and he uses the discursive strategies of interest management and collaboration and consensus to undermine the expertise of a specific prescribing doctor:

... there are plenty of GPs [general practitioners], at least in my and my friends' experiences, who are very up to date and knowledgeable about antidepressants. In America, GPs have had more clinical training in medications and chemistry than Pdocs [prescribing doctors], especially in how prescriptions interact with each other. In fact, I just had a lengthy discussion with my GP ... YESTERDAY about my current antidepressant medication treatment and she told me loads of useful information about what exactly they do, how they interact, why, and what I need to be careful of. My current Pdoc couldn't be bothered and gets annoyed when I try to discuss these things with her with any kind of depth... I suspect strongly that her reasons for not wanting to discuss these things too much are that she doesn't quite understand it herself or at least not well enough to explain it to me. The meds she prescribes are largely the same for all of her patients because the clinic she works in has a nice, cozy relationship with a certain pharmaceutical representative who visits at least once a week to check up on how they are doing and if they need any more trial samples. And when I talk to the other patients in the waiting room -- Surprise! -- we're all on the same thing or at least started with the same drug. Dismiss as coincidence?

Newsgroup posting

The poster invokes his, and his friends', experiences to convey their knowledge about depression and treatment and to convey their entitlement to discuss antidepressants. This collective experience forms consensus and gives the speaker's description greater plausibility and credibility. He then portrays his general practitioner as a credible information source by providing specific details about the conversation he had with her: "... she told me loads of useful information about what exactly they do, how they interact, why, and what I need to be careful of." The poster reports the conversation he had with his GP and by doing this he accomplishes sensitive social action—i.e., he undermines the expertise of prescribing doctors by comparing them unfavourably with his general practitioner (in the United States general practitioners (GPs) are legally permitted to prescribe medication to their patients or they can refer them to psychiatrists who then prescribe antidepressants (Pdocs)): "In America, GPs have had more clinical training in medications and chemistry than Pdocs...". This statement is presented as unproblematic and separate from the speaker: this statement is treated as a fact (Potter, 1996, p. 112). The poster contests the expert knowledge of prescribing doctors by suggesting that general practitioners have "better" expert knowledge.

The poster further undermines this particular prescribing doctor's expertise and credibility by emphasizing the doctor's alleged stake in prescribing certain medications because of her relationship with a pharmaceutical company. To build this description, the poster uses consensus and collaboration by claiming that he discovered that the other patients in the waiting room were all prescribed the same medication at some point. This demonstrates collusion between the doctor and the drug representative and therefore diminishes the prescribing doctor's credibility. Simultaneously, his account justifies why he perceives general practitioners as more authoritative information sources.

Stories also played an important role as a source of information that supplemented expertise:

Tami: would you give the same amount of authority to both of those sources [stories or experts]?

Sabina: To be honest, I'd probably give more authority to the person who's been through it than the doctor. Yeah, because I just think, don't get me wrong, I have total respect for doctors but that experience is really valuable. As long as well, as long as that person was better now. If they're still fucked up and trying to give me advice I'd be like, "Wooo." [both laugh]

Elizabeth was another interviewee who values stories for emotional support.

Tami: So where do you fall between expert opinion and other people's stories? Or experiences?

Elizabeth: Like which do I like better?

Tami: Which would you trust more?

Elizabeth: I don't know because I do trust both. I think I trust other people's stories in terms of when I feel really vulnerable I trust stories. When I feel like okay I can do this, I can go to the doctor and ask these questions I'm okay with expert opinion. So sometimes I want someone to take care of me and the story takes care of me because the story echoes what I feel.

Right? And you know even if I went to a doctor and ... their response to me was, "I've dealt with a lot of people with depression and one of my patients had this" or "I've experienced it" that would count as story for me.

Tami: Right.

Elizabeth: So it isn't even necessarily who it comes from, it's that there is something very personalized in it and ... that's validating for me.

Both Sabina and Elizabeth valued expertise and experience but they did not uncritically accept anyone's story. Although Sabina stated that she found lived experience more credible than professional knowledge, she provided the caveat that the person who was sharing his or her story or giving advice had to have successfully lived through depression to act as a credible information source. For Elizabeth, credibility was based upon the content of the story itself and not necessarily based on the authority of the source of the story. Seeking solace or having emotional needs addressed through stories were powerful reasons for Elizabeth to incorporate, or to consider, others' experiential or expert

knowledge in her coping strategies. For Sabina and Elizabeth the value of the information given by both experts and experientialists was negotiated and assessed according to their own situational context and that of the information provider.

6.4 Information practices

Interviewees and newsgroup participants built up or undermined the value of various information sources (whether expert or experiential) in order to justify their decisions. In the following sections I examine how newsgroup participants and interviewees constructed, negotiated, or undermined the value of expert and experiential sources as they were providing information to others, information-seeking, information encountering, or information-seeking on behalf of others.

6.4.1 *Information-seeking and question negotiation*

The newsgroups were conducive to information-seeking and participants drew on a variety of sources to answer questions. The following two messages provide a concise example of how expert sources were often used to answer questions:

Original post: Hello, Which herbs, oils, therapies, etc., are expected to be safe with Zoloft and Seroquel? I've read that St John's Wort, for example, should not be taken along with depression meds, because of the slight chance of having a stroke. What about valerian? Kava? Essential oils? etc etc etc. I'm not going gung-ho in favor of alternative treatments; I just want to know if one can expect to drink this or that herbal tea without having a problem.

Response: From my *Drug Guide for Nurses*, the only adverse herb is St Johns Wart.

Newsgroup postings

The respondent in the above message uses an expert source to answer the original poster's question in a straight-forward interaction. However, other questions answered on the newsgroups were probed and negotiated.

Many newsgroup posters asked and answered questions in a manner similar to conducting a reference interview (Ross & Dewdney, 1994). When they were answering

questions, some newsgroup participants would negotiate or probe the question, or encourage the original poster to provide additional information so that detailed answers could be given. In the following messages the original poster is taught how best to ask a question so that he or she can get the best possible answer:

Original poster: ... >This is rough story of the past year of my life- I wrote everything > that I wrote, because I feel that you need to know everything that > was > going on in order to truly understand what's going on in my head in > order to help me out.

Response: I tried to read your story, but it was too long and confusing. If you would like some advice, I would suggest you ask your question again, but more briefly. Focus on your current problems, your recent medication history, and what you would like to know. (The harder you make us work, the less likely you are to get something useful out of the effort!)

Newsgroup postings

Some respondents and original posters on the newsgroups probed the question or provided additional feedback (Ross & Dewdney, 1994). The following series of messages show how the value of information sources was dialogically constructed, how questions were negotiated, and how information was constructed through dialogue.

Original post: I guess you all are helpful here. So. Questions. Well, first, an introduction.

I always knew I was depressed. What I didn't know is depression is a treatable clinical disease. I always figured my feeling crappy was just part of life. But then someone said I need to learn about depression, and so I read up on depression on-line.

Holy crap! Apparently I'm not lazy, I don't have to keep losing my job due to apathy, I can have meaningful friendships, and I can feel good all the time!

So I'm looking for the next step. Every Web site says 'get help' and then goes straight to 'have weekly appointments with your therapist and doctor'. WHOA, ... Thats a lot of assumption there! So, 'getting help' means getting a doctor and therapist? Those things are not an option for me.

Then I found [newsgroup], and figured this place would be as good as any for help...

I did my homework. EVERY piece of information I've read stresses seeing a doctor, getting medication, regular visits, and therapy. I have some concerns:

- a) That's not an option for me. I don't have money. I don't have a doctor, or health insurance, or a therapist, and can't afford one.
- b) There's no experts here. Doctors don't know what to do. They just prescribe a random antidepressant and hope it works.
- c) Therapy just analyses thinking patterns and helps you eliminate stress in your life. I don't think I need therapy. I have a stress-free life and am quite aware when I'm having negative thoughts.

Here's my questions:

1. How do poor people, who don't know anyone, get prescription antidepressants? Or a doctor, or a therapist?
2. Why should I trust a doctor? You people here would be more knowledgeable.
3. Why should I bother with therapy?

and I guess that's it for now. Thanks for your help.

This poster has just realized that he has depression and he is new to the newsgroup. His information-seeking was triggered by "someone said I need to learn about depression, and so I read up on depression online." Acquiring lay knowledge about depression was the first step toward this poster's understanding his experience (sense-making) and pursuing treatment. This newly acquired information dramatically changed the poster's self-conception, "Holy crap! Apparently I'm not lazy...". However, other information acquired online had far less value for the poster because it did not conform to his preconceived ideas that he does not need, and cannot afford, the recommended treatment.

In his view, experiential knowledge trumps expert knowledge and his opinions about the medical profession borders on disdain—"They just prescribe a random antidepressant and hope it works." For this poster, other members on the newsgroups act as cognitive authorities because of their experiential knowledge of depression, "Why should I trust a doctor? You people here would be more knowledgeable."

Response 1: > b) There's no experts here. Doctors don't know what to do. They just > prescribe a random antidepressant and hope it works.

Things are a little more refined than that. For a start, GPs are in the best possible position to make, or get, a reliable diagnosis - your symptoms might be (partly or wholly) down to something that isn't "Depression"...

> 3. Why should I trust a doctor? You people here would be more > knowledgeable.

Doctors are trained, and experienced. A good few of them also have personal experience of being Depressed. No-one here or in any newsgroup or on any Web site can diagnose anyone's illnesses.

> 4. Why should I bother with therapy?

It often helps a great deal.

This respondent presents what many people consider an ideal scenario: working with a doctor who has personal experience with depression and who therefore has both experiential and expert knowledge about treatments and the disorder. The above respondent emphasizes the value of expert information sources.

Response 2: > 3. Why should I trust a doctor? You people here would be more > knowledgeable.

Not at all, people here are lay and simply do not have the necessary background and training to understand and apply the practice of medicine, try as they might. They have only their own experience, anecdotes they've read or heard and bits of data they've gleaned from various sources. In itself, that is a lot of knowledge, but it isn't applicable to the practice of medicine.

> 4. Why should I bother with therapy?

Because it works. For depression, it isn't only about negative thoughts, it's mainly about emotions and dysfunctional or absent behaviours...

Both of the above respondents defend, and explain, why expert knowledge is more credible and trustworthy than experiential or lay knowledge. Respondent 2 in particular describes how lay, experiential, and expert knowledge are perceived by many on the newsgroups—

lay and experiential knowledge are valuable resources but expert sources are preferable in terms of treatment (Borkman, 1990).

The original poster then reconfigures his questions because he is confused by the responses he received:

Original poster: As for everyone else's comments...not what I expected.... I suspect I'm missing something. so, lets try to find out why I'm confused.

- 1) Does everyone here have depression?
- 2) What is depression? Could you (briefly) describe yours?
- 3) What has everyone here done about it?...

