Seeking Understanding:
A Grounded Theory Examination of How Men with Cancer
Experience Help Seeking

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Amidst limited information on how men with cancer experience help seeking during illness, this study was organized around two research questions: (a) how are men with cancer perceiving, interpreting, and understanding needs and sources of support during illness? and (b) in light of these understandings, how are they building patterns of support (informal and formal) with others? Integrating a symbolic interactionist perspective and engaging a constructivist grounded theory methodology, in-depth, individual interviews were conducted with 30 men diagnosed with cancer. Participants included men with a variety of cancer types/stages, a diversity of occupational and educational backgrounds, and ranging in age from early 30s to mid 80s (mean age 59). Most of the participants were white, heterosexual, able-bodied, in a partnership, and born in Canada, although the study included men who identified as gay, gender queer, from racialized groups, single/divorced, and were immigrants to this country.

A substantive theory of how men with cancer experience help seeking was developed. Results indicate that as men experienced cancer as a ‘biographical disruption’ help seeking functioned as a way to both resist and adapt to identity threats. ‘Help seeking with a strong back’ allowed the men to solicit help from others (e.g. health providers, friends, family, others with cancer) in efforts to develop informational and physical resources important to resisting the threats, a process accompanied by attempts to maintain familiar ways of being and limit emotional engagement. In contrast, ‘help seeking with a soft front’ allowed the men to obtain assistance in efforts to acknowledge
and adapt to threats, a process engaged as men sought out others willing to hear their struggles, include them in a community sharing this experience, and provide them with guidance on how to live a life disrupted by cancer. Although both forms of help seeking could be valuable amidst illness, most men experienced help seeking with a strong back as relatively unproblematic and consistent with masculine ideals of leadership, control, and stoicism, while help seeking with a soft front was often less anticipated, less welcomed and less comfortable amidst gendered norms discouraging men’s recognition and expression of vulnerability. Recommendations for research and practice are provided.
Dedication

This dissertation is dedicated to each man who participated in this study and to the many others who walk this path. Through the courageous sharing of your joys and your pains, your continuities and your change, we learn and are connected. We are indebted.
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This journey is woven of many threads, built of countless engagements over many years that have challenged my certainties, broadened my field of vision, and given me the language and courage to explore. My appreciation of research, of how we come to know our world, was fundamentally informed by the teachings of my mother who illuminated the value of observation and those of my father who shared with me the joy of questioning. Even more, it was my parents who emphasized the importance of engaging all efforts with purpose, generosity, and integrity, a practice always imperfect, but worthy of continual pursuit. On this foundation all else rests.

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Part 1: Orienting
Chapter 1
Introduction and Purpose

Within the field of men’s health studies, a growing body of literature has focused on men’s willingness to engage medical supports when faced with signs and symptoms of illness. Accepting timely help seeking as a key factor in health experiences and outcomes, researchers are asking “why” and “how” men’s help seeking appears to be problematic at a broad level (Smith, Braunack-Mayer & Wittert, 2006) and why service use patterns vary among groups of men and across settings (Addis & Mahalik, 2003; Galdas, 2009). As researchers move beyond sex-based comparisons to consider gendered patterns in health and illness behaviours, much of this work has prioritized the influence of masculinity norms, or societal level expectations of how men should think, feel, appear and act (see Galdas, 2009).

Although the current literature on men’s help seeking offers valuable insights into why some men delay or avoid engaging health professionals, important gaps remain. In addition to a restricted focus on help seeking for male-specific or associated diseases (O’Brien, Hunt & Hart, 2005), understanding has been limited by insufficient attention to a diversity of male experiences (Galdas, 2009) and a narrow conceptualization of help seeking as a single decision moving men toward or away from clinical support. Most fundamentally, in focusing on the determinants of men’s formal, medical help seeking (emphasis on prediction), little attention has been devoted to how men, as gendered beings, are making sense of a variety of needs and supports as they navigate help seeking across the course of illness (focus on understanding).

Research Purpose

To help address these gaps, this grounded theory study has drawn on a symbolic interactionist (SI) perspective to examine how men with cancer experience needs and supports (formal and informal) across the course of their illness. As informed by an SI framework, this study accepted human actions as guided by a process of self-indication (Blumer, 1969). Accordingly, deterministic interpretations of help seeking were replaced with a consideration of the cognitive process by which men with cancer identify what is
relevant in situations across the course of illness, assess the meanings of these recognized objects, situate the self, and form responsive actions on the basis of these assessments.

Core in this consideration is the SI concept of identity and the associated concept of definition of the situation. More specifically, it is recognized that as an individual evaluates a situation, he operates as both a social agent and a social object. In this, he views himself through the eyes of others and uses his appearance and acts to assert identity claims, communicating where he has been, where he is now, and where he is going. Although this orientation focuses research on meanings and actions at the level of the individual in the course of the day-to-day experience of illness, this self-indication process is accepted as profoundly social. As an individual draws on a cache of meanings or ‘significant symbols’ constructed with others and builds acts with those around him, relational, institutional, and broad social forces powerfully cue perceptions, interpretations, understandings and behaviours. In this balance of agency and structure, even as individuals often conform to social conventions, meanings are always variable.

As integrated here, an SI lens shifts the focus of this study of men’s help seeking away from an effort to predict whether or when men go to the doctor and toward a consideration of how men are perceiving, interpreting, and understanding needs and supports across the course of their illness. In this focus on a symbolic world rich in possibility, gender is recognized as influential. As men are socialized into a society that positions men and women as distinct social objects, their definitions of situations and self throughout the course of illness are informed by the cognitive and emotional scripts they and others draw on to evaluate appropriate male performance: the shifting and often unconscious expectations of masculinities. As Connell (2005) succinctly explained, “gender is a way in which social practice is ordered” (p. 71).

However, in recognizing that a man’s sex category patterns his experiences and understandings, it is also accepted that men are influenced by the intersecting expectations of a variety of communities with which they align. Even more, men are recognized as agents, not “victims of socialization or biology” (Gray, Fitch, Fergus, Mykhalovskiy & Church, 2002, p. 44). The story of a man’s life has more than one plot line as he claims many social identities and builds a personal biography ensuring he is not
fully “leashed” by structural forces (Hewitt, 1989, p.190). Thus framed, this study examines how men, as complex persons, work with others to apply, modify and transform meanings and build responsive acts over the course of illness.

In addition to enabling an understanding of how men with cancer experience help seeking, this study attends to other gaps in the literature as it integrates the perspectives of a diversity of men and expands attention beyond a single medical consultation. More specifically, in appreciating identity as broader than gender, this study has considered commonalities and differences in how men make sense of their experiences. Further, in focusing on men’s lived experiences, this study has offered an opportunity to see beyond expectations of what constitutes help seeking behaviour, focusing instead on what was relevant for these men as they identified and prioritized needs (e.g. physical, emotional, and relational) and sources of support (medical and non-medical) and detailed how they solicited, accepted, and declined assistance.

Research Questions

Pursuing an understanding of men’s meaning making process during an experience of cancer, this study has been directed by two core research questions:

1. How are men perceiving, interpreting, and understanding needs and sources of support during their illness career?

2. In light of these understandings, how are men navigating help seeking; how are they building patterns of support (informal and formal) with others?

To examine these questions, I met with 30 men who had been diagnosed within the past decade with a range of cancer types, including lymphomas, leukemia, myeloma, and brain, throat, neck, colon, prostate, kidney, liver, and skin cancers. In the course of unstructured and semi-structured individual interviews, emphasis was placed on learning from these men how they defined situations and perceived themselves throughout their illness, with attention to their diverse interpretations of needs and sources/forms of support and related patterns of behaviour. Notably, as I focused on how men made sense of needs and supports amidst diagnosed disease this is not a study of preventive care practices (i.e. screening, health promotion, well-visits), nor is it a study of the outcomes of help seeking, as these are distinct areas of research and theory development.
Research Objective

Organized by a grounded theory methodology, this study oriented to the identification and examination of broad patterns across a complexity of individual lives; the construction of “second-order stories” (Daly, 1997). Driving this focus and process is a belief that this substantive theory of men’s health-related help seeking during a cancer experience can benefit a diversity of men, their support networks, and the services seeking to support them. More specifically, this theory is offered as a clarifying narrative that can both inform and challenge the efforts of those providing informal and formal supports to men with cancer and researchers examining men’s help seeking, in particular, and gender and health, more broadly.

More specifically, with theory oriented toward practice, the information gathered here can enable the capacity of friends, family and practitioners to engage men in timely use of effective supports, to help inform what supports are offered, how they are designed, and when, where, and in what manner they are delivered. Critically, as theory detailed here is grounded in the “lived experience of intersectionality” (Valentine, 2007, p. 18), there is opportunity to disrupt practiced assumptions about what men believe and do and challenge established norms of practice (Hankivsky & Chrisoffersen, 2008, p. 278) related to health services for men. In regard to the research community, this study addresses gaps in current understanding and the findings can stimulate a broader, more inclusive examination of how men navigate a complexity of needs and supports during illness. This focus interrupts narrow discussions of why men are not doing what they should be doing (i.e. seeking medical help), provides an opportunity to complement existing work on men’s help seeking, and encourages a broader scope of attention in future studies.

Finally, this study joins others in recognizing considerations of gender and health as relevant to both women and men. Centrally, it challenges a simplistic response emphasizing a singular or stereotypical view of men as disinterested in health or which seeks to offload the responsibility of men’s health onto women, patterns appreciated as products of a broader social system in the West positioning health as a woman’s issue (and the related positioning of women as “naggers” or “nurturers”; Robertson, 2007; Seymour-Smith, Wetherell & Phoenix, 2002). This orientation not only levels an
additional burden on women, but also creates an environment that positions men who do seek help as ‘deviant’ (McVittie & Willock, 2006; Seymour-Smith et al., 2002) and offers limited health supports and information designed with an informed consideration of men’s needs and preferences (Banks, 2001; Courtenay, 2000b).

**Why Cancer?**

Cancer is the leading cause of death in Canada (Statistics Canada, 2009). Although often discussed as a single disease, cancer is a group of more than 200 diseases defined by uncontrolled cell division and the abnormal tissue growth. Some of these are highly treatable while others are nearly always fatal. In their most recent report on cancer incidence and mortality, the Canadian Cancer Society (Canadian Cancer Society’s Steering Committee on Cancer Statistics, 2011) estimated that more than 177,000 new cases of cancer would be diagnosed in 2011 and approximately 75,000 individuals in this country would die from a form of cancer. More tangibly: 20 Canadians are diagnosed with cancer every hour of every day (CCSSCCS, 2011). Although there is a public perception that cancer is more common (and more deadly) among women (McCreary, Gray & Grace, 2006), Canadian men are more likely to receive a cancer diagnosis (compare 52.2% to 47.8%) and more likely to die from a form of the disease (52.6% vs. 47.4%). Among men, prostate cancer is the most common cancer diagnosis (excluding non-melanoma skin cancers) with an estimated 25,500 new cases in 2011, while lung and colorectal cancers are more deadly, with 11,300 and 5,000 estimated deaths compared with 4,100 from prostate cancer, as predicted for 2011 (CCSSCCS, 2011).

Although much of the existing research on men’s help seeking has focused attention on men with prostate and testicular cancer (forms specific to male anatomy), this study has included the participation of men with a range of cancer types. In this, I have not ignored cancer type or stage in the analysis, but my emphasis has been on commonalities in how a cancer diagnosis and its impacts were perceived and understood by the men, regardless of the location of their disease. Biomedical research considering cancer risks, treatment, and prognosis can benefit from a focus on a single form or stage of the disease, but research examining individual response (i.e. information needs, help seeking practices) can adopt a broader approach (e.g. Leydon et al., 2000; Ziebland et al., 2004). This more
inclusive approach is possible because of how cancer is conceptualized in Western society: not as a complex of related diseases, but as a monolithic, stigmatized and feared illness (Conrad & Barker, 2010; Smith, Pope & Botha, 2005).

More specifically, cancer is distinguished from “lived-with” chronic illnesses such as diabetes in its functioning as a “mortal illness” or a chronic disease perceived as life threatening and associated with long-term impacts, including those beyond consciousness (Conrad, 1987). Consistent with this positioning, in a meta-analysis of qualitative research on cancer and help seeking, Smith and colleagues (2005) found strong commonalities in help seeking across a range of cancer types. Arguing that the process of soliciting medical support for cancer symptoms was distinct from that for other diseases, the authors emphasized the influence of embarrassment over the affected body part and a perception of “cancer” as particular fearsome disease.

With its high incidence, often ambiguous signs and symptoms, difficult treatments, and potential for disfigurement and death, a diagnosis of cancer looms large in the cultural psyche and can be among the most significant experiences individuals face as one diagnosed or in their role as a loved one or care provider. Even more, amidst potent treatments, disruptive to body and mind, and evidence of a high frequency of clinical levels of psychological distress among men in the wake of diagnosis (Goldzweig et al., 2009), the value of understanding men’s use of a range of medical and psychosocial supports is emphasized. Although the base of knowledge has grown, there remains a need for the development of gender-sensitive research and theory development around cancer-related help seeking (O’Mahony & Hegarty, 2009; Smith et al., 2005). As the decision to include men with any cancer type in this study has helped expand the focus of men’s help seeking research beyond prostate or testicular cancer and supported the development of a more inclusive theory of help seeking during cancer, it extends the utility of this research to the experiences of thousands of Canadian men facing a diversity of forms of this disease.

A Note on the Structure of this Dissertation

Central to a grounded theory approach is the principle of theoretical sensitization. Although earlier grounded theorists were encouraged to enter study unfettered by expectations (Glaser, 1978), many now recognize the “difference between an open mind
and an empty head” (Dey, 1993, p. 63). As Dey explained, every researcher brings an array of experience and understandings to her research and the critical concern is how this knowledge is used.

Unlike research that draws on the existing literature to identify “definitive concepts” to measure or test, grounded theorists examine empirical and theoretical work (as well as personal and professional experiences) to attune themselves to contributions and limitations of current understandings and identify useful processes and “sensitizing concepts” (Blumer, 1969). These “starting points” in the analytic process (Charmaz, 2003) orient and broadly guide research as one moves into the field and develops theory. To this end, Corbin and Strauss (2008) argued that researchers should take stock of the values, assumptions, and understandings guiding their questions and process to nurture a “sensitivity,” or an awareness of the “subtleties of meaning” and an ability to identify what is most meaningful (Strauss & Corbin, 1990, p. 41). This is sensitivity gained by examining life from multiple perspectives by comparing, exploring, and building on ideas (Charmaz, 2006). Notably, there is value in a process of theoretical sensitivity across a research pursuit, from before data collection through theorizing (Daly, 2007).

In bringing assumptions and understandings to the fore, theoretical sensitization helps guard against a mistaken belief that an interpretive process is an objective exercise, an orientation that can lead a researcher to force her own ideas (Corbin & Strauss, 2008). More broadly, this process encourages “theoretical playfulness” or an expansion of one’s perspective that enables her to draw on a variety of possibilities, follow leads, and eventually “rein in” ideas that most effectively fit the data (Charmaz, 2006, p. 136). In this spirit, Daly (2007) explained, the process requires that researchers hold understandings “lightly,” giving space to explanations developed in the process of data collection and analysis. In the ultimate pursuit of developing theory, he continued, the sensitizing concepts one identifies in this process of examination and reflection offer suggestions, not prescriptions to guide inquiry. Researchers must be ready to abandon concepts that prove irrelevant to the experiences of those studied (Charmaz, 2006).

Consistent with this framework, this dissertation begins with a review of theoretical and empirical literature (Chapter 2), a discussion organized to identify and
elaborate on sensitizing concepts that have informed this study of men’s health related help seeking. Following this discussion, I detail the research design (Chapter 3) orienting and organizing the process of data collection and analysis, including my philosophical positioning, grounded theory methodology, and methods. In the context of research design, I also discuss the professional and personal experiences I bring to this work, seeking to make transparent my understandings, values, and interests and emphasizing the necessity of reflexivity across this research process (Daly, 2007). Finally, I present the research results, detailing central themes in how the men recognized and responded to needs across their illness (Chapters 4, 5, 6) and offering a substantive theory of men’s health-related help seeking during cancer (Chapter 7). This dissertation concludes with a discussion of how the findings support, extend, or challenge existing research in this area as well as a detailing of the limitations and implications of this study (Chapter 8).
Chapter 2

Sensitizing Literature

Accepting gender as a social force patterning how men experience illness, this review begins with an introduction to what it means to examine health through a gender lens, a discussion highlighting the social determinants of health ideology and detailing the focus of research in men’s health, where much of the work on men’s help seeking is conceptually located. Focusing in on the help seeking literature, I describe shifts in how researchers have examined men’s help seeking and outline what is currently known, empirically, about how men recognize and respond to illness. Highlighting the opportunities and limitations of this existing work, I describe how evolutions in the field of illness behaviour propel new ways of conceptualizing help seeking and detail how a symbolic interactionist perspective re-orient s the examination of men’s help seeking, emphasizing core concepts of identity and definition of the situation.

Gender and Health

As this study examines how men make sense of help seeking during illness, it is important to position this research within the broader domain of gender and health, an area of study recognizing gender (and sex) as influential in health experiences and outcomes (Johnson, Greaves & Repta, 2007). Responding to a long-standing tendency of health researchers to ignore the influence of gender, recent Canadian efforts to integrate gender into studies of health and illness have been dominated by the use of gender based analysis (GBA) or gender and sex based analysis (GSBA), as termed by the Canadian Institutes for Health Research, CIHR (Hankivsky & Christoffersen, 2008). Although it is critical to recognize that there is no “one size fits all” approach in this work (Sharman & Johnson, 2011), GSBA emphasizes the study of health differentials between men and women as it accepts that difference should not be assumed (CIHR, 2010). In this, research integrating considerations of sex- and gender-based factors including genetics, physiological functioning, and socio-cultural forces is oriented toward developing a stronger knowledge base important to enhancing health programs, policies, and research (CIHR, 2010).
Within the framework of GSBA, sex is conceptualized as the biological elements that distinguish males and females, while gender is specific to the social constructions (appearances, behaviours, attitudes) of what it means to be a man or woman. Rather than isolate the study of these forces, it is accepted that sex and gender often interact to influence health (CIHR, 2010). In other words, as men and women are recognized as distinct types of people, different expectations, opportunities, responsibilities are established, a social ordering yielding gendered patterns in health amidst an interplay of internal and external conditions (Annandale, 2009; Denton, Prus & Walters, 2004; Waldron, 1976; Williams, 2003). Or, as summarized by Papanek (1984), “women's and men's health and health needs are different both because of differences in their bodies and also because of differences in how women and men live, work and play” (p. 2).

Notably, while the intention of the GSBA approach is to employ a diversity framework considerate of intersections of race, class, sexual orientation and more, implementation of this approach has been criticized for (a) ignoring men as gendered beings, a limitation noted by others in regard to the field of gender and health (discussed later), and (b) positioning gender as more critical than, and separate from, other social locations in the lives of men and women (Hankivsky & Christoffersen, 2008). As Hankivsky and Christoffersen (2008) argued:

The lack of attention to how gender interacts with or is modified by other determinants of health or in fact may be less relevant than other factors wrongly essentializes the experiences of women [and men], reifies existing inequities among different groups of women [and men] and arguably leads to the production of faulty and incomplete knowledge (p. 273).

As health is influenced by whether one moves through the world as male or female, these are not tidy groups (Annandale, 2003; Schofield, Connell, Walker, Wood & Butland, 2000). What it means to be a man or woman varies across communities, a social reality that contributes to variability in the relationship between gender and health across populations (Doyal, 2000).

In light of this, some argue that researchers must move beyond the current limitations of GBA to engage more fully with the complexity of the social determinants of health, explicitly attending to a richer spectrum of health experiences as influenced by
an array of social locations or intersections (Hankivsky & Christoffersen, 2008).
Notably, although this call centres on the integration of other social identities, it can be extended to an even more inclusive identity-focused framework. As detailed later, a symbolic interactionist perspective has been employed in this study to recognize the complex composition of social locations as well as the intersecting influence of personal identity or that individual biography built and modified over time and place. However, prior to exploring this dynamic, it is necessary to first address the value of adopting a social determinants orientation in the study of gender and health.

**Social Determinates of Health (SDOH)**

A social determinants of health approach to understanding health experiences, outcomes, and discrepancies within communities is founded on an understanding that at this time in history, as illness is more often experienced as a chronic condition than as an infectious disease, how a society organizes and operates has a powerful influence on the health of individuals and communities. As Renaud (1994) explained:

> The ways in which society regulates employment and economic cycles, provides education, assists its members in times of economic or other difficulties, sets up strategies to counteract poverty, crime, and drug abuse and to stimulate economic and social growth have just as much, if not more, impact on health than do the quantity and quality of resources being invested in the detection and care of illness (p. 318).

In Canada, the social determinants of health are identified as including early childhood development, education, employment and working conditions, unemployment and job security, income and income distribution, food insecurity, health services, housing, social exclusion, social safety net, Aboriginal status, disability, race, and gender (Raphael, 2009). The SDOH model accepts that as individuals are inextricably woven into a multilayered, complex, dynamic context, these social placements are associated with different levels of access to power and resources, patterns influencing living and working conditions and the experience of health. In fact, it is argued that these social forces have a more fundamental impact on health outcomes than do individual practices (Mikkonen & Raphael, 2010). As Corin (1994) argued, although social and cultural environments are often perceived as part of the natural order, they are complex,
constructed “systems of interacting variables and processes” (p. 119). Individual acts and discrepancies in clinical experiences of health among groups (see Gil-Lacruz & Gil-Lacruz, 2010) cannot be understood in isolation from a consideration of these social forces. Health is powerfully guided by who one is and where one is (Doyal, 2000).

The SDOH model is enhanced by a consideration of intersectionality, a concept established by critical social scientists, primarily African American women (e.g. bell hooks, Kimberle Crenshaw, Patricia Hill Collins), who challenged the dominant second wave feminist thinking that prioritized gender over all other social identities (Hankivsky & Christoffersen, 2008). As detailed by Hankivsky and Christoffersen (2008), through this lens researchers can appreciate the influence of individual determinants of health not as additive, but as contributing to a complex array of new statuses established at intersections and which are to be appreciated in their full complexity. In this, the authors continue, researchers must refrain from assuming which social locations are most relevant, or most salient within a situation or context while also accepting that a variety of social forces are always at play in health experiences and outcomes.

Awareness of systemic forces influencing individual health experiences and outcomes is linked to contemporary public and clinical health efforts organized around ecological or systems health models, a perspective characterized by an appreciation of the multidimensionality and interdependency of individuals and their environments (Grzywacz & Fuqua, 2000). Amidst a variety of ecological or holistic paradigms researchers can apply to health, Grzywacz and Fuqua (2000) have highlighted Bronfenbrenner’s bioecological systems theory, an approach illustrating the direct and indirect impacts of social networks across context and over time.

Bronfenbrenner’s (1979, 1986, 1994) model attunes researchers not only to individual-level characteristics and goals (ontosystem) but also to the interacting dimensions of one’s social environment, including interpersonal relationships (microsystem), interactions across contexts such as work and family (mesosystem), interactions between social environments, one in which an individual does not participate but is impacted by, such as a partner’s work environment (exosystem), and broad cultural ideologies and policies guiding opportunities and understandings (macrosystem).
Finally, Bronfenbrenner detailed the chronosystem as a way of conceptualizing the influence of temporal shifts in the multiple levels of one’s environment (e.g. family structure, employment status, residence, and cultural ideologies around masculinity).

Awareness of how intersecting social forces influence experiences and behaviours, allows researchers to step past reductionist questions and responses in studies of human health (Grzywacz & Fuqua, 2000). More specifically, attention shifts from a focus on biological markers of disease (e.g. blood pressure) and primary risk factors (e.g. diet) to examine the “causes of the causes” of health and illness embedded in a mosaic of social locations influencing where individuals live and work, their relationships, their access to and use of health care, their exposure and response to stress, how they view and treat their bodies, their health knowledge, expectations, beliefs, practices, and more (Marmot, 2005, p. 2; Nettleton, 2006).

**Examining health and illness through a (kaleidoscope) gender lens.**

Informed by an awareness of the social determinants of health, including emphasis on intersectionality and the social system, efforts to understand and impact the health of Canadian men requires a carefully contextualized approach, both in terms of how issues are conceptualized and how research responds to them. Not only must research accept the interplay of the social and the biological, but it must also ensure that gender is put in its place as one among a variety of inextricable, intersecting forces acting within each life. Particular to this study, this awareness demands that the research process operate on an understanding that in a dynamic and complex social environment there is no single, universal male experience. In adopting this stance, it is important to be clear about how gender is conceptualized.

**Conceptualizing gender.** Detailing limits in how researchers conceptualize gender, Knaak (2004) argued that research can be compromised by a practice Bourdieu, Chamboredon and Passeron (1991) described as “spontaneous sociology.” This method of uncritically pulling popular concepts (e.g. gender) into scientific study, Knaak noted, has resulted in a problematic operationalization of the construct, including a tendency to view gender as a dualism (i.e. men, women) and position it as a social overlay on a biological sex binary (i.e. male, female), assumed as more fundamental. Challenging
researchers to adopt a more sophisticated conceptualization of gender, Knaak identified developments within the literature on gender theory helping to push understanding past a simplistic binary. Among these, she highlighted the integration of (a) a social constructionist paradigm accepting human perceptions as socially filtered, (b) recognition of the multidimensionality of gender, (c) acceptance of gender as a process (rather than a state), and (d) the appreciation of gender as neither dichotomous nor congruent with sex. In addition to detailing and elaborating on Knaak’s framework, I also emphasize (e) an appreciation of gender as relational and (f) how gendered patterns act back onto the body. As these distinctions are critical to the assumptions informing the focus and process of this study, I spend time with each.

**Seeing social first.** Arguing that gender is a more fundamental concept than sex, social constructionists have critically challenged a pervasive assumption of biological primacy. As Knaak (2004) noted, it is the “social institution of gender that makes us see bodies and sexual difference in the particular way we do” (p. 305). Detailed more fully in the latter discussion of the symbolic interactionist perspective, this understanding accepts that how individuals view the world around them, including the structure and functioning of human bodies, is mediated through the social environment. More specifically, although biological evidence emphasizes a complex anatomical and physiological continuum (Fausto-Sterling, 2000), it is according to a social convention of two sexes that each person is assigned at birth to a sex category (male or female) based on the apparent reproductive anatomy. As one does not often display his physical body, this assigned sex category serves as a proxy for sex (West & Zimmerman, 1987).

From infancy then, individuals learn how to locate themselves as male or female through social expectations communicated by family, peers, teachers, and others (Stewart, 2003). This process guides how a person is socialized into understandings, activities, and relationships and it influences how individuals learn to express themselves throughout life; how they present as men and women. Although exposed to a variety of gender norms (i.e. socio-historical and culturally specific expectations of how men and women should look, think, feel, and behave) according to intersections of race, class, sexuality, age and other social locations, individuals develop a gender identity, or a sense
of ‘self’ as male or female, in a social world where *taught* differences are often treated as biological facts (West & Zimmerman, 1987).

**Gender as multidimensional and multifaceted.** Gender theorists reject a simplified conceptualization of gender as a distinct, individual-level attribute, instead positioning it as both multidimensional and multifaceted (Knaak, 2004). Thus oriented, Knaak detailed, it is accepted that human practices, perceptions, relationships, institutions, and cultures are gendered. Included in this recognition of how gender functions at multiple levels, is acceptance that gender cannot be disentangled from other social identities positioning persons as similar to some and different from others. As noted earlier, researchers accept a kaleidoscoping of gender norms over time and place and with intersections of age, class, race, sexual orientation, and other forces.

However, concurrent with this array of ways to perform as a man or a woman exist powerful, practiced, and *idealized* images of masculinity and femininity (Connell, 2009). As Kimmel (2000) explained, not all “masculinities and femininities are created equal” (p. 91). Although meanings of what it means to be male and female are mediated through the social environment, Knaak (2004) reminds that this heterogeneity is balanced by an appreciation of a certain degree of cohesion of men and women as groups in the shadow of powerful societal ideals. Later, in the context of literature on men’s health related help seeking, I describe and discuss the patterns associated with idealized or hegemonic masculinity (Connell, 1987).

**Gender as a verb (not a noun).** Encouraging a more sophisticated conceptualization of gender, Knaak (2004) has also pointed to theoretical work emphasizing gender as an act, rather than a state. Most notably, West and Zimmerman (1987) argued that as men and women learn societal scripts detailing cultural and socio-historical expectations for how to manage their appearance and acts, they are learning how to “do gender” in manners consistent with societal expectations, scripts varying according to intersections of identity. In this, gender is accepted as a dynamic, interactive performance, rather than a stable individual attribute, and researchers can anticipate a range of normative expressions of masculinity and femininity over time and place. This understanding is key to individual and group level variability in gender performance.
However, the potential for variability is restrained by powerful social cues. As individuals work together to maintain a society in which men are like this and women like that, sedimentation of expectations and performances can lend an appearance of truth, imparting moral implications to an individual’s ability to follow binary patterns of appearance and behaviour prescribed for men and women (Connell, 2009). Certainly, a credible performance as a woman or man in a workplace today may not be what it was in 1950 and it might not be the same in a doctor’s office, a sports field, or a street corner, but there are sub-sets of rules, or social scripts, outlining which performances are more credible than others within each context. Thus, while gender is inherently fluid, few societies sanction much fluidity (Stewart, 2003). In this social reality, maintained at the micro and macro levels, and experienced at a personal level, it is easy to mistake gender for something one is, rather than what one does.

**Moving beyond binaries.** Although gender is often perceived as a dichotomous variable congruent with sex in popular and academic discourse, gender and queer theorists have critically challenged this view. Beyond the recognition of masculinities (Connell, 1995) and femininities, there is acceptance that gender identity is not strictly tied to sex (Knaak, 2004). Many perform gender in ways consistent with social parameters outlined according to assigned sex categories, but female bodies can perform masculinities and male bodies can perform femininities (e.g. see Halberstam, 1998 for a discussion of female masculinities). Or, as Butler (1999) argued, one can “trouble” gender. Not only are bodies more complicated than society constructs them to be, but a variety of transgender realities, from transsexual to drag to gender queer, evidence how individuals challenge normative links between sex category, gender and even sex.

**Gender as relational.** An understanding of gender as relational underlies the previous elements, but is important to emphasize amidst a tendency to treat masculinities and femininities as distinct. In focusing on the complex lives of men or of women, a researcher can lose sight of the inter-relationships, or neglect the social reality that these performances are built in relation to each other. As Kimmel (2000) noted, “men construct their ideas of what it means to be man in *constant reference* to definitions of femininity” (p. 90, emphasis his) and vice versa.
Guiding this relational assessment of “appropriate” gender performance across situations, is what Connell (2009) described as the gender order. Broadly, the gender order is a tool of social organization, operating through social institutions (education, medicine, politics, religion, media, family, etc.) and infusing the sense of what constitutes normal or natural relationships. It is not deterministic, Connell explained, but does outline parameters of socially sanctioned gender performances both between men and women and within these groups. Thus, when research considers gender at a situational, institutional or societal level, it is examining relationships: “ways that people, groups, and organizations are connected and divided” (Connell, 2009, p. 73).

**Gender performance moulds bodies.** As this discussion positions gender as a complex, constructed social performance, it is important to emphasize that these patterns have powerful implications for the body. As Connell (2009) noted, although the gender order is a social arrangement humans “bring into being,” researchers should not underestimate its influence on daily life. Just as individuals view the physical through a social lens, gendered understandings and related practices are written back onto bodies. In this, there is a “symphysis” or fusion of nature and nurture as social forces guiding how men and women perceive and perform bodies influence their physiological condition (Annandale, 2003). Or, as Butler (2004) argued, although individuals lay claim to bodies as something that is their own, they are “given over from the start to the world of others, bearing their imprint, formed within the crucible of social life” (p. 21). I provide a more detailed illustration of this idea later in the section on exposure to health risks.

**Summary.** As detailed over these sections, the integration of gender into academic study requires a rejection of much of what is often assumed about this concept. Gender is not a tidy social overlay on sex (an untidy structure itself), but rather a multidimensional, multifaceted, and dynamic process that takes on a variety of meanings at an array of levels according to cultural ideals and an individual’s social position. At the intersection of body and society, how an individual performs gender is not determined, but it is guided by strong social cues varying by intersections of identity and context. One can challenge expectations of how men and women should look or act, but performances always occur in the shadow of the gender order, a powerful pattern of
social organization positioning some ways of being as more valid. In this, the social and the biological remain intimately linked, as gender performance is initiated by biological cues and gender patterns “reach deeply into the body’s interior” (Annandale, 2003, p. 9).

In accepting gender as neither natural nor automatic, it is recognized as work, a social process with physiological impacts. It is no simple task to translate the complexities of this understanding into research methods. But this conceptualization of gender encourages researchers to stay nimble, with minds open to possibilities and diversities as they explore the health and illness experiences of men and women. More specifically, through this lens, research can explore the association between gender and health as evident in how individuals are exposed to health risks and how they respond to diseases, dynamics I discuss in turn.

In detailing these processes, it is of note that much of the broad-level work I present here attends to how men and women cohere as groups, rather than speaking to heterogeneity within these populations. Thus, the dynamics observed at this level do not speak to a diversity of individual experience, nor do they adequately address patterns among sub populations of men and women. However, this work holds value in highlighting broad processes related to health differentials between men and women and offers important illustrations of how body and society entangle. The intention is that this appreciation is not confined to these few examples, but that this review stimulates consideration of the many ways human health is socially influenced.

**Exposure to health risks.** Socio-historical and cultural expectation of men and women influence health as they guide the work men and women tend to do, the leisure in which they engage, what they wear and eat, and more. As detailed by Mikkonen and Raphael (2010), the current gender order yields a structure in which Canadian women tend to face systemically lower income opportunities and a greater burden of responsibility for childcare and housework, forces limiting access to social and economic resources, a key factor in health (Doyal, 2000). Among men, gender patterns emphasizing men as self-reliant and aggressive have been linked with heightened risks for social isolation and violence (Mikkonen & Raphael, 2010). Expanding on this dynamic, Courtenay (2003) argued that evidence building since the 1970s suggests that
men are more likely than women to engage in over 30 behaviours that increase the probability that they will experience injury, disease, and death including risk taking, abuse and substance use.

As gender patterns influence the daily lives of men and women, the impact is not just at the level of access to resources or differential risks for acute injury. As noted, these dynamics move into the body, influencing physiological functioning and altering the risks men and women face for chronic disease. Biologist Fausto-Sterling (2005) highlighted this integration through a focus on bone development, an area of study strongly oriented around assumptions of sex differences. Based on an awareness that isolated biological understandings are insufficient and misleading (Fausto-Sterling, 2003), she considered how gendered patterns in physical activity, diet, sunlight exposure (i.e. vitamin D), and smoking influence male and female osteo-anatomy over the lifecycle. Later, in a similar article focused on social patterns associated with race/ethnicity, she reiterated her claim that the “social produces the biological in a system of constant feedback between body and social experience” (Fausto-Sterling, 2008, p. 658, emphasis hers).

Similarly, Annandale (2003) has argued that a rise in skin cancer incidence and mortality among men is, in part, linked to social customs. Highlighting how shifting social expectations influence disease rates, she explained that as tanning gains favour with populations of men, they are less likely than women to protect themselves and more likely to have exposure on their back due to gendered clothing styles. This patterning results in a higher incidence of mid-back lesions among men, a site with worse prognosis than that most common among women: lower limbs. A similar rationale is commonly detailed to explain rising levels of lung cancer among women as linked with shifting social norms about the acceptability of women smoking.

As these examples demonstrate, gender cannot be dismissed in studies of health risk. While sex-specific differences (e.g. hormones, anatomical structures) can place men and women at risk for certain disease forms and progressions, a powerful and dynamic social reality is also at play. These realities, linked to the SDOH, can be challenging to measure at an individual level and will vary across populations, but they demonstrate
how gender influences how bodies are exposed to acute and chronic health risks. As Phillips (2005) argued, while it might not be accurate to consider gender as a cause of disease, it is part of the differential diagnosis.

**Response to illness.** More central to the focus of this study, gender is also relevant to how men and women subjectively experience, respond to, and report illness. To understand this patterning it is first necessary to delineate illness from disease. Although influenced by social forces, medical sociologists define disease as a physiological condition or biomedical state whereas illness is a subjective state of mental or physical imbalance or disrupted well-being (Brown, 1995; Cassel, 1976; Lorber & Moore, 2002). As Cassel (1976) succinctly explained, disease “is something an organ has; illness is something a [person] has” (p. 27). Disease can be a symptom’s source, but the interpretation of a sign as illness and the labels applied to it are social processes. In all cases, illness definitions are social constructions, although some are accepted as biomedical diagnoses while others remain as informal conditions (Brown, 1995). As elaborated later in the section on help seeking theory, the distinction between illness and disease is critical to understanding variability in illness experience (Mechanic, 1995).