Random thoughts:

Someone implied I don't have depression....I'm not sure why someone would say that, but I'm pretty certain. I took all the online tests and stuff. Any comments?

I get that people here don't understand the 'practice of medicine', but I'm just interested in depression. Hasn't most everyone here gone to a doctor? Multiple times? And taken lots of drugs? And know what works and doesn't? Your combined knowledge of depression is surely greater than any one doctor.

As for depression being treated by 'diet, exercise, meditation and social activity', isn't that a bit unrealistic? Depression, by definition, destroys those things. Getting out and socializing does not help me...

The original poster again emphasizes the experiential, claiming, "Your combined knowledge of depression is surely greater than any one doctor." The idea that the aggregate information found in groups results in better decisions (or in this case, better information about treatment) than what any single expert can offer has been explored by James Surowiecki (2004) in his book *The Wisdom of Crowds*. In terms of treating depression, the knowledge of crowds might not be greater than the knowledge of any single doctor because what treatment works for one individual might not work for another (as respondent 3 notes below):

Response 3: > Your combined knowledge of depression is surely greater > than any one doctor.

What works and who it works for are two different things. Depression has a whole bunch of possible causes and what works for any one individual depends on the causes for that individual. At the same time, depression has a whole bunch of possible effects that can require treatment and what works for those is unique to the individual.

> As for depression being treated by ‘diet, exercise, meditation and > social activity’, isn’t that a bit unrealistic?

Those, together with drugs and psychotherapy, are the only things known to be realistic, the only things that actually stand up to scientific scrutiny...

Newsgroup postings

While the experiences of respondent 3 are not explicit—she provides no details outlining her own struggles with depression—it is apparent that she has experiential knowledge of depression. All three respondents valued expert knowledge and the last respondent in particular defends treatments based on expert knowledge—those treatments that withstand “scientific scrutiny.” The respondents’ use of experiential and expert knowledge assists in building a credible response advocating a biomedical approach to treatment.

The original poster did not receive the information that he expected to and throughout this series of messages he continued to negotiate his information needs and questions with others on the newsgroup. While the newsgroup participants are not credentialed in the way that librarians are, they invoked and referred to expert sources in order to justify their positions and recommendations in the same way that librarians would use expert sources when answering a reference question.

The importance of emotional support is emphasized in the information-seeking literature (Harris & Dewdney, 1994) and in the reference services literature (Ross & Dewdney, 1994). The following series of messages exemplifies the importance of emotional support when giving and receiving information.

Original post: > Also, does this stuff really work? :-)

I will make one other comment: the people who write negative things about Paxil (e.g., it is impossible to quit), etc., come across as very hostile in their tone and non-productive. Sure, a friendly comment or two individually directed about it

might be useful but a blast of text a mile long that is very impersonal, simply is not useful at all.

Respondent: > if you explore the subject you will find in the USA... the Food and > Drug Administration...in the UK the National Institute for Health > and Clinical Excellence...in Australia the Therapeutic Goods > Administration..and safety bodies all over the world have > “spewed a bunch of noise” about the dangers of SSRIs..

Original poster: That is not the point. The point is that I don't like being blasted with a bunch of axe grinding text. I post expecting a conversation, not an axe to grind...

I have the Internet at my fingertips and have read lots of material about SSRIs. I just did not like being blasted with text about the evils of Paxil.

I came to this newsgroup to have discussions and talk to people about depression and to talk about a very difficult decision that I made to go on Paxil... If, in the course of conversation, someone says you know, Paxil has some downsides to it, then I would have been happy to have the conversation go in that direction.

Do you see the difference between that and simply having an axe to grind and grinding it at every opportunity? ...

Think of it this way. You are at a gathering talking with a group of people who all share something that you all have in common -- depression -- and one of the people says, “I just started Paxil”. Do you immediately start reading that person a long article? Do you blast away with a wall of information?

Or do you listen to their story? If you think their are risks to Paxil do you just blast them or do you engage them in conversation?

Newsgroup postings

When assessing and evaluating the information provided by others this particular poster does not want “a wall of information” but rather a “conversation.” This information provider was deficient in the view of the original poster because he or she did not listen, did not pay any attention to the original poster's situation or needs, had an axe to grind, and provided too much information (“a wall”) rather than engaging in dialogue (“a conversation”). The manner in which information is given is crucial for a successful reference interaction and it is evident that emotional support is a key criterion in this

poster's assessment of the value of the information provided by others. For the original poster, emotional support while making a difficult decision trumps experience and expertise.

6.4.2 Information-seeking on behalf of others

The Center for Studying Health System Change, a U.S., non-partisan policy research organization, reported that in the year 2007, 42% of adults searched for health information on behalf of other adults and 29% of parents searched for health information on behalf of their children (Tu & Cohen, 2008). In LIS, researchers are studying the practices of information-seeking on behalf of others or proxy information-seeking (Gross, 1995, 1999; Gross & Saxton, 2001; Morey, 2007) as well as developing the concept of the lay information intermediary—a person who searches for information for others (Abrahamson & Fisher, 2007). Among my interviewees, occasionally family and friends passed along unsolicited information to interviewees. For example, Elizabeth was grateful to family members (who also suffered from depression) who shared their experiences with various medications and other treatments with her. Not only was this information sharing comforting, but it gave Elizabeth increased confidence when she spoke to her doctor: “I could actually say, ‘I have this many family members who are taking this drug. And I know it’s working for them’ and they [doctor] were like, ‘that’s probably pretty good odds that it’s going to work for you.’” In addition, Oscar’s wife suggested that he try cognitive therapy after conducting research on its benefits and she also signed out a number of books about depression from the library for Oscar to read:

Tami: So when you had said that you did some reading about it [depression], do you remember were those mostly books or magazine articles or

Oscar: [wife] checked out books for me. And yes, I remember that there were certain books I even made notes I have little file cards and some of that made sense to me and other things didn’t...

Tami: It also sounds like [wife] quite often is the one that gives you information?

Oscar: Yes. Right. She is the one, she’s very gung-ho you know in pursuing matters.

Unsolicited information giving by others was not always welcome for other interviewees. When asked about orienting information some interviewees responded as blunters; they rejected information (Baker, 1996). Gwen explains that sometimes she ignored unsolicited, shared information from her fiancé:

My fiancé sometimes will see something about depression [an article or other publication], he'll bring it home to show me. And sometimes it's interesting and sometimes I'm like no, I'm not there today, you know...

I'm not thinking about depression right now, it's not what interests me right now. You know, like if I'm sitting at home and I'm working on my novel or something, and he comes to me with this thing on depression I'll be like, "That's interesting" and I'll throw it away...

Not because I don't care or anything but because my mind is here now and why would I want to bring my mind back to the depression if I'm not feeling it...

You know, it's almost kind of like avoiding because you don't want to remember and you don't want to think of yourself that way.

When presenting unsolicited information to interviewees, information givers had to balance a delicate situation in order that the information be accepted—they had to have a valid reason for sharing the information (beyond his or her own agenda); and both the information shared and the manner of giving the information had to be supportive.

6.4.3 *Encountering information sources*

Some interviewees and newsgroup participants unexpectedly encountered helpful information. During our interviews, two interviewees, Sabina and Elizabeth, cited the BBC Web site as a general orienting information source and as a surprisingly valuable source for depression and health information. Neither Sabina nor Elizabeth visited the BBC site to obtain specific information about depression—both women visited the BBC site for other reasons but while they were there, they unexpectedly acquired useful information (Erdelez, 1997, 2005). Some newsgroup participants also encountered information: "Way back in the 1980s, I decided seriously to pursue the Rx route (after reading an article in of all place _ New York _ magazine) It took several tries to find someone who would listen."

The newsgroups were particularly conducive to information encountering. The following responses were to an article from *Well Journal* that was posted on the newsgroup. It focused on various treatments for depression, “thanks for the article, [name]. it reinforces all that stuff that we know we ought to be doing. the more we think about it, the more likely it is to happen;” and “I am going to have to print that out and read it. Thanks for posting it.” Another newsgroup poster wrote:

I heard that physical activity (exercise) stimulates our body to produce endorphins which are feel-good chemicals (natural morphin analogues). It is said that sports ameliorates the mood. I’ve been a lazy bum all my life but now after knowing about this (thanks again to newsgroups and internet) I think I will start regular sports (running). I did it yesterday and there seems to be something happening.

This newsgroup poster is appreciative of, and values, the information he encountered on the newsgroups and the Internet. Newsgroup posters tried meditation, exercise, yoga, journaling and engaged in discussions about the meaning of depression in response to information that was posted to the newsgroups by various members. Conversely, information encountered on the newsgroups could be challenged or undermined as in the response below to an article titled, *Paxil is Forever*:

I did have some trouble once going off it, on two occasions, but unless there is some factual evidence (not just several people filing a lawsuit), its hard to know what actually was the source of their problems. They may have stopped it abruptly, or without the doctor’s supervision, taking other meds at the time, etc. Its hard to tell. In my experience, most of the SSRI’s have caused some problems.

In everyday, offline information encountering most people would dismiss information that was not congruent with their worldview. However, the dialogical and social nature of the newsgroups facilitated interaction and engagement with information that might be ignored in other contexts.

6.5 Conclusion

In order to build an account as factual people would draw on experiential, lay, and expert knowledge. They would use various discursive techniques to justify, or make

claims for using, or not using, CAM, or to construct the information sources they referred to as authoritative and credible. In justifying their CAM use or non-use, posters to the newsgroups often referred to expert sources like scientific research or expert knowledge. However, ideas about who was considered an expert and what was considered expertise were negotiated. The notion of who was defined as an expert was fluid and for many an “expert” did not necessarily refer to a conventional health practitioner. For some, a priest, 12-step program, or a CAM practitioner could all be considered expert resources. Doctors, not surprisingly, acted as cognitive authorities for many newsgroup members and interviewees and were invoked as an authoritative information source. While scientific research and expert knowledge were generally viewed as the most authoritative information sources outside of personal experience, occasionally personal experience (or others’ experience) could trump expert knowledge. Often expert knowledge was supplemented with experiential knowledge to strengthen claims and make justifications. A few newsgroup participants who acted as cognitive authorities were considered by others to be experts both in their experiential knowledge of depression and professional credentials.

As Borkman suggests, lay and experiential knowledge were particularly useful resources for providing coping skills and support (and when individuals were both giving and receiving information) and expert knowledge was turned to for diagnosis and treatment. Lay, experiential, and expert knowledge are fluid categories, and expert credentials or recognition in one realm (e.g., a highly regarded naturopath) did not necessarily translate to status as an “expert” in another realm (e.g., the same “expert” naturopath in a biomedical context would not be considered as having the expertise to treat depression). Many newsgroup posters were considered by others as having expertise in their experiences with depression—particularly when this expertise was perceived as collective knowledge.

Newsgroup users were usually treated as authorities in the realm of their own experiences (Wilson, 1983). Additionally, as Harris and Dewdney (1994) found, people prefer to receive information from those who are like themselves—in the case of the online support group other people with depression or intimates of people who cared for a person with depression. However, information was challenged, contested, or undermined—it was

not thrown like a brick into empty buckets (Dervin, 1983). Posters and interviewees tended to portray themselves as competent information-seekers and they supported these characterizations by constructing information sources drawn upon as credible and authoritative. This was evident in the information practices of newsgroup members and interviewees. In chapter seven I examine how newsgroup posters and interviewees use information as evidence, for sense-making, and to discursively support their positions. I also examine how newsgroup posters and interviewees share information.

CHAPTER 7

Information Sharing and Information Use

While any individual post may be wildly inaccurate and perhaps deliberately so, this generally will spark a response from more knowledgeable individuals to set the record straight, and so one can fairly quickly find the consensus view.

ah and the answers aren't in any newsgroup.

Newsgroup posting

7.1 Introduction and Overview

In LIS, researchers Tuominen and Savolainen (1997) use the discourse analytic approach developed by Potter to study the discursive use of information. They have called for a broader research agenda in LIS that moves the study of information-seeking and use beyond recording surveys and examining information sources and channels to analyzing information use as it is socially constructed in discourse.

The idea we are putting forward is that it is possible to focus on analyzing conversations (seen broadly as all kinds of spoken and written communication) when studying information use... In short, we understand information use as an activity that can, analytically, be divided into two phases: 1) construction of information and 2) using or utilizing the constructed information in action. Our research approach focuses on the discursive constructions of previously received or sought information and on how those constructions are put to use in talk or writing (p. 81-82).

They go on to further explicate their approach:

The major aim of the discursive study of information use is to investigate how information that is received or sought from some other source than the speaker's or writer's direct experience is discursively constructed or designed for accomplishing pragmatic social action (p. 89).

The application of discourse analytic techniques in LIS research can provide an apt prism by which researchers can study concepts such as credibility, cognitive authority, sense-making, information acquisition and sharing, and information use.

Kevin Rioux (2000, 2004, 2005) has further developed Erdelez's information encountering concept to theoretically explore information acquisition and information sharing behaviours. Information acquiring and sharing refers to a set of behaviours and processes in which individuals engage in:

- Storing representations of other people's information needs
- Recalling those needs when acquiring information
- Making associations between the information acquired and individuals who might benefit from, need, or want it
- Sharing this information in some way

The newsgroup format was conducive for information acquiring and sharing activity. Often information sharing was unsolicited but newsgroup members joined the newsgroups assuming that others would have similar information needs and wants and assuming that information and support would be shared on the newsgroup. Information sharing behaviours that were commonly found on the newsgroups included posting newspaper or magazine articles to the newsgroup to generate discussion, to answer questions, or to be helpful or newsgroup members would discuss their experiences with CAM or antidepressants.

In this chapter I answer the question: What are the information practices of people with depression? I specifically analyze the practices of information sharing and information use. I analyze how people use information discursively to build up and / or deconstruct accounts justifying why they do, or do not, use CAM to treat their depression. I also analyze how newsgroup participants and interviewees acquire and share information. Interestingly, the format, structure, and discursive strategies newsgroup posters used in telling their stories typically followed a similar pattern or trope. Newsgroup members used the X/Y format as identified by Wooffitt (1992) to support claims, they engaged in prescribing behaviour (i.e., telling others to try various treatments), they used the testimonial trope to buttress their claims, and they would often draw upon previously sought or received information to justify their healthcare decisions or to support their arguments and constructions.

7.2 Information Sharing—Working Up Descriptions Justifying CAM Use

Many newsgroup posters shared information while they were simultaneously building descriptions justifying CAM use. As Potter and Wetherell (Wetherell, Taylor & Yates, 2001) note, the process of using language in constructing the social world involves active selection as some descriptions or resources are included and some are omitted. The speaker may or may not be consciously and deliberately constructing the social world but “a construction emerges as they merely try to make sense of a phenomenon or engage in unselfconscious social activities like blaming or justifying” (p. 199). While constructing an account, speakers engaged in information acquiring and sharing behaviours as outlined by Rioux (2000, 2004, 2005) and they typically (but not always) shared information that supported their own perspective. In order to justify CAM use, speakers used the technique of fact construction to reify their descriptions as authoritative, literal, and solid. In the following examples, I discuss the discursive process of reification within the context of information acquisition and sharing.

Original post: Talk to your doctor about omega 3 fats - fish oil. I take 1.5 teaspoons of liquid fish oil a day. It cured my life-long depression. Cured. I've been taking it for 8 months, and I have not had a moment of the old depression. Yeah, life's troubles are still there, but the sting is gone... Well, I am NOT an “alternative medicine” kinda guy. But my incredible experience with fish oil made me realize that there may be natural therapies that do indeed work. Everyone is different, and fish oil may not work for you. But it had dramatic changes on my life, and it's very much worth a try. Also, google “omega 3 depression” and “fish oil depression” for tons of evidence that it works. Good luck. Try this.

Newsgroup posting

In this excerpt a CAM therapy is framed as a cure for this individual's depression—a significant claim that no interviewee made and only seven users made on the newsgroups. This poster employs a variety of discursive strategies to accomplish three things: he is constructing an authoritative account that cannot be easily dismissed or undermined; he is trying to convince others to try fish oil; and he is sharing what he believes is valuable information that can benefit others.

To construct an authoritative account, this poster uses the following strategies—he manages stake, interest, and neutrality, he builds his category entitlement by drawing on

his experience to support his claims, and he draws on empiricist and consensus discourse to construct impartiality. To perform action he builds his account and uses the techniques of quantification and extremization (using extreme case formulations to minimize and maximize descriptive dimensions). At the same time, the poster is both constructing and sharing information based upon his assumptions that others on the newsgroups would want to know about his experience and that he is addressing others' information needs.

The poster manages stake and interest to construct an account that cannot be easily dismissed or undermined, despite making a serious claim that fish oil cured his depression. First, he provides a disclaimer—he is “NOT an ‘alternative medicine’ kinda guy.” This disclaimer allows the poster to avoid any unwanted attributes that others on the newsgroup might take into account when judging the authority of his experience. According to Horton-Salway (in Wetherell, Taylor & Yates, 2001):

This disclaimer highlights a dilemma that is frequently faced by speakers. When they give an account, particularly a controversial one, there is always the possibility of having their version dismissed or discredited on the grounds of stake and interest. In ordinary conversations and interviews, participants manage such risk by means of a device that Jonathan Potter (1996: 125) has termed ‘stake inoculation’ (p. 155).

This poster manages stake and interest by portraying himself as skeptical of CAM until his mind was changed in light of experience: “... my incredible experience with fish oil made me realize that there may be natural therapies that do indeed work” and increased evidence: “Also, google ‘omega 3 depression’ and ‘fish oil depression’ for tons of evidence that it works.” For this poster, evidence was acquired through experience and by searching for published research that was found using the search engine Google. The poster provides another disclaimer by stating that “everyone is different and fish oil may not work for you.” By doing this, the poster validates his experience while simultaneously avoiding challenges to his account because he claims only that omega 3s worked for him. He does not claim that omega 3s will work for everyone. Consequently, it is difficult to undermine his account based upon his experiential claim (whereas the evidence found on Google can be challenged and debated).

Even though this newsgroup poster claims to have life-long depression and is therefore entitled to speak authoritatively about the topic, membership in a certain group or category does not guarantee that individual members will be perceived as authoritative. Membership and subsequent knowledge claims have to be built-up (and they can also be undermined). Wooffitt (1992) found that people use regular patterns when reporting extraordinary experiences (in Wooffitt's research, he studied accounts of paranormal experiences) in order to work up category entitlements. First, they had to build up their accounts as factual; and second, they had to work up their accounts so that they were categorized by others as "normal" rather than "crank" or, with the case of CAM, a quack. Wooffitt found that one way that people accomplished these two tasks was to produce accounts of extraordinary events in what he dubs the "X/Y format, where X is a very mundane thing and Y is the extraordinary thing." In the above excerpt, the mundane thing is taking 1.5 teaspoons of fish oil a day and the extraordinary thing is that it cured this individual's life-long depression. This X/Y format allows speakers to portray their first reactions to events as rational or normal—in this case taking fish oil is not something out of the ordinary. By using this pattern to establish their normality, the speaker creates a version of events that is both difficult to undermine and also plausible.

Another technique the poster uses is to draw on outside sources in order to construct his account as independent from himself and factual. In the above statement "Talk to your doctor about omega 3 fats" the speaker is constructing himself as the animator, the person who says the words, and "your doctor" as the principal, the person whose speech is represented. "Talk to your doctor about omega 3 fats" implies that not just any doctor, but "your" doctor will recommend fish oil for depression. This discursive move places the speaker's testimonial as something that can be verified by sources external to himself. He also constructs those external sources as authoritative, credible, and trustworthy because he is referring to "your" doctor, not just doctors in general.

People often build descriptions so that they play a role in action or in a range of activities or practices. Two of these actions evident in this newsgroup message are quantification and extremization (Potter, 1996). Potter (1994) writes: "quantification in one form or another is one of the most important devices used to manufacture authoritative factual accounts" (p. 50). Potter suggests that when analyzing quantification "there is

always a temptation to see these sorts of calculation and representational practices as simply clear and obvious ways to capture what is there; that is, to see them as merely descriptive rather than rhetorically constructive” (p. 190). However, quantification is used to do relevant action. In this message, the quantification of how much fish oil to take and the description of how long the poster has taken it for—“I take 1.5 teaspoons of liquid fish oil per day... I’ve been taking it for 8 months and I have not had a moment of the old depression...”—accomplishes two important actions. First, the author’s account is a prescription; he is describing precisely how much fish oil one should take per day as a treatment for depression and second, the “8 months” shows that this treatment has been successful for a substantial length of time. Indeed, many persons with depression have to continually experiment with antidepressants because they do not successfully treat depression for as long as fish oil has worked for this poster. By using numbers in this way, the speaker provides a credible prescription for fish oil and he provides an authoritative description of the effectiveness of fish oils by drawing on his experience.

The poster also uses extremization and minimization to justify his use of fish oil. Potter (1996) suggests that “The use of such formulations is a common descriptive practice that involves using the extreme points on relevant descriptive dimensions” (p. 187). These descriptions can be modified to maximize or minimize value, for example, or to build up a description as something good or bad. The statement that fish oil is “... very much worth a try” serves to minimize any risk that might be inherent in taking fish oil. At the same time that the poster minimizes risk, he uses language that maximizes the possible benefits of fish oil by stating “my **incredible** experience with fish oil” and “... it had **dramatic** changes on my life.” These descriptive words work to strengthen the case the poster is making.