It is not uncommon to encounter studies indicating that relative to women, men have a lower incidence of illness (Denton et al., 2004; Verbrugge, 1985). This pattern is often held in contrast to epidemiological reports indicating that men die earlier than women in Canada and most developed countries (Statistics Canada, 2008; United Nations, 2007) and face higher rates of mortality for 9 of the 10 leading causes of death, including cancer, heart and respiratory diseases, diabetes, and accidents in this country (Statistics Canada, 2008) and in the United States (Heron et al., 2009; Williams, 2009). Risks are even greater for sub-populations of men, including racial and sexual minorities and men with low incomes (Courtenay & McCreary, 2002; Williams, 2003). In the context of this data, Macintyre, Hunt, and Sweeting (1996) have noted, the perception that “women are sicker, but men die quicker” has achieved the level of paradigm, influencing both research and policy decisions and fuelling a cultural level association of women with illness and men with health (Williams, Annandale & Tritter, 1998).
However, some scholars have challenged this paradoxical pattern by moving discussion beyond a focus on epidemiological rates to examine the assumptions underlying this research. Most centrally, although morbidity data are often treated as objective measures of disease, it is increasingly accepted that these figures also reflect how individuals subjectively assess, understand, and respond to illness (Lorber & Moore, 2002; Mechanic, 1978; Verbrugge & Wingard, 1987). If, as research suggests, women are more likely than men (on average) to recognize concerns, discuss health, and seek help before an illness is severe, they will appear more ill in the epidemiological accounts; their morbidity rates will be higher, and researchers will assume women are sicker (Lorber & Moore, 2002; Verbrugge & Wingard, 1987).

As this flawed assumption informs an inaccurate portrayal of the health of men and women it also obscures a more interesting pattern: the social forces inflating women’s morbidity rates (i.e. willingness to talk about health and seek help before a condition is severe) might also support lower death rates by ensuring earlier diagnosis (Lorber & Moore, 2002; Verbrugge & Wingard, 1987). As Lorber and Moore (2002) noted, “women are not more fragile physically than men, just more self-protective of their health” (p. 18). Read in reverse, men are not more robust against illness, they are just less protective of their health.

Although it is wise to avoid simplified refrains in reference to health and illness, evidence suggests that men in Western societies tend to engage fewer health-promoting practices relative to women. In addition to participation in practices that carry greater health risks (detailed above), men, on average, also evidence more limited use of health services. Recognizing differential health outcomes as in part influenced by modifiable behaviors (Courtenay, 2003; Denton et al., 2004; Robertson, Galdas, McCreary, Oliffe & Tremblay, 2009) researchers interested in men’s health have noted evidence suggesting that despite their elevated health risks, men in Canada and the United States (especially those under the age of 65) tend to visit health providers at a lower rate than do women, even when accounting for obstetrical visits (Bertakis, Azari, Helms, Callahan & Robbins, 1999; Blackwell, Martinez, Gentleman, Sanmartin & Berthelot, 2009; Lee & Owens, 2002; Nabalamba & Millar, 2007; Pinkhasov et al., 2010).
In the context of a more complex appreciation of gender, these patterns are recognized not as individual level concerns: women are not *naturally* any better at caring for their health than are men. Instead, health behaviours and constructions of illness are accepted as gendered. There are different norms for men and women, including that women are socialized to be more attuned to health matters and more engaged in the health system relative to men, expectations that are maintained at the institutional level in regard to health service development and delivery. Further, there are gendered expectations for illness prevalence and presentation (consider heart attacks vs. depression) influencing how patients and practitioners respond to signs and symptoms of disease. To be clear, I am not suggesting that women are privileged in this dynamic; patterns in the social environment can critically compromise the health of girls and women, including access to resources and an expectation of women as more responsible when it comes to health matters. Instead, I am emphasizing that awareness of gendered expectations around health risks and behaviours and illness presentation and response helps avoid reliance on isolated biological interpretation of epidemiological findings in understanding health and illness patterns.

**Focusing in on Men.** As feminist scholars led an explosion of research on gender and health in the 1960s and 70s, researchers were slow to accept men at risk, particularly given their greater economic and social status (Courtenay & Keeling, 2000). As medical and social research long integrated men’s bodies and experiences as normative, limited attention had been devoted to masculinity as a factor in health (Sabo, 2004; Watson, 2000). Good, Sherrod & Dillon (2000) emphasized this point in reporting a ratio of one article on men’s health for every 47 articles on women’s health between 1959 and 1998. This absence of attention is consistent with a broader trend in which men’s dominant social positioning has obscured an awareness of how their lives, like women’s, are gendered (Doyal, 2000, Kimmel, 2007). Not surprisingly, “gender and health” became synonymous with “women’s health” (Annandale, 2009).

Although attention was delayed, some researchers in the 80s and 90s began to recognize men’s health as influenced by “what it means to be a man” (Courtenay, 1998, p. 279). Although an admittedly obscure state (Schofield et al., 2000), this lens enabled
scholars to examine the influence of masculinity and gender relations in how men experience health and illness, rather than limit focus to the study of male-specific diseases (Robertson, 2007; Sabo, 2000). In the pursuit of expanding consideration beyond the terrain of the male body, the Men’s Health Forum (2004) broadly defined men’s health issues as those arising “from physiological, psychological, social or environmental factors which have a specific impact on boys or men” and requiring specialized interventions for “boys or men in order to achieve improvements in health and wellbeing at either the individual or the population level” (p. 5). In this focus, the study of illness in men (i.e. men’s health) is critically distinguished from men’s health studies, an arena of exploration considerate of the broader social influences on health (Robertson, 2007).

Although initially oriented around the ‘hazards’ of the male gender role, critical feminist theory of the 1990s emphasized the necessity of contextualizing individual-level behaviours with recognition of structural power relations among men and between men and women (Sabo, 2004). As this awareness elucidated diversities among men as influenced by intersections of race, class, sexual orientation, disability, and other social locations, researchers continue to be encouraged to move beyond discussions of how adherence to a hegemonic (Connell, 1987), or idealized, masculinity ideology propels unhealthy behaviours (including resistance to help seeking) and consider a wider range of male experience (Crawshaw & Smith, 2009; Galdas, 2009).

In addition, some have called for greater integration of relational theories attending to connections in the health of men and women (Sabo, 2004; Schofield et al., 2000). Instead of treating men’s health as distinct from women’s, the relational approach links health outcomes of both groups, arguing that patterns in gender relations limit or enable health opportunities (Sabo, 2004; Schofield, 2000). Bird and Rieker (2008) described this as “constrained choice,” arguing that policies and practices in the home, workplace, community and government “differentially shape the health-related choices of men and women” (p. 54). In combination, these efforts are guided by the recognition that an “adequate theory of masculinity” cannot ignore the diversities among men nor the power relations infusing the gender order (Robertson, 2007, p. 32).
Summary. Recognition of the influence of gender on the experience of health and illness is a critical foundation for this study. In appreciating gender as a dynamic process entwined within a network of social identities and forces, and embedded within a broader social context, researchers can anticipate diversity amidst groups of men and variability within an individual’s experience and avoid facile, essentialist answers that offer little appreciation of the complex socio-cultural, psychological, and biological processes at play in health (Mechanic, 1978).

There is a need for research that adopts this inclusive approach. As developments in men’s health studies enable a richer understanding of how gender influences men’s experiences of health and illness, Robertson and colleagues (2009) have argued that there remains important research, policy, and practical work to be done to support Canadian men’s health in a way that attends to the powerful influence of social context and a diversity of identities. In particular, despite Canada’s leadership in social determinants of health, neo-liberal, or market-driven, approaches to health policy in this country have prioritized attention to efforts focused on driving individual lifestyle change. In this focus, there has more limited attention to systemic concerns, including “upstream” matters of men’s health (i.e. prevention of illness and promotion of health) and research and policy focused on developing and delivering gender-aware health services for men that complement the promotion of women’s health (Robertson et al., 2009).

Understanding Help seeking

Moving forward, there is value in summarizing the existing literature on men’s help seeking, identifying the knowledge presented in this current work, and detailing how research in this area can be challenged to enhance an understanding of how men respond to illness. To this end, I outline how the study of men’s help seeking has evolved over the past three decades and detail what is known about how men recognize and act on health concerns. Next, I identify several limitations in this work and describe how theoretical developments in the field of illness behaviour can critically inform research on men’s help seeking.

Following a brief introduction to the illness behaviour field, I introduce two orientations to conceptualizing help seeking: a dominant rational choice model and the
dynamic approach. Arguing for the integration of a dynamic orientation in studies of
men’s help seeking, attention is then devoted to how recognition of help seeking as an
interactive, on-going process propels a reconsideration of core concept of help seeking.
Notably, across this discussion, emphasis is on men’s help seeking in the context of
actual or feared illness, a process recognized as distinct to help seeking in regard to health
promotion (Robertson, 2007).

**Evolutions in the Study of Men’s Help Seeking**

As detailed by Addis and Mahlik (2003), over the past thirty years much of the
research on men’s help seeking has focused on sex-comparisons, a pattern consistent with
larger trends in men’s health research (Schofield, et al., 2000). This body of primarily
quantitative work has provided conflicting results amidst inconsistent use of measures
and data collection instruments (Galdas et al., 2005), but it has established a compendium
of data suggesting that men are less likely than women to seek medical help, tend to ask
fewer questions and receive less information when meeting with practitioners (see Addis
& Mahalik, 2003; Courtenay, 2000b; Lee & Owens, 2002; Williams, 2003). Although
garnering attention to men’s experiences, this approach has been criticized as it obscures
differences among men and similarities between men and women, is unable to explain
processes linked to variations, and it fuels stereotypes about its subjects (Addis &
Mahalik, 2003; Galdas, 2009; Schofield et al., 2000).

A second approach in men’s help seeking and men’s health research has been to
examine how gender role socialization impacts behaviour (Addis & Mahalik, 2003;
Good, et al., 2000; Moynihan, 1998), an approach consistent with the assumptions of sex
role theory. Positing that individuals are socialized to develop traits appropriate to their
sex, sex role theory replaces biological essentialism with a more social form (Connell,
2009; Messner, 1998). Giving tangible form to the dangers of the male sex role,
Brannon’s (1976) typology of masculine stereotypes has been influential in men’s health
(Pietila, 2008) and is evident in this work as men are described as oriented away from
“sissy stuff” or anything feminine, seeking to perform as the “big wheel” and the “sturdy
oak” as they demonstrate superiority and self-reliance, and to be willing to “give ‘em
hell” or demonstrate power, including through violence (Brannon, 1976).
In early iterations of sex-role theory it was argued that socialization functioned to allow men and women to fulfil distinct societal needs. However attitudes evolved as scholars refuted a core assumption that men and women are opposites and argued that the sex role system itself (i.e. expectations of how to be a man) is not functional, but levels contradictory and even damaging demands (e.g. Bem, 1979; Pleck, 1981). Along with feminist critiques, these arguments made problematic a single developmental path and gave rise to the theories of gender role strain and recognition of masculinity ideology as linked to socio-historical norms (Smiler, 2004). In particular, Connell’s (1995) notion of masculinities encouraged the recognition of a variety of ways of performing masculinity, varying by complex and intersecting social forces such as race, sexual orientation, and class, and carrying unequal power and different behavioural expectations.

In quantitative research, the sex or gender role lens has guided the use of ideology and conflict scales and in qualitative studies it has served as an assumptive base in exploring how men perceive, define and react to symptoms. In both realms, research pursues intra-psychic factors (i.e. norm adherence) to predict or explain help seeking patterns or offers structural arguments that health services are not conducive to male traits. As authors draw on gender role socialization and norms to make sense of men’s actions, this research sensitizes understanding of how cultural ideals around the male body and character can limit a man’s abilities to recognize a need for help or view help seeking as an obvious solution (Addis & Mahalik, 2003; Galdas et al., 2005; Good et al., 2000; Lee & Owens, 2002). As Kimmel (1995) tangibly illustrated: “real men don’t get sick, and when they do […] real men don’t complain about it, and they don’t seek help until the entire system begins to shut down” (p. viii).

In accepting variability among men, research informed by a sex role approach fills a gap left by sex-comparison work (Addis & Mahalik, 2003). However, by treating gender as a trait, this lens is unable to handle the influence of situational context, leaving a key clinical question unanswered: “Why are some men, under some circumstances, able and willing to seek help for some problems but not for others?” (Addis and Mahalik, 2003, p. 7; see also Galdas, et al., 2005). Although the sex role model remains a popular understanding of gender, it is criticized for assuming a dominant ideology is the norm,
treated gender as passively acquired, maintaining an essentialist and polarized characterization of gender, and as insufficiently attuned to power issues between and among men and women (Connell, 2009; Kimmel, 2007).

In levelling this critique of sex role theory, social constructionists have propelled a third approach to theorizing men’s help seeking (Addis & Mahalik, 2003). Although accepting that individuals learn social norms outlining expectations for appearance and act, constructionists argue that men and women manage their actions according to the situation to make their gender accountable to others present. As detailed earlier, gender is accepted as something one “does,” not who they are (Connell, 2005; West & Zimmerman, 1987). In any given situation, a man might follow a range of gender norms, challenge them, or step around them, but he acts knowing that others are evaluating whether his behaviour is appropriate for a man (West & Zimmerman, 1987). As Kahn (2009) described, through this lens masculinity is appreciated not as a condition, but as a cluster of experiences: “the complex cognitive, behavioural, emotional, expressive, psychosocial, and sociocultural experience of identifying with being male” (p. 2).

In acknowledging different ways of being a man, a social constructionist approach also accepts that certain ways of being a man carry more power or influence than others. More specifically, there is recognition of a hierarchy of masculinities (Connell & Messerschmidt, 2005), oriented toward a hegemonic ideal (Connell, 1995). The most valued way of being a man is recognized as shifting over time and place, though it is commonly recognized in Western cultures as associated with strength, success, control, capability and reliability (Kimmel, 1994). Few men can consistently claim these idealized qualities as many are marginalized or subjugated by virtue of age, social class, religion, race, ethnicity, sexual orientation, ability, health status, or other qualities. However, in this shadow, men work with others to comply (albeit imperfectly) with the dominant image, protest it through hypermasculine displays, or resist it, a process allowing for some patterning within groups of men (notably, though, Connell and Messerschmidt (2005) explicitly reject interpretations positioning this as a cataloguing of male types). In this social dynamic, performances of masculinity are recognized as not only multiple and socially built, but also carrying important opportunities for retaining,
regaining, or releasing power.

Within this perspective, health behaviours are viewed as performances of masculinity (Galdas, 2009; Moynihan, 1998), or as Noone and Stephens (2008) noted, “‘doing’ health reflects ‘doing’ gender” (p. 712). Through this lens, research accepts that a man’s help seeking behaviour might vary not only by his demographics, but also according to the situational context, the type of help needed, expectations of others (including institutional forces), and the risks of not obtaining support (Addis & Mahalik, 2003). Further, there is space to consider the health implications of men’s efforts to match their acts to the prioritized way of being a man (Courtenay, 2000b) and awareness that help seeking is influenced by shifting constructions of masculinities over time and place as men build meanings of masculinity with others and in relation to femininity norms (Noone & Stephens, 2008; O’Brien et al., 2005).

Oliffe (2007) argued that as the study of men’s health has been limited by a lack of attention to the context of men’s lives, a social constructionist lens offers an important opportunity to access “commonality as well as diversity” (p. 6) in how masculinities intersect with behaviors across the complexity of individual lives. Even more, a constructionist approach positions researchers to respond to the important criticism that the field of gender and health, in general, must more fully engage with the complexity of the social determinants of health and a richer spectrum of health experiences as influenced by an array of social locations, or identity “axes” (Hankivsky & Christoffersen, 2008). As space is made for variability among men and across one man’s experience, research from this perspective can actively oppose essentializing assumptions while also avoiding attributions of deficiency associated with masculinity.

**Empirical understandings of men’s help seeking.** Recognizing that sex-comparative research tells little about the nature of differences (Mechanic, 1978) and obscures diversity among men (Addis & Mahalik, 2003), this review focuses on research specifically examining help seeking among adult men in Western nations and in regard to physical illness. Much of the literature exploring these experiences is qualitative and focused on samples of men with prostate or testicular cancer or coronary heart disease, although relevant quantitative studies and reviews of help seeking associated with
broader health issues are also included. Notably, the relative majority of this literature emerges out of Western Europe, particularly the UK and Scotland, with more limited research from Australia, the United States, and Canada. Integrating gender role and social constructionist literature, this discussion is presented in two parts: what the literature says about how men (a) recognize and (b) act on concerns. As much of the existing work samples white, heterosexual, middle-class men, there is limited attention to masculinities. However, as possible, I integrate literature on patterns observed among lower socio-economic class men as well as men with disabilities and racial and sexual minorities.

**Recognizing concerns.** In the general literature on cancer-related help seeking, there is awareness that men and women can struggle to recognize symptoms of disease, particularly when these present as vague, unfamiliar, or if they perceive themselves as not at risk for a condition (Smith et al., 2005). Similarly, research focused on men points to delays in help seeking as men struggle to identify symptoms (particularly in absence of pain), normalize signs as having an alternate source (e.g. trauma, fatigue, stress) and/or trust that a condition will dissipate in time (Chapple, Zeibland & MacPherson, 2004; Gascoigne & Whitear, 1999; O’Brien et al., 2005; Richards, Reid, & Watt, 2002; Sanden, Larsson & Eriksson, 2000; White & Johnson, 2000). These patterns are not fully unique to men, but research suggests that men’s willingness to attend to physical shifts can be additionally constrained by gendered processes limiting their knowledge about health and comfort in taking too close of an interest in their bodies, viewing this as a feminine practice (O’Brien et al., 2005; Lee & Owens, 2002; Noone & Stephens, 2008; Robertson, 2003). As Courtenay (2000a) argued, social expectations of men as the stronger sex are maintained when men take risks and dismiss health needs.

More specifically, White and Johnson (2000) described men’s challenges in recognizing illness as a process of denial and rationalization, arguing that men can find it difficult to see themselves at risk, viewing acceptance of bodily dysfunction as a challenge to male invincibility. This notion resonates with Ollife’s (2007) description of how men in his study felt pressured to deny or conceal illness amidst social expectations of “a functional, resilient, ‘hard’ masculine body” (p. 9) and McVittie and Willock’s (2006) observations that men associated illness with a subordinated masculinity, a
perception compromising their willingness to seek help (and take on that altered way of being). Drawing on Foucault’s notions of “gaze” and “surveillance,” White and Johnson argued that as men try to make sense of bodily shifts they feel the gaze of family, friends, and health practitioners. This process is fundamentally problematic as men pursue an unattainable ideal of masculine form and action and often lack the medical knowledge to assess disease conditions. Moynihan (1998) described this as the “heavy burden of maintaining what we have been led to believe is ‘the making of a man’” (p. 1074).

Variability among men. The characterization of men as struggling to acknowledge their vulnerability is consistent with hegemonic masculine ideals. However, research indicates that not all men seek to (or are able to) comply with this directive. For example, Richards and colleagues (2002) reported class differences in how men perceived their risk for cardiovascular disease. Men from a poorer area were acutely aware of their vulnerability as they identified with a specific region marred by high rates of heart disease. As one man noted; “if you are looking for a candidate for a heart attack, you’ve come tae [sic] the right area” (p. 2). The authors contrasted this with responses from affluent participants who believed they held more control over their health, attributing heart disease in their family as related to poor lifestyle choices (mistakes they would not make). Similarly, Rose, Kim, Dennison and Hill (2000) found that although the African American men they interviewed accepted responsibility for dealing with high blood pressure, some perceived the condition as inevitable; as a “black disease.” (Notably, the heightened sense of vulnerability among the men of poorer economic standing and the black men in Rose et al.’s, study was not associated with increased help seeking.)

Acting on concerns. Even when symptoms are accepted as problematic, research indicates that men might continue to delay clinical engagement. In the general literature on help seeking, research suggests that men and women can struggle to engage medical supports due to fears of embarrassment in wasting a physician’s time or exposing a sensitive part of their body (Smith et al., 2005). Similar patterns have been observed in gender-specific research, as men are characterized as inhibited by concerns that they will be perceived as a hypochondriac (Chapple et al, 2004; Galdas, Cheater & Marshall, 2007; Gascoigne & Whitear, 1999; O’Brien et al., 2005) and struggling with painful and
embarrassing procedures, particularly as focused on private areas of the body (Chapple et al., 2002; Chapple et al., 2004; Evans et al., 2005; Gascoigne & Whitear, 1999; Shoveller, Knight, Johnson, Oliffe & Goldenberg, 2010). Further, men are described as particularly reticent around help seeking for emotional or mental health challenges (Addis & Mahlik, 2003; Moller-Leimkuhler, 2002; Moynihan, 1998; Galdas et al., 2005).

At a more fundamental level, discussions of restraints to men’s help seeking often carry the refrain that men are simply not as comfortable or as interested as women in matters of health. For example, researchers report that men tend to position women as regular-users of health care, as more interested in health, as having fewer ‘hang ups’ with discussing personal matters, as more able to practice healthy behaviours, or simply as more familiar with the health system (Chapple et al., 2004; Gasciogne & Whitear, 1999; Noone & Stephens, 2008; Robertson, 2003). Similarly, research by Seymour-Smith, Wetherell and Phoenix (2002) found that health practitioners were well versed in “what men are like,” endorsing dominant masculine ideals as they affectionately chided men as “hapless and helpless” in health matters and women as responsible, if a bit neurotic (p. 265). Notably, men who stood outside of this hegemonic form, including men without female partners (single and gay men) or who were perceived as “more feminine,” were invisible or seen as trivial users, akin to women (Seymour-Smith et al., 2002).

Embedded in these claims is the belief that health is a woman’s domain, an orientation pervading public discourse on men and health (Oliffe, 2007). As Oliffe (2007) argued, health practices are often associated with “feminine ideals of fragility, gentleness, and nurturing” ways of being recognized as the “antitheses of the robustness, stoicism, and self-reliance expected of men” (p. 3). Further, clinical help seeking has been described as disruptive to a masculine performance characterized by stoicism and strength (Chapple et al, 2004; Moynihan, 1998; O’Brien et al., 2005; Rose et al., 2000; Tůdiver & Talbot, 1999; White & Johnson, 2000), themes consistent with quantitative research highlighting correlations between adherence to traditional masculinity beliefs and perceived barriers to help seeking (Boman & Walker, 2010; Mahalik, Lagan & Morrison, 2006; Mahalik, Levi-Minzi & Walker, 2007; Wade, 2009). A feminizing of health participation is also maintained at an institutional level as
disengagement is perpetuated by a health system that does not always anticipate men’s participation or interest in health. Describing health settings as “no man’s lands” (Banks, 2001), some have argued that services can fail to consider men’s preferences in the development and delivery of health messages (Smith et al., 2006) as they target health information at girls and women (Courtenay, 2003).

Acknowledging this positioning of health engagement as a more feminine practice, some have taken care to emphasize that limited or delayed help seeking should not be taken as an indication that men do not care about their health. In particular, Robertson (2003, 2006) theorized that in a Western society where “good health” carries moral implications, men are challenged to balance a need to show they do not care about health with a belief that they should, what he described as the “don’t care/ should care” dilemma. In this social system, men can feel a responsibility to legitimize or justify their health behaviours, including their decisions to solicit supports (Robertson, 2003; Noone & Stephens, 2008; O’Brien et al., 2005), a patterning that resonates with the sociological notion of “accounts,” or statements individuals make to explain unanticipated behaviour (Scott & Lyman, 1968). In this awareness, discussion shifts from an assumption that men are not interested in their health or too stubborn to ask for help, toward a consideration of how men present themselves as ‘reasonable’ users of the medical system.

In a study of how men move toward the medical system, Smith and colleagues (2008) argued that men who might appear disinterested in health are actually engaged in a process of “self monitoring” to determine how best to “fix” the problem and get back to normal functioning. To this end, they described how men in their study engaged a period of information gathering, or “detective work,” following problem recognition, a practice allowing them to gather information necessary to making a decision about whether it was necessary to seek medical help. This research importantly resists assumption that men are inactive during this time. However, it must also be recognized that the process by which men assemble “facts” and decide how to respond is not divorced from gendered patterns and discourses influencing how men relate to their bodies and interpret legitimate engagement with the health care system. How men assess health and interpret illness is a process located with a particular social environment (see Saltonstall, 1993).
Those exploring ‘triggers’ toward medical supports have described men as delaying medical help seeking until pain escalates, there is a visible aberration or rapid change in signs or symptoms, or they experience complications making functioning problematic (Gascoigne & Whitear, 1999; Sanden et al., 2000; Smith et al., 2008; White & Johnson, 2000), a pattern of avoiding disclosure until absolutely necessary that can continue after diagnosis (Gray, Fitch, Phillips, Labrecque & Fergus, 2000). Notably, these triggers are not dissimilar from those identified in the broader population. As Mechanic (1995) argued, although physicians focus attention on identifying and treating underlying pathogens, patients (or future patients) are responsive to pain or discomfort, restrictions, and disruptions to well-being, an orientation that can delay an awareness of the presence of disease and the need for medical support. However, as men feel pressured to justify their engagement, the threshold of evidence might be higher.

Moving beyond individual-level perceptions, some have also considered relational factors influencing men’s movement toward medical supports. In this work, female partners (and other women in a man’s life) are often positioned as responsible for men’s health (Lee & Owens, 2002), key supports (Rose et al., 2000) and/or “tipping points” for help seeking or engagement in treatment (Chapple et al., 2002; Gascoigne & Whitear, 1999; Norcross, Ramierz & Palinkas, 1996; Parslow, Jorm, Christensen, Jacomb & Rodgers, 2004; Tudiver & Talbot, 1999).

Although evidence indicates that women can be influential, qualitative work suggests a more complex interaction than a simple matter of pressure and response. White and Johnson (2000) found that as men described partners as helping them sort through a response to symptoms, their stories indicated a pattern of yielding “control” to their wives only after they had accepted a need for help. Similarly, men in O’Brien and colleagues’ (2005) study positioned wives as validating existing concerns. As one man noted, “If it’s suggested to you that you shouldn’t be making an issue of your health, then you almost need somebody else to say to you ‘right, you need to make sure of this. There is something wrong’” (p. 509). This dynamic is consistent with Robertson’s (2003) argument that men might portray female partners and family members as pressuring them into help seeking as a way to legitimize their decision and maintain a competent
masculine identity. Notably, Sanden and colleagues (2000) found no difference in formal help seeking between men who had spoken with family or friends and those who had not, with both groups eventually persuaded by the same troubling symptoms.

Variability among men. As in the discussion of recognition of concerns, it is critical to detail variability in men’s experiences. First, research suggests that marginalized men face additional systemic barriers in soliciting help. In explaining the limited help seeking for chest pain among those of lower economic status, Richards and colleagues (2002) emphasized that not only did these individuals have more limited expectations of longevity, but they also feared being blamed for their condition as they anticipated engaging with a health system they knew little about. Critically, the authors continued, in contrast to participants from affluent areas who had high levels of health knowledge and a number of connections to the medical system through family or friends, few of those from the poorer area had a personal connection with this system.

Touching on similar themes of personal valuation and comfort in the health care system, Malebranche and colleagues found that the black men who have sex with men (BMSM) in their study were reluctant to visit a general practitioner as they attempted to navigate a medical system in which they felt judged and misunderstood (Malebranche, Peterson, Fulliove & Stackhouse, 2004). Detailing barriers of distrust and stigma, the authors explained that these men did not see their experiences reflected as they met with primarily white service providers. As one man in the study reflected, “I think a lot of times it’s just a culture. And a lot of these people [doctors] might be knowledgeable, but they’re not knowledgeable of the people they’re dealing with” (p. 102). Research with African Nova Scotians has also evidenced the challenges of racism, as men expressed feeling unwelcomed by practitioners (Evans et al., 2005).

Beyond these systemic barriers, theoretical work by Addis and Mahalik (2003) attuned to inter- and intra-individual variability suggests that men are more likely to seek help for common problems that are not central to their identity, particularly if their social group is supportive and they believe the benefits of asking for help exceed the costs. In this framing, it is recognized that as men perform masculinities, threats posed by clinical
help seeking varies by situation, disease, and one’s identity matrix. Empirical research tuned into these forces illustrates this complexity.

For example, Evans and colleagues (2005) found that relative to white men, black men perceived greater identity costs associated with prostate cancer screening tests (i.e. digital rectal exams). Explaining this pattern, the researchers argued that the threats were intensified as black men experience more limited opportunities to demonstrate a valid masculinity in a society that is marred by racism, a reality that could be reinforced by a peer group sharing this perception (see Winterich et al., 2009). In contrast, O’Brien and colleagues (2005) observed a diversity of orientations toward help seeking in a study of the experiences of a group of primarily white men, including evidence of how help seeking was used to *comply* with dominant masculine scripts.

More specifically, although reluctance to solicit medical help was evident among young and/or healthy men in their study, men who faced illness (e.g. Myalgic Encephalomyelitis/ME, Prostate cancer), who feared a loss of sexual functioning, or who had a job requiring fitness (fire-fighters), were less likely to resist clinical support or “push it further.” In explaining why these men were less threatened by help seeking, the authors argued that the men were responding to a “hierarchy of threats” to their masculinity. In other words, given their circumstances, help seeking was not always viewed as a threat to an acceptable masculine performance, but could be perceived as way of adhering to a prioritized performance. For example, although men with prostate cancer might view help seeking as a concession in the face of serious illness, fire-fighters perceived the practice of soliciting support as a way to *preserve* masculinity as members of an “archetypically masculine occupation,” (p. 514). Similarly, men with ME used help seeking to *restore* a socially competent masculinity through diagnosis as they struggled to fulfil traditional roles amidst the limitations of their illness.

Finally, research has demonstrated how men can draw on other aspects of their identity to resist Western hegemonic ideals that stigmatize help seeking. For example, Robertson (2003) found that the gay men and men with disabilities in his study were openly body conscious, legitimizing healthy behaviour and distancing themselves from the stereotypical image of men as uninterested in health as they cited a desire to “look
good” or sought to navigate circumstance of their disability. Similarly, in research comparing help seeking decision-making among UK-based white men born in that country and men who had immigrated from South Asia (over three decades previous), Galdas and colleagues (2007) observed important variations in cultural-level peer group norms. Most notably, the authors reported that men raised in India and Pakistan did not consider disclosing illness to family or formal help seeking as “unmanly,” focusing instead on wisdom, learning, and caring for health and family as core to masculinity. As one man noted, “Not to tell anybody, that’s not Asian that’s English” (p. 227). In reflecting on this dynamic in a later study, Galdas and Cheater (2010) argued that this pattern not only emphasizes how men orient toward different masculine scripts in relation to other aspects of their broader identity, it also suggests that there can be multiple hegemonic masculinities within a given context. In diverse societies, including Canada, not all men measure themselves and their performance against the same model, a reality made even more complex by the process of acculturation.

**Opportunities and limitations of the existing literature.** In the three-decade exploration of men’s health, researchers have come to recognize that men cannot be collapsed into a single group, nor can their experience be easily summarized. Aligned with the broader men’s health studies movement, research on men’s help seeking recognizes gender as a powerful social force. As some consider gender as a relatively stable trait and others explore how gender is constructed across situations, this collected work has critically enhanced awareness of patterns in men’s clinical help seeking. However, as detailed next, an understanding of how men solicit and experience support is limited amidst insufficient attention to masculinities, a focus on a narrow range of diseases, limited attention to relational dynamics, and a heavy causal orientation defined by the positioning of masculinity as a predictor of clinical help seeking.

**Insufficient attention to masculinities.** There is an increasing awareness within the literature that patterns of men’s help seeking are more diverse than the well-trodden stereotype of the reluctant male help seeker would suggest (Galdas, 2009). Although research indicates that men, as a group, are more likely than women to avoid or delay clinical help seeking, there is evidence of broad differences in service use by education,
socio-economic status, age, and race/ethnicity (Young, 2004) raising important considerations about patterns in the experience of men within sub-populations. As introduced in the section on social determinants of health, gender is not an isolated force, but one that blends with a diversity of processes.

Unfortunately, the understanding of how men’s help seeking varies by a complexity of intersections between gender, identity, and context (Galdas, 2009) is limited by a paucity of work attending to the lived experience of masculinities. As Courtenay, McCreary and Merighi (2002) detailed, research examining the influence of gender tends to neglect race and, conversely, that which examines race, often neglects gender. This concern is not unique to research on help seeking (Iyer, Sen & Ostlin, 2008), nor is it contained to race. Reliance on samples of Western, white, middle-class, able-bodied and heterosexual and men led Galdas (2009) to argue that with few exceptions (e.g. Galdas et al., 2007; Robertson, 2003) the literature on men’s help seeking offers a relatively narrow view of male experiences.

As masculinities are insufficiently examined and studies emphasize a dominant or single hegemony, research can perpetuate an inaccurate perception that all men resist help seeking (Galdas, 2009; Pietila, 2008) and that all men are resistant in the same way. This trajectory of study is not unexpected for a body of work based in the field of men’s health, a domain Pietila (2008) reminds, has been heavily inundated with considerations of ‘masculinity’ as a danger to health. However, in this approach, healthy performances of masculinity are marginalized and inattention to variability leaves researchers unable to build the knowledge necessary to informing a variety of programs and policies resonate with a complexity of experiences and trajectories (Evans et al., 2005; Galdas, 2009; Iyer et al., 2008). As Crawshaw and Smith (2009) noted, research must work against a conceptualization of masculinity that leads to a “trap of approaching men’s behaviours as fixed to some ‘essential’ maleness (or boys will be boys)” (p. 264).

Instead, acceptance of masculinity as a dynamic, socially located process must be integrated into research through explicit recognition of both individual agency and the influence of intersecting socio-structural forces, that intricate web of social determinants of health influencing access to power and, accordingly, resources. Gender is core, but it
stands neither as an independent nor isolated construct. As Hankivsky and Christoffersen (2008) detailed, in a Canadian context where an estimated one in five Canadians will be part of a visible minority by 2017, researchers cannot afford to ignore these “synergies” influencing health.

**Narrow focus on male specific (or associated) conditions.** A need for greater attention to a range of male identities is noted in the literature, but other limitations have not received the same attention. Among these is the understanding that a research orientation accepting gender as a force in men’s help seeking need not be limited to male specific (or associated) conditions. As research exploring men’s experiences tends to orient around a narrow range of conditions: prostate cancer, testicular cancer, and heart disease (see Cecil, McCaughan & Parahoo; O’Brien et al., 2005), there are both risks and missed opportunities in this narrow approach.

Broadly, there is the danger of implicitly maintaining an impression that men’s health is a study of impacts to male anatomy rather than an examination of how men experience health and respond to illness, more broadly. As outlined above, considerations of gender and health are linked to the body, but not limited by it. How men and women experience health and illness is a social process. Whether a man faces prostate or kidney cancer, Lupus or heart disease, his understandings and responses to illness are informed by how he understands himself as a man, as a physical and social being, and by his positioning in the gender order. More specifically, as research on male reproductive anatomy dominates study, emphasis on impacts to sexual potency can distort focus and inhibit a more expansive understanding of how gender intersects with illness experiences and behaviours. By integrating a broader range of illness, there is opportunity to consider commonalities and differences in men’s help seeking.

**Limited attention to relational dynamics.** Similarly, there is relatively little known about relational dynamics, both in regard to how men engage with others and with whom they connect for support. Although some have noted that female partners are influential, a focus on predicting behaviour has positioned wives as factors simply directing men toward medical care. In this orientation, research is ill equipped to consider how partners are relating across the illness career or how broad social forces are expressed in the context of
relationships, a question of value given evidence of a pervasive cultural discourse positioning women as “health supervisors” (Seymour-Smith & Wetherell, 2006, p. 265).

In one of the few studies explicitly examining relational dynamics between husbands and wives, Seymour-Smith and Wetherell (2006) found that women tend to “carry” the emotional elements of illness narratives when men and women interact in a medical setting, allowing men to comment on these elements while maintaining a distance from expressions of pain, grief, and fear. Bottorff and colleagues’ (2008) observed a similar dynamic in their study examining dynamics among husbands and wives in prostate cancer support groups. Critically, rather than arguing that men avoid emotional demonstrations, these findings draw attention to how men and women are interactively negotiating these elements, evidencing gendered patterns in emotion management (Hochschild, 1979, detailed later).

More broadly, limited attention has been devoted to how men interact with others in their broader social network, including other family members, friends, and colleagues. A wider scope of attention to relational dynamics can enable examination of the experience of men who do not have female partners (i.e. gay or single men) or have partners unable to provide support, as well as a broader study of how men construct meaning of their experience with a diversity of others and draw on these persons for help (i.e. lay source of help seeking). The value of this consideration is emphasized by powerful research illustrating the impact of social networks on health outcomes as perceptions of norms and risk are influenced by the appearance and acts of others (e.g. Christakis & Fowler, 2007). As emphasized by Addis and Mahalik (2003), social groups play a key role in how men interpret illness and construct acts. These networks of relations are worthy of attention.

Causal orientation. Perhaps the most critical limitation of the current literature is the nearly absolute focus on identifying predictors of clinical help seeking. Although the adoption of a social constructionist lens and associated recognition of variability in male experiences has challenged researchers to recognize that the process of responding to illness is not the simple and obvious “logical choice” it is often imagined to be, emphasis on masculinity as a determinant of men’s help seeking continues to focus research on a single medical decision. In this focus, little consideration has been devoted to how men,
as gendered beings, perceive and engage formal and informal help seeking as they move toward diagnosis and as they live with diagnosed illness.

Approaches focusing on gender as deterministic are important, but are too limited in an effort to understand the broader phenomenon of men’s health-related help seeking. This orientation not only limits an awareness of how men experience a diversity of overlapping and shifting needs (i.e. social, emotional, physical) and engage with a variety of informal and formal supports (friends, family, internet) over time, but also threatens to over-simplify the process of help seeking. As Pescosolido (2000) argued, the question of “how individuals come to recognize, understand, and cope with health problems” is a “deceptively simple” one (p. 175).

As part of the effort to address these limitations, it is helpful to draw on theoretical developments offered within the field of illness behaviour, a domain of study positioning help seeking as one of a variety of concurrent responses to illness. Emphasizing a distinction between rational choice and dynamic help seeking theories, I describe how the latter can support an examination of men’s help seeking that not only recognizes variability in men’s lives, but also attends to relational forces and the on-going process of navigating needs and supports across illness. Building on this discussion, I detail a more complex conceptualization of help seeking, identifying six key qualities important to sensitizing empirical and theoretical research.

Re-positioning Men’s Help seeking in the Context of Illness Behaviour

Help seeking has been studied from a variety of perspectives, including sociology, psychology, anthropology, and health and social service administration (Gourash, 1987). However, as research on men’s help seeking has aligned with men’s health studies (and, thus men’s studies, more broadly, see Crawshaw & Smith, 2009) much of this literature has emerged from the fields of psychology and health studies (Galdas et al., 2005). In this focus, there is little evidence that this body of literature is attuned to the work of medical sociologists who have developed much of the broader theory on illness behaviour, including help seeking, over the past fifty years (Young, 2004).
Since Sigerist first drew attention to social aspects of bodily changes in a 1929 essay, the *Special position of the sick* (Mechanic, 1995), the field of illness behaviour has developed around a consideration of the various ways in which “individuals respond to bodily indications, how they monitor internal states, define and interpret symptoms, make attributions, take remedial actions and utilize various sources of formal and informal care” (Mechanic, 1995). In contrast to research focused solely on biomedical processes, those working in the field of illness behaviour accept that to understand the complexity of how individuals experience and respond to acute and chronic illness, research must consider subjective perceptions and evaluations as well as environmental constraints and opportunities (Mechanic, 1995; Young, 2004).

Influenced by a prioritization of “orthodox therapies,” illness behaviour research has been dominated by quantitative efforts to predict medical service use, although the field also includes qualitative examinations of the process by which individuals adapt to illness (Quinn & Coreil, 2001, p. 93). In much of this work, social psychological theories considering interactions between patients and professionals (“What do the parties […] think and feel, and how do they act when placed in certain social situations?”) have had the greatest influence, but this research has also drawn on models focused on economics of access, geographic proximity to services, socio-demographic patterns in service use, and the influence of social networks in how individuals respond to illness (Young, 2004, p. 3). In exploring help seeking processes, more specifically, two theoretical approaches have been significant: the rational choice (or ‘dominant’) approach exploring who seeks help and the dynamic approach exploring when and how individuals seek help (Pescosolido & Boyer, 1999). These are briefly detailed in turn.

**Rational choice approach: who seeks help.** Guided by a biomedical model emerging in the late 1700s, early understandings of illness equated it with disease; symptoms were viewed as physiological facts (Armstrong, 1999). Accordingly, Armstrong (1999) has explained, illness perception and treatment were understood as clinical processes led by health professionals in formal institutions and lay individuals were seen to have a limited role in defining illness. Thus, when some failed to participate in the immunization campaigns of the 1950s, early studies of help seeking focused on
beliefs, attitudes, and motivations in an effort to predict behaviour, or explain why some individuals did not appropriately respond (Armstrong, 1999; Uehera, 2001).

Orientated around a single decision (i.e. did one seek medical help), early theorizing from this perspective prioritized psychological factors, treating social forces (e.g. gender) as individual attributes (Uehera, 2001). Calnan (1987) explained that this approach has been described as the “ballistic approach;” individuals are conceptualized as missiles to be launched into the health system and researchers identify factors (i.e. age, class, sex) influencing successful deployment. As the awareness of the role of networks and lay perspectives (discussed in the next section) developed, researchers began to recognize the influence of support systems and interpretations. However, in this dominant tradition research focus remained on the individual and his or her beliefs and actions (Pescosolido & Boyer, 1999; Pescosolido, 1992).

Relying on a rational choice perspective viewing help seeking as a voluntary, logical decision made by informed individuals who weigh costs and benefits (Pescosolido & Boyer, 1999), the dominant approach continues to guide research exploring why individuals “delay” treatment. With research questions intent on profiling users, tallying outcomes (e.g. duration of care, frequency), and predicting help seeking through measurement of psychological, structural, or demographic factors, this orientation is evident in empirical work drawing on health behaviour theories including Andersen’s socio-behavioural model, Azjen’s theory of planned behaviour, and Rosenstock’s health belief model (Armstrong, 1999; Pescosolido & Boyer, 1999).

**Dynamic approach: when, and how we seek help.** The sociological turn in the 1970s expanding the scope of dominant theorizing was also important to initiating a dynamic approach. As Pescosolido and Boyer (1999) explained, medical sociologists and anthropologists led two key shifts in theorizing: acceptance of subjective interpretations of illness and recognition of “illness careers.” First, awareness that individuals perceive, interpret and label symptoms in a socio-cultural context allowed scholars to consider symptoms not as biological facts, but as signs interpreted according to presentation (e.g. intensity), situation, socialization, past experience, and health knowledge (Brown, 1995; Coreil, Bryant & Henderson, 2001; Mechanic, 1989). Thus, it was recognized that one
might view himself as ill in absence of a pathogen or, alternately, not consider himself to be ill when faced with disease (Mechanic, 1995). Even more, this subjectivity allowed that definitions could evolve in response to shifting symptoms, interpretations and others’ labels (Coreil et al., 2001). As Lorber and Moore (2002) emphasized, illness is a social experience; “a broken leg may be a simple fracture, but it is experienced entirely differently by a professional athlete, for whom it is a career-stopper, and an office worker, for whom it is an annoying temporary encumbrance” (p. 6).

Second, inquiry into chronic illness, social supports and networks, and medical pluralism (i.e. many modes of healing, supports) led social scientists to re-cast help seeking as part of a dynamic, on-going, interactive process of decision making embedded within an illness career (Pescosolido, 1992; Uehera, 2001). Aneshensel (1999) explained that the sociological notion of “career” has been applied to non-work experiences as a way to study how individuals progress through a series of stages to a desired end. In the realm of illness, these stages are understood as oriented to recovery or, if a cure is not possible, enhanced quality of life (Aneshensel, 1999). Most applicable to non-acute conditions, the concept of an illness career reoriented research to descriptions over explanations as work was attuned to the dynamic action sequence engaged as individuals interpret, respond to, and manage needs and connect with a diversity of supports over the course illness (Pescosolido, 1992). In directing attention to the subjective experience (Karp, 1994), this work recognized that “just as the case notes get fatter, so does the catalogue of experiences” (Price, 1996, p. 276). No longer limited to a single decision, research could explore “pathways of care” to supports (Biddle, Donovan, Sharp & Gunnell, 2007; Pescosolido, 1992).

As summarized by Pescosolido (2000), the dynamic approach addresses three limits of the rational choice approach: (a) a conceptualization of help seeking as an either/or decision (what she calls the “tyranny of use/ no use”), (b) limited integration of deep understandings, or the meanings, processes and practices of help seeking, and (c) compartmentalization of illness, or lack of awareness of how health concerns pervade one’s life (p. 177). Fundamentally, a dynamic approach accepts a help seeker as neither a
“calculating individualist” nor “puppet” of a social system, but one who shapes and is shaped by her environment (Pescosolido, 1992, p. 1109).

Coreil (2010) explained that as researchers were attuned to the on-going subjective illness experience, work turned toward the creation of models capable of identifying stages of decision making in the context of social networks (e.g. Liang, Goodman, Tummala-Narra, & Weintraub, 2005; Pescosolido, 1992) or detailing categories of help seeking determinants more inclusive of perceptions and evaluations and considerate of competing needs and available resources (e.g. Mechanic, 1978). Despite this integration of subjectivity and context, some argue that lay perspectives are not sufficiently integrated into help seeking research (e.g. Broadhurst, 2003). An approach to amending this gap is through the use of illness narratives, an interpretive method of understanding meanings more recently entering the field of illness behaviour (Coreil, 2010).

Illness narratives. Illness narratives are a way to “give voice to suffering in a way that lies outside the domain of the biomedical voice” (Hyden, 1997, p. 49). In addition to the literal process of telling a story of illness with others, Frank (1995) argued that these stories can help one to metaphorically re-draw the path forward amidst the disruptive tide of physical changes. Although there are a variety of ways to study illness narratives (see Hyden, 1997), Frank positioned these as “self-stories,” patterned as individuals seek to make sense of an interrupted life and serving as a witness to experiences as one sifts through the past and envisions the future, seeking coherence. Thus, focus is as much on how people describe their experience as the content of what they share (Hyden, 1997). Amidst this work, Frank’s (1995) typology of illness narratives is well known, as he theorized three types of illness narratives common in Western society: Restitution, Chaos, and Quest.

The focus of my research is not an analysis of narratives and Frank’s work is not specific to the help seeking process. However, awareness of these story forms is useful as a “listening device.” In particular, as led by an interest in how illness challenges a sense of self in relation with others (a topic discussed later in the context of symbolic interactionism) and in accepting persons with illness as meaning makers, Frank’s work
critically integrates an expectation of diversity in how an individual builds and shares their stories with recognition that the form these stories take is constrained by sociocultural context. Frank’s narrative types are not true forms (i.e. individual stories do not follow these styles perfectly), they are not exclusive, and they are not exhaustive, but they do represent common forms from which individuals borrow to construct their individual story, how they find their own voice, and re-build their own narrative amidst an uncertain and multi-vocal post-modern world.

Restitution narratives, more common among those recently ill, are structured around expectations of future health. This narrative, Frank argued, is the default story of illness in a society where cultural discourse and health systems emphasize a return to social duties. Opposing sickness and wellness, stories are oriented toward how individuals regain “normal” (i.e. healthy) functioning. Body and self are disassociated and focus is on how medicine can “fix” disease. Faced with certain conditions, one can quickly “exit the kingdom of illness, sooner than later, good as new” (p. 92), but this narrative is insufficient in the face of chronic or terminal illness.

Chaos narratives are incoherent and oriented toward loss. There is no imagined restitution in these stories, no reflexivity, and little order as the storyteller is submerged under the immediacy of their pain. Frank described the telling of these stories as taking on an “and then” style, as the story is structured around interruptions to story flow. There is no clear, overarching story line to connect the pieces as one is pulled into the chaos of the lived experience, a body “imprisoned in the frustrated needs of the moment” (p. 98). Difficult to hear and often not welcomed in a culture preferring tales of resilience, the essence of these narratives is beyond words. “The voice that might express deepest chaos,” he explained, “is subsumed in interruptions, interrupting itself as it seeks to tell” (p. 105). The self is alone, Frank continues, as chaos builds a wall around the ill person and relationships become dangerous amidst acutely felt contingencies. As in Restitution narratives, the self and body are disassociated, but in these stories the self is not sustained as the disease (“it”) fragments the “me.” It is only when chaos has subsided and one is able to again see the past and the future that these stories can be offered as a self-story.
Opposed to Restitution narratives focused around the success of modern medicine and Chaos stories that are difficult to share (and hear) in the midst of experience, the Quest narratives allow one to tell their own story as they emphasize what they achieved through this trial. Framing illness as a journey, Frank draws on Joseph Campbell’s hero’s journey or monomyth, a well-trodden, cross-cultural narrative of the hero as one who:

Ventures forth from the world of common day into a region of supernatural wonder: fabulous forces are there encountered and a decisive victory is won: the hero comes back from this mysterious adventure with the power to bestow boons on his fellow man (Campbell, 2008, p. 23).

Aligned with Campbell’s framework, Frank described how Quest narratives take an individual through three stages: departure, initiation, and return. The *departure* is an awareness of a shift from normal functioning, signs and symptoms that can be initially refused or denied. When symptoms can no longer be ignored, diagnosis leads one into *initiation.* Often in retrospect, one defines this entrance and the associated physical, social and emotional experiences as offering transformative insight. In the final stage, *return,* the storyteller witnesses their journey to others, presenting as transformed. As illustrated by Oliver Sacks, “a whole life, a whole universe, had been compressed into these weeks: a destiny of experience neither given to, nor desired by, most men; but on which, having happened would refashion and direct me” (in Frank, 1995, pp. 123-4).

As self and body are brought into association, contingency is neither denied nor succumbed to, but viewed as a fundamental part of life. In this, one is not an autonomous sufferer, but a hero whose battle scars help him to see the “pain in the other’s flesh” (Frank, 1995, p. 127) and speak *with* others. As Frank detailed, this is the hero seeking enlightenment (Bodhisattva) not as one who conquers (Hercules). These “wounded storytellers” are not only giving shape to their new self, but are driven by an ethical obligation to connect with others. Through these stories, Frank argued, the ill can become “wounded healers,” a widely employed concept arguing that experience with personal injury enables “empathic bonds” with others who struggle (p. xii).

In contrast to research that might draw on stories of illness to mine facts or identify determinants of behaviour, an appreciation of illness narratives helps attune researchers to
how individuals make sense of their experiences and themselves as they construct meanings with others and traverse the shifting terrain of illness. As Hyden (1997) detailed, these narratives allow researchers to witness illness as part of an individual’s biography; “by weaving the threads of illness events into the fabric of our personal lives, physical symptoms are transformed into aspects of our lives, and diagnoses and prognoses attain meaning within the framework of personal life” (p. 53). This point will be emphasized later in my discussion on identity as a story of self.

**Broadening the conceptualization of men’s help seeking.** An evolving understanding of gender has challenged research on men’s help seeking to move beyond essentialist portrayals of problematic men and encouraged a consideration of how men work with others to perform masculinity through health behaviors, including requests for assistance. These developments emphasize the importance of attending to intersectional dynamics, including research considerate of the experiences of a diversity of men and which recognizes variability in men’s actions across conditions, context, and time. However, in absence of attention to evolutions in help seeking theory in the field of illness behaviour, research on men’s experiences has remained consistent with a rational choice approach as it profiles users, positions masculinity as a determinant of acts, and conceptualizes help seeking as an individual, rational decision to seek medical care.

The explicit integration of a dynamic approach can both expand the conceptualization of men’s help seeking and address many of the limitations of existing work in this field, as detailed above. In particular, this approach frees researchers from an impossible task of accounting for the complexity in each life (race, age, sexual identity, family structure, etc.) in efforts to predict who will do what and when. Even more, this approach recognizes that men’s illness, as a subjective experience, is not limited to male anatomy and integrates an appreciation of relational dynamics. Finally, and most critically, this approach allows research to pursue understandings of how men, as gendered beings, experience help seeking over the course of their illness career.

In challenging research to consider new ways of examining help seeking, the dynamic approach also disrupts practiced ways of conceptualizing the core concept itself. In particular, theoretical and empirical research focused on how men respond to illness-
related needs can benefit from sensitization to six intersecting aspects of help seeking as a subjective, interactive, and dynamic process. These include awareness that (a) help seeking is initiated by a recognized need, (b) help seeking is interactive, (c) help seeking can take on a variety of appearances, (d) help seeking is learned, (e) help seeking can be directed by a variety of strategies, and (f) help seeking does not always lead to the resolution of a problem. Complementing this discussion is a brief note on the related concept of help-accepting. In detailing these aspects of help seeking, I reference how these dynamics are touched on in the existing literature specific to men and consider how work can expand to engage with them more fully, thus fostering a more dynamic approach to the examination and understanding of men’s help seeking.

**Help seeking is initiated by a recognized need.** The presence of a pathogen is not sufficient for help seeking. This process can proceed only after an individual defines a situation as problematic and believes intervention is required (Kessler, Brown, & Broman, 1981). Recognition that subjective interpretations guide illness trajectories (Dingwall, 1976; Mechanic, 1989) encourages attention to how men perceive concerns and apply meaning to them. As signs and symptoms are interpreted according to situation, presentation, socialization, experience, and knowledge (see Brown, 1995; Coreil et al., 2001; Mechanic, 1989), those who are more tolerant of symptoms, able to ascribe them to other sources, or are drawn to deny illness may be less likely to seek help (Mechanic, 1978). This pattern can also hold true for non-physiological needs one might experience across the course of an illness career, such as information gaps, emotional struggles, financial needs, and strained relationships.

As noted, the literature on men’s help seeking is attuned to this dynamic with regard to the initial physiological signs of illness, as researchers examine how some men might normalize or misinterpret symptoms, thus delaying medical visits. Particularly interesting is the research considering the influence of social norms that discourage men from taking too close an interest in their bodies, positioning this as a practice reserved for women (Lee & Owens, 2002; Noone & Stephens, 2008; O’Brien et al., 2005; Robertson, 2003), considerations central to understanding when, why, and how men reach out for help. However, research can also consider this gendered process across illness, including
how men make sense of ongoing physiological shifts as well as emotional and social concerns during illness. Research has detailed men’s efforts to develop knowledge around potential as well as diagnosed conditions (Oliffe & Thorne, 2007; Smith et al., 2008) and this practice can influence how men define and redefine their needs.

Recognizing this interpretive process as influenced by the perceived definitions of others, there is also value is explicitly considering how men work with others in their lives to make sense of concerns. Apart from some attention to how wives might encourage men to see a doctor or engage in treatment (Chapple et al., 2002; Gascoigne & Whitear, 1999; Norcross et al., 1996; Parslow et al., 2004; Tuder & Talbot, 1999), there has been limited research on how others in a man’s life influence this interpretive process. Research can benefit from a nuanced study of the role of female partners, including that men may draw on partners to validate concerns (O’Brien et al., 2005; White & Johnson, 2000) or legitimize help seeking (Robertson, 2003). Even more, there is a need to consider the influence of others within a man’s social network (e.g. friends, co-workers, peers in a variety of social organizations), particularly given that not all men have female partners (i.e., gay or single men) or partners attuned to their needs.

Help seeking is interactive. Help seeking is a process of engaging with another person (or multiple others) to obtain support. The relational nature of this activity attunes research to interactive processes as men engage others in an “intensely personal” pursuit (Rickwood, Deane, Wilson, & Ciarrochi, 2005, p. 8). More specifically, those who accept health behaviors as performances of masculinity recognize that men construct this performance with others (health professionals, partners, friends, etc) in the course of illness. However, those addressing this dynamic in men’s help seeking have primarily focused on the patient–physician relationship.

In addition to a consideration of provider and patient expectations that can challenge an initial medical consultation (see above), some have explored the patient-provider dynamic in the context of a clinical visit. This work indicates that men tend to value communications with practitioners that are characterized by humor, empathy, frankness, competence, and promptness (Smith et al., 2008), qualities associated with an idealized masculinity image (direct, skilled) or which enable men to step away, even
briefly, from the emotional intensity of this exchange (Oliffe & Thorne, 2007). Although these patterns suggest efforts to present a more dominant masculinity, analysis by Oliffe and Thorne (2007) on the experiences of men with prostate cancer interacting with a male physician offers a more complex image, indicating a range masculinity performances in response to the inherent hierarchy in this dyad and demonstrating that the realities of disease can “disrupt” the dominant performance.

Examination of the complexity of interpersonal dynamics across the illness career is critical, and the important work on engagement with medical professionals can be complemented by the study of interactions more broadly and over time, including how men engage informal support persons (i.e., family, friends), illness support groups, and even online social networking groups. For example, there is compelling research exploring men’s engagement in cancer support groups, including their use of humour to not only manage discomfort in discussing sensitive topics, but also foster a ‘normal’ environment and build camaraderie with others in the process of soliciting help (e.g. Oliffe, Ogrodniczuk, Bottorff, Hislap & Halpin, 2009). Further, the rapid proliferation of web-based health information and interactive websites (i.e., web 2.0) might deserve special attention as this medium has been shown to introduce important shifts in how health information is exchanged and integrated, including how information gathered online is used to support face-to-face modes of help seeking (Ybarra & Suman, 2006).

**Help seeking can take on a variety of appearances.** Help seeking can take the form of a discussion about a problem or a specific request for assistance or advice in a variety of settings (Gourash, 1978). In particular, research suggests that stigmas (Goffman, 1963) associated with a condition as well as sociocultural norms around help seeking influence not only whether an individual asks for help but also how they engage, including the use of indirect approaches to soliciting support (Kim, Sherman, & Taylor, 2008; Williams & Mickelson, 2008), such as hints, complaints, and displays of negative affect (Barbee & Cunningham, 1995). Amidst limited attention to how men approach support solicitation, Tudiver and Talbot (1999) reported that physicians in their study perceived men as more likely than women to use indirect methods of sharing around health concerns, providing general information and relying on health providers to ask
specific questions. Notably, indirect methods are associated with less supportive responses from potential help providers (Williams & Mickelson, 2008) and this finding is congruent with patterns of limited clinical exchanges between men and health providers, as detailed earlier.

Those studying men’s help seeking have devoted more attention to foundational concerns of stigma and sociocultural variability. Broadly, expectations of male independence, strength, and stoicism have been linked to stigmas around men’s help seeking (Addis & Mahalik, 2003). More specifically, as noted earlier, theoretical and empirical research stepping into intersections of identity (gender and more), conditions, and context has illustrated how social prohibitions vary in relation to group norms, disease form, and context (Addis & Mahalik, 2003; Evans et al., 2005; Galdas et al., 2007; O’Brien et al., 2005). Particular to disease form, conditions perceived as severe (e.g. cancer) or preventable (e.g. AIDS) tend to be more stigmatizing (Crandall & Moriarty, 1995). Research on the experiences of men with prostate cancer indicates that this disease can present a double stigma as associated with the potential for a loss in sexual potency (Gray, Fitch, Phillips, Labrecque, & Fergus, 2000). Furthermore, depression and mental health concerns, including those associated with physical illness, are frequently cited as particularly threatening to a masculine presentation of stoicism and emotional restraint (Addis & Mahalik, 2003; Moller-Leimkuhler, 2002; Moynihan, 1998; O’Brien et al., 2005).

Whether or not men adhere to social expectations around the resiliency of men’s bodies or the valuation of self-reliance and stoicism, these scripts are part of the discourse around men’s health in Western society (Oliffe, 2007), a story line that can influence how comfortable men are soliciting support, which supports they engage, and how ready others are to provide them with assistance (Moynihan, 1998). Kim and colleagues (2008) recognize this important bidirectional reality in their assertion that a request for help is partially influenced by a “mutual understanding about the propriety and efficacy of seeking such support” (p. 519).

Existing work has taken the critical step of drawing attention to variability in how threatening medical help seeking can be for men in relation to their condition and the
context of their social and cultural communities, but work can be challenged to consider the influence of these patterns on *how* men engage with others to address an array of challenges. Although men might delay or even avoid formal requests for help in the face of certain conditions, this does not mean they are inactive (see Smith et al., 2008). In the face of stigmas and prohibitive norms, men might adopt a variety of approaches (e.g. coping, self-care) by which they respond to needs over their illness career. Some of these will be more effective than others. Even more, research must be alert to indirect approaches to soliciting help, as well as acts conforming to the more obvious, ask–receive exchange that may occur in a clinical setting (though this is, as noted, rarely simple).

**Help seeking is learned.** Whether engaging informal or formal supports, individuals must learn how to *effectively* obtain help from a diversity of others for a variety of needs in a range of contexts. This matter can become more complex in the face of novel or ambiguous experiences and within rigid systems such as formal medical services where procedures for soliciting help are more prescribed. In all cases, though, individuals are neither innately prepared nor naturally competent (or incompetent) at this endeavor. Accordingly, research must consider not just attitudes toward help seeking but also opportunities for skill development.

This matter has received limited attention in men’s help seeking research, where focus on individual-level actions has limited the integration of detailed consideration of how men learn to care for their health. As noted earlier, research suggests that men tend to perceive themselves (or men in general) as less comfortable and less interested in matters of health relative to women (Chapple et al., 2004; Gascoigne & Whitear, 1999; Noone & Stephens, 2008), an observation complemented by work emphasizing these patterns as products of a social system positioning health as a woman’s issue. With the exception of sports-related training, it is argued that boys and men tend to receive more limited formal and informal guidance on how to care for their health, including the provision of informational materials/ programs and practice of regular medical visits (Banks, 2001; Courtenay, 2000a). This dynamic emphasizes the need to consider men’s prior experiences with the health system and help seeking *and* how their ability to effectively engage supports might develop with practice.
**Help seeking can be directed by a variety of strategies.** As noted, existing research has prioritized a study of why some men are reluctant to seek medical help in the face of problematic signs and symptoms. Although framed as a *barrier* to help seeking, this is a process some in the education field refer to as a form of non-adaptive help seeking (Karabenick & Newman, 2006). Less often considered in research on men and illness are other help seeking strategies, as detailed by Karabenick and Newman (2006), including relying on others to do what one does not want to do himself (a second form of non-adaptive help seeking) and requesting information and support that effectively allows the individual to mitigate or eliminate a challenge (adaptive help seeking).

This framework challenges research in men’s help seeking in two key ways. First, it draws attention to less obvious forms of help seeking during illness. For example, studies have described men as active users of information during illness. In particular, researchers have noted how men with cancer pursue information on the nature of their disease, treatment options, and management of side effects, including attention to how they engage female partners (Bottorff et al., 2008; McCaughan & McKenna, 2006), support group contacts (Breau & Norman, 2003), and Internet resources (Seale, Ziebland & Charteris-Black, 2006) in this process. Further, previous work indicates that men can draw on partners and complementary health providers in efforts to enhance physical status through diet and exercise (Gray et al., 2000; Oliffe, Davison, Pickles & Mroz, 2009) in the context of illness. Although not often framed as ‘help seeking’, engaging others in these efforts is consistent with an adaptive help seeking approach, a process understood to facilitate short-term, situation-specific problem solving as well as enable learning that can increase one’s capacity to address future challenges (Newman, 2008).

Second, although those concerned with the individual and social costs of not seeking timely medical care are justified in focusing on why some men avoid or delay care, there is value in adopting the framework of non-adaptive help seeking. As Biddle et al. (2007) argued, research on help seeking, in general, could benefit from examining the perceptions and interpretations (“drivers of action”) that move individuals away from supports rather than simply viewing these as ‘barriers’ to the process. Awareness that perceptions of need and meanings of help can pull men from supports is implicit in
existing work on men’s help seeking, particularly the research adopting a social constructionist approach accepting health behaviors as performances of masculinity. However, a framework of non-adaptive help seeking enables consideration of how avoidant help seeking (and dependent help seeking) practices can limit men’s ability to address concerns in the short term and contribute to long term vulnerabilities (see Newman, 2008).

At a broader level, whether research emphasizes barriers or non-adaptive processes, there are risks associated with prioritizing how men do not seek support. In addition to perpetuating an assumption that all men resist help seeking (Galdas, 2009; Pietila, 2008) and marginalizing other performances of masculinity, this approach neglects how men engage in adaptive forms of help seeking for a range of needs (not just medical). Even more, work is not attuned to how men develop capacity (including help seeking skills) to address illness-related challenges across the course of a single illness career and over a lifetime. For example, researchers can anticipate that men with experience working through health challenges, both physiological and mental, might be differently attuned to needs and supports relative to men lacking this experience.

Help seeking does not always lead to the resolution of a problem. Finally, solicitation of support does not automatically result in receipt of beneficial assistance (Gourash, 1978). Given the complexity inherent in the process of help seeking, as indicated across this discussion, this sixth sensitizing element is of little surprise, but of critical importance. In arguing for the medical and social value of engaging with others to address illness-related challenges, it is not sufficient to examine whether a man seeks help. Research must also consider whether the need is addressed. As noted, existing work considerate of this dynamic recognizes the role of patient–provider communication in health outcomes (e.g., Oliffe & Thorne, 2007), including indications that relative to patterns observed among women, men’s interactions with practitioners tend to be brief and result in more limited transmission of information (Courtenay, 2000a) and that health providers can fail to deliver health messages in a manner sensitive to how men are socialized in Western society (Smith et al., 2006).

Although current work centers on episodic clinical visits, this consideration
increases in significance as help seeking is recognized as an ongoing, interactive process fuelled by medical and nonmedical challenges. Specifically, it can be theorized that unsuccessful engagement with a medical provider, family member, friend, or other support can influence a man to seek alternate avenues or experience unmet needs (and limited capacity or skill development) that can continue to have impacts throughout his illness and beyond. In particular, the challenge of addressing mental health challenges associated with illness and the enduring individual, relational, and social costs of untreated depression among men (Moller-Leimkuhler, 2002) highlight the need to evaluate the impact of psychological as well as physiologically focused interventions.

In developing methodologies that support an examination of the impacts of a diversity of men’s help seeking processes, awareness of the interactional nature of help seeking (as detailed) emphasizes the importance of viewing outcomes as a product of the relationship between the one seeking help and the one in a position to provide it. As Collins and Feeney (2000) have explained, “A capacity for intimacy and sense of confidence that one is valued by others appear to be vital both for recruiting social support and for providing sensitive care to others” (p. 1071). Acceptance of the interactive nature of help seeking requires consideration of the impact of this bidirectional process over the course of the illness career. Not all seekers are adept at soliciting support, not all carers are skilled at providing it, and not all challenges amenable to solution.

A note on help accepting. Although the focus of this study is on how men pursue help from others, it is important to recognize other ways individuals obtain support when facing illness, including taking advantage of help that is offered, unbidden, a process that blends into discussions of help seeking. As Ackerman and Kenrick (2008) detailed in a discussion of human interdependence, human survival is tied to an ability to pool resources, to cooperate, to share. Even more, they argued, while there is much made about the isolation of individualist societies, individuals are often more generous than “models of the ‘rational man’” suggest (p. 119).

For a variety of reasons, humans help each other. But as with help seeking, the concept of help accepting is layered with complexity and individuals do not always
accept what others offer. Ackerman and Kenrick (2008) explained this within the context of “trade-offs;” energy expended in one direction is not available for another. They asserted that traditional explanations of why individuals refuse help emphasizing self-esteem (and related concerns over inequity or a loss of freedom) obscure a more complex process of decision-making. Instead, they argue for the value of considering how individuals balance trade-offs of costs and benefits as identified in a specific context. Thus, just as a diversity of help seeking needs, supports, and behaviours can be perceived, avoided, or enacted, acceptance of help is a similarly complicated process. Decisions to accept or reject help might not always appear rational, but are often based on a subjective assessment of risks and gains as perceived with a specific, interactive context. From this perspective, research is called to engage in a careful study of decision-making, rather than relying on a detached assessments or an assumptions that individuals are behaving irrationally.

**Summary.** Advancements in the field of illness behavior can help push the conceptualization of help seeking beyond the “tyranny of use/ no use” (Pescosolido, 2000). As a dynamic approach accepts help seeking as an interactive, ongoing process of formal and informal support seeking, researchers can acknowledge this engagement as influenced by perceptions, interactions, skills, and strategies and varying in methods and outcomes. Even more, emphasis is not on whether men responded “correctly,” (as defined by the biomedical model), but on how they are making sense of their experience and engaging in a range of acts as they recognize a variety of needs, supports, and forms of help seeking. The sensitizing elements detailed above are particularly relevant given the current focus of research on men’s help seeking, but there are, undoubtedly, more to consider. The field of illness behavior is vast (Young, 2004), offering a diversity of theoretical orientations and array of empirical understanding that may prove beneficial to scholars exploring men’s experiences.

**Moving Forward**

A symbolic interactionist (SI) perspective is useful in shifting focus from a pursuit of determining factors in clinical help seeking to a study of how men experience help seeking, in all its complexity, across their illness career. Consistent with increasing
emphasis on interpretive approaches to accessing meanings of illness (i.e. shift to
narratives), SI provides a framework for considering how men interactively build
meaning of their experiences, themselves, and others in the course of their day-to-day
response to illness. As this approach requires researchers to listen to men’s voices
(Watson, 2000), it enables an examination of the influence of social norms around men
and help seeking as detailed by much of the current work while also giving space to
recognize men’s agency. To use Wrong’s (1961) terminology, this approach allows
researchers to challenge an “over-socialized” view of men as simply pushed and pulled
by society.

Men’s help seeking has not been studied in detail from an SI perspective, but
there is a rich tradition of interactionists contributing to understandings of health and
illness by exploring phenomena often taken for granted such as the body, emotions, and
suffering as areas of theorizing (Charmaz & Olesen, 2003). In contrast to much of the
work on illness, SI offers an “insider” view, shedding light on the subjective experience
as it orients research to how men make sense of symptoms, engage with supports, and
integrate new understandings of self (Conrad, 1990). Even more, this approach accepts
men as more than their illness: not as patients (or future patients), but as people living
with illness in diverse ways (Conrad, 1990).

Symbolic Interactionism: Reorienting the Study of Men’s Help seeking

SI is a theoretical perspective based on the understanding that an interpretive
process guides human actions. Among the fore-parents of SI, George Herbert Mead is
thought to have had the greatest influence on this perspective through his efforts to move
pragmatist ideas into a theory and method (Sandstrom, Martin & Fine, 2010). Best
known for his collected works in Mind, Self and Society, Mead (1934) argued that
humans are shaped by society to such an extent that it is impossible to separate biological
from social (Meltzer, Petras & Reynolds, 1975).

Emphasizing that human behaviour cannot be understood in separation from the
society that both precedes the individual and endures after (Meltzer, 1967; Prus, 1995),
Mead described how individuals draw on social processes and tools as they come to
know themselves and others and as they perceive, interpret, and respond to life’s
uncertainties, conflicts, and ambiguities. More specifically, this position held that meaningful communication requires a capacity for imaginative activity: the ability to engage in role taking and use shared symbols (Meltzer, 1967).

First, when met with a gesture one can take on the role of the other. She imagines the other’s perspective and intentions as she anticipates acts and consequences. She also responds to her own gestures, envisioning the image of herself she wants to place in another’s mind. Role taking, while core, is not sufficient for cooperation. To coordinate acts, humans also rely on a shared language. As a pragmatist, Mead asserted that the physical objects, images, gestures, sounds, and words constituting perceived reality are symbolic; they carry no inherent meaning (Reynolds, 2003). To enable communication, individuals work together to establish ‘significant symbols,’ or meanings of objects that are ‘intersubjective’ (Prus, 1995). Constructed as persons interact with each other in relation to an object (“mutual adjustment”), symbols learned through socialization are not limited to one’s experience and can be produced when an object is not visible, applied to other objects, and modified (Mead, 1934, p. 78; see also Meltzer, 1967). In this interactive process, Mead argued, there is always opportunity for a misalignment in the intention of and reception of the symbols used to communicate (Stone, 1970). Or, as Stone (1970) noted, in this interactive dynamic, “meaning is always a variable” (p. 395).

As role taking and significant symbols help individuals to communicate and pattern acts together, through this process persons are establishing and re-establishing society itself (Musolf, 2003). Even more, Mead argued, individuals become human through this interaction; the self is a social object given meaning through the language of society (Meltzer, 1967). A capacity for reflexive role taking allows one to see his ‘self’ as an object, “to take the attitude of the other toward himself” (Mead, 1934, p. 134). As one examines and evaluates this object through the eyes of others, he draws on society’s symbols to apply meanings to the ‘self’. Cooley termed this ‘the looking glass self,’ and emphasized its ongoing development in relation to face-to-face interactions whereby one obtains self-feelings such as a pride or shame as they interpret how others perceive and respond to them (Cooley, 1902/2009; Meltzer et al., 1975).
For Mead, the development of ‘self’ began in infancy and progressed through three stages later termed the preparatory, play, and game phases (Reynolds, 2003). In the preparatory stage, an infant imitates others, but does not understand what her gestures mean. Role-playing takes shape in the play phase as she move outside herself, pretending to be someone else. However, these roles are unstable as she lacks a unitary view of self, seeing each role as distinct. Finally, the child enters a game stage where she simultaneously adopts multiple roles to respond to the expectations of multiple others. Mead labelled this community of interests the ‘generalized other’ and believed that in recognizing a general standpoint (i.e. social or community norms), a child achieves a sense of self and can act with consistency across situations (Meltzer, 1967).