This speaker justifies the use of CAM by drawing on empiricist discourse as well as consensus and corroboration discourse. The poster draws on empiricist discourse by shifting agency from human actors to data or research: “... a cardinal feature of the empiricist repertoire is its attribution of agency to experimental data: ‘the results show’, ‘the data support’, and so on” (Potter, 1996, p. 157). The poster enacts this when he refers to “... **tons of evidence** that it works.” The poster is not held accountable for what information an individual will find (or the usefulness of that information) if he or she

follows his instructions to “google ‘omega 3 depression’” but he intimates that the information gathered will support his conclusions that fish oil is effective. Consensus and corroboration discourse is drawn upon by this speaker as he implies that the reader will discover, after executing the searches, innumerable individuals, experts, and scientific sources that support his claims. Indeed, searching Google using this search string retrieves 1.9 million hits of which the third hit is a research article from PubMed documenting the effectiveness of omega-3 fatty acid for treating depression.

By providing a prescription for taking fish oil with exact measurements of a dose, describing how long this regimen has worked for (8 months), and by providing specific search strings and instructions, this poster is also sharing information. He has used a number of discursive techniques in order to construct an authoritative account, and simultaneously, he has shared this information with others and he has built up the credibility of the information he is sharing. The author of the message is also carrying out action: he is encouraging other newsgroup members to search for information and evidence; he is encouraging others to try treating their depression by supplementing with fish oil; and he is encouraging others to talk to their doctors about fish oil. The discursive strategies used by this poster are nuanced, subtle, and complex and they serve to build the poster’s credibility.

The authors of the following messages provide additional examples of how people use many of the same discursive techniques discussed above to justify CAM use and to buttress the usefulness of the information they were sharing:

Original post: Subject: Fish oil, fish oil, fish oil

I am a convert, big time, and I want to spread the word. Believe me, I ain’t from the big fish oil industry. I have nothing to sell. I just want to help people if possible.

Anyway, I have suffered from moderate depression my whole life...

Therapy did nothing for me, though I threw myself into it. SSRIs helped immensely. Prozac then celexa helped me very quickly, and made me less angry, bitter, self-loathing, irritable. Only thing is, the sexual side effects were nearly as bad as depression. And after a while the emotional flatness “depersonalization” feeling that so many people have becomes quite brutal in its own way.

Finally, about 5 months ago I went on an all out internet search. I looked for everything: meds, supplements, electro cranial massage. I wanted SOMETHING to help. Not a quick fix - hell, I've been introspecting for 30 years now, to no avail.

Anyway, I start reading about fish oil, and figure what the hell. I try it, take 1,000 mgs a day of a brand that purifies for heavy oils and has high EPA/DHA ratio. After a few days I simply feel better. I keep taking the oil. For the past 4 months my md has been stable. Totally frigging stable. I don't want to smack people on the street. I don't sit and wonder if I'm the most disgusting human being that ever lived. I feel damn good.

Now, my short attention span hasn't been helped too much, and my anxiety is still there, although it seems to have lessened. But the mood stabilization is real. I haven't felt this good, this long with no side effects in... well, since I can remember.

Here's the mechanism that I've read about: the brain requires omega-3 fats - which fish oil is full of - for the serotonin receptors to work optimally. Omega -6 fats, which our western diets are full of, are not optimal for this purpose. Some have posited this as at least one etiology of depression.

Soooo, loooooong post, and I'm sorry if it's boring. But I beg you: try fish oil. Get a brand that purifies the oil of heavy metals, which I'm guessing is a good proxy for quality. Take it every morning (1,000 mgs) with breakfast. Stay with it. And tell me how it's going! Good luck.

Newsgroup posting

This poster uses a number of discursive techniques to build his account justifying fish oil as an excellent treatment for depression. He starts working up his account by first explicitly stating what his interest is in posting his message: "I am a convert, big time, and I want to spread the word." He also uses an extreme case formulation in the preceding opening sentence by describing his position using religious metaphors. He continues by immediately using stake inoculation: "Believe me, I ain't from the big fish oil industry. I have nothing to sell. I just want to help people if possible." These statements portray the poster as providing an unbiased account (he does not have a stake in the fish or CAM industries and he is not trying to sell any products) as he builds his case. The only interest he has is to help others which is one of Rioux's (2005) criterion of information sharing. He portrays himself as pro-active about treating his depression and carefully outlines all the different medications and therapies he has tried which serves to build his category

entitlement to speak authoritatively about treating depression. He draws on the “give it a try” trope also used by other posters: “I start reading about fish oil, and figure what the hell. I try it...”

This poster refers to his experience with fish oil to build a strong case for others to try it. He is direct when it comes to prescribing: “But I **beg** you: try fish oil.” This extreme case formulation (Pomerantz, 1986) maximizes the value of fish oil as a treatment for depression—the poster is not merely suggesting that you try fish oil, he is begging you to. This poster further justifies his own use of fish oil, and his prescription for others to try it, by providing specific detail outlining how fish oil works, what kind of omega fats a person requires, and how much and what kind of fish oil a person should take for the greatest benefits. He does not construct fish oil as cure-all, however, as he is careful to point out what areas fish oil has not helped with. This additional information shows that the poster is unbiased. The poster clearly works up his descriptions and uses previously sought information to culminate in action: to convince others to try fish oil. Not only are this poster’s instructions specific and carefully constructed to build his account, the information sharing is detailed and based on the poster’s belief that his recommendations have great benefits.

Original post: Over the past five years, I too have had many of the same symptoms of depression. I was diagnosed with something called dysthymia, which is mild depression that can last for decades. I went on Zoloft, and absolutely hated it. I didn’t like the feeling of being artificially happy all the time. I’ve done alot of research on what’s called Omega-3’s. You may have heard of them. They’re fatty oils that come from fish like salmon. They’re promising in the field of depression treatment. I have had great success with omega-3’s, and encourage you to try them also. They’re very inexpensive, and you can get them at any health hut like GNC.

Newsgroup posting

This message is more subtle than the previous two posts but the discursive techniques used are the same: the poster portrays herself as pro-active about treating her depression thereby building her category entitlement to speak about treatments; she draws on her experience with fish oil to imbue her account with authority and credibility; she refers to research that she has read (creating “out-there-ness” and using previously sought information to strengthen her account) and she draws upon expert sources (“the field of depression

treatment”); she explains what omegas are and where to find the best source of them (fish oil); and she shares detailed information about where fish oil can be purchased. Again, the action she is accomplishing is to convince others to try fish oil as a treatment for depression and she accomplishes this by sharing information and using discursive strategies that support her account.

In the following post the speaker is discussing different CAM therapies but here, too, there are a number of common discursive strategies and patterns evident in the poster’s attempt at creating an authoritative version of events.

Response: [name], I was skeptical of EFT [emotional freedom technique] at first too, but it works! It is truly amazing. It won’t solve all of your problems, but it really helps with intense or painful emotions. It helps you to tolerate them, thus decreasing their intensity, and your pain. When we learn to tolerate our emotions without trying to get rid of them in some way, they actually lose their intensity and their hold on us. I suggest giving it a try. There isn’t anything about it that is or could be harmful. You don’t even need to believe it will work.

Newsgroup posting

In this message the poster encourages others to give emotional freedom technique (EFT) “a try” because it “really helps with intense or painful emotions,” and “There isn’t anything about it that is or could be harmful.” The poster contrasts the effectiveness of the treatment (maximization) with negligible risks (minimization). She builds her account by portraying herself as initially skeptical of EFT but, based on the effectiveness of her “amazing” experience she now believes that EFT is a beneficial treatment. She explains how it works. An interesting discursive technique she uses to build up her account is her use of “I,” “we,” and “you.” She uses “I” twice; both times to make declarative statements: “I was skeptical...” and “I suggest giving it a try.” She uses the pronouns “you,” “we,” and “us” to directly address and include the reader. This allows the poster to draw on her own experience and accomplish action, but directly addressing the reader might assist the reader in feeling invested in what the poster is saying. The statement, “You don’t even need to believe it will work” links the practices of biomedicine and CAM with religious ideas about faith, belief, and healing and it minimizes the risk of trying EFT.

In all of the above posts, the posters engaged in the act of prescribing—building a case and then telling others to try certain treatments. Much of this information was shared in order to be helpful and to benefit others. Newsgroup posters would draw on experiential knowledge, expert knowledge and expert information sources, and previously sought information to justify why they believed their recommendations were beneficial.

7.2.1 Information Sharing—Testimonials

All of the above messages are testimonials (statements testifying to benefits received). Testimonials often present a narrative that is constructed from the point of view of an individual character—what Potter (1996) calls internal focalization (p. 164). Internal focalization is a narrative style that renders one character’s point of view more prominently than others: “The reader watches with the characters eyes and will, in principle, be inclined to accept the vision presented by that character (p. 164-165). In the above messages, the posters were skilful at rhetorically presenting their point of view and experiences in ways that strengthened their accounts and they created a sense of shared understanding with other newsgroup members. In contrast, the original poster below uses the same discursive strategies as the previous two posters but he is not as rhetorically adroit and, consequently, he attracts negative commentary. The original speaker does not build a sense of “we” or “us,” instead, he alienates other newsgroup participants.

Original post: I used to have severe, major chronic depression that lasted for years. I had given up on life and shunned having any real life dreams or goals for myself anymore. I was just unemployed, angry, and in a deep abyss of depression. I wished I were dead... Then I got taken to a mental hospital for a couple of weeks. They gave me Zoloft, which worked great, but only for a few months. So drugs are NOT the answer. Also, I came to find out that therapists in general suck, They were worthless and very very stubbornly unhelpful. So I read a lot of self help books. They helped me with my psychological issues, but they still didn’t make my depression go away.

The thing that finally worked was NUTRITION. I started eating healthy, and I felt much better. Then I started eating even more healthy and my depression went away 100%... By far the most important thing is to eat fresh fruits and vegetables. I also eat salmon and I take fish oil pills to get Omega 3 fatty acids. I recommend reading “Eating Well” by Dr. Andrew Weil. There are other good nutrition books too, but they basically say the same things...

NOW, I have kept reading self help books and I have kept learning and improving myself... I grab life by the horns and I make the most of every day. My goal is to become a multi-millionaire. I feel 10 feet tall and unstoppable.

So I recommend that everyone with depression eat the healthiest diet that they can. And if you tell me that it doesn't cure your depression, then as far as I'm concerned, you are a liar or you did a lousy job of choosing healthy foods to eat.

I know there are a lot of whiners here and probably people who will try to make a joke out of what I said, but I'm writing in case there is anyone here who is not too much of a jackass to follow and benefit from my advice.

Response 1: i wonder who he's trying to convince

Response 2: so where's the plug for your new book? link?