Mead’s developed self has two parts: ‘I’ and ‘Me’. The ‘I’ is the self as subject: one’s impulsive, undirected tendencies. The ‘Me’ is a sense of self as object that is developed through role taking, known to others and shaped according to attitudes, expectations, and values common to a group (Howard & Hollander, 1996; Meltzer, 1967). Even more, the ‘Me’ includes previous ‘I’s’, a history of gestures and remembrance of others’ responses (LaRossa & Retizes, 2008). As Meltzer (1967) described, Mead’s concept of selfhood emphasizes that individuals have a mental life (a mind), can interact with and change themselves, and can control their behaviour. Directly, in the interplay of ‘I’ and ‘Me,’ humans are social agents and objects. Their behaviour holds potential for creativity and conformity, novelty and social control (Meltzer, 1967).

Influenced by evolutionist beliefs that humans continuously adapt to the world, Mead argued that in viewing her surroundings, one selects objects in accordance with needs, thereby creating her environment (Reynolds, 2003b). Up to this point, humans differ little from other organisms; in familiar situations they engage in routines or habits, impulsively responding to stimuli (Meltzer, 2003). Humans become unique, Mead argued, in how they deal with problems.

In a society of constant interaction there are many opportunities for ambiguity (Meltzer, 2003). When new situations, divergent paths, or incompatible impulses challenge one’s way he attempts to make sense of what is happening (Meltzer, 2003;
When challenged, he hesitates; he thinks. In this, he assesses consequences and considers potential paths or ‘lines of action’ as he decides what objects mean (Reynolds, 2003b). Mead located the mind in this reflection, positioning it not as a developed brain or a capacity to think but as a social product built in interaction and emergent in the face of problems (Prus, 1995; Sandstrom et al., 2010).

Meltzer (2003) has detailed five processes core to Mead’s view of the mind: reflexivity, role taking, self-indication, significant symbols, and internal conversation. In this, as one views his ‘self’ from the standpoint of specific and/or generalized others (i.e. reflexive role taking), he points out to himself what is meaningful. His interpretations of these selected objects (i.e. self indications) are built using the shared language of our society, that ‘universe’ of symbols and meanings learned (and revised) through communication with others. In this, minded activity originates and functions as an internal dialogue between the ‘I’ and ‘Me’ (Meltzer, 2003).

Though driven by impulses, acts contain the minded process: perceptions, interpretations, and a ‘consummation’ or satisfaction of impulses (Meltzer, 2003). Behaviour, then, is not social merely because it is conducted with others. The use of role taking and symbols ensures that human acts are social because the meanings influencing interpretations of experiences and selves are constructed through interaction; individuals incorporate the acts of others into their own (Meltzer, 1967; Prus, 1995). Mind, self, society, and action are inextricably intertwined.

**Formalizing SI.** Herbert Blumer, Mead’s student, built on this work to move SI into a framework for empirical study. Focused on the individual in interaction, Blumer (1969) detailed three core assumptions of SI: (a) people act toward something based on meanings they ascribe to it, (b) meanings are products of social interaction, and (c) meanings are modified through an individual’s interpretive process. Although SI has gone through evolutions since Blumer’s time, these three premises remain a touchstone for the perspective (Fine, 1993).

Applied to theorizing on men’s help seeking, these premises support a different way of examining men’s acts. First, focus shifts from a search for determinants of behaviour toward a consideration of an indeterminate social process by which men work
with others to handle the ‘problem’ of illness. Specifically, a man is recognized as an agent, his acts are not determined by attitudes, stimuli, or motives (i.e. structural or psychological factors), but by his interpretation of the social (e.g. doctor), physical (e.g. clinic), and abstract (e.g. illness, need, support) objects he perceives throughout his illness career.

Second, it is accepted that the meanings of the objects a man perceives amidst illness are not inherent, individual, or static. Instead, they are defined in the context of the situation and through his interaction with significant others (family, friends, health professionals) as well as his awareness of the expectations of communities and society more broadly. As Blumer (1969) emphasized, individuals learn (and revise) meanings as they engage in the world around them, observing how others interact with objects. Third, it cannot be determined what objects a man will consider meaningful during illness as he might emphasize or ignore certain physiological signs, challenges, or support opportunities. Further, it cannot be assumed which meanings he will apply to objects perceived (including notions of illness, need, support). He might be aware of multiple meanings of an object, but as an interpreter he “selects, checks, suspends, regroups and transforms” meanings according to the situation as he considers his line of action (p. 5).

Blumer’s view of human behaviour is applied to how individuals complete ‘joint acts’. Described as an act influenced and guided by what others do (Sandstrom et al., 2010), joint acts such as help seeking are achieved when one fits his individual line of action with others. Blumer detailed three characteristics of joint acts important to sensitizing thinking about men’s help seeking. First, most joint acts are routine and below consciousness. Although still dependent on a process of designation and interpretation, common acts are often treated as natural expressions of societal norms or values (i.e. culture). Second, joint acts are linked to larger networks. A medical visit, for example, is associated with a range of diverse acts, including staff training and the organization of the health facility. Last, joint acts arise out of previous actions and must be understood in this historical context. A medical visit, then, is informed by the prior experiences of both health professionals and clients. This description of social life emphasizes that as individuals use role taking and symbols to integrate others’ acts into
their own, the social life they are building is contingent, inherently dynamic. As Plummer (2000) argued, in pursuing an understanding of how individuals interactively acquire a sense of who they are, adjust to others, fit together acts, and build society, attention can be devoted to individual experience, but it is accepted that one’s sense of “self”, interpretations, and acts are never separate from the “other.”

Core to this study of how meanings guide acts is the SI notion of identity. In contrast to research focused solely on gender identity (either as a trait or process), SI considers identity as situated (Stone, 1981/2005). As I will detail, identity is the story of self as a distinct individual and as a member of communities, a story written and rewritten in the course of day-to-day interactions. Through the lens of this complex and dynamic narrative individuals perceive, interpret, and understand their world; they construct the meanings applied to self, others, and experiences as they organize acts.

Because questions of identity are inextricably linked to context (Altheide, 2000), I briefly detail the concept of definition of the situation (what is going on?), before focusing in on identity (who am I in this situation?) and reviewing how these are negotiated with others. As in the broader review of the literature, the intention here is to clarify sensitizing concepts useful to understanding the process by which men make sense of needs and supports during an illness career and how these cognitive and emotional assessments worked out with others can influence the process of help seeking.

What is going on? Thomas (1931/1967) argued that to understand human behaviour one must consider not only the objective elements of a situation, but also how these are subjectively perceived. In this, there is recognition that individuals vary in regard to which objects they notice, how they define these, and how they respond to them. Although prioritizing subjective perceptions, Thomas did not deny intersubjective forces. He wrote of “codes of society,” explaining that impulsive definitions compete with those provided by society. Consistent with Mead, he accepted that individuals are born into a world where definitions are established and learned through socialization. In understanding how one comes to know his world as “a given,” originating before them, and within which they are one of many (see Sharrock, 1999), it is useful to consider how socio-cultural schema or scripts pattern perceptions and interpretations.
Zerubavel (1999), a cognitive sociologist, argued that individuals think not only as humans and as individuals, but also as social beings. The meanings they apply to objects, he asserted, vary among “thought communities,” across context, and over time. Specifically, in recognizing gendered thought communities, researchers can anticipate that women and men not only learn to notice certain objects as meaningful in the course of an illness career, but also learn different meanings for these objects, meanings further informed by other thought communities to which they belong (e.g. class, religion, race). Similarly, Strauss (1969) drew on Shibutani’s work to detail “worlds” (e.g. health, medicine) patterned by shared perspectives. In this, Strauss emphasized both the shared meanings of objects and how communities organize thinking about who participates in a situation and what happens there. As these worlds encourage commitment not only to individual others, but to agencies and institutions, it is useful for researchers to consider in which world an individual stands as he defines a situation (Strauss, 1969).

How individuals define a situation is informed not only by their thoughts, but also their emotions. As Franks (2003) argued, emotions colour perceptions and compel thinking through a “sensual embodiment” that leads individuals to feel their social duties, morality, and conscience. Likewise, cognitions guide emotive experience. Franks illustrated this bidirectional interplay well when he explained that, “in embarrassment, the blood flows into blushing faces because our societies and circulatory systems dictate it” (p. 790). Although emotions have been insufficiently explored in SI (LaRossa & Reitzes, 2008), the perspective enables an examination of emotion that accepts physiological aspects of emotion, but focuses on how emotions often accepted as natural are socially structured and defined (Fields, Copp & Kleinman, 2006; Franks, 2003).

Hochschild’s interactionist theory of emotion management is a useful tool for grasping how emotions are socially defined and modified. Accepting emotions as driven by biological processes, Hochschild (1979, 1983) argued that individuals suppress or evoke emotions in the short or long term to align how they feel with how they believe they should feel: “We feel. We try to feel. We want to try to feel” (1979, p. 563). Depending on the context, different “feeling rules” are set (funerals vs. weddings) to establish the extent (degree of emotion), direction (sad, happy), and duration of feelings.
appropriate to a situation. These rules influence the assessment of whether one “should” feel something, or if they have a “right” to an emotion (Hochschild, 1979) and they vary according to social group. Pertinent to men’s help seeking, Hochschild (1983) and others (see Franks, 2003) recognized that individuals learn gendered scripts that establish distinct rules for men and women. As Shields, Garner, Leone and Hadley (2007) noted, gender-emotion stereotypes powerfully structure expectations about who is entitled to an emotion. These anticipations inform how individuals evaluate self and others, integrating the gender order into emotional responses accepted as natural (Franks, 2003; Shields et al., 2007).

In sum, definitions guiding men’s acts in the context of illness are not built in ignorance of practical consequences and conditions nor are they unguided by social forces; they are not “up for grabs” (Sharrock, 1999, p.128). Interactionists accept that the social world, including systems of patriarchy or class, can be understood in the context of how broad social forces are expressed in the day-to-day (Fine, 2003). Although many cognitive and emotional definitions of a situation are possible, those with more power in a society have greater opportunity to construct or draw on dominant definitions reflective of their reality (Altheide, 2000, Stewart, 2003). As Stewart (2003) explained, in a social system in which men tend to hold political, economic and relational power, the language, assumptions, and values individuals draw on in engagements and which structure laws, policies and institutions are informed by the experiences of these dominant males (rather than those of women and men with less power). Similar patterns are found in relation to race, class, sexuality, disability status, and other social locations. This is not to suggest that these definitions are absolute, but in an intersubjective or “obdurate” (Blumer, 1969) reality, social expectations emphasize some definitions over others, informing how persons establish (and challenge) consensus on what is thinkable and ‘feelable’ in a situation.

In Western society, expectations of men and health are woven into communication at the individual, institutional, and societal level. As noted, Oliffe (2007) highlighted common cultural discourses about masculinity and health including a perception that in caring for his health a man risks his place in society, that masculinity is
expressed in denying or enduring pain, that evidence of health competence is feminine, that health professionals find men “puzzling,” and that health systems are feminine spaces. Through an SI lens, research accepts these scripts as cues to how men define what is going on. As work explores men’s cognitive and emotional assessments of illness, need, and support, researchers must be attuned to these powerful expectations infusing discourse and acts at micro and macro levels; these are the models men reference in rationalizing departures from expectations. However, in accepting meaning as variable space is made for interpretations influenced by a mixture of agency, interactants, and context. Attending to how men resist, accommodate, and transform expectations, research can anticipate many trajectories.

**Who am I in this situation?** Chicago school interactionists view identity as an emergent social process (Vryan, Adler, & Adler, 2003). In this spirit, Stone (1970) explained that identity is not the self, but parts of the self interpreted by and known to others: it is “what and where a person is in social terms” (p. 399). As identity is “situated,” Stone continued, an individual locates himself and others as he recognizes social objects as different from some and similar to others. This process is key to human interaction, as categorization offers a type of shorthand (imperfect as it is) as one seeks to organize his behaviour with others (Foote, 1951). As Foote illustrated, “a rose of any other name may smell as sweet, but a person by another name will act according to that name” (pp. 484-485). However, identity does not become a meaning of the broader self (self-concept) through this positioning alone. Others can attribute identities to an individual and that person will learn many perspectives as he interacts with others, but he selects only a few as his own (Foote, 1951). To become a meaning of the self, an identity must be both claimed by and affirmed by others within the context of a situation (Stone, 1970).

As beliefs about what is happening in a specific situation serve as a “backdrop” for what is deemed appropriate in attitude and act (Altheide, 2000, p. 6), these definitions direct identity claims. Whether a man seeks to present himself in a way consistent with situational expectations or whether he challenges definitions, identity serves as a symbol to indicate his status, feelings, and intentions (Schwalbe & Mason-Schrock, 1996) and it
helps him align his acts with others. As societal forces inform his thoughts and feelings about his self and his acts (Vryan et al., 2003), it is through this identification process that a man asserts who he believes he is as well as who he wishes to be (Charmaz, 1995). In other words, if I know who I am here, I know how to act. Even more, in my action you know who I am. In this process, identity is a story of self that a man draws on to navigate the uncertain and shifting environment of illness and the needs associated with it. As will be detailed, this story is linked to his physical body and it is dynamic.

**A story of self.** Hewitt (1989) argued that although it is important to conceptualize identity as a situated process, two correctives are needed. First, identity is not only a placement worked out in a situation, it is also a resource one brings to a setting. In this, he emphasized the difference between situated identities, temporary perspectives adopted to accomplish the goals of interaction, and personal and social identities comprising the self-concept individuals carry across settings (see also Vryan et al., 2003). Second, as a resource, identity helps one adjust to a complex and problematic world. To conceptually integrate these elements highlighted by Hewitt, it is helpful to think of identity as an individual’s story, an approach to understanding identity used in a variety of disciplines, from sociology (Giddens, 1991) to neuropsychology (Broks, 2004). As Giddens (1991) argued, a sense of self is found in a reflexive “capacity to keep a particular narrative going” (p. 54, emphasis his). Within the broader, evolving narrative personal and social identity are interwoven story lines constructed and modified as individuals take on situated identities in the course of our day-to-day engagements. I discuss each form.

**Personal identity.** As a man seeks to integrate their past, present, and future into a coherent story of self, personal identity can be appreciated as the story known by those closest to him (Allan, 2007). Although socially structured, this unique set of facts (i.e. name, biography, body) allows a person to recognize himself as *separate* from others (Hewitt, 1989; Vryan et al., 2003). As Hewitt (1989) detailed, personal identity offers a sense of continuity, integration, identification and differentiation enabling individuals to see how what they are doing is related to what they have done and will do, provides a sense that their thoughts, feelings, and acts fit together, and allows one to see himself as part of society while emphasizing who he is as a distinct person. Thus informed,
researchers can anticipate that as a man interprets the realities of his disease and identifies needs and supports, he is drawing from a lifetime of experiences and identifications to highlight certain elements in a situation and shadow others. For example, a man who has struggled with depression, physical limitations, or relationship dynamics in the past might have integrated these experiences into his sense of self and, thus, be differently attuned and responsive to these elements of his experience.

Social identity. Also offering continuity, integration, identification and differentiation, social identity (e.g. student, man) emphasizes an individual’s connections to community and culture rather than his distinction from society (Hewitt, 1989). This is the story told from a distance (Allan, 2007). Defined by how one appears (virtual) or in terms of what he possesses on closer inspection (actual), social identity locates individuals within a societal structure and is associated with attributes (e.g. honesty, occupation) deemed appropriate for group members (Goffman, 1963). Although persons are agents, Goffman (1963) argued, these anticipations are transformed into expectations, even demands. Thus, social placements, particularly those more salient, allow community needs and meanings to inform how one views himself and organizes his acts (Hewitt, 1989; Vryan et al., 2003). As social identities position a man and structure his opportunities, experiences, and definitions of self, they also pattern his personal narrative. This is the lens most often used in men’s help seeking research; how men draw on a story of self built in reference to gender norms (intersecting with race, sexual orientation, age) to guide their illness response. However, while a critical thread of identity, it does not operate in isolation.

Situational identity. The story of self is continually built and modified in the course of daily life as individuals take on situated identities. These context-specific roles, or perspectives (e.g. patient, doctor) allow individuals to engage in everyday interactions (Hewitt, 1989; Vryan et al., 2003). They are assigned by others and asserted by individuals as they draw on social norms outlining roles necessary to complete a joint action. An ER visit, for example, calls for health professionals and patients alike to carry out their respective roles. However, these roles offer only approximate guidelines. Even more, Hewitt (1989) argued, the roles individuals adopt are fundamentally problematic,
as they encounter situations with unexpected elements, evaluate each other’s performance, and try to balance a contribution to the group goal (e.g. treating illness) with a desire to remain distinct individuals.

The intricate, evolving story of self helps carry one through this complexity. As detailed by Mason-Schrock (1996), individual’s “stories are like containers that hold us together; they give us a sense of coherence and continuity. By telling what happened to us once upon a time, we make sense of who we are today” (p. 172). In the context of the situation, the parts of one’s personal identity emphasized and the saliency of certain social identities aid a negotiation of who one is and what he should do as an individual and as a member of broader communities. Notably, in the course of interactions the meanings of these identities can shift (explored later).

*Strategies of self-construction.* To meet the demands of a problematic world, there are broad patterns in how individuals build a story of self, and Hewitt (1989) has detailed several strategies of self-construction in Western society. First, “exclusivity” promotes social identity over personal, an approach exemplified by members of some ethnic groups or religions. In this approach, community serves as a reference, or generalized other, as individuals construct and judge themselves. In a society rich in choice, exclusivity offers security through aggressive conformity to community standards, a continual need to demonstrate loyalty, and a belief that common purposes supersede individual desires.

An alternate strategy, “autonomy,” allows one to seek freedom in society and abandon the constraints of specific communities. Personal identity takes precedence over social and an individual defines and pursues his own goals as an abstract generalized other offers principles, not concrete rules. Though a useful strategy in a diverse society, the autonomist can be tempted by ready-made templates offered by the pool of communities in which he is embedded. Thus, most adopt a third, “pragmatic,” strategy in which one builds meanings of self in society and as part of a community; both personal and social identities are relevant in the day-to-day. Moving across contexts, taking multiple perspectives and considering two generalized others (community and society), there is opportunity for conflict, second-guessing, and a sense of competing pulls, not
only by the disparate meanings for objects, but also by others in one’s life, close and
distant, individual and collective, who assert definitions and expectations (Hewitt, 1989).

Hewitt’s theory is useful to men’s help seeking research, sensitizing work to the
forms and demands of self-construction. In particular, depending on their strategy, men
will feel different “pulls” as they respond to illness. Current research tends to treat men’s
acts as influenced by a single template (i.e. dominant masculinity), but in a diverse
society men are challenged to be individuals as they are simultaneously beholden to many
communities, offering a variety of expectations of how to be a man, a partner, a friend, a
patient. As Hewitt’s theory emphasizes, men are pulled not only by broad scripts, but
also through expectations of family, friends, and health practitioners. Each strategy is
challenging, but a pragmatist’s balance, or “middle path,” requires continual attention and
explanation as one seeks to build a coherent story and present a socially desirable image
while facing a complicated set of choices, options to leave or stay within a community,
and opportunity for dependence and independence (Hewitt, 1989).

**Embodied.** Accepting identity as a social process does not mean dismissing the
reality of the physical body. Through the lens of SI, embodiment accepts an intimate
connection between bodies, selves, and social interaction (Waskul & van der Riet, 2002),
accepting the perceiving mind as “incarnated” Merleau-Ponty, 1962, (p. 401).
Masculinity is socially entwined with men’s bodies (Connell, 1995) as the performance
and structure of the physical influence how a man perceives himself as a social object,
guide his experiences, and inform the meanings he creates (Overton, 2002). As Connell
(2005) described, in the social world masculinity is:

A certain feel to the skin, certain muscular shapes and tensions, certain postures
and ways of moving, certain possibilities in sex. Bodily experiences are often
central in memories of our own lives, and thus in our understanding of who and
what we are (p. 52-53).

Grounding in embodiment is particularly relevant to men’s help seeking as gender
performances are judged in relation to bodies, and illness can lead to physical shifts and
altered state of body consciousness (Charmaz & Rosenfeld, 2006). In men’s health
studies, researchers over the past decade have considered how bodies compromised by
illness or disability can complicate a man’s ability to present a valued masculinity as one who is controlled and powerful (Chapple & Ziebland, 2002; Gray et al., 2002; Kelley, 2009; Oliffe, 2006; Robertson, 2006). In this focus, Oliffe (2006) explained, a social constructionist framework allows researchers to examine how an “altered body is reformulated, rejected, and/or reconciled in relation to masculine ideals” (p. 428). From the first physiological shift, to the naming (and re-naming) of illness, through the process of treatment and into recovery a man can experience his body in a multitude of ways. Theory must be sensitive to this. Just as biology cannot fully explain an individual’s social experience, neither can men escape the social reality of their flesh. This understanding is explored in more detail throughout the following sections.

**Dynamic.** Regardless of a man’s self-construction strategy, his story is continually being written, modified, and re-interpreted as he interacts with others. Across an illness career, he must locate himself as he determines what is going on, who he is and what he does. In this process, Foote (1951) explained, persons not only claim different identities, but also re-negotiate meanings of claims according to the context and expectations of interactants. Even more, as individuals interpret the world around them, they are evolving as they learn and revise concepts and reorganize their acts (Strauss, 1969). In this flux, Jenkins (2004) argued, researchers would do well to replace “identity” with “identification” as it is easy to forget that who individuals are is never final. Although every situation has standard and unique elements, identity can feel more stable in conventional situations where meanings are often close at hand; individuals know what is going on, who is who, and what to do (Foote, 1951; Strauss, 1969). In other situations they can encounter many unknown elements or a “problem,” in Mead’s terms (Foote, 1951). In these contexts, Foote (1951) contended, the definition of the situation is uncertain, identity unclear, and individuals can become disoriented.

There are many opportunities for disorientation in modern life as individuals move from role to role, each shift an opportunity to be aware of who one is in that context (Hewitt, 1989). Even more, problematic situations can significantly challenge a sense of self. Daly’s (1992) work on interactive resocialization highlights how individuals work to “remold” familiar identities in the face of challenges (e.g. parenthood in the face of
infertility) and Strauss’ (1969) concept of “turning points” details how critical incidents can lead one to reassess a sense of self. As individuals move in and out of phases, identity shifts can be the outcome of a gradual or sudden process, be fostered by institutions or occur unplanned, and be accepted, denied or even unnoticed (Strauss, 1969). Overall, recognition that identities are neither automatically applied nor stable challenges the belief that identity is attained and then maintained (or, in Strauss’ analogy, once an egg, always egg whether fried, scrambled, or boiled). Instead, Strauss argued, as individuals come to know themselves again, these new meanings allow them to re-evaluate their past and open new realities, different motivations, and alternate acts.

Illness has been positioned as an opportunity for identity turning points (Charmaz, 1995; Frank, 1997; Riessman, 2003). As Frank (1995) detailed, illness can cause one to lose the “destination and map” guiding their life (p. 1). Focused on chronic illness, Charmaz (1983; 1991; 1995) drew on an SI perspective in her illustration of the challenges to personal (sense of mortality) and social (wage-earner, male) identities and resistance to turning points caused by disease. Coining the term, “loss of self,” Charmaz (1983) described how those facing illness can experience a “crumbling away of their former self-images” as they struggle to retain control over their present and future and engage in a way of life they have come to know as theirs (p. 168). In a society where autonomy is valorized and “doing” prioritized over “being,” Charmaz argued that dependency, fragility, and a loss of functioning can critically impact a sense of self.

In later work, Charmaz (1991) detailed resistance to these identity shifts, demonstrating how when faced with illness, some cling to a valued identity, maintaining practiced claims about who they are and will be. As inconsistencies accumulate between a desired and lived self some might modify or temper their claims, but fictional identities are established in this space between reality and hope. Whether intentional or not, these fictions offer protection against uncertainty and engagement in the painful reality of illness and others in one’s life can be complicit in this process of perpetuating a fabricated image of the self. For example, a man facing a terminal diagnosis might maintain that he will eventually return to employment, with his partner, friends and/or coworkers participating in this fiction through their acceptance or encouragement of his
intention. In this process, his perception and use of supports can be critically compromised. Eventually, amidst medical and social pressures, a fictional identity can become too difficult to maintain and a turning point defined in retrospect, offering a diversity of trajectories as one renegotiates a sense of self (Charmaz, 1991).

For many, Charmaz (1995) argued, adaptation to illness is an on-going task as conditions change and individuals are challenged to re-establish who they are. In work specific to men, Charmaz (1994) detailed how illness challenges a “taken-for-granted” masculinity as defined by activity and autonomy, particularly among men who do not have others helping preserve this troubled identity (p. 270). Similarly, others have argued that physical losses and awareness of vulnerability can lead some men to reject traditional parameters of masculinity or renegotiate a sense of self as masculine (e.g. Gray et al., 2002; Kelley, 2009; Oliffe, 2006; Robertson, 2006). Overall, these transitions indicate not only adapted meanings of what it means to perform as a man, but also reverberating shifts in self-construction, more broadly. As Hewitt (1989) argued, when a sense of continuity is challenged, additional identities must be integrated, and the balance of identification and differentiation reconstructed.

**Negotiating what’s going on and who’s who.** Individuals work together to negotiate the meanings of situation and self. This is identity at work. Thus, to achieve a joint act, such as help seeking, interactants must communicate where they have been, where they are now, and where they are going (Stone, 1970). As McCall (2003) explained, individuals “act upon each other” (p. 327). Amidst a variety of contexts, the negotiation of definitions and identities between individuals or among groups is far from simple. In common situations where persons are similarly socialized, it can be easier to agree, with definitions even accepted as natural. Other times, parties might disagree, leading interactants to yield to one definition, try a “working consensus,” or end an interaction (Sandstrom et al., 2010). This complexity is emphasized by variation in the connection individuals feel with others (Prus, 1995). In temporary interactions roles can be improvised, while membership in an organization or institution (e.g. marriage) indicates more enduring, designated roles (McCall, 2003). In framing definitions and identities (i.e. meanings) as accomplishments, the work of Stone and Goffman is useful.
Stone (1970) contended that the human ability to identify with another person (i.e. the process of role taking as detailed by Mead) requires that persons first make an identification of the other. This process, he maintained, is facilitated through appearance. Individuals use signs, including clothing and grooming, gestures, location, and language (e.g. “name dropping”) to interpret others and “call out” in others the same identification they hold for themselves. This process, Stone argued, “sets the stage” for what content and forms of communication are deemed appropriate (p. 397).

Similarly, Goffman’s work sensitizes research to how individuals use appearance, setting, and verbal and non-verbal communication to manage how others view them and define situations in the course of face-to-face interaction. Consistent with the focus of dramaturgy, Goffman brought together acts and meanings as he explored how persons build realities with others (see Edgley, 2003). In this, his work is consistent with the Chicago school as it emphasizes social norms and roles as framing interactions, not determining acts (Meltzer et al., 1975). A theatre metaphor has limits (and critics, see Burns, 1992), but Goffman’s ideas sensitize research to the intricate work involved in face-to-face negotiations of reality.

In his discussion of impression management, Goffman (1959, 1967/2005) argued that when one enters a situation he offers a performance to let others know how he defines it and locates the players, particularly himself. Whether offered on a rigid front stage (professional or public settings) or a more relaxed backstage (personal or informal setting), a chosen “line” is one’s situational identity or, as Goffman’s described, his “face,” an image of self in the eyes of a real or imagined audience. Seeking to have this identity affirmed individuals communicate using direct, often verbal “expressions given” and indirect, non-verbal and at times unintentional “expressions given off” (e.g. facial expressions).

As there is much an individual cannot tell others about his beliefs, attitudes, and emotions within an interaction, he also uses the setting (e.g. furniture, layout), his appearance (e.g. clothes, hair) and manner (e.g. posture, gestures), to build a “front” that is easily understood by others and will convince them of his claims. For example, a man presenting himself as impacted by illness, might display medicine bottles, allow a less
tidy physical appearance, or permit others to see him laid up in bed. In contrast, one choosing to limit other’s awareness of his compromised state, might hide these signs, isolate himself, or make efforts to exhibit strength. With those who know him well his front can be relaxed, but he will take more care among others, recognizing that the information they glean from his performance can greatly influence how they perceive him. This work is often subconscious. As Schwalbe and Mason-Shrock (1996) argued, although one might initially choose signs to make an identity statement consistent with social norms (e.g. clothing style), selection can transition into habit, a practice of “cognitive economizing” (p. 120).

**Working in teams.** Although one can individually negotiate meanings, this work often happens in teams. As Goffman (1959) explained, teamwork can be relational as multiple people adopt compatible situational identities to maintain a definition audiences expect. It can also be more individual as one stands as both actor and audience to his own performance. Guided by an internalized moral standard, one might act in a way he does not believe in, but feels is expected by an unseen audience, or the generalized other, in Mead’s terms. In the context of a physician’s office or a family’s home, individuals are drawing on expectations of how one behaves as a doctor, male patient, partner (and more) to guide interaction. For example, if parties expect a man facing illness to respond with stoicism and self-reliance, they (including the man himself) will work together to negotiate this performance, a process limiting supports sought and offered.

Notably, as teams must agree on what is going on, an achieved, consensual reality is often reduced to a “thin party line” (p. 85). Thus, whether accomplished by groups or individuals, teamwork is characterized by discord as well as accord, deceit and disclosure, and is vulnerable to disruption (Goffman, 1959). This notion draws attention again to Seymour-Smith and colleagues (2002) contention that health professionals construct men as hopeless or childlike in matters of health. As they argued, there is value in considering how men negotiate their identity as patients in light of these dominant discourses framing interactions.

**Managing emotions.** Hochschild (1979, 1983) emphasized the negotiation of definitions and identity as an emotional as well as cognitive process. In the service of
emotion management (detailed earlier), she explained that individuals employ conscious and unconscious efforts to align a felt emotion with feeling rules of a situation. Drawing on Goffman’s work, Hochschild (1983) described how adherence to rules within a situation offers predictability and a sense of belonging. “Affective deviants” are those violating these social norms: “Not to feel embarrassed in certain situations,” she explained, “is to violate the latent rule that one should care about how the group handles or mishandles one’s identity” (p. 225).

In this discussion, Hochschild pulls back from Goffman’s focus on situations, to identify how work is structured across individual moments, as facilitated by institutional and individual expectations. In addition, although Goffman was primarily interested in how individuals seek to appear to others in a social context, Hochschild positioned emotion work as introspective as well. Accordingly she contended that individuals perform “deep” as well as “surface acting” as they use cognitive (e.g. changed thoughts), bodily (slowed breathing), and/or expressive (trying not to cry) strategies to actually shift an emotion or appear to feel what they perceive they should feel, drawing research attention to the influence of both specific and generalized others. Notably, as consistent with SI principles, the expression of emotions is not limited to what an individual says, but is evidenced in how he appears and behaves.

Interactionists are not interested in the physiological essence of emotions (just as they are not interested in whether one’s cognitions are “true” in some absolute sense), but in how social expectations structure emotional experiences (Hochschild, 1983). In this study, Hochschild’s detailing of the social nature of emotions sensitizes research to the value of considering which emotions are generated across the illness career, how emotions influence interpretations, how men respond to emotions, and how they express, suppress or rework feelings. For example, in recognizing this process as situational and relationally influenced, one can expect that an array of perceptions, interpretations, and understandings can lead a man to avoid asking for help as he works fear, sadness, and other feelings into a more acceptable emotion. Or he might selectively seek supports, deeming an expression of certain emotions as appropriate in some environments and relational contexts (e.g. partner vs. friend vs. medical professional). Whether one offers
an emotion he perceives as “owed” to others, plays with expectations, or colludes with others to defy them, Hochschild’s theory emphasizes emotions as socially informed, *chosen* expressions “given off” to confirm that individuals are who they claim to be.

**Avoiding missteps.** In this dynamic, individuals use “face work” to ensure that their acts are consistent with a face they want to present (Goffman, 1967/2005). Thus, if this man believes he should maintain an image of strength and stoicism despite feelings of weakness, anguish or fear, he might avoid situations where threats are likely (e.g. public outings, discussions of his illness), pursue ‘safe’ outlets where he perceives that his physical or emotional condition will be accepted as reasonable (e.g. in the company of others in a similar situation), or he might try to explain falters or request forgiveness. Individuals use poise to manage their own embarrassment in the face of missteps and tact to accommodate those of others. Notably, as Goffman argued, maintaining face is not an objective of situations, but highlights the codes to which one adheres.

Because an individual’s face is chosen and shaped in relation to known social attributes associated with how a situation is defined, one can experience shame, embarrassment, discomfort, or nervousness (Goffman, 1959) or guilt (Hochschild, 1983) when their performance is challenged or their face deemed inappropriate to a situation. For example, if a man presents as unperturbed by his cancer diagnosis (a display he interprets as appropriate for a man in his situation) and later begins to cry at a family dinner, he might experience shame, imagining his act is perceived as a violation of his claim as stoic or of his performance as a competent male partner. Although intensely personal, his face is borrowed from society and can be withdrawn if a performance is deemed unworthy of it (Goffman, 1967/2005).

As individuals seek to conceal displays inconsistent with an idealized front or face, an attribute severely discrediting expectations is a stigma, or a negative status overriding other attributes (Goffman, 1963). More specifically, Goffman’s (1963) highlighted three main forms of stigma: “tribal stigmas” (race, religion), “blemishes of individual character” (alcoholism, mental illness), and “abominations of the body” (physical deformities, illness). Goffman’s concept is based on an acceptance that although individuals present with a variety of differences (e.g. race, gender) that would,
in absence of social context, make no objective difference or may choose a variety of paths within a situation, these actions and associations are judged through a process of social consensus as more or less worthy or appropriate for a group member.

Building on Goffman’s work, Link and Phelan (2001) highlighted four core components of stigma, including: (a) a distinguishing and labelling of differences, (b) a negative association of the difference, (c) a separation of ‘us’ without a difference and ‘them’ with it, and (d) status loss and discrimination. This concept sensitizes understanding of research indicating that men tend to have more limited health knowledge and exposure relative to women and can find health services embarrassing or “unfriendly” (see Banks, 2001; Courtenay, 2003; Smith, et al., 2006). Theoretically, one could expect that some men might avoid help seeking due to a fear of losing face, due to the nature of a physical concern (an abomination of the body) and out of concern that they are not performing appropriately as a male (blemishes of individual character).

The physical body is prominent in the process of managing impressions. Humans are embodied as they imagine how others view and evaluate their body and in how they adorn and manipulate it; they not only have a body culturally defined according to race, sex and other characteristics, but they also do a body (Waskul & Vannini, 2006, p. 6). As introduced earlier, unlike identities more or less apparent in a situation, claims as a man or woman (linked to sex category) are continually negotiated, as individuals seek to provide a credible performance.

Beyond these on-going obligations, illness can force a body to lose its normal “transparency,” becoming conscious and taking a more central role in how individuals view and present their self (Waskul & van der Rieta, 2002). In this heightened consciousness, Frank (1995) argued, individuals are more fully engaged in the ongoing challenge to control bodily functions, balance association with their bodies (i.e. where one is on a continuum between having a body and being a body), navigate their relationship with other bodies (a monadic, separate body or a dyadic body, connected to others), and manage their expression of desires for and through their bodies. In this negotiation, bodies are forcing selves that must try to integrate this more complex,
embodied reality. As Frank summarized, even as an individual and those who care for him resist change, “a new body calls for a new self, nothing less will do” (p. 68).

Emphasizing the element of control in this process, Cahill (2006) argued that in Western society where health is equated with mastery of body, illness that publically exposes an “unruly” private body can threaten a sense of competence (p. 75). Whether experiencing the “abject embodiment” of a disfigured or “grotesque” body (Waskul & van der Riet, 2002) or a more subtle loss of trust in its functioning, physical shifts propelled by disease can lead one to readjust the image he holds of how others see him, can find it difficult to maintain identity claims, or feel shame in his loss of face (Charmaz & Rosenfeld, 2006). This can prompt one to modify claims or try to manage a preservation of self-concept amidst change (Waskul & Vannini, 2006). Some illnesses are particularly threatening. As noted, conditions perceived as severe (e.g. cancer) or preventable (e.g. AIDS) tend to be more stigmatizing (Crandall & Moriatry, 1995) and, as noted by Gray and colleagues (2000), stigmas can compound when feared diseases (e.g. prostate cancer) compromise a valued gendered performance (e.g. sexual impotence).

**Summary.** A capacity for reflexivity and use of symbols allows individuals to interpret their world and self in social terms. As Goffman’s work emphasizes, there is a vast intricacy in the process of negotiating meanings and aligning acts with others. Conventions might guide this work and situations may be routine, but none are automatic and all are potentially problematic (Schwalbe & Mason-Schrock, 1996). As Prus (1995) noted, Goffman players are fully alive: “they think, they watch, define, and try to anticipate the other, they plan, they perform. They make mistakes, and they readjust, sometimes individually and sometimes with the cooperation of others” (p. 80). Through this complicated dance the story of self evolves and acts are engaged.
Blumer (1969) argued that the test of research is not how researchers use protocols or tools, but whether their research questions and processes are consistent with the empirical world they seek to understand. Central to Blumer’s assertion was a challenge to the rote application of natural sciences methods and criteria to the study of social life, an argument that resonates with Weber’s notion of verstehen or the belief that to apprehend human acts, research must access the subjective meanings driving them (Hammersley, 1989).

Careful not to overly prescribe the research process, Blumer drew on Cooley’s notion of sympathetic introspection as he called researchers into relationship with those studied, an effort necessary to exploring the interactive, interpretive processes prior to inspecting them. As Blumer (1969) detailed, research must lift the “veils” obscuring the activity of group life and to do this, one must get close, engaging in “careful and honest probing, creative yet disciplined imagination, resourcefulness and flexibility in study, pondering over what one is finding, and a constant readiness to test and recast one’s views and images of the area” (p. 40). Thus, as others record demographics, pursue latent factors, or detail structural constraints to predict or explain help seeking, an understanding of meanings requires that I hear the stories of those living the reality I seek to understand. With this emphasis, I present my philosophical positioning before describing grounded theory methodology and the implications and process of my selected research methods.

My Philosophical Positioning

My role (epistemology)

In my focus on meanings and interest in how men perceive, interpret, and understand needs and supports during illness, I have adhered to a more subjectivist epistemology. More specifically, in recognizing a continuum (Daly, 2007) between a purely objectivist orientation that seeks to access and explain an external reality and a purely subjectivist position that accepts the absolute relativity of knowledge, I have
positioned myself closer to the subjectivist end of this scale while accepting an intersubjective, or shared, reality.

As consistent with symbolic interactionist principles, I accept that while a “world out there” exists independent of human comprehension, it takes on form, a particular appearance and meaning, through human observation (Blumer, 1977). Even more, I recognize this observation process as fundamentally social in nature, accepting that as social beings, humans work together to establish significant symbols, or meanings, of the social, physical and abstract objects they perceive. In this, although an individual can selectively apply, challenge, or modify meanings in handling the perceived world, the symbols he has at his disposal in this process are shared, learned through ongoing processes of socialization and communication.

In this process, I have not sought a final truth, but located shared truths. Further, I have accepted that any image of reality, built through the cooperation of social beings, is not fixed, but “continually recast with the achievement of new discoveries” (Blumer 1969, p. 23). Finally, as I engaged in this close exploration, I have accepted that I am part of the process of knowledge construction. Like the men I study, I bring my own subjectivity to the world I examine. Or, as Blumer (1969) detailed, “whether we be laymen or scholars, we necessarily view any unfamiliar area of group life through images we already possess” (p. 36).

**Paradigm (beliefs, habits, tools)**

Paradigms help orient and communicate the beliefs, habits, and tools guiding the research process (Daly, 2007). This scientific orientation has critical implications for how one answers the ontological, epistemological, and methodological questions encountered throughout the research process (Guba & Lincoln, 1994). As Guba and Lincoln (1994) argued, in detailing one’s paradigm emphasis is not on proving the validity of an approach, but on persuading the reader of the utility of this positioning.

Consistent with my belief that individuals subjectively perceive and construct an intersubjective reality, this study has been organized within a social constructionist/interpretivist paradigm. More specifically, in accepting that individuals draw on
significant symbols as they perceive, interpret, and understand themselves and their world, I have prioritized the study of discourse (written, verbal, and non-verbal) to access how the men participating in this study make sense of reality. As Prus (1995) noted, a methodology intent on examining the interactive process of meaning making must handle an intersubjective reality, accessing how individuals interpret themselves, others, and experiences and examining how people influence others (and resist/ accommodate other’s influences) and how they act individually and with others (pp. 18-19). This focus requires research methods adaptable to learning achieved throughout the course of study, as one develops familiarity with those studied (Blumer, 1969), a challenge often leading researchers to rely on interviews, story-telling, and/or observations (Daly, 2007). These tools enable access to “thick descriptions” (Geertz, 1973), those historically and contextually located, detailed constructions of personal experience through which the “voices, feelings, actions, and meanings of interacting individuals are heard, made visible” (Denzin, 2001, p. 100).

On this philosophical base, I accepted the critical need to get close to the lives I wished to study. Engaging men in discussions of how they perceived, interpreted, and understood needs and supports during times of illness, I sought detailed descriptions and prepared to engage with multiple experiential realities. In this, I was less concerned with understanding what actually happened and more with how they made sense of their cancer-related experiences. In accepting myself as a participant in this construction of meaning (noted above), I accepted a responsibility to be reflexive about the beliefs and assumptions I brought to the process, carefully considering how my experiences and practiced assumptions influenced my selection of this topic of study, the process by which I engaged with research participants, and how I interpreted their experiences in particular and as a whole (see Daly, 2007). Over the next section, I describe how this approach took in this study, as organized by a grounded theory methodology.

**Grounded Theory Methodology**

Grounded theory is both a qualitative research method and research product. Bringing researchers into close contact with those they study, grounded theory methods (GTM) offer broad guidelines orienting researchers to the examination of social and social
psychological processes and organizing data collection, management of analyses, and development of substantive theory to explain or describe social processes (Charmaz, 2005). Critically, the theory that serves as the goal of this research process is attained through an intensive process of collecting and analyzing data; it is not derived purely through speculation or personal experience (Strauss & Corbin, 1998).

Influenced by the assumptions of the Chicago school of symbolic interactionism (Blumer, 1969), GTM operates on an assumption that in a dynamic social reality, humans are reflexive, social beings who use shared symbols to interpret their world, build and convey meanings within context, and guide acts. In this orientation, grounded theory joins the practical issues of daily life with a means of exploring a shared basis of experience (Watson, 2000). Prioritizing an emergent design that enables the flexibility necessary to remaining focused on participant experiences, a grounded theory approach engages a researcher in concurrent data collection and analysis so that she is able to follow leads and seek out meaningful information (theoretical sampling) in the course of the study. GTM was well suited to the needs of this study, as I examined how men perceived, interpreted, and understood needs during illness and how they acted as individuals and with others to respond to these. This approach allowed me to consider the lived experiences of men and structured the research process in a way enabling the development of substantive theory.

A brief history

Introduced by Glaser and Strauss in 1967, grounded theory was initially positioned as a correction to a perceived overemphasis on theory verification in sociology as well as concern with a tendency to simply “tack on” a theoretical explanation at the end of empirical research (Charmaz, 2003; Glaser & Strauss, 1967). As Charmaz (2006) summarized, Glaser and Strauss sought to move qualitative research from a practice of describing social life toward a pursuit of offering broader, conceptual explanations of it. In pursuing sociological theory that served as a useful, clear, and understandable guide to explaining behaviour, Glaser and Strauss (1967) argued that theory could be “discovered” by a researcher systematically working with data. Theoretical influences and other insights might emerge from elsewhere, but they must be brought into relation with
collected data for theory to be developed. Because theory generated in this way is so intricately woven into lived experience, they argued, it is more enduring.

Methodological differences eventually divided Glaser and Strauss, leading Strauss to partner with Corbin, and presenting the research community with two versions of grounded theory (Strauss & Corbin, 1990 and Glaser, 1978). The Glaserian and Straussian approaches to grounded theory divide primarily on the grounds of how the research is conducted (Walker & Myrick, 2006). Whereas the quantitatively trained Glaser stressed a more controlled relationship with data (resisting early interpretations, letting data “speak” through meticulous and reserved constant comparison over many cases) in the pursuit of accessing reality, Strauss and Corbin offered a broader set of tools encouraging more manipulation of the data in an effort to verify the developed theory (Charmaz, 2005; Walker & Myrick, 2006).

Despite these differences, it is argued that both approaches share an epistemological tendency to position the researcher as an objective observer, seeking “facts” and ensuring thematic “accuracy” (Charmaz, 2005; Daly, 2007), though in a recent edition of Corbin and Strauss’ (2008) guide, Corbin evidenced constructivist influences in her detailing of grounded theory. Some argue these leanings have been present since their 1990 edition (Mills, Bonner & Franics, 2006). Regardless, as fuelled by post-modern critiques, a constructivist re-visioning of grounded theory has been notably led by one of Glaser and Strauss’ students, Charmaz (2000, 2006), who has critically challenged an implicit assumption of objectivity in the methodology.

**Constructivist grounded theory**

A constructivist grounded theory (CGT) approach is based on an assumption that the process of gathering, analyzing and interpreting data is never neutral. Consistent with a symbolic interactionist perspective accepting multiple perceptions and the joint construction of meaning, researchers adhering to a CGT approach position themselves as participants in the construction of understanding. As Charmaz (2006) detailed, theoretical understandings offered through grounded theory offer an “interpretive portrayal of the studied world, not an exact picture of it” (Charmaz, 2006, p. 10). In other words, themes and theories do not rise up from the data, but are placed over it as
researchers offer interpretations of the subjective realities of interviewees (Charmaz, 2005; Daly, 1997; Daly, 2007). Focus is on interpreting the meanings of an experience or process, not accessing a truth (Charmaz, 2000).

As constructivist grounded theorists remove the “cloak of neutrality,” they openly wrestle with the task of interpreting the expressions of those who are interpreting their world (Charmaz, 2005, p. 511; Daly, 2007). Giddens (1984) described this as the “double hermeneutic” of social research, arguing that scientists must balance two levels of meaning: (a) first order constructs, or the world as interpreted by “lay actors”, and (b) the “metalanguages” or second order concepts built by researchers (p. 374). Even more, second-order concepts can circulate back into first order concepts as individuals interpret them. In encouraging interpretive researchers to consider this dynamic, Prus (1995) emphasized a critical point that in the social sciences “objects” of study are not passive, but rather actively guide learning through their openness and restraint.

Thus, a CGT approach requires researchers to not only reflect on the influence of their own past, knowledge, and interests on the relationships they establish with research participants, the questions they ask, analyses they conduct, and theories they generate (Charmaz, 2005; Daly, 2007), but also recognize participants as active partners, able to “act back on researchers” (Prus, 1995, p. 18). To disregard “intersubjectivity, multi-perspectives, reflectivity, activity, negotiability, relationships and process” as facts of group life is to “violate central qualities of this subject matter” (Prus, 1995, p. 18). As my discussion of the practice of GTM is detailed through this constructivist lens, it is important that I speak directly to the ‘self’ I brought into this study before I detail the methods used in this study.

**Situating myself as the researcher**

Corbin and Strauss (2008) argued that qualitative researchers are driven by a desire to engage in the dynamic process of exploring complicated lives and relationships, to step into the chaos of lived experience and to make sense of diversities, both commonalities and differences. In this mix, a researcher does not seek distance, but rather a connection with others at a human level as the whole self is brought into the research process (Corbin & Strauss, 2008). This engagement requires comfort with
ambiguity, maintenance of flexibility, and a commitment to reflexivity (Corbin & Strauss, 2008), or the awareness that researchers do not discover meanings; they help build them (Mauthner & Doucet, 2003). As Stanley and Wise (1983) argued, the self can be omitted from the research product, but it cannot be removed.

Arguing for the influence of the self in research at a fundamental level, Krieger (1985) asserted that researchers must connect discussions of those studied with those about the self; these are not independent. Each person brings “idiosyncratic patterns” of recognition to the world around them and how one knows herself influences how she knows others (p. 309). “If the understanding of self is limited and unyielding to change, the understanding of the other is as well” Krieger wrote, and “If the understanding of the self is harsh, uncaring and not generous to all the possibilities for being a person, the understanding of the other will show this.” (p. 320). It is not the thoughtful use of self in research that endangers the quality of research, she argued, but rather not doing so. This process of self-recognition makes transparent a multitude of influences on work and allows researchers to explicitly wrestle with assumptions and expectations they bring about their topic of interest and human possibilities to this interaction (Krieger, 1985).

Recognizing researchers as woven into their work, reflexivity enables a deliberate process of “scrutinizing one’s subjectivity” (Kuczynski & Daly, 2003, p. 384). Across the research process, from the inception of the project through the communication of findings, one is called to explicitly examine her experiences, choices, and interpretations in a way that makes clear the beliefs and interests that shaped inquiry (Charmaz, 2006). Even more, reflexivity can guide insight into the experience of others, offer comparative cases, and stimulate thinking (Corbin & Strauss, 2008). As Dupuis (1999) described, “qualitative research is a mutual journey taken by both the researcher and the researched” (p. 45). One moves into this journey, she argued, not only as co-constructers of an uncertain future, but also as a person with a past. Thus, although I include moments of reflection across the detailing of my methods, I begin this discussion by first detailing the focus and values I brought into this study.

**What I brought into this study.** I was raised in a home where diseased bodies and ill selves were part of dinner conversation. My mother was a medical/surgical nurse
and I was captivated by her stories, as she uncloaked the flesh that rarely received airing and introduced me to people I would never meet, but about whom I asked each evening. With her balance of frankness and sensitivity, I knew we were to hold these stories carefully, but not reject them as unfit dining companions. As children, my brother and I spent countless hours in hospital waiting rooms and patient floors, my mother dropping us off as she started her evening shift and my father taking us home after his day at work in information services at the same hospital. I have vivid memories of those times, peering over my book to watch others walk in and wheel out, of journeying down halls, peeking into patient rooms filled with a slow rhythm of machines pulling at weakened bodies, the agitated strains, resigned whispers, connective laughter. In those moments, I observed lives reoriented around illness. Though buffered from the acute challenges in these experiences, I was fully alert. Those lives, those activities felt important.

Later, I joined those who did the coming and going, who filled the rooms, as I visited with family and friends whose lives had been upended by disease, some of whom would not leave that space. No longer just an observer, the stories of illness became those I told, that were shared with me. As I blended these experiences with my master’s research examining cultural understandings of health and illness and, later, my work as a community based health researcher focused on public health programming around chronic disease, I began to grow aware of the stark divergences in our public and private discourses about illness. Most significant to this awakening was an experience during which I was charged with writing a report detailing the cancer incidence for my Region. Over the course of several months, I spent my workdays analyzing cancer data and my evenings helping to care for a friend whose body and self were rapidly being consumed by metastatic breast cancer. In this report, my friend – one of the most vibrant people I have known – was another data point. This was a dissonance I found challenging to reconcile.

My childhood experiences had primed me to an appreciation of illness narratives and my adult relationships were shifting how I engaged with the study of health. Simply, the morbidity and mortality rates I sought to catalogue in order to detail the health of my community felt frail beside the robust personal stories to which I was a witness, so disconnected from the lived experience of illness. I accepted the utility of these statistics
in our effort to monitor disease, but then, as now, I was dissatisfied with the superficial story they offered. Instead, I was drawn to the stories within those numbers, the experiences of complex individuals woven into networks of relationships, uncertain and confident, hopeful and despairing, resistant and compliant, selectively directing their rationality and, at times, resisting the expected trajectory. I grew intrigued by how, as Pescosolido, Gardner and Lubell (1998) have described, we “muddle” through illness.

My interest in the stories men tell, more specifically, developed in the context of my work with a sexual health program and with a research group evaluating cancer social support programs. In each of these environments, the focus of our programming was primarily oriented toward girls and women, respectively. When the opportunity arose to develop a testicular cancer awareness campaign targeted at adolescent boys, I was eager to hear their voices. I found myself surprised by both the intensity and careful display of their interest. In contrast to similar groups I had run with teenaged girls in regard to cervical cancer, these boys appeared to be walking a narrow path between soliciting desired information and giving the appearance that they already knew, or didn’t care, about the answer. Later, in conversations with my colleagues who were experienced public health nurses I became attuned to how little we knew about connecting with these boys.

Similarly, in my work evaluating cancer support services, we continually struggled to accommodate the extremely low sample size of men in our surveys, in part a reflection of their relatively low levels of participation in the support services. My concern here was not just that our programs were not being targeted to or accessed by men or that we seemed to know little about how to engage them, but that there appeared to be little momentum to correct this. I felt that this inertia was partially fuelled by an implicit (and at times explicit) expectation that men simply could not be counted on to take on the responsibilities and opportunities offered to women. In effect, the health of boys and men became the burden of girls and women. In this space, I believed we were doing a disservice both to men and to the women in their lives; that our ability to attend to these gaps required that we first set aside practiced, low expectations of men and second, that we listen; that we value men’s stories, hear them, and prepare ourselves to be surprised.
As I accept that I am not fully aware of the range of influences guiding my research interests (Doucet, 2008), these experiences are among those I draw on as I reflect on how my own journey led me to this research process. I recognize these as influential to developing my knowledge and informing my values in the pursuit of understanding men’s health related help seeking, orienting my interest toward subjective meanings of illness, and attuning my awareness of the importance of listening to men’s stories. Importantly, these experiences (and other associations) are not provided as a static record or travel log.

Although the complexity is often underplayed, matters of past, present, and future are interrelated, dynamic considerations. Just as I recognize the present as shaped by my subjective evaluations of past events and anticipated futures (see Lollis, 2003), I also accept that in the midst of human agency, the past (and future) is fashioned by elements of the present to which I attend; “the long and short of it is that the past (or some meaningful structure of the past) is as hypothetical as the future” (Mead, 1932, p. 12). Key in this dialectic is that as I continuously interpret my experiences, or “organize” my world (Mead, 1934, p. 25), meanings of where I have been, am, and will be are built in relationship and, thus, always malleable. As Mauthner and Doucet (2003) argued, reflexivity is a time-bound process, a pursuit occurring in “degrees” with some influences easily identified amidst the research process and others requiring “time, distance and detachment from the research” (p. 425).

**An on-going process.** Amidst the ever-evolving “specious present” (Mead, 1932) unfolding across this research process, I endeavoured to remain connected to the self I brought into this research process and the self altered by it. More directly, drawing on Dupuis’ (1999) four strategies of reflexive methodology, I sought to (a) engage my full self in this process, not just as a researcher, but also as a fellow human, (b) practice empathy as I recognized connections between the men in this study and me, making use of the emotions, as well as the cognitions, I experienced in this process, (c) engage a positioning of participants and me, the researcher, as collaborators in the construction of knowledge, and (d) explicitly integrate these dynamics in the communication of my research practice and theoretical work. This process is faithful to the orientation of
constructivist grounded theory not only in approach, but also in presentation. I continue to touch on this process of reflexivity as I detail my research design and results.

**Research Methods**

The nature of the research problem shapes the chosen methods (Charmaz, 2006). Consistent with my interest in exploring how men make sense of needs and supports in the face of illness, the level of analysis in this study was individual men facing illness and the unit of analysis was their description of experiences related to a range of needs and supports throughout their illness career. Directed by this focus, I engaged in-person, unstructured and semi-structured interviews using an emergent design framework, an accepted method of gathering rich data on individual experience (Charmaz, 2003). More particularly, Morse (2001, 2003) has argued that this approach enables the development of coherent narratives, important to studying process and is of particular value in examining the experiences of people facing illness. Within this structure interviews are “conversations with an agenda” (Daly, 2007, p. 139). The agenda I brought to the discussion was an interest in understanding the process of help seeking, and my assumption was that by exploring individual men’s perceptions and interpretations and the conditions and sequences of their activities, I would be able to identify broader social processes.

Prior to detailing the specific activities enacted across the process of data collection and analysis, it is important to clarify some foundational assumptions about the researcher-participant relationship within the CGT tradition. First, as indicated above, I accept researcher neutrality as neither possible nor desirable (Fontana & Frey, 2005). Second, I view myself as a co-constructor of knowledge. Thus positioned, I both accepted my own subjective process and recognized the research participants as “partners” in the construction of located understandings. As Charmaz (2003) detailed, although interviews start with a central research problem, they progress as participants build a discussion together. In walking the path toward the goal of developing understanding regarding the social process of men’s help seeking, I sought to enable a more symmetrical researcher-participant relationship (Gubrium & Holstein, 2003); an approach that “humanizes” both the researcher and participant and which enables each of
us to share in the responsibility of developing concepts that capture their experience (Rubin & Rubin, 2005).

In navigating this path, I engaged several strategies. First, as noted, I participated in an on-going process of reflexivity, building memos detailing not just themes in the stories, but also reflections on my assumptions in the process and how I was being impacted by it (an activity continuing through the write-up of analysis). Second, I sought to exercise transparency with the men around the values, assumptions, and agendas I brought to this study (Daly, 2007), moving beyond the responsibilities detailed in the consent process and ensuring that I engaged honestly and remained open to questions or concerns before, during, and after the interview.

Third, rather than engaging participants as subjects to be “mined,” or endeavouring to “squeeze” understanding from them (Fontana & Frey, 2005), I recognized the men in this study as experts and agents. In this, I did not simply solicit information on their experience, but invited them to reflect on the meanings of their acts and patterns I was observing across the interviews, and to link these together in more coherent explanations (Daly, 2007). Further, while I accepted the need for deliberate care in engaging the men around difficult experiences, I also accepted Corbin and Morse’s (2003) reminder that research participants are agents and should be respected as able to exercise control over what they share and how they do so.

Finally, I have sought to maintain transparency in how I offer interpretations of the men’s statements and shared experiences, seeking to avoid a presumption that I know with certainty their thoughts and feelings. I do not claim that power was equalized through these acts (certainly, it was my interests that initiated the discussions, and I have yielded control in piecing together the higher order narrative), but this orientation was important to working toward a partnership approach across the research process.

**Recruitment**

Upon receiving ethics approval from the Research Ethics Board at the University of Guelph (approval #10Jun20), I began the recruitment process, seeking to engage 25-30 men who had received a cancer diagnosis in the recent past. Although there are few
concrete prescriptions for sample selection in grounded theory studies, Morse (2000) has argued that researchers should consider several factors, including study scope, topic, data quality, study design, and inclusion of shadowed data (participants reflecting on others’ experiences).

Acknowledging these guidelines, the interviews included in this study were designed to explore a specific element of men’s illness experience: help seeking. Notably, although help seeking was defined broadly and consideration extended over the entire illness career, research questions centred on retrospective perceptions of men’s needs and supports, a defined and confined area of study and one not requiring multiple sessions with a participant. Given this, my advisor and I agreed that 25-30 participants should be sufficient, though we were open to seeking additional participants, should that target be inadequate for theory development. As I engaged in these interviews, I found that the interviews elicited rich data. In nearly all cases, the men were focused and intent on detailing their experiences in full and keen to ensure we covered all elements of interest. In this, saturation was achieved well before the 30th interview.

Recruitment was facilitated through the support of two local non-profit cancer support organizations, Wellspring Cancer Support Network and HopeSpring Cancer Support Centre, which agreed to circulate promotional materials (see Appendix A) for the study within their broader network. An effort to complement this recruitment with advertising through a local hospital-based cancer centre was explored, but was declined as this organization was already involved in the recruitment of clients with cancer for a separate study and was concerned about overlapping interests. Moving forward with this recruitment structure, I connected primarily with men who had participated in cancer programs run by these centres, with a smaller percentage of research participants who had not used these services, but had learned of the study through friends or relatives (often women) associated with these centres.

Given the relatively low rates of men participating in cancer support services, I recognized that the men using supports offered through Wellspring and HopeSpring could be distinct in relation to those men who had chosen not to engage these types of services. However, I did not view this as a barrier to developing understanding around
men’s help seeking. In fact, this recruitment structure allowed me to learn how men both perceived and experienced these support processes, including how they navigated their way around social expectations emphasizing these services as associated with more feminine strategies of handling cancer-related needs. This dynamic would become important to exploring a full range of informal and formal help seeking processes across the course of an illness career.

As supported by the cancer support centres, recruitment progressed swiftly and I quickly began to receive emails and phone calls from the 30 men who would participate in this study. In fact, I was soon in an unanticipated position of letting men know that I had reached capacity for the interviews. Several indicated disappointment and one called to actively petition for the value of including him in the study (due to a cancellation, I was able to include this individual). I interpreted this overwhelming and fervent interest as a strong indicator of the value of this topic of study and a challenge to an assumption that men are neither interested in, nor comfortable talking about their health and illness experiences. Further, as will be discussed in the results section, many men explicitly emphasized their interest in this as an opportunity to talk about their experience, while others noted the need for an enhancement of services for men with cancer (particularly those with non-prostate cancer diagnoses), a process they were keen to support.

Beyond the analytical considerations accompanying this response, my memos reflect how I found this process challenging, more personally. In particular, I felt as though I were rejecting persons willing to open up to me about a time of suffering. I recognize that the men did not necessarily perceive the process as such, but I see this tension as the start of the heavy sense of obligation I would feel throughout this process, as I positioned myself as responsible for carrying these stories forward in a meaningful way. Given my discomfort with turning men away and the potential opportunities in responding to this high rate of interest in the study, my advisor and I decided to add a focus group to the research design as a method of moving analytic work toward intervention. I invited men whom I was unable to interview to participate in these sessions that would be run after completion of the dissertation, and over a dozen agreed to participate.
Recognizing that the experience of needs and supports during times of physical illness is private and can be emotionally charged (Lee & Renzetti, 1990), I initiated my commitment to maintaining trust and confidentiality within this recruitment phase. While the standards of informed consent gave me a tool within the interview by which to make participants aware of the process and purpose of the study and their rights within it, the email and telephone conversations engaged in the recruitment phase allowed me to begin the process of transparency. In these exchanges, I not only solicited more detail on their cancer type and stage, but also provided details on the focus of our discussion, noting that the interview would explore their thoughts and feelings related to a range of needs and supports during their illness. This communication was important to preparing the men for the interview, but it also built in space for them to retract their offer to participate or to let me know whether they would be challenged to discuss or remember these elements. Once they had affirmed their commitment to participate in the study after receiving this additional information, we started the process of scheduling the interview time and place. Notably, one man chose to pull out of the study at this stage, while the remainder moved forward.

**Meeting the Men.** The sample of men recruited to participate in this study was unrestricted by ethnicity/race, class, cancer type/stage, and relational status, though I did restrict participation to adult men. Given my goal of theory construction, I focused on obtaining high quality interviews that would help me address theoretical needs, rather than assembling a large volume of participants or obtaining a representative sample of men (Kvale, 1996).

In addition to responding to basic demographic questions, I invited each man to introduce himself to me, to move beyond the standard information on his social locations and provide a window into his personal identity, or biography of self. In particular, I asked him to reflect on how another person might describe him or, if he was uncomfortable with that approach, how he might describe himself to someone. In accordance with the diversity these men expressed in so many ways, some spoke freely and comprehensively as they offered detailed introductions, while others were more
sparse and tentative in their descriptions. Both approaches were welcomed as I accepted whatever the men felt comfortable sharing.

Over the next few pages, I offer brief participant biographies. These descriptions of self, composed of a range of social and personal locations, are not used to compare or contrast groups of men, and for this reason I do not provide a demographics table. However, there is value in presenting the diversity of voices contributing to this substantive theory. Even more, as each man claimed a unique and evolving biography, the experiences and positions infusing his self-story influenced the meanings he drew on and worked with others to build as he made sense of the objects in his life. In the context of this study, this most clearly comes into play as I describe how men engaged with the dominant script of masculinity: how they performed masculinities.

In these descriptions, pseudonyms are used (some chosen by men, others assigned by me) and some details are omitted to enable confidentiality. As will be apparent, most of the men had been diagnosed with cancer within the previous five years, while for some it had been nearly 10 years since they had first learned of their disease. More specifically, at the time of the interview some of these men were living with a cancer that would be terminal in a short period of time. For others, challenges were ongoing amidst a chronic condition or disease recurrence. Others had just entered a period of waiting to see if their disease had been eradicated and still others, several years down the line, had received formal notice that their cancer was in remission.

The men participating in this study ranged in age from their early 30s to mid 80s, with two-thirds of the participants aged between 50 and 69 (mean age = 59). Each was able bodied, had a family doctor at the time of his diagnosis and nearly all were white, with the exception of one man of East Indian background and one of Asian descent. Most of the men had been born in Canada, two had immigrated from Western Europe and one from the Caribbean, although all had lived in this country for well over ten years. Three men identified as gay. Although nearly all men presented as cisgender (or gender-normative), one man described himself as gender queer (and heterosexual). Notably, in the presentation of these biographies, it should be assumed that the men were born in Canada and identified as heterosexual and cisgender unless otherwise stated.
Over two-thirds of the men were parents and twenty-four were married or in common law relationships (most with women, one with man). Three men were divorced or separated and three were single. At the time of the interview, ten men were employed full time (two of whom were self-employed), nine were retired, two were semi-retired, six were on disability leave related to their cancer, one was transitioning into a new work role, and one man was in the process of looking for work. Finally, although I do not link the biographies to educational status, the men had a range of backgrounds including the participation of three men with less than a high school diploma, three with a high school degree, eight with a College diploma, two with some university, eleven with a University degree, and three with post-graduate degrees.

**Micky.** A retired salesperson and married father of adult children, Micky was in his early 60s at the time of the interview. When diagnosed with prostate cancer in 2000, doctors estimated that he had only a few years to live. Although experiencing several recurrences of his disease, Micky outlasted those projections as he underwent a variety of treatments including surgery, radiation, and hormone therapy. In describing himself, Micky emphasized that he is someone who is powerfully curious about the world around him and who “tells it like it is,” adding that while he is often right, he will always admit it when he is wrong. He perceived that others see him as someone who speaks out of his love for humanity.

**Clint.** Marrying later in life, Clint was a government worker in his early 50s and the father of teenagers. When diagnosed with an early stage kidney cancer in 2008, Clint received a good prognosis as he immediately underwent surgery to remove the mass, noting that he was one of the “lucky ones” who had his cancer caught early. In describing himself, Clint emphasized his nervous nature and tendency to think outside the box as well as his loyal, caring, people-based and community-focused way of being.

**Chris.** A retired tradesperson, Chris was a married man in his early 70s and the father of adult children. Diagnosed with non-Hodgkin’s lymphomas in the 2007, Chris underwent surgery and chemotherapy to treat his condition. Highly involved in his faith community as a leader and a volunteer, Chris emphasized his love of helping others, including those he has never met.
**Andy.** A married man in his mid 40s, Andy was the father of young children, and worked multiple part-time jobs. Diagnosed with non-melanoma skin cancer in 2010, his condition carried a good prognosis and was treated with radiation, although Andy recognized himself as at a high risk for recurrence of skin cancer. Preferring the “quiet life,” he described himself as someone who enjoys spending time at his cottage and helping others.

**Dan.** Dan was diagnosed with advanced head and neck cancer in 2002. In his late 40s at the time of the interview, this married salesman and father of young adult children, was given only a couple of years to live when first told of his disease. However, following extensive radiation and surgical treatments he lived well past this initial projection and considered himself disease-free. Dan described himself as one who enjoys life, is a social butterfly and is easy-going, noting that it took a lot to get him angry (though when he did, he noted that he “blows”).

**Michael.** When diagnosed with prostate cancer in 2007, Michael was going through a separation from his male partner. His disease was identified at an early stage and treated with surgery and hormone therapy. Single, without children, and in his early 60s at the time of the interview, Michael was semi-retired and working part time for a community organization. He described himself as spiritual and as one willing to speak openly about his experiences.

**Keith.** A married father of adult children, Keith transitioned into retirement from a high-stress management job following radiation and chemotherapy treatments for advanced throat cancer, diagnosed in 2008. In his mid 50s, Keith described himself as physically active and enjoying retirement life, while also looking for opportunities to volunteer with cancer support agencies.

**Alfred.** Diagnosed with a non-aggressive prostate cancer in 2002, Alfred received a good prognosis for his disease as he underwent radiation treatments. In his mid 80s, this married man with an adult child moved to Canada from Eastern Europe in 1950s and was retired from his work in government. Alfred described himself as a lover of classical music and noted his interest in politics, world affairs, and high performance cars. Though
he acknowledged a more high-pressure life in the past, he noted that he had “calmed down” with age.

**John.** First diagnosed with Waldenstrom’s Macroglobulinemia in 2001, John later received a second, unrelated cancer diagnosis, conditions treated with chemotherapy and radiation, respectively. In his late 70s, this married father of adult children was semi-retired from his work in senior management and described himself as someone interested in a diversity of topics. He noted that he preferred to avoid conflict, had a social bent, and tried to be gentle with others, though he acknowledged that could also be a bit “stubborn.”

**Arthur.** Arthur, a late 60s, married father of adult children was diagnosed with colorectal cancer in 2009. His cancer was more advanced than initially thought, though was treatable through a combination of surgery and chemotherapy. A retired educator, Arthur described himself as empathetic and interested in helping others through work in the community. He noted his enjoyment of travelling and camping with his wife, and while he found joy in most of his days, he noted a belief that the bad ones were important to appreciating the good ones.

**Oscar.** Diagnosed with throat cancer in 2010, Oscar’s disease was treated with radiation therapy. A married man in his late 50s, Oscar immigrated to Canada from Western Europe well over a decade ago, had no children and was employed in senior management. He described himself as enthusiastic about much in life, humble, and a bit uncomfortable with too much attention. His passions included cars, golf, and his job.

**Marc.** Married with adult children, Marc was diagnosed with an early stage colorectal cancer in 2009, a condition treated with surgery. In his mid 50s, Marc immigrated to Canada from Western Europe in the 1970s and was self-employed. He described himself as an avid researcher.

**Bill.** Although married at the time of his diagnosis with Chronic Myelogenous Leukemia in 2005 (a on-going condition treated with medication), Bill was separated at the time of the interview. In his early 60s, this father of adult children was employed by the government and described himself as actively engaged in “self work” for over thirty
years. He noted that he had a strong sense of spirituality informing how he viewed himself and the world around him, adding that he valued control and believed he was responsible for guiding his own life.

**Jakob.** Diagnosed with prostate cancer in 2010, Jakob was given a good prognosis and his disease was treated surgically. Married with adult children, Jakob was in his 60s and self-employed. He noted that he enjoyed his work and described himself as compassionate, empathetic, and eager to help others.

**Justin.** A single, gay man in his early 60s and without children, Justin was diagnosed with advanced prostate cancer in 2006, a condition treated surgically. Formerly employed in the health field, Justin noted that he struggled to find work after his cancer. In describing himself, he emphasized that while he had been very social before his cancer, he lived a quieter life now, struggling with the lasting physical and economic consequences of his disease.

**Brian.** When diagnosed with acute lymphoblastic leukemia in 2005, Brian was given a 50/50 chance of surviving his cancer, a condition treated with chemotherapy and radiation. In his early 30s at the time of the interview, this married man without children, worked in the technology sector and described himself as a “student of life,” noting that other people fascinated him and he was interested in what motivates them and how they were influenced by their experiences. It was important to Brian to have opportunities to engage his mind and try new things.

**Jack.** In his early 50s, Jack was a married man with young adult children. Diagnosed in 2009 with follicular lymphomas, a chronic condition treated with chemotherapy and medication, Jack had been given a 20-year life expectancy, as doctors expected the progression of his disease to outdistance the current medical therapies designed to treat it. With a diverse employment background, Jack had little physical energy for work due to his disease and described limited employment. He described himself as the child of immigrants who instilled in him a strong ethic of family, honesty, and hard work and a belief that he could achieve anything. He enjoyed farming, economic analysis, and cloud watching and described his religion as “entropy.”
Randy. Randy was diagnosed with advanced oropharyngeal cancer in 2007. Given a 30% chance of survival at two years, his disease was treated with surgery, radiation, and chemotherapy. A married father of teenagers, Randy was in his early 50s, and on disability leave from his work in management. He described himself as the “strong, silent type,” noting that if he had something to say, he would say it, but otherwise stayed quiet. He liked to help others, expected little in return, accepted life as it comes, and preferred the company of those who kept to their word.

Jim. Diagnosed with multiple myeloma in 2005, Jim’s chronic condition had been treated with chemotherapy, stem cell transplants, and medication. In his early 60s, this married father of adult children had to leave his job in senior management because of his cancer and was on disability. Describing himself as a very driven, goal focused, type-A person, Jim noted that although his disease restricted his participation in outdoor activities, he continued to love these pursuits and also noted his interest in a wide range of topics, including arts, business, science and religion.

Dave. A divorced father of adult children, Dave was a retired tradesperson in his mid 60s. Diagnosed with advanced colorectal cancer in 2010, his disease was treated with a combination of surgery, radiation, and chemotherapy. Dave described himself as a “typical white male baby boomer,” noting that he had enjoyed a lot of advantages in life that contributed to his financial and professional success, but that he had also maintained a strong social conscience. He enjoyed spending time with his grandchildren.

Andrew. Diagnosed with a chronic form of Hodgkin’s Lymphoma in 2007, Andrew underwent surgical and chemotherapy treatments for his condition. In his early 40s and working in the non-profit sector, Andrew identified as gender queer and although he had been dating a woman when diagnosed, he was in a new relationship at the time of the interview. He described himself as an artist and one who took a Buddhist approach to life, attempting to “go with the flow.” He noted that he was working to use the learning from his experience to help others with cancer.