Response 1: > so where's the plug for your new book? link?

it was right where he said , reading "Eating Well" by Dr. Andrew Weil

Response 3: Another know-it-all who says that he has the universal answer and if it doesn't work, it's your fault. Oh and drugs don't work because the one he tried didn't and therapy doesn't work because he tried a couple of quacks. I'm not saying that nutrition's not important, but it's not the universal cure.

Response 4: Good for you, [name], but just because this regiment worked for you it doesn't mean it is the answer for everybody. On a different note, some of what you said, e.g. "My goal is to become a multi-millionaire. I feel 10 feet tall and unstoppable." reminded me a bit of Tom Cruise when he was (is) in his hypomanic phase.

Newsgroup postings

To buttress his claims and to create a credible account, the original poster provides a detailed narrative outlining all of the treatments he tried and he provides specific information about his diet, his approach to life, and his evaluation of people who choose not to follow his wise counsel. To challenge the original poster's account construction,

respondents 1 and 4 reinterpret the details of the original poster's account to create and support a different narrative. Respondent 1 recasts the meaning of the details of the original poster's account via a simple statement: "I wonder who he's trying to convince." This statement suggests that the details outlined in the original message can support an alternate narrative: Instead of trying to convince other people with depression of the genius of his methods, the poster has constructed this particular narrative because he must continue to convince himself of the merits of his methods. In a similar way, respondent 4 undermines the original poster's account by making the unfavourable comparison to the "hypomaniac" Tom Cruise. This comparison reworks the details provided by the original poster to hint that the original poster might be an unreliable reporter or perhaps generally unhinged.

While internal focalization typically gives the individual constructing the report an advantage in terms of relatability (the reader has access to his or her thoughts, feelings, and perceptions), this poster squanders any advantage he might have for having his account being accepted by others. First, he attacks anyone who chooses not to follow his advice. Second, he ignores others' unique situations such as not being able to treat depression solely with nutrition. Third, and most importantly, his prescriptions for treatment are based primarily on his experience—a rhetorical strategy that was not always accepted by other newsgroup members. For example, respondents 3 and 4 object to the original poster making generalized claims that nutrition can cure depression based on his individual experience.

Respondents 1, 2, and 3 undermine the original poster's message by highlighting the poster's stake—he is interested in convincing others to purchase *Eating Well* and to follow his recommendations for treating depression. Respondent 3 in particular is clear in his or her assessment of the original poster's message—he or she does not accept the original poster's status as a credible reporter. It is evident from the responses on the newsgroup that the original poster's testimonial was not accepted as a credible information source. However, despite having his account challenged, the original poster's message did generate discussion (instead of being ignored) and in the above example, respondents 3 and 4 concede that nutrition might be a valid treatment option for some people.

In contrast, in the following examples, CAM non-use is justified because CAM is built up to be ineffective, useless, and possibly dangerous, or alternately, biomedical treatments are worked up to be authoritative. In the following example, a newsgroup poster uses a variety of discursive techniques to create an authoritative account of his use of Lexapro, an antidepressant, over CAM options:

Original post: All during this time, I was continually in one-on-one therapy and group therapy, and I read countless self-help books, dutifully completing all the “homework,” filling notebook after notebook with recollections of my childhood, and tracking my thought-processes and my moods. I tried Chinese herbs, nutrition, exercise, yoga, prayer, fasting, alternative medicine—you name it, I did it. Nothing worked at all until Lexapro. It’s truly great stuff! It’s almost too wonderful to be believed.

Newsgroup posting

The message above illustrates how people use the same discursive techniques to justify why they do not use CAM as they do to justify why they do use CAM. In this example, the poster builds up his category entitlement to talk about treatments for depression by portraying himself as proactive—trying all kinds of CAM therapies to treat his depression or to feel better. This allows the poster to discursively orient his experience in a way that he can make and justify his claims for Lexapro. By drawing on his experiential knowledge, and by using a testimonial trope, the poster accomplishes two things: first, he frames CAM as ineffective compared to the allopathic medication Lexapro and, second, he strengthens his claims for Lexapro. The poster also provides another example of Wooffitt’s X/Y format—he tried all kinds of CAM treatments to manage and treat his depression (mundane, normal, or rational thing) and then suddenly, Lexapro worked (extraordinary thing). Utilizing a wide range of discursive strategies allowed interviewees and newsgroup members to create, build, and work up credible accounts or authoritative versions of accounts. Whether the poster was justifying CAM use or non-use did not matter; the discursive techniques used were the same.

Testimonials were most often evaluated and assessed as a reliable or credible source of information if the author’s experience was congruent with another person’s experience or if the author’s beliefs, values, opinions, or ideas about treatment, healing, or

medicine were congruent with another person's worldview. Testimonials were a specialized form of information sharing where posters presented information with an internal focalization. It was assumed that other newsgroup members would benefit from, need, or want the information these posters were sharing. The act of prescribing—giving prescriptions for treatments—and trying to convince others to try the treatment was a special form of information sharing.

7.3 Information Use

As explored in chapter 6, newsgroup users and interviewees used a variety of strategies to build up or deconstruct the authority and credibility of information sources they invoked to create authoritative accounts. Building upon my analysis of the processes of constructing and using credible information sources, in the following section I examine how information is used as evidence and I examine the discursive use of information.

7.3.1 Discursive use of information

As Tuominen and Savolainen (1997) explain, the purpose of studying discursive information use is to investigate how information that is received or sought from some source other than the speaker's or writer's direct experience is discursively constructed or designed for accomplishing pragmatic social action (p. 89). Within the context of CAM use or non-use, the social action individuals were attempting to accomplish is justifying or making claims for why they did, or did not, use CAM to treat their depression. To create authoritative accounts individuals tended to refer to specific information sources that were perceived as credible such as scholarly, scientific research, or popular publications like newspaper and magazine articles, or they would refer to specific universities and research centres like the National Institutes of Health or the Federal Drug Administration. Individuals would also draw on more general, less specific information sources such as "research," "evidence," "Web sites," "books," "reading," "learning," and "information" when making and justifying claims. In the example below, I have taken portions of the messages listed in section 7.2 and highlighted the phrases I wish to analyze by distinguishing them in bold font.

I've done alot of research on what's called Omega-3's. You may have **heard** of them. They're fatty oils that come from fish like salmon. **They're promising in the field of depression treatment...**

In this example the poster draws on, or refers to, information that was previously sought or received in order to construct an authoritative account justifying CAM use or non-use.

Tuominen and Savolainen (1997) theorize that the discursive use of information is based on the sensitive process of footing (Goffman, 1981). Footing characterizes different conversational practices and “production formats” of speech such as animator, author, and principal. Goffman writes, “A change in footing implies a change in the alignment we take up to ourselves and the others present as expressed in the way we manage the production or reception of an utterance. A change in our footing is another way of talking about a change in our frame for events” (1981, p. 128). Footing is an important concept in building up descriptions because it allows a speaker to manage distance, neutrality, and accountability in their descriptions.

In the example, “**I've done alot of research** on what's called Omega-3's. You may have **heard** of them. They're fatty oils that come from fish like salmon. **They're promising in the field of depression treatment...**” the poster changes footing from being the principal of the message to acting as the animator. By referring to “research” he positions himself as a messenger reporting on the views and findings of researchers and he is sharing this information with other newsgroup readers. Because he is now acting as an animator who is simply reporting the findings of this research, and not acting as the principal of his claims, he manages distance, neutrality, and accountability. This poster is not held accountable for the veracity of the research because he is simply reporting the views of scientists and medical professionals. The statement, “You may have heard of them,” provides further distance from this individual's claims because the poster implies that there is so much published research evidence about the success of omega-3s in treating depression that almost everyone would be familiar with it. The statement: “They're promising in the field of depression treatment” serves a dual purpose. First, the statement assists in working up this poster's distance and neutrality—he is merely reporting factual claims made by others that have emerged from the “field”; i.e., scientific research. Second, this statement strengthens this poster's portrayal of himself as a competent,

credible, and trustworthy information seeker. By making this statement the poster implies that he has read, understood, absorbed, and had his outlook altered by new information about omega-3s. Finally, the information sources that the poster refers to—scientific and medical research—are typically viewed as relatively unbiased and trustworthy sources by most newsgroup posters (whether they used CAM or not) and by all interviewees. This poster’s discursive use of information and the particular information sources he refers to all serve to build an authoritative account.

Similarly, in the following message the poster draws on “published reports” and “conflicting reports” about sources of EPA and DHA (the fat found in fish oil that is useful for treating depression) to manage distance and neutrality. He is reporting on research but not as the principal.

Response: > In practise you need fatty fish or >fish oils capsules to provide the required amount of EPA and DHA.

Mostly true. But note that there are published reports claiming that purselane contains EPA and DHA. Purselane is a common weed and a salad fixing, prominent in the diet on Crete. (cite not handy, but I’ve got it somewhere.)

There are conflicting reports as to whether humans can make adequate EPA from linolenic acid (a short chain omega 3.) Several of the reports that said that adults can’t indicated that the ability is lost at adulthood...

Newsgroup posting

Interestingly, the poster provides a caveat to the reports he refers to—“cite not handy, but I’ve got it somewhere.” Although the poster does not provide exact citation information, he provides enough detail so that his account and the information he shares is viewed as plausible to other newsgroup members.

The following series of messages provides an example of how the poster used previously sought information to justify not exercising. Exercising was the most recommended treatment for depression so this poster was building a case for a sensitive point.

Response 1: > That's right. Not all therapies are for everybody. Some people get > psychological stress from physical stress, those people would be made > worse by exercise.

Original poster: Articles lauding the 'exercise makes you happy' approach don't seem to mention that. Nor does anyone else, to judge by the press - or indeed the USA's Center for Disease Control in their advice about treating Depression (an earlier thread in this group contains my references and thoughts about that).

Response 2: > Who is telling you that if you get more exercise you'll feel less >depressed? Is there anyone really doing that? Anyone worth listening to?

Original poster: Press reports that start out with things such as .----- | The body of evidence supporting exercise as a treatment for depression | and other mood disorders continues to grow. Many psychiatrists and | psychologists urge their patients to get more exercise and make other | lifestyle changes. '-----

which to me means 'if you stop being Depressed, then you won't be Depressed any more'.

Newsgroup postings

The poster in this example is trying to accomplish sensitive action. Many persons living with depression advocate exercise as a means of treating depression and the original poster is challenging the merit of this treatment. The poster relays the information he has read about or heard about (creating out-there-ness). This approach allows him to make a delicate point without having his own expertise or experience dismissed. The discursive use of information allows the poster to maintain distance and neutrality while contesting the perceived wisdom about the benefits of exercise in treating depression. Furthermore, the information sources the poster refers to are credible—he specifically mentions the Center for Disease Control and articles published in the popular press. However, the claims made by the original poster about the totalizing discourse that exercise is good for you is challenged by respondent 2. When the original poster is pressed to provide additional information he quotes from a specific article. Respondent 2's question, "Anyone worth listening to?" challenges the authority of the discourse creators; she challenges the expertise of experts.