Pete. Pete was a retired white-collar worker in his early 60s, married and the father of adult children. Although initially diagnosed with Myeloma nearly thirty years ago, Pete’s condition converted in 2008, a transition requiring chemotherapy, medication, and a stem
cell transplant. In describing himself, Pete noted that his family came first. He identified as a shy and compassionate “people-person” who valued his sense of humour. Although he had limited energy due to his disease, he continued to enjoy playing music, golfing, and adventuring into nature with his dog, enjoying both the reflection and recreation offered by this setting.

Terry. Diagnosed with chronic lymphocytic leukemia in the mid 1990s, Terry did not require the medication used to treat his disease until 2008. In his early 80s and married, he had no children and was retired from a career in the health field. In describing himself, Terry noted that he had an “inquiring” mind, enjoyed the study of music as well as the scientific exploration of “why things happen as they do,” including philosophical and psychological phenomena. He also emphasized that he would prefer to spend an evening discussing theology over a night at the pub watching a football game.

Fred. Fred was a divorced father of adult children and a retired health provider and manager in his late 60s. Diagnosed with late stage Non-Hodgkin’s Lymphoma in 2003, his disease was treated with chemotherapy, radiation, and a stem cell transplant. Fred described himself as someone who feels younger than the calendar would suggest. A religious man, he valued his sense of humour and enjoyed art, cooking, and spending time outdoors. He also noted that he was attentive to others, loved asking questions, and doing things “sensibly.”

Gerrard. Gerrard was diagnosed with advanced Non-Hodgkin’s Lymphoma 2005, a condition treated with chemotherapy and radiation. In his late 40s, married and the father of a teenager, Gerrard was transitioning out of a role in senior management. He described himself as a competitive, driven and goal-oriented person who achieved positive results.

Richard. Diagnosed with a terminal and aggressive Glioblastoma Multiform in 2009, Richard’s cancer was treated with radiation and medication. In a long-term committed relationship with his male partner, Richard was in his early 40s and was on disability leave from his work in the service industry. He described himself as one who approaches others with kindness and who was a problem solver, emphasizing that he was highly committed to helping others.
Nico. Nico was diagnosed in 2007 with an Oligodendroglioma, a slow growing, but incurable brain tumour treated with surgery and medication. Having immigrated to Canada from the Caribbean in the 1970s, Nico was a late 40s, married father with teen and young adult children, and was on disability leave from a career in the technology sector. Nico described himself as one who was helpful to others, family-oriented, and curious about life. He had a passion for art, the outdoors, and building, and a drive for knowledge, which he also encouraged in his children.

Earl. Diagnosed with a highly treatable prostate cancer in 2008, Earl underwent surgery for his disease. In his mid 50s, this married father of adult children worked in a white-collar profession. Describing himself, Earl emphasized relationships as particularly important to him, noting that he came from a close family and had strong connections with his partner, children and friends. He was involved in professional development, enjoyed golf, music, socializing and quiet times and noted that he was honest, emotional, and someone who enjoyed life’s simple pleasures.

Brad. Brad was diagnosed with terminal liver cancer in 2009, a condition requiring surgical and medicinal treatments. In his early 60s, this married father of adult children was on disability leave from a white-collar profession. Brad described himself as family-oriented, opinionated, spiritual, intuitive, open to new things, and not very materialistic. He noted that while he could no longer be active in the competitive sports he loved, he continued to enjoy the social aspect of these activities. Brad also shared that his wife would describe him as kind.

Joseph. In 2004 Joseph was diagnosed with a terminal Glioblastoma Multiform, a condition treated with surgery, chemotherapy, radiation, and medication. Having lived well beyond a projected one-year survival associated with his disease, this married father of young adult children was in his mid 50s and on disability leave from a white-collar profession. In describing himself, Joseph noted that he believed in smiling, laughing, and brightening up someone else’s day. He was a golfer, a musician and a writer who was active in his faith community.
The interview process

With the exception of one session, each scheduled interview was carried through at the agreed upon time, with no need to reschedule meetings. The discussions ranged in length from just over an hour to more than three hours, with most interviews running at around one and half hours. Just over half of the sessions took place in the participant’s home, although I also met men at cancer support centres and local coffee shops, in accordance with their preferences. Although the interview was designed to be a one-on-one session, in two cases a man’s partner chose to be present, with one woman contributing to the discussion and a second woman more occasionally adding in her thoughts as she carried out other tasks around the home. A third man requested that I speak with his wife on my way out of the interview session. Although these dynamics were challenging, I maintained an approach of directing my questions toward the man and focused on his shared experience within the analytic process. Each man was offered a $15 gift certificate as a token of appreciation for his participation in the study.

Each session began with the completion of the consent forms and a request to audiotape the interview. Although others have observed that men can be reluctant to read the detail of consent documents, including study aims (Oliffe & Mroz, 2005), nearly all the men involved in this study took time to review the details before signing. After they had finished reading the document, I took time to highlight elements, including a shift in focus from the pre-treatment phase to the entire experience (discussed later), their right to refuse to answer and end participation, and my commitment to confidentiality amidst the risks of qualitative data reporting (i.e. that those close to him might recognize his story). While a few men (and one man’s partner) sought explicit confirmation that actual names would not be associated with the final document, most emphasized that they were not concerned about confidentiality, with some even inviting me to use their name, an offer I declined. Notably, in this presentation, the process of ‘justifying’ openness detailed in the discussion was also engaged in the interview setting, as the men stressed to me that they had nothing to hide and were eager to help others with cancer.

None of the men refused any of the questions, though several asked to have elements left off the record out of concern for impacts on others or threats to their work,
requests I took care to follow. Ethical clearance was obtained for follow-up sessions, as needed, but this was not required. However, several men offered to stay in contact, indicating that I should contact them with any questions encountered as I worked with their transcript. Further, I followed up via email with several men to obtain additional biographical details missed in during our interview.

**Taking a “sweep of the landscape.”** Consistent with an emergent design, the first 5 interviews were unstructured. Although I came into this study with critical sensitivities developed through my engagement in the literature and as influenced by my professional and personal experiences, by limiting the structure I imposed on interviews at this early stage, I was able to take a “sweep of the landscape,” to stay grounded in the men’s experiences and learn what questions to ask and what leads to follow in order to bring some scenes in for closer study (Charmaz, 2006, p. 14; Daly, 2007). More specifically, this interview structure allowed me to hear and adapt to what the men were sharing while avoiding a tendency to overlay my preconceived notions on the respondent’s experience (Charmaz, 2002; Rubin & Rubin, 2005).

In seeking to limit my voice in these early sessions, I entered discussions with an interview guide detailing broad processes or areas of interest (see Appendix B), but relied on grand tour questions (Rubin & Rubin, 2005) to encourage the men to direct the content and pace of the discussion as they told their story. In this, I focused my energies on active listening, interrupting their story only for clarification and reserving specific questions or requests to revisit an element of the narrative until after the man had completed his story (Morse, 2003). Most men appeared comfortable with this approach, although a few were surprised by it, evidencing an expectation that I would lead by asking questions that they would answer. However, after some gentle guidance and confirmation that I wanted to learn about what was most relevant to them, most moved smoothly into a detailing of their experience.

As a relatively inexperienced interviewer, this structure was challenging. After so much time spent exploring the literature and constructing the research plan, it was difficult to let go, to trust in the process. In addition to generalized concerns around how the men might be evaluating me, my memos reflected worries that I would ‘miss’ key
processes. However, the benefits were soon clear as this planned flexibility allowed my
gaze to be broadened and directed by what the men prioritized. More specifically, in
these early interviews I became acclimated to the language and imagery relevant to their
experience and found some of my assumptions dismantled.

First, I learned that my initial focus on the pre-treatment period was insufficient. For many, illness was not observed or experienced until the diagnosis was received. Further, the needs that tumbled from this initial quake and the associated aftershocks continued for some well after treatment. Second, I became attuned to the powerful complexity of experiences beyond the medical process of diagnosis and treatment. While many were active in their care, as they learned about their disease, identified and sorted through treatment options, and even challenged medical protocols and care decisions, much of their work was directed outside the health care system, as they navigated through the experience and managed an informal network of supports.

Across these early sessions I also began to find that the most challenging aspect of talking with the men about help seeking was talking about “help seeking.” This was not surprising. Help seeking is a heavy concept, laden with impressions of extreme weakness and dependency, threats intensified during illness. I quickly learned to step carefully around this term too easily resisted, instead talking with the men about challenges, limitations, needs and supports. This approach was not only consistent with a broader conceptualization of the concept, as discussed in the literature review, but was also in accordance with how the men navigated the process as their stories evidenced relatively few incidences of direct requests for help. In fact, even those emphasizing the importance of reaching out for support struggled to describe a time when they did this. Instead, they used a range of individual and interactive strategies to address perceived challenges and were selective in how they labelled requests for assistance, a dynamic discussed later.

**Focusing in.** Moving beyond these initial sessions, interviews became more structured as I took a lead in exploring elements of the men’s experiences, a process enabled by theoretical sampling. In an emergent design framework, theoretical sampling allows a researcher to base analytic choices or next steps in the data collection process on concepts derived from the analysis of previous interviews (Corbin & Strauss, 2008, p.
More specifically, this core practice in grounded theory integrates a concurrent process of data collection and analysis to ensure that the on-going determination of who to talk with next, what questions to ask, and where else to look for more information is guided by meaningful patterns observed in the data (Daly, 2007). As summarized by Corbin and Strauss (2008), “data collection leads to analysis. Analysis leads to concepts. Concepts generate questions. Questions lead to more data collection” (pp. 144-145).

With the speed of recruitment, there was little time for transcription or coding between meetings, a challenge common in research where interviews must be ‘seized’ as they become available. In the absence of time available for formal review, I drew on my memoing practice to identify areas of exploration. Memoing is an important tool in managing a grounded theory study from the early stages of development through to the presentation of findings/results (Daly, 2007). As Strauss (1987) explained, throughout the life of a project, researchers are engaged in an internal dialogue and memos offer a record of “insights, hunches, hypotheses, discussions, implications of codes, additional thoughts” and more (p. 110).

Engaged before and after interviews, this process allowed me to record thoughts in a way that not only tracked ideas (and personal reflections), but also informed the formulation and revision of theory (Corbin & Strauss, 1990). As Charmaz (2006) emphasized, memos allow researchers to actively engage with data, develop ideas, and fine-tune analysis. In this process, I could directly work with concepts (rather than raw data), an activity that allowed me to identify gaps and pushed my work toward greater coherence. More specifically, I used memos to record detailed observations, identify key themes and unanticipated areas of interest, map out dynamics I was observing, and edit my interview guide to eliminate questions that weren’t working well and add others prompted by the discussion and which allowed me to pursue themes. My advisor and I met periodically to review these questions and the emerging themes. Through this process I modified my informal question guide multiple times across the course of the interviews.

Thus, as I moved beyond the initial five interviews, my questions became more specific (e.g. Appendix C). As I was led through the terrains of the men’s experiences, I
began to “actively [pursue] explanations,” drawing on learning from each discussion to organize follow-up questions that allowed me to explore concepts (i.e. significance of phrase, process or object) and themes (i.e. a relationship between concepts) and to fill in missing information as I moved to the next interview (Daly, 2007, p. 104; Rubin & Rubin, 2005). As many men were eager to outline their story, I retained the initial tour question, but also began to encourage more time spent exploring dynamics within it. Using this initial story as a map, and drawing on learning from previous sessions, I asked the men to focus in on certain points and provide “mini-tours” of certain events (Rubin & Rubin, 2005). Further, I probed for reflections on how they came to notice challenges, how they defined these (thoughts and feelings) and how they decided what to do next. Used judiciously, these verbal and non-verbal probes helped me to guide the conversations in a way that addressed gaps, clarified ideas, explored contradictions and exceptions, and ensured that the discussion remained directed toward addressing the focus of the research (Rubin & Rubin, 2005).

Across the interviews, I drew on sensitizing concepts identified in the literature review as “points of departure” (Charmaz, 2006) amidst the rich context of their experience. Guided by an SI perspective, I focused on meanings, seeking to understand how the men made sense of their illness experiences: what shifts they perceived, what these meant to them, and how they responded to the meanings through individual and interactive lines of action. I encouraged the men to reflect on matters of identity, asking them how they viewed themselves and their acts through the eyes of others. In this process, I often had to encourage men to move beyond an initial focus on detailing their medical profile: diagnosis, staging, and treatments. Notably, this description could be extensive as men identified physicians by name, highlighted which treatment centre they used, and spoke in tremendous (even stunning) detail about the nature of their disease, tests, and treatments. Among some, it felt that this was a story they had told before, perhaps with partners, friends or in a support group. Men with prostate cancer, the majority of whom were associated with a prostate support group, seemed particularly comfortable with this type of story, demonstrating a high level of knowledge about diagnostic tests and treatment options, likely a function of the treatment options available to those with this form of the disease and the process of sharing in these groups.
While recognizing the importance of these operational elements as part of their story, I also encouraged the men to consider inner conversations, a discussion facilitated by questions inviting them to reflect on what was going through their mind and what they were feeling at critical points (e.g. when the doctor gave them their diagnosis, when they had to reach out to others). We talked about how friends, family, and health providers acted toward them, how they saw themselves and others over this time, and how these interactions influenced their ability to deal with the challenges of their illness. Recognizing a dyadic and bi-directional relationship between help-seeker and care provider and the access of support as a joint act or process, I also explored the men’s confidence and trust in the support of specific others (who they sought out, who they avoided) and how they experienced others’ ability, interest, and willingness to provide care.

As this study is guided by the recognition of help seeking as a gendered experience, I invited the men to reflect on the influence of prominent gender scripts, outlining men as strong, stoic and self-reliant, while recognizing and addressing a broader complexity in self-construction. Finally, in accepting identity as situational, relational, dynamic, and embodied, I explored with the men how their cognitive and emotional perceptions, interpretations, and understandings of self, other, and events shifted over time and experiences, as they continued to write and re-write their story of self. Some of these questions appeared more challenging to answer, particularly as I asked the men to reflect on the meaning of certain losses and actions or as I invited them to take on the perspective of others. Across this process, I was open about my intentions and my, at times, seemingly obvious questions, explaining to the men that I wanted to see this through their eyes and was intent on avoiding assumptions about what they thought. Many were responsive to this, though it was at times challenging to access the subtleties of the experiences as we delved into dynamics that many noted had not previously been considered in detail.

A commitment to transparency and respect, initiated at recruitment, was carried into the interview space. I continued to share openly about my research goals, emphasized my appreciation of their willingness to help me learn through their sharing, listened with focused interest as they described their experiences, and took care to
demonstrate, through verbal and non-verbal indications, that I carried no judgement on their perspectives or choices. These efforts, important to developing the trust and rapport key to enabling a safe space for an interviewee to share his experience (Kvale, 1996), were not engaged to manipulate men into disclosing what they would otherwise keep private. Rather, this approach allowed me to demonstrate respect for their experiences and perspectives (Charmaz, 2006) and emphasize my commitment to make good use of the their time, avoid unnecessary intrusions, follow up on promises, and ensure I did no harm (Rubin & Rubin, 2005). In this winding process, rapport often came quickly, accompanied by what I accepted as open and honest sharing.

Although my voice was increasingly engaged over the course of the sessions, the interviews remained discussions. From the first through the last I carried a solid sense of myself as learner. These men not only granted me access to a profound and intimate part of their life, but also offered me a wide space to explore. I was continually humbled by their generosity toward my inquiries and their eagerness to shed light. There was much laughter, but there were also moments of silence, caught voices, and tears, both fought and accepted. These dynamics were not always anticipated by me or by the men expressing these emotions. Some shared that they were surprised by the intensity of their feelings, noting that they thought they had moved past this degree of emotional acuity while others acknowledged an awareness that their emotional pain was still raw, even many years later. A number of men described the interview as therapeutic, appreciative of an opportunity to share their story.

**Reflecting on engagement.** As detailed in the previous discussion on the role of reflexivity in the research process, I accepted this practice as on-going in the context of a constructivist grounded theory approach. In particular, in appreciating a close relationship between the interviewee and interviewer, I sought to maintain an awareness of my “human self” (Dupuis, 1999) amidst the activity of data collection, actively and explicitly exploring my assumptions, preferences, discomforts, fears and even my joys. In this study of identity processes, my reflexive attention was particularly oriented around the intersecting and complex selves the men and I brought into interactive space and how we performed these across the discussions. Further, I attended to how I experienced
these sessions, considering not only how I led or responded to ideas we discussed, but also how my story has been influenced by the experience of engaging with these men’s lives, a process of reflexivity continuing today, and one that I expect will continue to evolve into the future. These dynamics are discussed in turn.

**Intersecting identities.** Pini (2005) has argued that while the force of gender is never absent from the interview process, some research settings, topics, and partnerships are more overtly gendered than others. Given my focus on gender and illness behaviours, a popular discourse positioning health as women’s responsibility, and my positioning as a woman interviewing men about this topic, I had good reason to anticipate that these sessions would be ‘overtly gendered’. Thus, I explicitly considered gender not just as a force cuing men’s understandings of help seeking, but also as process within the interview itself.

In preparing for these sessions, I became aware of Schwalbe and Wolkomir’s (2003) assertion that in the context of an unstructured interview, men acting as interviewees have an opportunity to present a “valid” display of masculinity, as well as have it evaluated and even challenged. Further, I developed an appreciation of how the form of questions and the identity of the interviewer can function as a sub-conscious threats to a man’s ability to present as rational, in control, or powerful (Schwalbe & Wolkomir, 2003). This awareness was complemented by my reading from a relatively limited literature on the relationship between female interviewers and male interviewees (for discussions of men interviewing men, see Oliffe & Mroz, 2005; Robertson, 2006). Thus, I was aware of Arendell’s (1997) description of how some men in her study treated her as a token, “nurturing” woman who would listen to stories and elicit emotions, while others positioned her as a possible romantic partner. Further, I read her description of how some men, responding to threats akin to those detailed by Schwalbe and Wolkomir (2003), sought to assert control of the interviews by aggressively taking the lead in the discussion, challenging her motives as a woman interviewing men, or by questioning her competency.

As these discussions attuned me to some of the potential interplay, my recognition of gender as an interactive performance and my own positioning as one who bends some
gender norms through appearance and act, allowed me to resist moving too quickly toward absolutes as I prepared for and engaged in these interviews. When discussing gender dynamics in interview settings (or elsewhere), it is easy to slip into a simplified conceptualization of gender or confuse it with sex as researchers lean toward global statements about how men and women interact. However, research must be prepared for a variety of intersecting presentations of self that are not neatly organized into a false male/female binary. For example, Pini (2005) has highlighted how female interviewers can perform a variety of gender identities (e.g. friend, feminist, sexual being) in interviews with men (see Lohan, 2000) and how some can modify their appearance to sidestep traditional feminine performances (see Lee, 1997). In other words, how men and women perform gender does not always follow prescribed patterns, these performances can shift, and in this mix there can be an array of dynamics that facilitate and challenge interactions. Gender, after all, is not a trait of the participants, but a dynamic, constructed process.

In structuring an appreciation of this complexity in regard to the interview dynamics I might encounter, I was informed by Pini’s (2005) argument that the influence of gender on an interview process is more expansive than who is interviewing whom, but rather part of a larger question: “who is asking whom about what and where?” (p. 204). Specifically, in detailing the “who” and “whom,” of interviews, Pini (2005) emphasized the intersectionality participants bring to the process, noting that in her work, it was not only her gender presentation, but also her relative youth that influenced how the men engaged with her, an awareness equally applicable to the complexity of self the men brought into the sessions. Similarly, Daly (2007) has encouraged researchers to reflect on the complexities and dynamism of their own positions as well as those with whom they build understandings.

Even more, Pini has intertwined this complexity of personal identity with the focus and location of interviews. For example, in her discussions with male leaders of an agriculture organization about the absence of women in their elected leadership (the “what” of the interview), gender relations was an explicit and contentious topic. Even more, in this rural environment, the “where” of the interviews, there were strong beliefs
structuring how men perceived the extant reality, arguing that women’s lack of involvement was “natural.” Across the complexity of intersecting personal and social locations, Daly (2007) has noted, there are few certainties on which to hold and researchers are advised to practice continual reflexivity or “ongoing vigilance” around how these dynamics play out in situations (p. 202).

Although daunting, I accepted these complicated dynamics, both in the research process and product, as difficult complexities central to my understanding of this phenomenon, not as subjectivities to be left at the margins (Pini, 2005). Even more I recognized them as neither “inherently problematic nor beneficial,” but forces about which I had to be aware (Broom, Hand & Tovey, 2009, p. 63). Thus, as I sought to maintain consciousness around intersecting identities, I recognized that I engaged with these men as a white, upper-middle class, young adult woman presenting a non-traditional gender expression, who has advanced education, is early in her academic career and has not experienced a cancer diagnosis. While all but two men shared my racial profile, most were at least 20 years older than I, and in many cases our educational and economic class placements varied. My sexual identity was different from most who identified as heterosexual, though three identified as gay. Most presented a more normative male gender identity, though one identified as gender queer.

In working amidst this dynamic, my early memos reflected assumptions I was building about the men as I moved into the session, noting how I was beginning to draw a picture of each individual based on a few lines shared via email or over the phone, anticipating some men as more expressive, others as guarded. This imagining of the diversity of masculinities I might encounter was further nuanced as I arrived at the meeting location and met the men. In noticing these expectations, I restrained myself from letting my hunches around their gender presentation control my actions, allowing myself to be surprised and ensuring that I did what I could to enable a wide path for performance. More actively, I took care to create a safe space, monitoring my verbal and non-verbal responses and actively emphasizing that I recognized a diversity of ways of being a man while also maintaining awareness of how men might be orienting toward and
away from masculine ideals within our discussion, a consideration I integrated into the analysis.

In particular, as I recognized emotions as both challenging and central to the story (Daly, 2007), I sought to balance my commitment to not forcing men into spaces of discomfort, with a responsibility to not pull away from difficult feelings or aspects related to their illness. This was challenging, particularly as some men appeared embarrassed by their own emotional expression and I found myself responding empathically and also struggling with how to respond in those moments. Across this process, I often found my assumptions disrupted as interviews progressed. Most notably, many of the men that I expected to be distant or reserved, or who even began to participate in the discussion as gruff, could move into a startling openness about their experience, when given space. I was continually surprised by the candour offered.

Monitoring my own presentation of self, my memos reflect anxieties around my hair, how I dressed, how I sat, how I asked questions, even whether it was appropriate to accept the offered glass of water. In this, my attention was on whether my presentation of self (i.e. my appearance and acts as symbols of a diversity of identity positions) would create distance and whether I would be accepted as a ‘respectable’ academic, someone who evidenced both the intellectual talent for the analysis and the responsibility to do something with it, elements I viewed as important to their willingness to trust me with their story.

It quickly became clear that these were points of unnecessary fretting. The men seemed unperturbed by my interview style, appearance, or age (though two noted that they could not imagine me as a professor, an unexamined comment I chose to attribute to my relatively youthful appearance, rather than my aptitude!). In fact, based on broader experiences, I believe my gender identity (independently and as a window on my sexual identity), my relative youth, and my reserved nature, might have facilitated communication around highly personal experiences. From my perspective I presented neither a romantic opportunity nor a competitive threat.

Rather, what I perceived as more relevant were differences in our health status and, among some, our educational profile. In monitoring my own feelings during
recruitment and in preparation for the interviews, I was acutely aware of my accelerating tension levels as I moved into discussions with men with very advanced or terminal diagnoses. In these sessions, the pressure I placed on myself to perform effectively was heightened as I recognized these men as choosing to offer some of their more clearly limited time to me and to this project.

More broadly, across the sessions, I noticed how the men and I were each acutely aware of my status as one who had not been diagnosed with cancer. This was evident as nearly every man I met explained that those who had not lived with cancer could not fully understand the experience. However, as they sought to make this clear (and I accepted their assertion as true), this understanding did not restrain men from sharing their story with me. In fact, this awareness might have propelled them to put into word elements that could go unspoken in the company of those who shared this experience. Further, I took this as an opportunity to probe more deeply into their experience, requesting their patience as I asked them to walk me through the nuances of their thoughts and feelings. A second area of distancing was evident, as some men appeared uncomfortable around demographic questions on education, acknowledging me as a PhD student and taking time to explain why they had not obtained higher degrees or stressing their work related successes. Recognizing this, I began to leave the demographics to the end, emphasizing these as less critical than their story and seeking to clearly demonstrate that I was not responding with judgement, a positioning that was consistent with my beliefs and perspective.

As I sought to navigate dynamics of difference and access theoretically rich stories, I reflected on, and engaged, strategies advised by Schwalbe and Wolkomir (2003) for interviewing men, including phrasing of questions to level perceived hierarchies associated in the interviewer/ interviewee relationship. These subtle strategies of emphasizing the interviewee as the expert, ensuring that he felt a degree of control over the interview progression, and careful exploration of emotional elements (e.g. link to concrete events, indirect approaches, start with thoughts and move back to feelings) also helped to manage differences in health status and power dynamics related to education.
Even more, they blended with the emergent design framework, emphasis on establishing research “partnerships,” and the unstructured/semi-structured interview format.

Beyond how I asked questions, I noticed myself leaning into other strategies directed at creating cohesion. Most notably, I found myself mirroring men in posture, tone, and speaking pace, a dynamic that was not deliberate, but is a common social psychological phenomenon shown to enhance a sense of connection (Chartrand & Bargh, 1999). Further, although I limited how much I disclosed about myself (preferring to maintain a focus on their experience), I noticed how I highlighted elements of my own biography to achieve a connection with their presentation. For example, among the gay men, an easy camaraderie emerged as we immediately recognized each other as claiming a shared identity. I evidenced a personal understanding of living with anxiety with a man positioning himself thus and with those speaking extensively about their faith, I indicated that I had an appreciation of this community through my religious upbringing.

I accept the value in considering how personal and social locations infuse the interactive process, but I believe what was most critical in these sessions was that I remembered that while I was participant, I was a participant in understanding their story. In this, I recognized these interviews as not too dissimilar to interactions engaged in the course of work, family, and social life, wherein a web of dynamics influence whether individuals connect in a way facilitating open sharing. Diversities in identity positions can challenge initial engagement, but I believe many of these can be overcome through a sincere demonstration of respect for the other and what they have to say. This orientation does not smooth the path or release one from an obligation of on-going attentiveness to dynamics, but it does lessen the, at times, paralyzing fear of stumbling.

Evidenced through my memoed frustrations regarding questions I neglected to ask, concerns over how I could have asked them better, and chastising about how I could have performed better, my manoeuvring across this data collection process was both challenging and imperfect. However, as I learned a great deal along the way about how to do ‘this’, I also found myself becoming less concerned about being perfect. Every situation will have unanticipated complexities, but what remains fully in the control of the researcher is to engage participants with respectful humility, careful attention, and a
desire to learn. With time, I found myself less preoccupied with what might pull us apart and more focused on what led to our coming together: a shared commitment to building understanding through the sharing of difficult experiences.

**Feeling impacted.** Beyond my awareness and efforts relating to the dynamics of intersecting personal and social identities, I also maintained an active reflexivity around how I was impacted by these interviews, a matter relevant to how I participated in discussions and how I engaged analysis. Most centrally, I found the interviews draining to an extent to which I did not anticipate and for which I was not fully prepared. The ethics process required that I offer psychological support resources for men who evidenced distress, but I was unprepared for how I would struggle in the process. Wray, Markovic and Manderson (2007) have highlighted a lack of recognition of, or training/support related to these dynamics in academia, a matter particularly relevant to qualitative researchers studying difficult events. My experience was not different. Although some stories and sessions were more challenging to witness than others, over time the cumulative intensity weighed heavily, particularly as I engaged in 3-4 interviews per week.

The men’s stories triggered personal memories and, even more, I found myself feeling intensely for the well-being of these individuals I barely knew. Although we had spent only a couple of hours together, many had let me into an intensely personal space. I was a stranger seeking help from them and within the safety of this dynamic some noted that they were sharing elements of their experience they had not previously shared with family or friends. In the shadow of this, I struggled with a sense of impotence and incompetence, knowing I could not take away their pain and worrying that the one thing I could attempt to do – this study – would not do justice to their story. I struggled against these feelings, denying the impacts and criticising myself for making this about me. Further, I was reluctant to talk about my experience in great detail with my partner, friends, or my advisor, as I was not keen to relive the stories or display ‘weakness’ that I did not feel was justified. I was not the one who was ill, after all.

Although my commitment to these men fuelled my efforts to remain fully present in the interviews, I experienced an impulse to quickly move away from their stories after
the session had ended. This was an approach impeded by the need to engage in concurrent analysis and reflexivity in the service of theoretical sampling. Thus I found myself struggling under the heaviness of these stories, trusting that time would move me through. Only after the interviews ended did I realize that my determination to go it alone, head down, and highly controlled, resonated with the story line many of the men shared with me. While I certainly do not place my experience in witnessing these stories at the same level of intensity experienced by those living them, I did gain empathy. It is no simple task to reach out when you just want to get through.

Analyzing and Interpreting Data

Corbin and Strauss (2008) described qualitative analysis as a dynamic process of examining a phenomenon to understand its nature and function, an activity appreciated as both a science and art (Patton, 2002). In this mix, Patton (2002) suggested, researchers seek to make sense of a tremendous amount of data as they work to build a story communicating something about the lives studied. While often framed as a stage in the research process, Daly (2007) has argued that researchers engage in analysis from when they first identify a topic of study though to their positioning of research results. In this section, I focus on the analytic activities I conducted concurrent with the process of data collection, as I moved through transcribed data and sought to apply abstract meanings to the experiences shared across the interviews.

As a first step, recorded interview data were transcribed in full (all voices included). I completed the first five transcripts, a process important to immersing myself again in the stories, attuning me to how I was asking questions and responding, and enabling the early process of theoretical sampling. A professional transcriptionist completed the remaining documents, and we worked together to ensure that the transcripts reflected pauses, emotional expressions, and other elements important to analysis. All transcripts were imported into MAXQDA.

Focusing on the activity of working through the gathered data, grounded theory methods guide researchers through the process of breaking data into analytic pieces and systematically reorganizing these parts to detail a theoretical story. At base, analysis is the practice of asking questions of data (i.e. what does this mean?) and interpreting
meaning (coding) as one engages in a process of constant comparison: examining each code, concept and category relative to the others and assessing these for similarities and differences (Charmaz, 2006; Corbin & Strauss, 2008). This is not a linear process, but one that takes the researcher back and forth between levels of understanding across the course of interviews (Charmaz, 2006). As Daly (2007) described, there is a “dynamic interplay” between observation and conceptualization, an abductive process by which one seeks understanding (p. 227). As noted, memoing is critical to working through decisions and advancing this process toward the development of theory.

Consistent with my adoption of a constructivist approach to grounded theory, my analytic practice prioritized Charmaz’s (2006) description of initial and formal coding (as well as theoretical coding, as influenced by Glaser, 1978). However, I also recognized the value in integrating some of the conceptualization of the practice as offered by Corbin and Strauss. Notably, although long focused on the organized activity of open, axial, and selective coding (Strauss & Corbin, 1990, 1998), in the third edition of the Basics of Qualitative Research (2008) the authors no longer dictate these three stages, encouraging a more flexible approach.

Although Charmaz has advocated for adaptable decision-making embedded in the context of one’s data, it is easy to be drawn into an ambitious effort to find a single and specific best way to move data into theory, to fret over whether one is doing it (or has done it) “right.” This concern is emphasized by the broader, ongoing evolutions in grounded theory itself, a methodology lacking a single, unified path of practice (see Dey, 2004). However, I accepted a rigid application of grounded theory as not only antithetical to the spirit of constructivist grounded theory (a flexible process directed by the words of research participants), but also as disruptive to the process, potentially leading me to “suppress” understanding and “stifle” creativity (Charmaz, 2008). Or, as Dey (2004) argued, the notion of simply applying a methodology is fundamentally problematic. Instead, researchers should consider how methodology informs an understanding of the process of research.

In conceptualizing a more fluid (yet still rigorous) approach, Dey (2004) suggested that researchers would do well to envision grounded theory analysis as a
process of moving a patchwork mosaic into a composite picture. Others have described this process as constructing a story (Daly, 1997). In both metaphors, as coding and memoing allow researchers to repeatedly engage with participants (Charmaz, 2006), there is opportunity to consider the meanings of experiences and identify and organize pieces into patterns. Theoretical sampling and saturation help challenge interpretations and enable richness and depth to these pieces brought together to build the overall image or story that lends understanding. The intent is theorizing and grounded theory methods help do this (Charmaz, 2006). Thus, in detailing my analytic process, I focus on the objectives of my work, rather than the labels that overlap and evolve. To this end, I organize this discussion according to Daly’s (2007) four stages of grounded theory analyses: (a) creating concepts, (b) creating categories, (c) making linkages, and (d) creating a theoretical story.

Creating concepts. As I began the process of engaging with transcribed data, initial (or open) coding allowed me to break down the volumes of text into meaningful segments. This is recognized as a creative process (Daly, 2007) and researchers are advised to move quickly and systematically through the data “line by line,” immersing themselves in a focused study of fundamental processes described by participants (Charmaz, 2006). Corbin and Strauss (2008) stressed a “brainstorming approach to analysis,” or openness to a range of analytic possibilities (p. 160). Specifically, I drew on Charmaz’s (2006) advisement to attend to actions and analytic concerns (not just themes), considering key questions including: What process is at issue here? How can I define it? How does this process develop? How does the research participant(s) act while involved in this process? What does the research participant profess to think and feel while involved in this process? What might his or her observed behaviour indicate? When, why and how does the process change? and What are the consequences of the process? (p. 51).

In applying analytic labels to these pieces, I used the language of participants (“in vivo” codes) and borrowed terms from my experience or the literature. In “acting upon” the data, I prioritized the use of gerunds (e.g. revealing, feeling, wanting) in an effort to direct attention to process (Charmaz, 2006, 2008). In all cases, terms I applied to the portions of text were treated as “provisional, comparative, and grounded in the data”
(Charmaz, 2006, p 48). By immersing myself in the data (rather than my preconceptions and expectations), these codes helped me to preserve and identify my interpretation of the men’s acts, dilemmas, rationales, events, relationships, and other elements in their stories. This process was not always smooth, as the multitude of codes and the meanings they conveyed took on dizzying proportions. However, as I worked through the individual cases, repeatedly engaging with the participant’s words, the process of constant comparison allowed me to build abstract concepts or labels for groups of codes with shared characteristics; a process of finding patterns across incidents (Daly, 2007).

**Creating categories.** As I worked to compare concepts with concepts, I drew on Corbin and Strauss’ (2008) description of the process, as I began to detail these at various levels of abstraction, with lower-level concepts (e.g. pain, fatigue) forming a foundation for those at a higher level (e.g. physical restrictions). As these higher-level concepts, or categories, served as collections of codes sharing some manner of association, I continued to use a constant comparative process to explore their properties (e.g. intensity, timing) and property dimensions (e.g. severe, late) to further define the category (Corbin & Strauss, 2008). These abstract codes, defined by their richness and ability to capture broader concepts, became the provisional theoretical categories I would use to build the substantive theory (Charmaz, 2008). Notably, this process is recognized as one of the most challenging stages in grounded theory analyses (Daly, 2007) and I experienced it as such. Accepting this, I attempted to stay with the complexity, consulting with my advisor and recognizing the “valley of despair” as a normal part of the grounded theory process and the risks in moving too quickly toward restrictive order.

**Making linkages.** As I worked toward the broader storyline capturing the meaning of participants’ experiences, I began to focus my attention on how the pieces fit together. More specifically, I moved through the categories, subsuming some as subcategories, leaving others as distinct, but linked, and considering the “axis” bringing together a broader category. Charmaz (2006) described this activity of identifying relationships between categories as theoretical coding. To facilitate this process, I asked questions of the data, bringing a diversity of lenses to this pursuit. In this, I considered patterns in light of cultural elements (e.g. social norms, values, beliefs), areas of focus.
(e.g. physical, social, emotional), strategies (e.g. ploys, goals, tactics), facilitators and barriers to action (e.g. social distancing, invitations), the context (e.g. private, public) and sociological concepts such as identity-self (self-image, transformation, self-worth).

In the course of this analytic process, I sought conceptual saturation, or the condition in which additional data offered no further understanding of a theoretical category. Notably, Charmaz (2006) emphasized saturation not as the repetition of themes, but as a quality of theoretical richness focused on the properties or qualities of a category. In other words, patterns are not sufficient; analysis must pursue a rich complexity of properties within patterns. Or, as Corbin and Strauss (2008) described, the pursuit of saturation is fuelled by a need to go “beneath surface explanations” (p. 148), to not just identify themes, but also elaborate on their complexity. Theoretical sampling, as noted earlier, is conducted in the service of this condition (Charmaz, 2008). Elements of saturation started to become apparent well before the final interview, however as I engaged a process of theoretical sampling, I continued to pursue richness within repeating themes across the interviews, seeking to delve deeper, reach wider. By the end of the interview period, I felt I had achieved a richness supporting theory development.

**Creating a theoretical story.** It is not sufficient to develop a list of theoretical concepts. “To generate substantive theory,” Daly (2007) has explained, “is to tell a story about the stories our participants have told us” (p. 235). This process has been organized as part of the practice of theoretical coding (Charmaz, 2006), selective coding (Strauss & Corbin, 1990, 1998) and a process of integration (Corbin & Strauss, 2008). Across these labels, the analytic task I faced was to decide which theoretical categories should be dropped and which retained in the service of building a complete and coherent theoretical story line (Charmaz, 2006). Even more, I needed to identify the narrative thread tying the pieces together.

In constructing theory, much attention has been devoted to the development of a core category. As Corbin and Strauss (2008) detailed, this is a category that is central to the story, is logical and fits the data well, has the ability to explain the main message of the research, and brings together the elements (or categories) into a single narrative. This core category, they continue, might be defined by one of the categories built in the course
of analyses, but might also be developed in situations where none of the existing categories sufficiently captures the story.

While focus on a single core category can be a worthy goal in the context of a specific study and can help keep the theorizing process more manageable (Morse, 2001), I was attuned to arguments that within a complex and multi-vocal reality the pursuit of a single, “core category,” researchers can rob a theory of its complexity (see Dey, 1999; Morse, 2001). Seeking to remain open to the data, I set aside expectations around a single or dual category, drawing instead on Charmaz’s (2006) metaphor advising researchers to focus energies on a conscientious and intensive coding process allowing one to move the “bones” of analysis into a functional skeleton.

Across this process, memoing, including a practice of reflexivity regarding my theoretical interpretations, remained critical, and I continued to use these strategies to postulate ideas, rework thoughts, and challenge my thinking as I engaged with categories. In this activity, I also recognized an abductive process informing my thinking. As my thoughts were consumed by the analysis, I found myself considering how the categories and relationships I observed in these men’s stories aligned with or varied from those I encountered in the course of my daily life in the form of fictional narratives and those sparked in thinking related to unrelated courses and discussions with friends and family. This process is aligned with Daly’s (2007) advisement that researchers think metaphorically, considering, “what are similar kinds of stories that might help me to see this more clearly?” (p. 237). As I took care to remain centred in the men’s experiences, this was a useful and unavoidable practice that challenged me to shift around the mosaic pieces, disrupting my comfort in some formulations and encouraging me to try out new arrangements, or new metaphors. Amidst this evolving process, the final test, of course, was whether the constructed story sufficiently captured the men’s shared experiences.

Notably, I found it challenging to distil the great complexity evidenced through these men’s stories into a tangible and coherent narrative. Certainly, the process of grounded theory is demanding, as one carefully navigates through a sea of pieces, carefully attending to each, and making the difficult decisions required. Although there is a critical freedom in its offering of guidelines over prescriptions, the absence of clear
rules or absolutes could be unnerving as I often questioned the appropriateness of my choices and next steps.

Even more, I found the process difficult at a personal level. After spending so much time immersed in the vibrant and complicated details of these men’s stories, I struggled in letting go of some of the nuances, feeling as though I was dismissing parts of their experience as less important. I accept the value in building a broader theoretical story important to elucidating the underlying, common processes shared across experiences. This is key to moving research to practice. However, I was also keen to ensure that I did not reduce these men in the process, that when I presented them to the reader, they remained complex individuals. I have attempted to carry this balance into the reporting of my analysis as I have sought to present a coherent theory that lends understanding, but which does not simplify the lives contributing to its formation.

**Evaluating Grounded Theory**

In evaluating grounded theory, theorists move away from the language of validity and reliability often applied to quantitative studies (Corbin & Strauss, 2008). Even more, consistent with the pragmatist foundations of grounded theory and the interpretivist focus of CGT, in my work I have sought truths (not truth) that enable understanding around men’s help seeking. As noted, the theoretical story must resonate with the experiences of the men who agree to talk with me. My work, then, has organized toward the construction of a substantive theory that is faithful to the experiences of those studied, saturated, plausible, explanatory, integrated, parsimonious, focused on a specific aspect of reality, suitably complex, generative, and which offers potential for linkages to more formal theory (Daly, 2007, p. 238). This focus demands a different set of questions in evaluating work, a matter Charmaz (2006) addressed in outlining four basic criteria for assessing constructivist grounded theory: credibility, originality, resonance, and usefulness.

**Credibility.** Relevant to both procedures and outcomes (Daly, 2007), credibility includes a consideration of how theoretical sensitivity was utilized, participants selected and relationships maintained, whether a researcher achieved sufficient familiarity with the topic and richness of the data (range, number, depth of observations), whether categories were systematically achieved and are comprehensive and logical, and whether
a researcher provided enough detail to ensure that the reader can assess claims made (Charmaz, 2006; Daly, 2007). In adopting a more subjectivist approach in this study, I sought to enable credibility through a process of reflexivity and transparency, offering clarity regarding my epistemological assumptions and methodological practice and seeking to be explicit in the presentation of the research results about my role in theory construction. As Mauthner and Doucet (2003) argued, to enable a reader’s confidence in their work, researchers must be “self-conscious and articulate about their role in research processes and products” (p. 424). Integrity is critical (Daly, 2007).

**Originality, resonance, and usefulness.** In speaking to the remaining evaluative criteria, Charmaz (2006) described originality as a measure of whether categories offer new insights and if the theoretical story is significant: if it challenges, furthers, or fine-tunes existing ideas. Resonance speaks to whether categories are rich and expose what is often assumed and if theory draws attention to the associations between the macro and micro levels: the institution or collective and the individual. Usefulness is evaluated according to how applicable a theory is to the lives of individuals and whether it indicates some more generic processes to be explored in other substantive areas. In this, theory must be judged on the basis of that basic pragmatist concern: “how does it contribute to making a better world?” (Charmaz, 2006, p. 183). Notably, as I have sought to meet these criteria, my focus on building original, resonating, and useful understandings has been distinct from the production of testable theory, the intent of more objectivist versions of grounded theory (O’Conner, Netting & Thomas, 2008).

**A note on generalizability.** Researchers working in a positivist tradition focused on identifying a single, common truth, would argue that the sample of men who agreed to talk with me is not representative of all men diagnosed with cancer and challenge the theoretical sampling process, viewing as problematic the lack of standard questions across interviews. Within their epistemological framework, these concerns are appropriate. However, probabilistic or statistical generalizability was not my aim. Instead, as I spent time with these men, following theoretical leads across their stories on the path to developing a broad story useful to understanding men’s help seeking during times of cancer, I sought analytic generalizability (see Kvale, 1996). In other words, the
question is not whether this theoretical story is predictive of behaviour, but whether it enables a broader understanding or insight into men’s experiences.

More ambitiously, in addition to supporting practical efforts related to the enhancement of supports for men with cancer, my hope is that the substantive theory developed here will be useful to influencing formal theory around men’s help seeking. In this pursuit, the theory would be elevated beyond the context of cancer, moving the specific concepts into a more generic or abstract form. Of course, that process extends beyond the focus of this study, as it requires that this theory be explored in other substantive areas (Glaser & Strauss, 1967; Gobo, 2004).

Summary

Amidst scholarly engagement with theory, less attention has been devoted to the process of theorizing. As Kuczynski and Daly (2003) contended, conventions in knowledge sharing and a strong hypothetico-deductive orientation toward theory testing in the social sciences has resulted in limited discussion of the complicated process of theory development, instead portraying theories as “magical coins that are pulled from behind [a researcher’s] ears” (p. 380). As I have attempted to detail throughout this discussion of research methods, a constructivist grounded theory approach emphasizes that the development of theory is no slight of hand trick.

Beyond the challenge of defining a research area, investing in an ongoing process of theoretical sensitization, and identifying individuals willing to share their experiences, I have experienced the vast complexities in how I interact with participants, examine my participation in this process, and work to move a diversity of complicated, concrete, lived experiences into a more abstract story or theory. In building “second order stories” (Daly, 1997) that coherently bring together the interpretations of participants and researchers, I have become familiar with the reality that this work is not linear, it is not tidy, and it is not amenable to prescriptions.

Instead, I have drawn on principles offered by those with experience in walking this path, using these as signposts directing me to continually engage with the multitude of voices (those of participants and my own), to adapt to what I am learning, to cycle
back, to practice creativity, to conscientiously and transparently move pieces toward patterns, and to trust in this complicated and uncertain process. In pursuit of understanding, this journey is a worthy one, for as Charmaz (2006) offered, “The path may present inevitable ambiguities that hurl you into the existential dislocation of bewilderment. Still, when you bring passion, curiosity, openness, and care to your work, novel experiences will ensue and your ideas will emerge” (p. 165).
Part 2: Research Results

Over the next three chapters, I describe how men moved toward their diagnosis and how they perceived and responded to illness. Following this presentation of research results, I offer a substantive theory of how men with cancer experience help seeking. As much ground will be covered in this discussion, it is helpful to have a high-level map outlining the terrain (Figure 1).
Chapter 4

“I really wasn’t expecting it,” An unanticipated turn

In working toward an understanding of how these men perceived and navigated needs and supports across the course of their illness, it is important to start at the beginning of their story: how they moved toward their clinical diagnosis. In this first chapter of the research results, I describe how many of the men walked a winding path to learning that they had cancer and I detail how this unanticipated turn in their personal narrative dismantled assumptions of health, a discussion divided in two sections, (a) considering signs and (b) an abrupt stop.

This chapter is important to setting the stage and highlighting a powerful turn in how the men perceived their health, but it is relatively brief and not part of the broader theory of help seeking built from the men’s lived experiences. I made the decision to exclude this from the theory based on an appreciation of pre-diagnosis help seeking as distinct from the men’s process of soliciting and accepting support after they were informed of their cancer, an awareness developed in the context of the interviews (see Methods) and which is consistent with the literature (Robertson, 2007). As will be detailed, prior to diagnosis men who noticed physical shifts (and not all did) oriented their efforts toward a determination of what was happening in their bodies, considering when to seek medical help in clarifying and repairing physical abnormalities. However, after these men received confirmation of disease, their attention shifted to handling what was happening to their ‘self’, more broadly, considering not just an impaired body, but also navigating the problematic changes in how they participated in social life and responding to the emotional impacts accompanying serious illness.

Although there are resonating patterns across the pre and post diagnostic period, my theoretical work is necessarily centred on how men moved on from the point of diagnosis, in the wake of this ‘problem’. This is one of many difficult choices required in developing a coherent and focused story of men’s help seeking. Thus, the majority of the results section is devoted to that process and divided between two subsequent chapters: *Illness disrupting ‘me’,* where I detail how the men interpreted the impacts of their illness, and *Responding to the disruption*, where focus moves to how they oriented to
their illness, positioned themselves and others, and engaged strategies of response. These discussions of needs and responses inform the help seeking theory detailed in Chapter 7. But first, we start at the beginning.

**Considering Signs (A winding path)**

The men described a diversity of paths taken to the point of learning they had cancer. For some, there were no clear signs or symptoms, their diagnosis coming from routine blood work or a screening test. For others, the first indication that something was wrong was acute: a seizure or blinding headache prompting immediate medical consultation. However, for most men there was a gradual awakening to concern. They might notice physical oddities, but alternate explanations were often close at hand as they trusted in their health and were immersed in the complexity of daily life. Over the next section I detail patterns in how the men described (a) noticing changes, (b) finding explanations, (c) trusting in health, and (d) becoming concerned.

**Noticing Changes**

Their disease might have taken a variety of courses and the men experienced differing degrees of concern in the face of these shifts, but each man evidenced a surveillance of changes in his physical appearance and performance. As the men described how they came to sense something had changed in their body, their stories highlighted attention to visible and acute signs or symptoms: extreme pain, fatigue, blood, excessive sweating, lumps, lesions, and seizures. For example, Brad shared how he recognized blood in his urine as a sign that he needed to call his doctor, though he was tempted to cancel his appointment when it briefly subsided:

…One morning I…I got up and I had ah blood in my urine and it was ah bright red. So um…ah I called ah my…my doctors office and made an appointment and then I…I urinated more during the day and the next day and I didn’t have any blood so I was going to, ah, call and cancel and the next morning I had ah a…I passed a blood clot with… which initially it meant I…I just couldn’t urinate and I was building, um, pressure…it was quite uncomfortable and then this blood clot passed and that ended any idea of cancelling the appointment (laughing).
Beyond these signs of concern, the men were particularly attentive to changes that persisted, that interfered with their work, and those perceived as ‘unusual,’ or lacking a clear explanation. Bill, for example, became concerned when he began to notice a “trend” of worsening symptoms and Clint talked of his growing concern about the “arbitrary” and “mysterious” pains he felt.

Others in the men’s lives participated in drawing attention to changes in their appearance and/or physical functioning. For some men these observations highlighted changes that had eluded their consciousness, but in most cases the comments by family members, friends, colleagues, and other health providers (e.g. dentists) appeared to validate what the men had already noticed: they seemed tired, had a visible or palpable sore/lump. As Andy shared, prior to his diagnosis multiple people had noticed his skin lesion over the years, noting this exchange with his young nephew: “[the lesion] wasn’t that nice and he goes, ‘Uncle, what’s wrong with your back? You got something ugly on there.’ And, I’m like, Uncle’s got a sore [laughs].”

Finding Explanations

Although intense or visible changes (pain, blood, and lumps) appeared to heighten concern, even acute signs could be set aside if a condition did not persist, was not incapacitating, or if a man was easily able to ascribe a different rationale. Most men, wrestling with ambiguous signs, appeared to find alternate explanations with relative ease. In most cases, the explanations did not evidence great leaps in logic, but were based in context of their life as the men attributed shifts to individual quirks, a lack of exercise, stress, injuries, cold/flu, side-effects of other medical problems, changes in patterns of activity and, for the older men, aging.

For example, Nico shared how he initially attributed the headaches associated with his brain tumour to a sinus infection, choosing to treat it with Tylenol, while Jim described how he linked his back pain to over-exercising an aging body, thinking to himself, “you know it’s like you know you’re getting old buddy, it’s time to you know stop…stop doing this shit.” Dan talked explicitly about the difficulty in extracting symptoms of concern from the general mix of life:
[T]hey said, “well did you have headaches?” Well, I’d headaches – migraine headaches, as a kid and being in my job […] so you get headaches, but it wasn’t like I was having one every day, or, you know, every second day or something like that. […] So, you know, couple Tylenols, done, boom. [And] they said, “Well, you know, have you lost your appetite?” Well, no, I still eat pretty good when I get home. […] And they said, you know, “are you tired?” I said, no, I go to bed [late] and I get up [early] …I’ve been doing that since I, since I was probably about 16. So no, I don’t feel any different.

**Trusting in Health**

Beyond gaps in their knowledge about ‘what cancer looks like’, for most of the men this process of assessing physical changes appeared to be influenced by a strong degree of confidence in their health. As I invited the men to describe their health before the cancer, or reflect on the nature of health, more broadly, many presented themselves as rarely or never ill. Further, they emphasized their maintenance of a healthy weight through exercise, eating right, taking vitamins, avoiding excessive drinking and associating good health with an absence of restriction: not feeling pain or taking medications, doing what they want to do, not missing work. As Randy described, “to me healthy is not having to go to the doctor or not [pause] not in pain enough to phone…to call the doctor.” Bill offered a striking example of this orientation. After explaining to me that he had always enjoyed good health, he later referenced a severe heart attack he had experienced twenty years previous. Although this event had brought him close to death, it had not disrupted his sense of self as healthy, unlike his diagnosis of chronic Leukemia, a condition marked by limitations to daily functioning, but unlikely to be the cause of his eventual death.

Defining health in this way, men who had not been ‘sick’ in the past had a lifetime of experiences reinforcing confidence in the quality of their health. Further, this orientation could be strengthened in the course of non-problematic visits with medical professionals. A number of men described checking in with a physician about oddities as they participated in regular physical exams or consulted about unrelated challenges, and interpreting the discussion in a way that left them feeling confident that the often subtle changes were normal, or at least of minimal concern. This could be an even more
significant challenge for older men, as changes were easily attributed to the advancing limitations of aging. Earl, a man in his 50s, illustrated this well:

The local doc, you know, when I go for my annual physicals again would ask the questions…you know urination…no problem, you’re up at night? Ah, sometimes you know if you drink a lot of fluid, you’re going to be up at night right. But in the norm? No. Um any erectile, you know, and he was very forthright…any problems with getting an erection? No. Any problem maintaining an erection? No…sometimes. Um any problem with the…with the quality of the erection? Well sometimes. And you know I remember him saying too, well, you know, you’re not 25 anymore.

As serious illness was not part of their personal narrative, these men did not appear to be actively rejecting sickness as much as focusing elsewhere; sickness was not a logical conclusion so there must be another answer. As Dan shared, “if I’d been someone who had been sick all the time, maybe I would have paid more attention, but because I wasn’t, it didn’t dawn on me.”

Even more, the signs and symptoms were in competition for the men’s attention. Illness does not wait for a convenient time to manifest. It enters full and active lives comprised of an array of existing obligations and pressing responsibilities. Even as physical signs were perceived as concerning, some men described efforts to balance the often ambiguous shifts in their health with attention to more clearly defined priorities including work demands, trips, the health of others, and relationship struggles. For example, Keith described how he kept “shoving” his worries to the back of his mind as he focused on “more important fish to fry” at work, Fred noted that although he anticipated he had cancer, he was determined to not have it “screw up” a trip he had planned, Randy detailed how he waited until his wife’s health issues were taken care of before he took action on his own, and Michael explained how his failing relationship dominated his attention, leaving him feeling unable to devote energy to a concerning PSA level:

My PSA […] was very high […] so consequently my [General practitioner] made an appointment with the urologist. […] But the time I should be going was actually the time that my marriage ended. So I actually cancelled the appointment believing that this could take place at another time when I was in better shape or whatever.
As combined with a confidence in their health, the often vague physical shifts could make the solicitation of clinical help feel less urgent, as men worked around the impositions of a compromised body, or self-medicated with pain medication (“vitamin I,” or ibuprofen, as Jim noted), waiting for the worry to pass and focusing on concrete demands of daily life. For many, this strategy had worked before and there was no clear reason to believe it would not this time.

**Becoming Concerned**

Although some men had immediately sought medical help in the face of incapacitating or acute conditions or symptoms they could not easily explain away, for many it was not a single sign or condition that prompted or inhibited medical consultation, but a juggling of multiple forces pulling them toward and away from medical consultation. As noted, in the context of a full life, men experiencing problematic signs and symptoms actively reconciled some concerns, struggled to interpret others, and considered others’ perspectives on what was happening to their body as indicators of concern appeared, shifted, and even disappeared.

Brian’s story helps illustrate this process. Over the course of two months, Brian had experienced swollen lymph nodes, night sweats, and fatigue, struggling to sleep due to increasing levels of discomfort. In the context of his life and experience, there were multiple explanations at hand, and he initially concluded that he had mono or a viral infection, while also considering that he might have been drinking too much (he noted that he had been on vacation when the symptoms began to emerge and noted that the beer was plentiful and of excellent quality). Although he became increasingly concerned as his lymph nodes became hard to the touch, Brian did not schedule a doctor’s appointment until his dentist expressed serious concern over the size of his lymph nodes, appearing on a routine x-ray, and advised him to see a doctor. Notably, although many of the men positioned themselves as deciding, fairly independently, to seek medical support, others, like Brian, described themselves as responding to the encouragement of partners, friends, and other health care providers (e.g. sports therapists, dentists).

**Reviewing options.** As the men evaluated signs and symptoms, their path to diagnosis was also influenced by how they perceived the utility of medical supports. In
our discussion of their perceptions of clinical services, each man demonstrated an awareness of the social discourse positioning men as reluctant to seek medical help. As Michael detailed: “There is that male mentality, like in other words, oh I can get through this or it’s just this or it’s just that. And I don’t go to a doctor […]. I think that many men think that.” However, not all men aligned with that position in either belief or act, with some even challenging practiced patterns through a conscious efforts to care for their health through medical help seeking. Brad, drawing on his experience in a health-related industry, noted that he had heard many talk about how “men don’t go to see their doctors, men ignore symptoms, men will not seek advice…all those things which is, ah, statistically true.” In response he decided, “Well, it’s not going to be me.”

Those men who did express a reluctance to engage the medical system (unless absolutely necessary) emphasized their own resilience, arguing that they had always been healthy and not in need of medical services, detailing a high tolerance to pain or highlighting, as Chris did, their history of success in handling concerns: “sickness could never hardly put me down.” In this, some men rationalized that most concerns go away with time, evidencing a preference to allow their body to work through challenges. In a similar vein, some suggested that being overly attentive to the body could cause problems to surface. As Marc noted, “I know that people see doctors, they always manage to find something wrong with you […] the less you go to see them, the less you’ll find out for trouble so don’t go there and you’ll be fine (laughing).” It was clear that Marc did not believe that the health system would actually make him sick, but rather that he believed in the resilience of his body to overcome most conditions without intervention.

More often, the men I met described themselves as regular users of the medical system. In fact, for those without signs or symptoms of disease it was often their participation in regular screening or physical exams that had led to the identification of their disease. Even more, some men had actively petitioned to be involved in screening programs ahead of the normal schedule. When I asked them to talk about why they thought their behaviour varied from a more dominant narrative, they offered a variety of rationales including those linked to experience and identity.
For example, some men described how they had watched others suffer due to delays in seeking help or had grown concerned about their health as those close to them were diagnosed with illness. Others pointed to an active lifestyle requiring regular clinical visits. As Jim noted, “I’ve been so physically active and I break things, I smash things, I tear knees and I do this shit…I don’t have a problem going to a doctor.” Some men emphasized that they simply cared about themselves, as Alfred noted, “well I always thought, as I say, I mean not really want to overdo it, but I’m fairly important person (laughing).” Finally, some explained that they had always lived outside dominant male scripts. As Michael shared, being gay meant that he was “different,” so “that sort of goes along with going to the doctor and taking care of myself, all that kind of stuff.” Notably, even among men expressing comfort in making use of the health system, there remained emphasis on legitimate, ‘reasonable’ or ‘wise’ use, as they carefully distinguished themselves from those who go to the doctor too much. As Fred noted, “I’m not a hypochondriac running off to the doctor all the time. I go to the doctor reluctantly, but I try to go wisely.”

An Abrupt Stop

For many of the men, the path to diagnosis continued to be a winding one, even as they reached out to health providers. In some cases symptoms were misdiagnosed, in others tests were inconclusive, and for still others the staging and prognosis of their disease at times trailed far behind the initial identification of the presence of cancer in their body. Regardless of how the men’s individual stories twisted and turned in navigating the terrain of their knowledge, experience, condition, and context, the impact of their diagnosis of cancer was abrupt.

In learning of their disease, the narratives were brought into alignment. Deliberations over the meaning of symptoms or utility of the medical system ceased and competing concerns related to family, work, or social lives were pushed to the side. Nearly every man described entering an intense state of shock as he faced a body that had, unexpectedly, gone off course. In this problematic moment, they were disoriented. They felt “numb,” described time moving as a “blur,” as they entered into a “daze,” or a “robotic trance.” As Oscar explained, although he had been concerned about his health
and was undergoing testing, he did not anticipate cancer. In receiving the news through a phone call from the specialist he described himself as “stunned” noting that he “came straight home, I didn’t know what to do. Because I don’t know what you do, do (laughing). It’s not the phone call you expect. I really wasn’t expecting it.”

This sense of shock appeared to be fuelled by a sudden collision of two stories of self: a sense of self as healthy confronted by a sense of self as dying, the impact of which appeared to take away their breath, if only for a moment. Before their diagnosis, some men, like Marc, had felt immortal: “[I am] my own god, or whatever, and so therefore nothing is supposed to happen to me” or were at least intensely confident in their ongoing health. Others, like Nico and Dave, argued that they had no reason to expect illness given a lifetime of good health or an anticipated longevity based on the experiences of family members. Still others had anticipated different vulnerabilities. For example, Gerrard had committed to a life complicated by heart problems:

I remember getting that call from ah Dr. R and he said we’ve got your results and he says, it’s cancer…it’s non-Hodgkin’s Lymphoma. And I said, um, I said no…I said I’m going to die of a heart attack and he says, Gerrard, you’ve got cancer. I said no…I’ve got…you know, I’m going to have a heart attack and I said I got to go and I hung up and oh shit…I was sitting there shaking in my office uncontrollably because you know…yah…cancer never ran in my family…

Even among men who had family members (e.g. partners, parents, grandparents, etc.) who had been diagnosed with a form of the disease, cancer was not an anticipated part of their own storyline. As Jack explained, cancer is something other people with “bad luck” get. For some men, descriptions of how family members and friends responded not only with concern, but also with a mirroring sense of shock seemed to further establish or even justify their own sense of dissonance. While some may not have been feeling well, it appeared that they had not released their narrative of good health (i.e. not sick) until their doctor stated: “you have cancer.”

This shock could be particularly acute among men who had not experienced any signs and symptoms of illness, but it was evident even among those who acknowledged lifestyle practices that carried well-known cancer risks (e.g. smoking) or had noticed
concerning physical changes. For example, Oscar, a long time smoker, drew on the responses of others to emphasize the validity of his shock in receiving a diagnosis of throat cancer, explaining that others were also in “complete shock…even though I was a smoker. So…they said it was still a shock.” Similarly, even men who anticipated some form of disease based on observed shifts were not protected against this jolt. Earl, a man who had actively petitioned for a PSA screening test, explained that although he was “prepared to hear the worst” when the news came, it shook him: “I was fairly composed in the office but when I got to the car I…I let it go. […]…it…it…it hits you and…and it’s and I don’t know how else to…describe it, it’s like a death sentence.”

As evident in Earl’s struggle to find the language to describe this moment, hearing the doctor speak those words levelled a fundamental and nearly indescribable shock. Not only had their narrative of health been severely disrupted, but they were also facing a disease perceived as unlike others. At least initially, cancer was interpreted as a deadly, brutalizing force; a hegemonic narrative casting a heavy shadow over the specific realities of the form found in their bodies. Although a few men asserted an immediate confidence in their survival or downplayed their degree of concern (a position some later would describe as an act of “denial”), most of the men did not describe themselves as harbouring much hope when diagnosed, instead detailing intense feelings of devastation and fears of suffering and death. Cancer did not just mean they were not healthy, it meant they were facing an imminent and difficult death.

In giving shape to this “dreaded disease” as Chris described it, many initially pulled from narratives outside the medical literature. In this focus, their anxieties were horribly fleshed out through specific remembrances of how others they had known had suffered, been disfigured, or died difficult deaths from a form of cancer, giving limited attention to the form or stage of the disease these others had experienced. For example, Andy, a man with a non-melanoma skin cancer remembered how a friend had died from melanoma, noting his expectation was that if you had skin cancer, “you’re toast. Right. Like he lasted two years. I got skin cancer – I’m going to last two years? I’ve got two years left of my life?” Similarly, Jim explained:
…When I was in my teens up till 20, um, the common perception that I held and I think most of my peers held was if you got cancer…you died, that was it. Um, it was only the rare individual who somehow managed to beat it. Um, you know a couple of friends…they were like high school acquaintances […] that I knew…they got cancer…they died. You know like I think that everybody I knew that got cancer…died. So I assumed you know when I was given a diagnosis of cancer…that I was going to die. The men were not alone in reaching for this culturally dominant definition of cancer. As Michel noted, in this society, “we do associate cancer with death, you know, not so much heart disease and stroke, which is exactly the same thing, can lead to death. But cancer is somehow associated with death.” Even more, men experienced this connection at an interpersonal level as they described how those around them assumed they were dying in learning of their cancer diagnosis. As Randy explained, “a lot of people when you’re dealing…when you say you have cancer, the first thought they have is, oh, you’re going to die.”

Although some men were facing a terminal diagnosis, others would eventually modify this definition of cancer as a death sentence. As they took in more information on the specifics of their condition and prognosis in the moments and days after receiving the news, many began to reframe their perception of this threat. Depending on the specifics of their cancer type, stage, and treatment options they may or may not die from the disease, they may or may not be facing critical or enduring impairments. But while they might not be facing certain death from cancer, this fear did not always fully dissipate. Even more, as will be discussed later, they continued to be challenged by other’s maintenance of this stigmatizing association between cancer and death.

**Summary**

It should not come as a surprise that most of the men walked a winding path to diagnosis. The process of identifying disease is accepted as a complicated process for men and women. As Bury (1982) argued, non-communicable conditions, the dominant form of illness in the 21st century, are insidious; they “do not ‘break-out’ they ‘creep in’” (p. 170), a reality challenging how individuals recognize and legitimate illness. “There is rarely anything in an individual’s biography,” Bury (1982) continued, “which provides an immediate basis for recognition of the illness as illness” (p. 171). Amidst this common
complexity, there also appeared gendered patterns informing how men walked the twists and turns of this path to diagnosis. Although these findings are not integrated into the broader substantive theory of help seeking, there is value in reflecting on key elements in relation to existing research, particularly as this period preceding diagnosis is the focus of much of the existing research on men’s help seeking.

As detailed in the literature review, it has been argued that a man’s ability to recognize and respond to problematic signs and symptoms as evidence of illness can be compromised by a discomfort in attending too closely to his body (a feminine orientation) and a practiced sense of invincibility. As fuelled by social expectation of men as strong, controlled, and robust, this complex patterning likely infused how these men made sense of perceived physiological shifts. However, as the men detailed their pre-diagnosis experience, their stories more tangibly reflected a conscious struggle to reconcile problematic signs and symptoms with a powerful narrative of good health built on the basis of past experiences, a narrative they held onto until their cancer diagnosis forced them to yield that claim. Robertson (2007) has argued that men tend to define ‘health’ as (a) the absence of illness and (b) an ability to function. Consistent with orientation, although many of these men had endured minor ailments or even significant physical traumas over the course of life, few had previously experienced what they believed qualified as ‘illness’.

This practiced expectation of a healthy body informed how the men perceived and interpreted physical shifts preceding diagnosis. Similar to what others have observed, the men engaged in active “self monitoring,” noticing changes in their bodies, considering possibilities, and assessing shifts in light of how their body had performed in the past (e.g. Smith et al., 2008; White & Johnson, 2000). In this evaluative process, a strong confidence in their health and the association of illness with a loss of function allowed many of the men to accept some shifts as minor or transitory. This accomplishment was further facilitated by the often-ambiguous signs and symptoms linked with a variety of cancer types (Smith et al., 2005), physical anomalies often not well known, nor easily identified, particularly at the early stages (Stubbins, 2009). As long as they could continue to move through the day in relatively familiar ways or find a suitable
explanation for the shift (e.g. individual quirk, muscle strain, marker of aging), a sense of health could be maintained. As long as they remained ‘healthy’, medical consultation was optional.

Concern was heightened by changes the men interpreted as obvious indicators of possible disease, including compounding signs and symptoms characterized by significant pain or a visible aberration recognized as problematic (e.g. lump, bleeding), physical shifts that eluded explanation, or which disrupted their ability to engage in valued activities. These patterns in symptom evaluation resonate with a common lay emphasis on discomfort/pain and restriction as indicators of a need for clinical help (Mechanic, 1995). Even more, they are consistent with those observed in research specific to men’s experiences, as detailed in the literature review.

This dynamic is consistent with Robertson’s (2007) assertion that while the binary positioning of health and illness common among men can stigmatize help seeking during times of normal physical functioning, in the context of strong evidence of concern, men can justify medical consultation, recognizing themselves as “serious” users of the system. In contrast with arguments that help seeking is fundamentally at odds with an idealized masculinity or that the initiation of medical help seeking requires men to take on a more subordinate ‘ill’ identity or at least accept an inability to align with a robust masculine ideal (McVittie & Willock, 2006; White & Johnson, 2000), certain physical shifts appeared to offer these men a legitimate reason to connect with health professionals, even as the pace with which they moved toward help would vary in the context of rich lives and differing biographies.

As these stories align with Robertson’s (2007) discussion of the “don’t care/should care” dilemma men navigate as they seek to balance an impression that they are not overly concerned about their health with a willingness to repair it, as appropriate, they also illustrate how clinical help seeking can be legitimized in degrees. These men, interpreting particular physical shifts as evidence that something had malfunctioned in their body, could come to accept medical support as an appropriate and even responsible response given the nature of the disruption. However, unlike a nearly absolute acceptance of clinical help seeking as legitimate after their diagnosis (discussed later),
this early period of engagement was vulnerable to disruption. As the men continued to recognize themselves as ‘healthy’ until the moment they were told they had cancer, clinical help seeking could be delayed or tentatively engaged as alternate explanations were considered, competing concerns took priority, doubts lingered over whether medical engagement was critical, and men could be reliant on validation of their concerns from others around them.
Chapter 5

“I was under assault,” Illness disrupting ‘me’

Although the initial diagnosis of cancer had profoundly disrupted the men’s sense of self as healthy, the process of defining and understanding the self as ‘ill’ took form in the context of the reverberations of their disease, as they experienced tangible shifts in the compositions and rhythms of their lives. As Fred described: “I was under assault.”

For men who had not experienced signs or symptoms of disease, this transition could be initially complicated by an absence of clear physical indicators of illness. As Justin shared:

[It’s] so hard with cancer to believe…to believe you’re sick. You know because, um, you know if you’re sick and…and you know…you know like when you blow your knee, I mean you’re in a lot of pain…you know. Well I had no pain…whatsoever…none! I felt as good as ever. And…and yet I’m told that I’ve got a very serious tumour.

Even more, a couple of the men actively denied their diagnosis, preferring to maintain a trust in a sense of self as healthy despite the specific and highly contradictory storyline offered by their physician. For example, Dan, a man who was initially told that his diagnosis was accompanied by an average survival of only two years, shared that he “trusted my instincts” explaining that “I didn’t feel sick, so…how could I really, it couldn’t be, it couldn’t be what they were saying, you know, and um…there was probably still some of that denial mode at that time.”

Despite these initial struggles, as their disease progressed and treatments commenced most of the men detailed a litany of difficult questions and an onslaught of severe and on-going physiological, cognitive, emotional, and relational shifts. It was in this context of an altered body and adjusted daily rhythm that many began to experience their illness. Pete’s story powerfully illustrates this process. Although he was diagnosed with multiple myeloma (a slow developing type) in early 1980s, it was not until 30 years later, as he sat in a chair in the chemotherapy ward receiving an IV, that he recognized himself as sick, as a ‘cancer patient’:
[My wife and I] were in the Chemo ward and um it’s ah… there’s… it’s quite a mix of chairs and beds and there’s people sitting around and hooked up to ah… ah various ah you know bags of you know they’re all different and ah you’re… you’re nervous about the whole thing right ah and then, um, they… they hook you up and […] it just takes a matter of seconds but you know it was just to me a defining moment you know because that was the moment where I stopped being me and I became a cancer patient.

Similarly, Terry described how his plans for dealing with his initial diagnosis were put on hold in the absence of clear shifts in his daily life, commenting:

When the diagnosis did arise in [the 90s] I thought maybe I had better start considering this of what’s going to happen down the line but then I was doing so well and nothing was happening I thought ah you know I…I’m doing fine…let’s just carry on.

These statements emphasize the point made by medical sociologists: that disease and illness, while often connected, are not always operating in unison. The men’s narratives of good health were disrupted at diagnosis, but the process of re-defining themselves as ill appeared to involve not just the specific knowledge of disease, but also tangible shifts in ways of being. Even more, across their illness career, as physiological, cognitive, and emotional conditions evolved, treatments commenced and completed, losses and uncertainties were noticed, overcome or endured, and dynamics between self and other adjusted, their determination of what they were facing, what they needed, and, thus, how they should respond, continued to adjust. Simply, their definition of what it meant to be ‘ill’ could remain unstable amidst shifting conditions and as mediated through an interactive as well as internal definitional dialogue. For some, this process would continue well beyond the period of treatment. Over the next section, I explore these evolving needs of illness, as highlighted in the men’s stories. Notably, in describing these needs, I borrow Fred’s language of “assaults,” recognizing this term as capable of encompassing the extensive range and intimacy of the challenges men detailed in relation to their illness.

**Noticing the ‘assaults’**

To understand how the men responded to the needs associated with illness it is necessary to examine what they included in their definition of what it meant to be ill:
what did they notice, what did they prioritize? In studies of help seeking it is easy to be
drawn into a cataloguing of needs: medical, physical, emotional, financial, relational,
social, and spiritual (and more). These are relevant. But in the course of our discussions,
these men detailed a tremendous variety of stories. Each came to his experience and the
interview with a rich and developing narrative and was tuned into different elements.
Even more, their experiences, as shared with me, were influenced by a range of timelines
and prognoses, treatment protocols and impacts, and embedded in a variety of social
networks. Pursuing commonalities across diverse trajectories, I considered undercurrents
in how men interpreted the multitude of challenges amidst illness.