In the following example, the original poster discursively uses information previously acquired from a nutritionist and doctor to support her claims and to challenge ideas about what treatments work best for mild depression versus “a major psychiatric disorder.” The poster also uses information to strengthen her claims that the original poster was acting irresponsibly.

Response: I was diagnose[d] with MD [manic depression] about five years ago. I went through the whole range of treatments both conventional and not. I went throughvegetarian diets, ultra vitamin courses any thing apart from take the medication that would eventually work.

Then a nutritionist told me that lithium was a natural element and this would be the drug of choice both from his point of view and the doctors.

During in highs of mania there is a change in brain activity and chemistry which needs to be corrected by prescribed drugs. Maybe for mild depression vitamins could be used and could work but to suggest to people with a major psychiatric illness that these could work is dangerous to say the least.

We people with MD don't take these drugs lightly. We need them to function as part of the community and to suggest anything less is to expose very vulurable people to all sorts of dangers. You obviously have very little experience of mood disorders and I suggest that you do a little more research before spouting your vitamin theory over the newsgroups.

Newsgroup posting

The idea that “real” depression, or in this case manic depression, can only be treated with allopathic medication is presented in order to challenge claims made by the original poster that vitamins can treat depression. In order to justify her claims and to challenge the original poster, this respondent draws upon the information she received from a nutritionist (who also happened to invoke the expertise of doctors in his explanation). The poster moves from writing about herself, and her own personal experience, to using the pronoun *we*. In effect, this consensus and collaboration discursive move strengthens the poster's claim by speaking for untold numbers of people who, the speaker implies, would agree with what she has written. She draws upon the experiences of other people with manic depression to support her claims by using the word “we.” Last, the speaker discursively uses expert biomedical knowledge to strengthen her position. She

suggests that there is very little scientific research or evidence that supports the original poster's claims about the efficacy of vitamins to treat depression.

Last, the two postings below show how discursively using information could be supportive:

Original post: ...I am attempting to slay the dragon (anxiety, depression, probably a wee bit'o OCD in there) using exercise, healthy diet, fresh air, lots of water, meditation, etc. Do I hear anyone laughing out there? ;o) Yes... I've been a wee irritable, have been crying more (now that I'm not a sedated zombie)... but I have real hope for freedom from meds.

Response: I've gone off all i tried, and gone back to them when the need arose. It may be that your "Live healthy" routine will work for you, I hope it does, and good luck with it. If it doesn't, the pills will be waiting. Be careful how far you slide down before realizing/admitting how bad the depression is getting. that is an area where I had trouble. I've read that the nutrition/exercise works for some people, maybe you'll be one for whom it does.

Newsgroup postings

People use information discursively to accomplish sensitive action which entailed everything from justifying a treatment to establishing that an individual did indeed suffer from depression by referring to online quizzes, doctors and other medical professionals, and interpersonal sources. The discursive use of information is predicated on the individual invoking information sources other than his or her direct experience or speech. Using information discursively requires the speaker to shift footing. To strengthen or justify claims, and to build up the credibility of accounts, people often used information discursively.

7.4 Conclusion

People used previously sought or received information to buttress their justifications and to construct credible, authoritative descriptions. They referred to information sources such as healthcare practitioners, clergy, family, journal articles, friends, scientific research, popular articles, institutions, books, and information found on the Internet. Posters and interviewees tended to portray themselves as competent

information-seekers and they supported these characterizations by using information as evidence, for sense-making, and to discursively support their positions.

Chapter 8

Summary and Conclusion

Treating or managing depression often forms a project of life where information is needed to solve practical problems such as learning about different treatment and management strategies and / or information is needed for sense-making and meaning-making (orienting information). How newsgroup participants and interviewees conceptualized depression—as a biological disorder that required biomedical attention or as having its genesis in other personal attributes or life traumas or history or a combination of both—influenced an individual's information practices in terms of how they sought, shared, and used information, what kinds of sources she or he drew upon to construct authoritative accounts, and what information he or she considered helpful. Individuals used a variety of discursive strategies such as fact construction, building their category entitlement, drawing on empiricist discourse, and using information to support their arguments, justifications, and evaluations, to construct information sources as valuable, and to justify why they did, or did not, use CAM.

As Strauss and Corbin point out in the third edition of *Basic Qualitative Research* (2008) talk, on its own, carries no guarantee that the discourse will be treated as factual:

...the descriptive details chosen by storytellers are usually consciously or unconsciously selective, based on what they saw or heard, or thought important. Though description is often meant to convey believability and to portray images, it is also designed to persuade, convince, express, or arouse passions (p. 54).

Descriptions have specific functions and serve specific purposes. Descriptions (and narratives) are empowering and selective. Descriptions and narratives stand in for speakers' arguments and they allow speakers to take positions without explicitly advocating them. They are empowering because they allow the speaker to frame the information they are presenting in a way that is supportive of the speaker's viewpoint and they allow speakers to strategically frame arguments and decide upon what information to include or exclude (Perrin, 2006, pp 68-79). In framing a narrative or description, both newsgroup participants and interviewees were selective about what information they

shared (choosing those details that supported their point of view or experience) and both newsgroup participants and interviewees constructed descriptions and narratives that allowed them to make and justify claims for using, or not using, CAM to treat depression.

8.1 Information Sources, Expertise, and Experience

People drew upon biomedical, expert, experiential, spiritual, and embodied ways of knowing to justify using, or not using, CAM. While biomedical authority and expert knowledge were often preferred information sources, cognitive authority is negotiated by individuals and oftentimes individuals will reject information that is not congruent with their own experiences regardless of the authority of the information source. As Giddens (1991) has noted, people in modern societies are confronted by multiple experts and, thus, conceptualizations about what constituted expertise and who was considered an expert were negotiated. A person could act as a cognitive authority without necessarily having certified or credentialed expertise in healthcare or experiential knowledge of depression. A priest, friends, or spouses were considered experts, or affective authorities (McKenzie and Neal, in press), in the area of support for some interviewees and newsgroup participants, for example.

In addition, as Wilcox (2010) notes, ideas about what is considered expertise, and who has expertise, are socially consensual. Authority is negotiated by communities. In a recent study examining affective authority McKenzie and Neal (in press) consider a new approach to studying cognitive authority in which an individual makes decisions about an information source not based upon cognitive processes but rather by the “social practices whereby a community collaboratively negotiates what counts as an authoritative information source.” This type of negotiation was particularly evident on the newsgroups as people would deconstruct biomedical research, discuss newspaper or magazine articles, comment on others’ experiences, take into account the speaker’s previous posts (if applicable), their orientation to CAM, depression, or biomedicine, or other relevant elements of the speaker’s biography in their authority assessments.

People challenged, dismissed, or undermined biomedical knowledge by invoking their experiential knowledge of depression. People use disclaimers, build their category entitlement, and prescribe a course of action to others in order to lend their experiential

knowledge greater authority. Speakers frequently invoked a disclaimer—“it worked for me but might not work for you”—when describing successful experiences with unconventional treatments or treatments that have not been scientifically tested to avoid challenges from others regarding the authority of their accounts. In addition, biomedical conceptualizations of depression were often contested or not even considered by some newsgroup participants who focused on spiritual or embodied ways of knowing about depression. As Solomon (2001) points out and as two interviewees and many posters on the newsgroup suggest, depression may provide the impetus for individuals to seek spiritual guidance or expertise from information sources outside biomedicine.

People were generally considered authorities in the realm of their experience (Wilson, 1983) but experiential knowledge is not authoritative knowledge. Those who relied solely on experiential knowledge to make controversial claims about the effectiveness of CAM often undermined their accounts if they attempted to create an account justifying the use of a CAM therapy while simultaneously arguing that others should not use allopathic medication. In these instances, references to quackwatch.org, snake oil salesmen, and definitions of “real” depression were made by others on the newsgroup that easily undermined the speaker’s claims. For posters who claimed a CAM treatment such as taking fish oil supplements was superior to allopathic medication invoking expert, scientific knowledge such as published research studies or acting as the animator (Goffman, 1981) of their physician’s words provided a much more compelling account than merely drawing upon experiential knowledge. Typically, however, people invoked expert information sources that supported their experiences, thereby using a combination of experiential and expert knowledge to justify, strengthen, or make claims. When justifying CAM use or non-use, newsgroup members and interviewees drew upon diverse information sources.

8.2 Authoritative Knowledge

Knowledge derived from the Western scientific research process, including both professional healthcare practitioners’ knowledge and biomedical research, was the most authoritative knowledge for treating depression. People did not need to provide justifications or a rationale to explain why they used Western medicine; it was taken for

granted that the underlying scientific method of Western medicine made sense. Interpersonal biomedical information sources, research studies, and controlled trials were preferred sources and were considered authoritative by both CAM users and non-users. Speakers often referred to clinical trials showing the benefits of taking St. John's Wort or using acupuncture, for example, to strengthen their claims for using these practices to treat depression. Only one person questioned the value of the scientific method.

Although there was much dissatisfaction expressed about doctors, psychiatrists, side and long-term effects of medication, the pharmaceutical industry, the ineffectiveness of medication, and the politics of medicine, newsgroup users and interviewees did not question the scientific research process or the knowledge derived from this system. Interviewees and newsgroup users could readily justify using allopathic medication to treat depression by invoking biomedical evidence and drawing on empiricist discourse to support their claims about treatment benefits.

Interestingly, some CAM users participating on the newsgroups suggested that many CAM therapies are holistic and as such they are not designed to be parsed and tested using the same research methods (e.g., the gold-standard, double-blind, randomized control trial) as allopathic treatments. A few posters and two interviewees were adamant about not using conventional medical services or allopathic medicine at all for the treatment of depression because they were frustrated by its ineffectiveness, side effects, cost, or they believed they did not need medication to treat their depression. These posters reflect a larger debate among some CAM practitioners about the role of scientific evidence in CAM practices. Should CAM practitioners integrate with dominant healthcare services by using an evidence-based approach to test the efficacy of CAM treatments or is CAM truly an alternative to orthodox medical practice where evidence-based approaches are not the most appropriate ways of testing the efficacy of treatment?

Many newsgroup posters and nine out of ten interviewees used one or more CAM therapies to treat or manage their depression. CAM therapies were constructed by many as "natural," "harmless," or "worth a try" which served to minimize any risks that might be involved with using CAM. CAM use provided the means by which some people living with depression could debate and contest biomedical ideas about depression and conventional treatments. CAM presented people with alternative ways of thinking about

the aetiology of depression, treating depression, and it allowed people to shift their perspective and invoke other ways of knowing—e.g., drawing upon embodied knowledge, experiential knowledge, or knowledge gleaned from interpersonal sources as a means to counter biomedical information. For some, CAM use and the use of different methods to derive knowledge or different ways of knowing, influenced an individual's information practices and was related to Savolainen's mastery of life concept.

8.3 Everyday Life Information Practices

Newsgroup participants and interviewees used a number of common tropes to justify or strengthen their claims about the effectiveness, or ineffectiveness of CAM and / or orthodox medicine. Speakers would provide disclaimers, give testimonials, use regular speech patterns such as Wooffitt's (1992) X/Y formulation to explain extraordinary phenomenon, invoke empiricist discourse, use information discursively, and construct themselves as competent information-seekers and users in order to give their arguments and justifications greater credibility.

To create authoritative accounts, make claims or justify decisions, it was imperative that individuals portray themselves as competent information-seekers and information users. While I expected that individuals would draw upon both expert and experiential knowledge to make claims and to justify their decisions both to themselves and to others, I was surprised to find how important information use was to individuals in reifying and ironizing accounts. For example, people challenged research findings, bestselling authors, experts, and each other which allowed speakers to portray themselves as people who could find, understand, and use complex information. For some people who were considered by others as poor fact constructors and incompetent information users, their accounts were often dismissed, derided, or ignored.

One of the primary purposes of the newsgroups was to provide a forum for both seeking and sharing information. An additional activity evident in the newsgroup threads was what I have coded as *prescribing*—to designate or order the use of as a remedy (Merriam-Webster). Newsgroup posters would not just share information with others; they occasionally prescribed certain remedies such as supplementing with Evening Primrose oil or trying meditation or an allopathic medication to treat depression. To convince others of

the merits of the treatment, they would use certain discursive strategies, invoke authoritative information sources, and discursively use information in an attempt to lend their prescriptions authority.

Individuals also sought both orienting information and practical information to problem-solve, conceptualize their depression, to find meaning, to treat depression, to justify and make claims, and to evaluate and assess new information. Savolainen (1995) suggests that orienting information and practical information are often intertwined. While much activity on the newsgroups and much discussion with interviewees centered on seeking practical, problem-solving information such as finding effective treatments for depression, orienting information also plays a strong role in treating and managing depression. Orienting information sources such as newspaper and magazine articles, Web sites, newsgroups, and other daily or regularly consulted media, or embodied information, assists with day-to-day monitoring of the “order of things” (where “things” stand for everyday life activities) and “mastery of life” (the active care of the order of things) related to the ELIS (everyday life information-seeking) model.

The ELIS model was developed by Savolainen to elaborate on the social and cultural conditioning that underpins the use of information and people’s preferred information sources as it pertains to information-seeking in everyday life. Savolainen argues that mastery of life is associated with “pragmatic problem-solving” (p. 144). My findings suggest that mastery of life is also associated with information use that is meaning-making for individuals. For social constructionists, meaning-making “refers to collective contest over interpretation. Institutions, repertoires, and rituals offer a set of ready-made—though always contradictory—interpretations that allow people to assimilate information into established categories of understanding” (Kurzman, 2008).

My findings indicate that everyday life information-seeking solves practical problems for persons with depression; it is helpful in taking care of “mastery of life” and developing a sense of coherence; and it assists people living with depression in meaning-making. Newsgroup participants and interviewees saw themselves as engaged in a life project in which managing depression required them to become expert information seekers, users, and sharers. Unlike others who can afford to be less vigilant about knowing themselves, these individuals see themselves as constantly monitoring themselves and the

outside world for clues about their well-being. This work can sometimes have an additional payoff: becoming a “better person” or learning perseverance:

Emma: One of my friends who also had depression said to me, “You know you’ll be a better person for this when you’re done.” Like when you come through this. So that was the expectation that I had, that I would be a better person. That really I was dealing with issues that probably should have been dealt with a long time ago... and you know it’s true I wouldn’t take it back.

Dylan: I think over the years it [depression] made me realize that there are ups and downs to life. It’s given me a sense of perseverance—that one should attempt to deal with things as best as one could and carry on. At this point in life... I don’t worry about these things much anymore. I would like to think that it wouldn’t come back again but I had an episode of it just about three years ago... so I would say now I’m pretty comfortable with my life. I have no regrets; it would have been nice if I hadn’t had to deal with all these things. I was the person that I was.

Stories get told about depression in which information practices lead to a kind of meaning-making that gives validation to the suffering and work involved in living with and managing the condition. As Dylan mentioned, persevering over depression can be a powerful personal accomplishment. One poster wrote, “there is no happy pill and nor should there be” implying that depression was something to be worked through, struggled against, and hopefully overcome.

8.4 Implications for Library and Information Science

A number of implications arise from this study for librarians and other information providers and for the discipline of library and information science. Practitioners must balance their professional obligation to retrieve, evaluate, and give valid, accurate, and trustworthy information that they deem the most authoritative with the needs and wants of their users. Bernd Frohmann (1992) argues that librarians privilege information that is based on medical or scientific research in an attempt to give the profession greater legitimacy. What constitutes “evidence” for a librarian is the same as what constitutes “evidence” for a medical practitioner. As a result many LIS studies focus on the validity, reliability, and authority of information—i.e., expert knowledge. Experiential knowledge

or other ways of knowing are often a secondary consideration, if they are considered at all. Expert knowledge constitutes authoritative knowledge for librarians and information providers and while these sources are important to recommend to users, they do not always provide a complete picture of the experiences of people living with depression. As McKenzie and Neal (in press) suggest, non-traditional authoritative information sources such as newsgroup discussion forums and medical blogs can be incorporated into consumer health information resources offered to users in libraries and information centres.

My research findings also indicate that people use information to make meaning. During the process of meaning-making, people can become proficient information seekers, users, and sharers. In LIS, researchers have tended to focus on people's information practices as they solve practical problems. I suggest that more empirical evidence is needed to increase our understanding of the information practices of people as they construct meaning.

One of the most frequently cited studies in the information behaviour literature is the study by Harris and Dewdney (1994) quoted in section 3.3 that outlines the following information-seeking principles:

- (1) Information needs arise from the help-seekers situation.
- (2) The decision to seek help or not to seek help is affected by many factors.
- (3) People tend to seek information that is most accessible.
- (4) People tend first to seek help or information from interpersonal sources, especially from people like themselves.
- (5) Information-seekers expect emotional support.
- (6) People follow habitual patterns in seeking information (p. 19-27).

My own research supports the principles outlined by Harris and Dewdney. Both interviewees and newsgroup participants sought information that was accessible, they expected emotional support from information providers, and they sought information from interpersonal sources. Importantly, people living with depression sought information from others like themselves. Typically newsgroup posters seeking help would post a message to the newsgroups (informal source) prior to visiting a doctor. Although many newsgroup

participants encouraged other posters seeking advice to see a professional healthcare practitioner, informal sources were used first. Interviewees, too, tended to prefer seeking information from informal information sources such as family and friends before seeking information from formal sources. It was clear that newsgroup participants (or those who care about them) and interviewees expect and want emotional support from information providers.

However, when both newsgroup participants and interviewees were engaged in information-seeking, they often asked questions that subtly (or not-so-subtly) framed the kind of information they wished to receive. For example, a newsgroup member who believed that St. John's Wort was effective asked others for information such as journal articles that reinforced his or her view. Other posters directly asked for recommendations for CAM therapies (if that is what the poster or interviewee wanted to use or try) or allopathic medication (if that was the treatment the poster or interviewee wished to use). Additionally, both newsgroup participants and interviewees justified their healthcare decisions by referring to articles or books where the author or authors provided evidence that supported the poster's or the interviewee's point of view. Thus, an area for further research is an additional information-seeking principle: people seek information that supports their worldview, beliefs, or values.

In addition, a finding from many newsgroup participants and interviewees is that considerable information-seeking is done on behalf of others. This practice has implications for librarians in terms of the reference interview, question negotiation, and the mediation of online sources. Although studies have been done on gate-keepers, imposed queries, and lay information mediaries, more research is needed to understand collaborative information behaviour and what the implications of this practice might be for librarians and other information providers. Furthermore, librarians can apply their skills at organizing and making accessible information by including vetted online community resources into their library offerings via wikis or other social networks.

There are a number of implications arising from this study for LIS as a discipline. Discourse analysis is a research method particularly well-suited to uncovering information practices such as how people use and share information to argue, justify, assess, evaluate, and build (or deconstruct) authoritative, credible accounts. This method can assist

researchers in answering questions about how information is used, how users construct themselves as information-seekers and users, and how information is constructed and used to make an individual's activities and the activities of others meaningful and understandable. This method of analysis may be particularly useful when applied to health decision making. In addition, there is a dearth of research studying the social practices of discursive use of information, information sharing, and information collaboration in domains where knowledge is contested.

8.5 Conclusion

Ultimately, finding an effective treatment for depression, whether it was CAM or conventional medicine, was the primary concern of most newsgroup users and interviewees. Most posters and interviewees were open to complementary practices because they wished to leave no option untried or because their current treatments were ineffective and required experimentation. Participants in the online newsgroups drew on various forms of information and evidence as authoritative in order to justify claims but experiential knowledge was used most often to justify the use or non-use of CAM.

Knowing how people seek, use, and share information when making healthcare decisions, as well as understanding how patients use experiential and expert knowledge to justify and assess information about contested knowledge domains may assist LIS researchers in determining effective ways of developing and delivering consumer healthcare information via libraries and information and referral services. Insight into how patients use experiential and expert knowledge as information sources, how patients discursively justify, assess, build up, and deconstruct arguments, and how patients seek, use, and share information is critical to developing services that will be useful for information-seekers, particularly if patients are expected to provide input into their medical care.

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Appendix A

Sample Interview Schedule

Introduction

Thank you for agreeing to talk to me about your experiences with depression. Your time and input is greatly appreciated.

Today I will be asking you a few questions about your history of depression, how depression has affected your life in terms of work and relationships, what kinds of things you have done in order to treat or manage your depression, and where you have received advice, help, and support. I also will be asking you about where you went to get information about depression and how you decide what help or advice is the best.

In order to ensure confidentiality this tape will just be numbered. There will be nothing that will identify you personally and I will not use your name in any recordings, writings, or presentations of this research.

Do you have any questions before we begin?

Topic area: History of depression and current situation

1. Can you start by talking about your experiences with depression?
 - Probes:
 - a) How long have you had depression?
 - b) When did you first experience an episode of depression?
 - c) How did you know that you were depressed?
 1. What did you feel like?
 - d) Were you able to find any help or support?

Topic area: Construction of depression

1. How does, or how has, depression affected your life? What kinds of problems has it created for you?
 - Probes:
 - a) How does it affect relationships? Work?
 - b) How does it affect you personally?
 1. What do you think about your depression? When I say the word *depression*, what comes to mind? What does it make you think of? In addition to being an illness that needs to be treated or managed, does it represent something more?
 2. How has having depression affected how you think about yourself or your life? How has managing or dealing with depression affected how you think about yourself?

Topic area: Treatment of depression

1. What have you done in the past to treat or manage your depression? What are you doing now to treat your depression?

Probes:

- a) Do you currently take prescribed medication to treat depression?
 1. What are your opinions about antidepressants?
- b) What does your doctor suggest you do to treat depression?
- c) Do you do anything to treat depression yourself in addition to what your doctor suggests? How did you find about it?
- d) Do you do anything to treat depression yourself instead of what your doctor suggests? How did you find out about it?
- e) Have you ever tried using herbal supplements, acupuncture, yoga, meditation or prayer, exercise, or dietary restrictions or that kind of thing to help treat depression?

Topic area: Information sources

1. Who would you ask or what sources would you use to get information on depression?

Probes:

- a) Have you done any research or reading on depression?
 1. Do you recall what type of material it was? Books, newspapers, articles, support group, Internet?
 2. Was this information helpful to you? Why or why not?
- b) How do you decide what information is the best?
- c) Has your doctor or other health practitioner ever told you something or recommended a treatment that you thought was unhelpful? If so, what did you think about that information?
- d) Has anyone else recommended something to treat depression that you thought was unhelpful or that you disagreed with? How did you respond?

Appendix B
Sample Recruitment Letter

Date

Dear

I am a Ph.D. student in the Faculty of Information and Media Studies at the University of Western Ontario. Under the supervision of Dr. Catherine Ross, and as part of my degree program requirements, I am studying the ways in which people with depression treat or manage their depression, how they decide on certain treatments, and what role advice, help, or information plays in making these decisions.

My research focuses on an oftentimes overlooked area—people’s lived experiences coping with depression. I’m interested in finding out what people’s perceptions are of depression, how depression has affected their lives, and what kinds of information or help they find trustworthy or useful when treating depression. My research involves interviewing people who have experienced an episode of depression in the past or people who are presently dealing with depression.

I am writing in order to seek XXX’s assistance in recruiting participants for this study. Specifically, I would like permission to display my information posters and place pamphlets or flyers in the main office.

Due to the persistent stigma associated with mental illness, I would like to emphasize the precautions I will take in order to ensure confidentiality. First, participation in the interviews is completely voluntary and the questions will be on the topics outlined above. Participants may withdraw from the study at any time or refuse to answer any questions. Interviews will be tape-recorded and may last from 45 minutes to an hour and a half. Second, the interviews will be transcribed and all names or any other information that may identify an individual will not appear on any notes, records, or details associated with this research to ensure confidentiality and protect privacy. All data provided will remain anonymous in any subsequent reports or notes.

In exchange for permitting me to place flyers and pamphlets in your main office I would be happy to provide a summary of the results of the research, when available, for you to read or to do a presentation for interested staff members. Please feel free to ask me for clarification or elaboration if you have any questions. Thank you for your time and attention regarding this matter.

Sincerely,
Tami Oliphant
Ph.D. candidate

Appendix C
Sample Recruitment Poster

Have you ever suffered from depression?

Participants needed for research study

I would like to find out about people's experiences with depression, how people treat or manage their depression, and where they go for help, advice, and information. This study is part of my doctoral research at the University of Western Ontario.

- I will meet at a time and location convenient for you
- Interviews will take approximately 45-60 minutes
- Identity will remain strictly confidential
- Participation in the study is voluntary
- **If you like to participate in the study or for additional information about the study** please contact Tami Oliphant at:



Appendix D
Consent Form

Contested Knowledge and Information Behaviour: Treatments for Depression

As a participant in the study “Contested Knowledge and Information Behaviour: Treatments for Depression,” I understand the general nature, purpose and procedures of the study as explained to me by the researcher.

I also understand that none of the materials resulting from my participation in the study will identify me. I further understand that I may withdraw from the study at any time without having to give a reason.

I hereby give my permission for:

- (a) tape-recording of my conversation with the investigator;
- (b) educational and research use by the investigator of tape-recordings and transcripts made from the conversations.

Participant’s signature

Investigator’s signature

Date

Tami Oliphant

Appendix E
List of Prescription Drugs Mentioned in
Selected Newsgroup Threads and by Interviewees

Atarax
Ativan
Bespur
Celexa
Citalopram
Cymbalta
Depakote
ECT – electro-convulsion therapy
Effexor
Elavil
Iamictal
Klonopin
Lexapro
Lithium
Lustral
Luvox
Mirtazapine
NAC
Nardil
Neurontin
Pamelor
Paxil
Premarin
Prozac
L-tyrosine
Melatonin
Risperdal
Remeron
Sarafem
Selegiline
Seroxit
Serzone
Tofranil
Trazodone
Trileptal
Tegretol,
Xanax
Zoloft

Appendix F

CAM Therapies Mentioned in Selected Newsgroup Threads and by Interviewees

5-HTP—a neurotransmitter, 5-hydroxy-tryptophan (5-HTP) is a compound created in the body which is used to regulate serotonin levels in the brain and the central nervous system.

It is taken as a supplement.

Acupuncture

Affirmations

Amino acids

Co-enzyme Q10

Cognitive therapy

Cranial sacral therapy

Diet—e.g., giving up gluten, sugar, alcohol or certain foods, eating a moderate amount of l-tryptophan containing foods like milk, bananas, pineapple, chicken, etc., everyday.

DMAE—dimethylaminoethanol—is a chemical found in fish but also made in the brain and is taken as a supplement.

Ear candling

Essential oils

Evening primrose oil

Exercise

Flaxseed oil

Gingko biloba

Ginseng

Homeopathy

Hydration

Journaling

Kava Kava

Light therapy

Liquid colloidal minerals

Massage

Meditation

Neurofeedback

News fasts

Omega 3 oils

Rapid eye therapy

Reading

Regression therapy

Reiki

Shamanism

Spanking

Spirituality

St John's Wort

Talk therapy

Tranquility—the proper name of a supplement used for depression and anxiety.

Valerian root

Visualization
Vitamins—B, C, D, multi
Volunteering
Yoga

Neither prescription nor CAM

GHB—Gamma hydroxybutyrate (GHB) is a central nervous system depressant. In Canada it is legal to distribute and use GHB for controlled medical and scientific purposes. In the US, GHB was sold in health food stores as a performance enhancing additive in bodybuilding formulas until the Food and Drug Administration (FDA) banned it in 1990. GHB became a Schedule I Controlled Substance in the United States in March 2000.

Appendix G

List of Canadian Mood Disorder Organizations and Support Groups

Local: London

Canadian Mental Health Association, Ontario, London-Middlesex --

www.london.cmha.ca/bins/site2.asp?cid=284-301&lang=1

London Health Sciences Centre -- www.lhsc.on.ca/mhcp/

Mood Disorders Program – www.london.cmha.ca

Recovery Inc. (Mood Disorders) – 200@recovery-inc.com

Regional Mental Health Care -- www.sjhc.london.on.ca/mhl/mhl.htm

The Health Line, London-Middlesex --

www.thehealthline.ca/cat1.asp?region=london_middlesex&cid=26

Provincial: Ontario

Canadian Mental Health Association, Ontario -- www.ontario.cmha.ca/index.asp

Centre for Addiction and Mental Wellness -- www.camh.net/

Mood Disorders Association of Ontario -- www.mooddorders.on.ca/

Ontario Gerontology Association -- www.ontgerontology.on.ca/opmhan.htm

Ontario Ministry of Health and Long-Term Care --

www.health.gov.on.ca/english/public/pub/mental/depression.html

National

Canadian Health Network -- www.canadian-health-network.ca/servlet/ContentServer?cid=1048003175135&pagename=CHN-RCS%2FPage%2FGTPPageTemplate&c=Page&lang=En

Mood Disorders Society of Canada -- www.mooddorderscanada.ca/

Public Health Agency of Canada -- www.phac-aspc.gc.ca/mh-sm/index.html

Appendix H

List of Complementary and Alternative Medicine Organizations

National

Alternative & Integrative Medical Society -- www.aims.ubc.ca/home/
 Canadian Association of Naturopathic Doctors -- naturopathicassoc.ca/
 Canadian College of Naturopathic Medicine -- www.ccnm.edu/
 Canadian Federation of Aromatherapists -- www.cfacanada.com/
 Canadian Health Network – Complementary and Alternative Health --
<http://www.canadian-health-network.ca/servlet/ContentServer?cid=1047656077028&pagename=CHN-RCS%2FPAGE%2FGTPageTemplate&c=Page&lang=En>
 Canadian Interdisciplinary Network for Complementary & Alternative Medicine Research -- www.incamresearch.ca/index.html
 Homeopathic Medical Council of Canada -- www.hmcc.ca/public/Default.aspx
 Integrative Health Institute, Mount Royal -- www.mtroyal.ca/integrativehealth/
 Natural Health Products Directorate -- www.hc-sc.gc.ca/ahc-asc/branch-dirgen/hpfb-dgpsa/nhpd-dpsn/index_e.html

International

Complementary and Alternative Medicine (evidence based resource), NZ -- www.cam.org.nz/
 Complementary and Alternative Medicine (peer-reviewed open access journal), US -- www.biomedcentral.com/bmccomplementaltermmed/
 National Cancer Institute, Office of Cancer Complementary and Alternative Medicine, US -- www.cancer.gov/cam/
 National Centre for Complementary and Alternative Medicine, US -- <http://nccam.nih.gov/>

Curriculum Vita

Name: Tami Oliphant

Education: University of Western Ontario
London, Ontario, Canada
2004-2010, PhD

University of Alberta
Edmonton, Alberta, Canada
1999-2001, MLIS

University of Alberta
Edmonton, Alberta, Canada
1992-1994, BA

Selected Awards and Scholarships

Ontario Graduate Scholarship (Value: \$15,000)	2005; 2008
Social Sciences and Humanities Research Council (Value: \$20,000)	2007
Beta Phi Mu International Library Science Honor Society (GPA of at least 3.75 on the 4-point scale)	2001
Lesley Heathcote Graduate Scholarship in Library and Information Studies (Value: \$6,500)	2000
Graduate Studies and Research Tuition Scholarship (Value: \$3,095)	2000

Related Work Experience

Sessional Instructor
Faculty of Information and Media Studies
University of Western Ontario
2007-2009

Teaching Assistant
Faculty of Information and Media Studies
University of Western Ontario
2004-2008

Sessional Instructor
School of Library and Information Studies
University of Alberta
2003-2004

Selected Peer-Reviewed Publications

- McKenzie, Pamela and **Tami Oliphant**. (2010). Informing evidence: Claimsmaking in midwives' and clients' talk about interventions. *Qualitative Health Research*, 20(1), 29–41.
- Oliphant, Tami. (2009). "I'm making my decision based on my experience": Constructing authoritative knowledge about treatments for depression. *Canadian Journal of Information and Library Science*, 33(3/4), 215–232.
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