Thus oriented, as I listened to the men describe how the presence and progression
of their disease and its treatments compromised their bodies and minds (and threatened
ever greater restrictions), I became attuned to how these shifts destabilized their ability to
anticipate their future self and to present their normal and valued present self. More
specifically, as detailed over the course of this chapter, the men’s stories highlighted how they struggled with (a) a troubled future and (b) a discordant present, identity disruptions
often accompanied by (c) a lack of certainty around how to handle these shifts, and (d)
feelings of isolation amidst the destabilization following their diagnosis. As Bill
poignantly shared, amidst this disruption, he lost a sense of influence over how he lived,
feeling as though he were “riding along with” life. These themes, as joined with those in
the next chapter describing how the men responded to these assaults, will inform the
theoretical story offered in the Discussion chapter.

As I move into a discussion of the particulars of these categories of assault, it is
important to remember that the quality and composition of these threats shifted over the
course of the illness career, intersecting, blending, fading, and raging across individual
lives. Some assaults would be actualized, others would remain at the level of threat, and
the composition and weight of each would vary across each man’s life, influenced not
only by the demands of his disease, but also by his past experience and future aspirations.
In the pursuit of theory, it is neither possible nor desirable to go into every permutation,
but it is important to recognize that the picture offered here is in broad strokes. While I
do attend to experiences diverting from the more common narrative, the primary focus is
on what was shared, sacrificing detail for the benefit of a clearer image that can guide us into the discussion of how the men responded to these assaults.

**My future is troubled**

While a sense of control over the future is always fragile, in absence of major disruptions individuals are more able to operate with an assumption that there is sufficient data and security to look ahead, to build plans for their future self, and carry them through. However, for these men, as their cancer diagnosis disrupted the narrative of health and they came to view themselves as seriously ill, their anticipated future became problematic. In capturing this theme it can be helpful to envision the rippling of water after a rock is tossed into it. Although the intensity of this disruption varied across the men’s experiences (the impact of larger or smaller stones), in nearly all cases the troubled water in the wake of diagnosis challenged their ability to see the future self they had long envisioned, at least for a time. Instead they faced, as Michael shared, “the great fear, the fear of what is this, the fear of the unknown.”

In the early stages of their illness career, a lack of clarity regarding the specifics of their prognosis weighed heaviest as the men awaited test results that would more clearly identify or stage their cancer. For many, this was the most critical piece of missing data as they sought to re-gain a vision of their future. It would indicate whether they would live or die, and if they were dying, how much time they had left. As Earl explained, in waiting for more specifics “You’ve got ten thousand questions and…and…and three answers.” Even more, this uncertainty was on display as others became aware of their condition; Earl continued, “and of course you know as we were telling the families, there were questions that come up and we’re saying we don’t know…we don’t know…you know we’re telling you what…what we know.”

Regardless of the duration of time passed, many of the men described an agonizing sense of immobilization during this waiting period. As Clint shared, “It’s totally out of your control, so you have to let it go, and you’re just sitting there when [the doctor] opens the damn door” (his emphasis). Similarly, Arthur explained that the worst part of his cancer experience was waiting for his test results, “Waiting to see if I passed, you know, and I think I’ve said that to some people, it’s like having written an exam and
waiting for your results…you think you did okay but you don’t know.” While Clint’s emphasis on “sitting” highlights a nearly complete sense of lost agency, Arthur’s characterization of this process as a “test” suggests efforts to retain some control while finding it outside his grasp. However, in both cases and across stories, the men found themselves waiting for others to provide the information required to see their future.

Until they had that information, the future was both expansive and unknown, easily populated with fears of physical suffering and death, scripts readily offered by the dominant narrative of cancer. While a few asserted that they remained confident that their future was in tact (i.e. they would survive, be fine), most described at least moments of profound uncertainty infused with a sense of great hopelessness, sadness, and anxiety. Some men spoke specifically to being overcome, emotionally, by this wave of fear. As Clint shared, in the days after learning he had kidney cancer, he struggled intensely amidst his fears, “I didn’t handle it well at all. And I don’t know about other people, but I can, I think because of my personality, mentally I didn’t handle it well at all. I cried all weekend.” Even more, in recognizing the impacts of their disease on those close to them, many described their loved ones as sharing this terrifying uncertainty in those early days around what might lay ahead, characterizing those close to them as “shaken,” scared, “freaked out,” worried, anxious, stressed, and sad as they learned of the diagnosis.

As their cancer was staged, the future could begin to take form, but often remained terrifyingly unstable as the men anticipated the physical impacts of their disease, struggling to envision how they would experience day-to-day life as it progressed. For those with terminal conditions, the diagnosis could erase the future self toward which they oriented. As Richard shared, his long-anticipated plans for retirement disintegrated when his death was “written on [his] forehead,” reflecting “that’s what sometimes I find with life is wrong. [We] make plans and none of us really concentrate on the possibility of this not happening.”

Even men diagnosed with treatable conditions described how their future remained problematic or uncertain amidst fears of ineffective treatments and a body compromised by extreme pain, incontinence, erectile dysfunction (ED), nerve damage, negative reactions to drugs or other treatments, or limited to such an extent that they
would be unable to move, care for themselves, think, or communicate in ways they had
known. The prognosis provided them with the statistics, the odds, but it was difficult to
build a future on these numbers. As many gaps remained in their vision of the future,
anxieties continued. Oscar explained:

…They say you’ve got a 70 percent chance and that’s pretty good but…I’ve […] been to the Casino with a lot worse (laughing) odds than that, um, but at the same time you… you sit and you look out at the back and you start thinking what happens if…you know supposing I don’t come out of this. Supposing you know the cancer could eventually kill me, is everything in order? Do I have um…do I have my life in order? Do I have finances in order…is [my wife] going to be okay? And so, yeah, that does go through your mind. Ah even though you know you’ve got a positive attitude and everybody is pretty positive that things are going to work out okay, you still think about it.

As these complications threatened their confidence in their ability to maintain familiar ways of being, the men worried over impacts to relationships and about their family’s ability to cope in their absence. Although some noted a delayed recognition of the impacts on others as those around them withheld reactions or as they focused on treatments, most of the men described how the uncertainties posed by their illness cascaded over others: family, friends, valued colleagues. In particular, as many explained how cancer “[affects] everybody in the family,” some shared how their families fell into turmoil amidst the fear associated with this disrupted future; children pulled away or acted out, partners sunk into a depression, and those they cared about made decisions that compromised their own physical health. As Jack shared, his wife, frightened of a future without him, began engaging in some unhealthy practices:

[But] you know, she, um, started drinking more. Ah, she started smoking. Um, basically you know as I told her she’s trying to kill herself before I die…she agrees (chuckle). Why not? You know ah (chuckle), um, and…and she has, um, not…she’s not looking after herself as she…before she used to go to the gym probably three times a week and then she went to Yoga and stuff like this and she doesn’t do any of that anymore.

Eventually, concerns about their prognosis and the impacts of the disease transitioned into uncertainties over the surgical reports, blood tests, and CT scans that would indicate the efficacy of treatments and evolved into more general fears about
whether the cancer cells would spread or return, whether they would be taken through this experience again, and whether they could survive a second, third, or fourth recurrence. For some, their cancer type carried a high likelihood of recurrence, for others the disease would be chronic with flare-ups that could not be anticipated and/or which might be increasingly difficult to treat, and for still others, their disease was unlikely to return. However, many continued to experience profound uncertainty around what lay ahead, recognizing cancer as an often-devious group of diseases. As Dave shared:

…The rest of my life I’ve got to face ah starting off every three months, then every six months, then every year and then every two years…you hit the five year mark and they say okay, you’re all right. But no matter what you’re still going to have that in the back of your mind…if something changes. You know is it back?

The intensity of these anxieties could move from the fore of consciousness over time, but they could return quickly with acuity, prompted by the emergence of a physical shift or in hearing how others had endured deadly recurrences, including stories from those with differing diagnoses and risks. As Jakob explained, although his surgery for prostate cancer was completed and deemed successful, he returned to a state of profound discouragement over his future when a much older man in his prostate support group experienced a recurrence. Similarly, although Marc’s colorectal cancer was caught early and was associated with a good prognosis, his reading about another man’s experience with brain cancer evoked acute fears about this own future: “and I’m reading through this knowing that cancer does spread and whatever over time and I’m thinking oh my God, I got operated early July…like you know where is this going?” Even more, this acute sense of vulnerability was not always limited to cancer recurrences. As Michael noted, a body that could not be trusted was capable of betraying in other ways: “Like… um, like I am an asthmatic but that has always been under control but now I have cancer and, you know, what else, what other surprises, body, are you going to give me.”

These stories evidence men on alert. Even as answers accumulated in the course of their illness career and the men moved months and years beyond treatments, their future could remain severely troubled. A sense of confidence or trust in their bodies had been dealt a powerful blow through this unanticipated diagnosis and their guard was
raised. In this, the men recognized not only the limits of their body, but also the challenges posed by an insidious and persistent disease. Peering into an unclear and frightening future, most continued to struggle to imagine a future self as secure as the one they had known before diagnosis, finding themselves (and often those who loved them) forced to struggle with the continued possibility of an unfamiliar, restricted, and vulnerable way of being. If not now, maybe later.

My present is discordant

As uncertainties around their future disrupted an ability to carry their narrative into the future, limitations in their ability to physically, cognitively, and relationally function in ways they valued troubled their comfort with their present self. Amidst the assaults of their disease and its treatments, the men described a painful and exhausted body and clouded mind, a physical and cognitive weakening they could not control. As will be detailed, while these physiological disruptions were difficult, their impact was experienced more fully as the men struggled to present themselves in ways they valued, describing themselves as uncomfortably restrained and exposed. These disruptions to trusted ways of being are discussed in turn.

Experiencing an altered body and mind. Although not all the men experienced intense pain, many detailed how the progression of their disease and treatments wrought severe physical challenges: mouth sores, aches and nausea, blinding headaches, urinary retention, abscesses, lymphedema, excruciating bone pain, nerve damage, vascular necrosis, and more. Separate from, or as a companion to this pain, most described experiences of extreme exhaustion, a form unfamiliar and difficult to characterize. As Jim shared, “I couldn’t lift my fucking head off the pillow…I mean it was like…you were just…it’s just like…it’s like you were dead with your eyes open…I…it’s hard to describe. I mean…you’re just unbelievably sick.” Jim’s struggle to find words capable of expressing the depth of his experience emphasizes the profound shift from how he had previously experienced his body as an active and proficient outdoors person.

For many, this profound physical weakness was made even more problematic with its, at times, lack of clear origin, the rapidity of its onset amidst highly potent therapies, and for some, its persistence. Arthur detailed this sense of disconnect when he
explained that during his experience with cancer he felt “weak” for the first time in his life and struggled to make sense of the feeling because only “days prior to…to my operation, I was skiing in [Europe] (laughing). So…and then you know it wasn’t…it wasn’t a car accident, I didn’t get hit by a truck and so, I think, that was perhaps the most debilitating.” Experiences of pain were difficult, but they appeared to be more expected than this weakness. Even more, pain was consistent with their definition of what illness looks like and, in this, accorded a valid and often limited ‘time out.’ In contrast, the often-enduring exhaustion resulted in unanticipated and on-going constraints that some attempted to work around, with limited success. Fred’s story illustrates this tension as he described trying to work in his garden shortly after a treatment:

…There’s an element of pride within me um I found it very, very difficult at… at one point the, um, the…the Chemo agents…I got too much, and I was in my garden. I went out to pick peas […] Well, I knelt down in the ground to pick the pods and…and ah to get them into the basket [pause] and I tried getting back up…I couldn’t…I was so weak.

In addition to secondary losses to their ability to fulfil roles (discussed next), experiences of pain and exhaustion limited the men’s ability to perform basic physical functions, capacities often unnoticed until they were disrupted. Although some stressed that their situation “could have been worse,” for many, the discomfort and fatigue were of such a degree as to restrict their ability to move through their day as they had. Depending on their cancer type and treatment regime, men described losses in their ability to walk or move about, limited sexual functioning, restricted abilities to talk, eat, to control their bladder and bowels, and to stay awake. These shifts could result in a periods of dependency and embarrassment. Micky, a man experiencing incontinence after his prostate cancer surgery, described one particularly difficult experience:

I went out to a business luncheon with some friends of mine – I was trying, two business associates I had from before, that I tried to get together with them – and put them together. And we had a real nice business luncheon at ah…[coffee shop], which is not, you know, a schlock place, and as we got up to leave, I reached over the bench to get my coat to put on…and urine came flooding out like Niagara falls, all over the bench, all over the floor...all over me, in front of the entire restaurant.
For some men, these challenges would endure as they dealt with chronic conditions or underwent treatments that permanently eliminated certain forms of functioning, but for most the shifts were temporary, associated with their treatment regime.

Beyond the restrictions associated with physical pain and exhaustion, the men also described an eroding of their cognitive abilities. Although not universally experienced, some men detailed how fever, the intensity of drugs, and, for some, brain masses contributed to losses in memory or limited their ability to think clearly. Most commonly, those affected described “chemo brain,” detailing how treatments left them unable to complete tasks previously engaged with little thought. Similar to patterns with exhaustion, this limitation appeared particularly difficult to make sense of, as it was not accompanied by pain or other limitation requiring disengagement with regular activities; they could physically participate in regular activities, but could not participate as they had. Jack illustrated this challenge as he described a trip to a store to buy running shoes. Positioning himself as in a space of “feeling normal” between treatments, he detailed his unanticipated panic as he found himself unable to make a simple decision:

I went to the store by myself to buy running shoes and […] there’s two brands that I buy […] I always get the same thing…walked into the store by myself, looked at the wall of shoes, could see the brands that I like there […] but you could not make the decision of what ones to buy…or even to try on. And a sales clerk came to help me and everything and I basically was in a bit of a panic because I couldn’t make the decision…

These physical and cognitive limitations, particularly those that endured, were often associated with feelings of anger and frustration as the men experienced a body that could no longer perform as it had. As Joseph succinctly explained, “I don’t want to be like this.” Further, the men recognized that others in their lives were feeling the impact of these constraints as partnerships were strained amidst shortened fuses fuelled by the pain, exhaustion, and confusion. Oscar described how he would get “nippy” with this wife, imploring her to “leave me alone and I’m trying and trying. And she had to tolerate that because I was…my nerves were on edge because I didn’t want to do this thing you know, I didn’t want to…this feeding tube was horrible.” And Micky, a man who had been dealing with his disease for nearly a decade amidst multiple recurrences, recognized his family members as having grown fatigued with his complaints, explaining: “…so they
just, you know, would just say – say you have to go to the bathroom, don’t… complain when you’ve soaked the chair….don’t get angry, just get up and go.” As these complications entered the men’s lives, in process, they were also entering the full lives of their families and friends, challenging those providing care.

Beyond the direct physical and emotional toll of bodies and minds compromised by their cancer and its aggressive treatments, the men detailed how these shifts disrupted familiar ways of being, pushing them into a daily routine that was both unwelcomed and increasingly incongruent with how they had lived before. This is not to suggest that these men had enjoyed fully unrestricted lives before diagnosis. Few do. But in the throes of illness, the assaults on the body were assaults on the self as the men were unable to perform in ‘normal’ and valued ways in their families, social networks, and workplaces. As detailed next, the men’s stories highlighted how they particularly struggled with a way of life that was increasingly restrained and exposed.

**Feeling restrained.** In the early stages of their illness, short-term plans (e.g. vacations, work plans, etc.) were disrupted as treatment regimes commenced and days were increasingly devoted to the requirements of their disease: waiting for treatments and appointments, engaging in tedious and taxing procedures, and revising schedules to accommodate physical and cognitive limitations and risks, and even other’s desire to see them. Life as a ‘patient’ threatened not only intense physical discomfort, but could also position the men as secondary to their disease as they were inserted into a medical system that sometimes felt more focused on their disease than them. Jack described this as feeling like a “cog in a wheel,” amidst a regimented schedule that involved “your blood test at eight, see your doctor at nine, getting your Chemo at ten and you’re out by four or five o’clock and you’re gone.” While for many men, this positioning was limited to a confined period of treatment, for those experiencing chronic forms of the disease, there was no perceived end, no light toward which to work. As Jim detailed:

…it bothers me that I don’t get away from the drugs. I mean it’s like I’m on it every friggin’ day…it’s like I just want a break. You know what I mean? Like I just want to get away from it for a little while but I can’t. It’s like if you back off even for a couple of weeks…you know those proteins are going to climb…
In combination with the requirements of their medical treatments, the men described how the physical and cognitive shifts constrained their participation in familiar activities. They detailed shifts in work status as some were forced to take a leave from work while others moved into early retirement, disability leave, or severely reduced work opportunities, changes requiring not only adjusted daily rhythms and compositions, but also financial considerations. They described how they lost an ability to eat, have sex (without medical assistance), drive a car, engage in leisure activities (or at the level they had before), carry out activities around the home (e.g. raking leaves, vacuuming, fixing what is broken), and be there for family, more generally.

Again, while these shifts in daily patterns were temporary for some, for others they would endure. Although they recognized many of these restrictions as a natural and even necessary part of the illness process, these threats to the practices and rhythms of normal life challenged their ability to perform as the person they believed they were. As detailed next, across the diversities of lives and conditions, the men emphasized disruptions to their ability to act as an independent and vital presence in their families and communities. Certainly, not all disruptions were equally feared or mourned and the composition and significance of losses varied according to the context of the men’s lives (e.g. whether they had a family, a job, etc), but in focusing on these elements over others, the men highlighted these ways of being as valued elements of a competent self.

*Struggling to live with independence (struggling against dependence).* Even when transitory, the physical and cognitive constraints posed by illness could compromise the men’s abilities to direct their own movement through their day. For some, this threat was fully actualized as their bodies and minds altered to the point at which their ability to complete basic actions was fundamentally compromised; dependency on others became unavoidable. But even among those men who maintained a significant degree of independence the threat remained significant, as they struggled against limits and feared increasing restrictions. Thus, as capacities were reduced in varying degrees, many described how they watched as those around them stepped forward to accommodate their physical and cognitive restrictions, caring for their weakened body, driving them to appointments, taking on additional tasks in the home,
carrying more of the financial load, and adapting activities to fit their compromised energy levels. In this interactive dynamic, losses were not theirs alone. An inability to live with a familiar independence meant that others carried an additional “burden” or, at least, bent to their needs.

These accommodations could be less threatening when the men perceived them as temporary and requiring minimal engagement on the part others (e.g. a ride to the treatment centre), particularly as they engaged the support of those individuals viewed as more obligated to assist, such as partners, family, or close friends (a dynamic discussed later). Even so, the men recognized how their adjusted state troubled practiced relationship dynamics as partners and families could grow fatigued and even annoyed when laden with increasing responsibilities. As Jakob shared, his wife’s efforts to balance his care, her parent’s illness, and her job, led to her exhaustion and a need to impose boundaries on what she could offer, explaining how she told him she “didn’t have it in me anymore…I’m getting really tired” and suggested that he needed to start taking care of himself to a greater extent. In reflection, he acknowledged her anger as justified, noting that he “was sort of still sitting there waiting for her to help me.”

As many of the men had limited experience in relying on others for basic physical supports, these shifts would not only compromise their ability to perform in other valued ways (as detailed next), but also appeared to level a direct blow to their sense of competence as defined as the ability to do for one’s self (or at least not relying on others to do for them). As Terry described: “Yah that ah…ah that takes you down a notch or two to be dependent. Ah, I’ve usually been one who pretty much looks after my own issues.”

**Struggling to live with vitality.** In addition to struggles to independently care for themselves, the men’s stories highlighted how illness troubled their ability to engage in normal activities with the same quality of energy they had known before cancer. Vitality is a broad term meant to capture a range of interconnected and valued ways of being that signified to the men that they were living in a manner characterized by vibrancy and essential impact. In this, focus centred on the activity of a self-directed self: how they performed and what they provided. More specifically, the men’s stories highlighted how
they valued a way of being in the home, with friends, and at work that was physically 
robust, sexually competent, and distinctly useful.

*Physically robust.* A number of the men emphasized a valuation of physicality in 
day-to-day life. The activities of a strong, active body engaged in golfing, cycling, 
gardening, or walking not only offered many an outlet for stress, but also were 
recognized as core to familiar ways of presenting themselves as competent. For example, 
Micky detailed how his incontinence restricted him from engaging in physical pursuits 
with family and friends, leaving him feeling like a “drag” and distant from the “outgoing” 
man he used to be. In reference to losing his upper body strength after surgery for neck 
cancer, Dan explained, “it would be very easy to feel…like you’re half of the […] man 
that, you know you were, type of thing.” And for Brian, a man in his 30s who 
experienced a hip replacement because of treatments, the loss of ‘normal’ mobility 
conflicted with an emphasis on active spontaneity in his definition of how to be a young 
man:

That was depressing [pause] for the simple fact that…not that I was a runner 
before…I played some soccer you know amateur with […] friends. But, 
um, [pause] ah I like the ability to run. Um, get drunk and run around in my 
backyard and be silly and…and fool around with your buddies [in the city] 
and you know but the ability to walk normally and run normally if that’s 
taken away from you…which it was ah for me…is ah huge impact.

*Sexually competent.* Similarly, limitations in sexual functioning and decreased 
passion around sexual intimacy appeared to frustrate some men’s sense of competence. 
For both married and single men, an apparent perception of sexual potency and interest in 
sexual intercourse as core to intimacy meant that an inability to physically “perform” in 
these ways could compromise their sense of how to be a suitable intimate partner. This 
could contribute to a sense of increased distance between partners. As Brian explained, a 
decrease in his own desire for intimacy had a “huge impact” on his relationship with his 
wife and one with which they continued to struggle years after treatment ended. This 
challenge could also limit single men from exploring new relationships, post cancer. For 
example, Justin described how he had become a “loner” after his cancer, no longer 
joining with friends to go out and meet other single men, as he believed the ED and stress 
incontinence resulting from his prostate surgery made him an “inadequate” date:
I’ve been on, I think, maybe two dates in four years. […] Um, I get very tight, very ah…very nervous […] I just figure well what…you know what’s the sense? And um so I’ve…um very much a loner now or um…very much alone I guess is…is the word. […] I’m really not, ah [pause], you know, going all out to ah…ah to find a partner because ah…you know, because I’m worried, because I feel inadequate.

_Distinctly useful._ As the men described disruptions to their work and family life, their stories highlighted how an orientation toward vitality also operated beyond the mechanical functioning of their physical body. In particular, they emphasized the importance of being able to perform in a way that brought benefit to others and that in this contribution, to feel valued, needed, and respected by others as they contributed at work and home. First, men engaged in the work force described how illness challenged not just their ability to be physically present in the workplace, but to also be engaged as one who took leadership and delivered on obligations, a disruption that could remain even after the treatments concluded. As Nico described, the on-going cognitive and emotional limitations associated with his brain tumour severely troubled the confidence he had in his ability to be the kind of employee he valued, explaining that while he had “always been the first person to put up my hand to do the worst job (laughing) you know” now he worried that he would “let down” his colleagues.

Second, these men described how the restrictions in their illness limited their ability to be useful at home. Among the diversities of their lives, this could be discussed as the ability to contribute to the basic operation of the home, as an ability to economically provide, and/or protect their family. First, in regard to general contributions, the men noted an array of chores they could no longer complete (e.g. raking leaves, changing light bulbs, shovelling the walk, walking the dog, vacuuming the rug, and fixing what is broken) either during their treatments or, for some, due to longer-term impairments. Although some men were not threatened by the loss of certain chores (as Terry noted, he was more than happy to give up vacuuming), these losses, particularly those associated with physical strength, could trouble a sense that they offered something uniquely helpful to their family. Jack poignantly illustrated this when describing his inability to open a jar for his wife due to the ravages of his chemotherapy treatments he lamented, “You know like the stereotype thing… what’s a husband for?”
Beyond these daily tasks, some men expressed a particularly intense anxiety about their ability to contribute, economically, to the basic needs of themselves and their family amidst a difficult combination of lost work income (temporarily or permanently) and high drug costs. Not surprisingly, these financial concerns appeared more acute for men facing treatment regimes requiring significant time away from work, who had more limited drug plans and/or savings or a need for drugs not covered by government plans, and men who did not have the buffer of a second income (i.e. single men, men who were sole income earners in the family). However, the threat could move beyond the matter of how much money was coming into the home, as some emphasized a particular desire to be the person in the family who “brings home the bread.”

In detailing their inability to contribute in the home either by completing their portion of the chores or bringing home a pay cheque, the men recognized that those who loved them struggled with these shifts as well. As Joseph shared, he believed it was difficult for his wife to witness his inability to contribute around the home, noting that he believed it was a “burden” on his wife to have to live in this new reality, “having to, you know, see the things that I can’t do any more.” Even more, the men recognized that their inability to perform as valued meant that others would take over these particular responsibilities. In this, they could struggle to see where their value remained. For example, although Jack accepted that he needed to begin to teach his wife and children how to take over some of his roles in the home, it “hurt” as his family became more “independent” relying less him to be “Mister Fixer.” Further, as Brian explained, it was not just a loss in his ability to economically provide that was threatening to his competence, but that his wife had to take over that responsibility for him:

…I mean ah [pause] um from a…as a guy you’re sort of bred to, you know, be that person who brings home the bacon so to speak, right? And certainly my situation was no different. [My wife] worked part-time but the idea was we’d have kids, she’d take care of raising them, she wouldn’t work. And I know it sounds chauvinistic but there’d be a meal waiting for me when I came home. You know that was our…we were both comfortable with that, you know. Um, to all of a sudden have that kind of flipped on its head, now my wife is…ah the part-time job is kind of…could become our sole income and she still has to take care of the house and also take care of me now you know. Your sense of being a man kind of becomes diminished …right?
Often closely associated with this valued provision role was a discussion of threats to their ability to offer a distinct contribution in their family as protectors. In particular, men with a partner and/or young children described how they struggled with a fear that they would not be able to protect those they loved, both from the pain associated with their illness and its impacts, as well as the possibility of their death. Gerrard’s story illustrates this well. As he shared that the “hardest” part of his experience was telling his young daughter about the diagnosis, I asked him to say more about why this exchange was particularly difficult. He explained, “Well, like for me the biggest part was my daughter not growing up with a father…you know that…you know what if?” Later, we centred in more on what being a father meant to Gerrard and, in part, it was about protecting his daughter. This form of contribution was often described as a distinct aspect of being a father and partner for other men. Randy spoke to it directly as he shared that as his cancer limited his ability and energy to engage in life, he felt a loss in his valued role in the family, as a husband and as a father: “Before all this was going on I was sort of a…um [pause] a protector, guardian and everything. Their…their needs and wants came first.” Notably, this sense of obligation was not limited to their positioning of their present self. They carried it into the future, emphasizing that they were responsible for the provision and protection of their loved ones, even after they died. As Dan explained,

I guess, I…ah…and I don’t know, I don’t think it’s a…it’s not like I’m afraid to die, I don’t think. I just think that…[...] I know how tough it would be for [Judy] to be on her own, and I guess probably it’s the male side again, you’re the, you know, the, the, you’re supposed to be there for everybody, so you need to be there.

As evident, the men’s descriptions of how illness compromised their strength, sexual competence, and ability to be useful referenced dominant social expectations positioning men as powerful, potent, breadwinners and guardians. Some men also spoke to the influence of these gendered scripts more explicitly. In this, men positioned elements of these valued ways of being as essential, or part of the DNA of being a man. As Dave explained, men are “hardwired” to be providers. However, even as most acknowledged these prioritized ways of being as socially constructed pressures, they
described them as intimately woven into their expectations of how to be a competent man, a partner, and a father. For example, Jack noted that while he recognized that his drive to provide for his family was informed by being raised in “an old fashioned setting where […] the husband is the man of the house, he’s the provider, he looks after and does stuff around… does the physical work and, you know what I mean, like that sort of thing,” he experienced this as a very “personal pressure.” Similarly, Brian, the youngest man in the group, detailed how influential these social directives had been in informing what he valued in himself, even though they had largely operated below his consciousness before his diagnosis:

And so going through Leukemia, all that stuff that made you a man even though you didn’t realize you were playing that part, all of a sudden gets removed. You know um…you can’t perform in the bedroom. You know, you can’t bring home the money. You can’t um…you can’t…you can’t be that shoulder for your wife to cry on because you’re kind of crying yourself. You know, um…all those sort of things yah definitely have a big impact I would say for…for a lot of guys and I know they sort of share because I’ve spoke to a few different guys.

**Feeling exposed.** As noted across this discussion, these shifts and restrictions in functioning were not experienced in isolation. The men found their once private, controlled, and competent body and mind betraying them in public ways. Whether this was in the garden where the family or neighbours might witness their falters, with a stranger at a shoe store, in the workplace as they endured another week off work, or in a coffee shop with friends and strangers, their compromised self was mirrored back to them in the eyes of others. They felt the gaze of others on them, feeling exposed in ways that were both unfamiliar and threatening. In particular, the men described how others responded to their bodies with fear and assumptions of weakness.

**Others see me as off-putting, dangerous.** The men detailed how friends, family, even strangers pulled away from their bodies and from them. Although some men who had previously struggled with their weight wryly joked that cancer is a “hell of weight loss” plan, their illness often brought unwelcomed physical changes that were not just internally tumultuous, but also externally obvious. Whether changes were limited to the period during active treatment (weight loss/ gain, hair loss, wounds not yet healed), or endured following surgical interventions, the recoil of others highlighted a body that was
out of control, unfamiliar, and disturbingly damaged. For example, Andy struggled amidst off-handed comments about his “disgusting” lesion, exclaiming, “well, yeah, it is, but… what can I do, I wish I didn’t have it, like, people don’t want to be disgusting,” and Dan and Micky reflected on how others responded with discomfort to their bodies viewed as both foreign and diminished. In particular, Dan shared how his son struggled to see him behind the abrupt physical changes associated with his neck dissection, noting, “he probably thought, well, that’s not my dad” and Micky detailed how his son reacted in shock to the reduction in the length of his penis as a result of a prostatectomy. Describing an exchange in a fitness centre change room he shared, “and so, he finally said, like, [whispering] where’s your penis? Ahh, I said, right here. He looks…and says I thought you were kidding.”

The men also recognized their bodies as dangerous as they described how friends and family drifted away as they learned of their diagnosis. Joseph described this frequently noted challenge: “They just disappeared from my life like…some of my closest friends before I got sick are gone [pause] just gone.” In explaining these shifts, although some men noted that others were simply “uncomfortable” or “uncertain” how to respond to them, others attributed this reaction to the stigma of cancer, or serious illness, perceiving others as afraid of their disease and viewing them as contagious, dangerous. As Jim shared, many people in his life “just don’t do sick well. I mean it’s like…it’s like they’re going to catch it…it’s like they’re afraid of it.”

**Others see me as weakened.** More profoundly, the men recognized themselves as weakened in the eyes of others. Although it was difficult to observe the anxiety, stress, even discomfort in they eyes of friends and family, these reactions could be seen as more about the struggle of the other. In contrast, when the men felt others looking upon them with grave concern, viewing them as the “walking dead” as Randy characterized it, they described how this gaze threatened their sense of competence, particularly as it directly conflicted with the prioritized performance as one who is physically robust (detailed above).

Notably, among some men a certain level of concern could be accepted as valid. At least for a time, they did feel physically weakened and they had good reason to be
amidst difficult and highly disabling treatments. Accepting this as a part of the illness process, some empathized with how others were forced to witness their compromised body. As Terry shared, “I think in my wife’s case it was very troubling for her to see me who had always been healthy and active and so forth suddenly very ill.”

However, many could experience this concern as forcing them into a position they were not inclined to take, particularly when their sense of their own capacities did not align with the attributions made by others or when a perception of weakness endured past the treatment period. Some men, like Chris, fully disregarded the need for it, explaining, “Oh yeah, they worry about me more than I do,” while others could find a bit of humour in it. As Jakob, shared, he found it amusing when his friends, actively searching his body for the ravages of cancer misinterpreted the impacts of his increased exercise regime as a sign of a deteriorating body. Other found less humour in this process, describing how others “looked at you different,” expecting a dying or limited body. Jack described this as a “poking and prodding” in search of weakness, explaining:

…”It’s a big curiosity thing. Um, you know […] there were a couple of, um, parties last year around Christmas time where…that we were invited to just so they could take a look at me, and poke and prod. You know like people that normally wouldn’t […] but last year it was like, you know, oh please come by. […] You know, now everyone’s sort of like what’s he look like? How’s he doing? Have you seen him?

LW: Like under a microscope kind of thing?

Yah, oh you’re definitely under a microscope

Whether the concern offered by others was perceived as appropriate, regretful, or even as an attack, in this exchange the men were witnessing their limitations through the eyes of others. Their profound and often unprecedented sense of weakness was made visible, complicating their ability to demonstrate their competence in valued ways.

I am unsure how to handle this

As the men described these powerful disruptions to the future and present, they also described a tremendous discomfort in their position as a novice ‘sick person.’ Most had little experience with the difficult and shifting reality of illness confronting them not just with physical and cognitive limitations, emotional turmoil, and limited capacities, but
also with confusing medical terminology and processes, financial losses, and complicated
government forms and services. Arthur spoke on behalf of many of the men when he
explained, “Well I didn’t know what to expect… ah I’ve never been sick before […]”
Troubled seas are difficult to traverse when you are a seasoned sailor. They can be even
more harrowing when you have no sea legs.

Among those given choices around treatment, many described significant anxiety
around this decision as they positioned themselves as unprepared for the task of making
potentially life-altering choices about the timing and composition of complicated medical
therapies, particularly within often short windows of time. Marc highlighted this tension
as he detailed anxiety in the burden of choosing between two treatments offered by
specialists, while lacking the knowledge and experience that he believed would allow him
to move forward with greater confidence. He explained that he felt uncomfortably
pressured to be the “referee,” deciding which specialist had the better play.
Overwhelmed by the decision, he explained to his family doctor, “this is not my cup of
tea” and was frustrated in her response that it was “not her cup of tea either” explaining
that her response put the decision “back on my lap. I had to decide between the two of
them […] who was right or wrong.” Other men evidenced similar tensions, struggling to
make choices that stretched them beyond areas of comfort, past their domains of
expertise.

For some, the choice was not only what treatment to use, but also where to access
it, and how to pay for it. As John explained, “So there’s quite a bit of decision making to
try to make and also if you did make a decision ah where were you…how are you going
to access this…this protocol?” These deliberations over how best to handle the
challenges did not always end once the decision was made, as they worried over whether
they had made the right choice. Jack, facing a chronic form cancer described continued
anxiety over the quality of his choices:

I mean, sometimes I think, should I have done the Chemo when I did or
should I have maybe waited? Because I could have waited…you know it’s
like…no point…no need to do it then…I could have waited another year or
so but then, um, you know it’s…it’s do you do it when you’re younger
and stronger or wait until you get sicker then weaker and you might have
more complications or whatever.
Even as these hurdles were crossed, uncertainties remained as men struggled to handle on-going physical complications (as detailed above). A medical provider might help them to anticipate side effects and inform their response to these complications in the course of active treatment, but not all did. In this unclear and shifting space, the men described significant levels of uncertainty around how to handle unanticipated complications and, with little experience with illness, struggled to gauge whether their experiences were “normal.” In addition, financial realities could continue to emerge, as men experienced longer periods away from work or as drug coverage policies changed. As will be detailed in the section on how men responded to the assaults of illness, many of the medical, physical and even financial uncertainties would be addressed through a process of information gathering (with others or independently). However, the information gleaned through their research and consultation efforts did not always leave the men with a clearer sense of what to do. As Earl shared, an appointment with his naturopath left him even more overwhelmed amidst the rapidly approaching threats:

I remember coming out of that hour…hour and a half, um, confused and…and just overwhelmed I mean the way I was feeling […] everything was very overwhelming at…at that point. It’s like holy crap death sentence. Um, you know time isn’t my friend. Um, options still to be explored. […] Um, you know a lot of anticipation so a lot of um emotional stress it…it would be a fair way of putting it… and all around the uncertainty.

Although they were not always sure which path to choose, most men were clear on what type of data they needed to inform treatment decisions. Often more challenging to address were matters beyond medical treatment or the purview of their physicians, including how to handle emotions, both those expressed by others and their own. As noted, the men observed a range of emotional reactions from family, friends, co-workers, and acquaintances over the course of their illness. These were not only uncomfortable for some men, like Gerrard who explained that he did not “want to see tears you know because we don’t…I don’t think men in general deal with you know emotional…” but could also be seen as too much to handle amidst other demands. As Brian shared, as his parents grew depressed in response to his failing health, “it became clear that I almost
had to start taking care of them,” a dynamic he perceived as incompatible with his efforts to care for himself, explaining “I can’t take care of you and me at the same time.”

In regard to their own emotions, along with the frustrations and anxieties associated with limitations and losses, many described pervasive feelings of sadness. In addition to observing sadness carried by others, most described feeling “down,” “crappy,” depressed, and “sorry for myself” amidst their grief, wondering “why me?” Although a few men dismissed the notion that they struggled emotionally or characterized these emotional struggles as momentary, most men described these feelings as overwhelming, unpredictable (and uncontrollable), and intertwining.

Further, they endured. A sense of sadness, frustration, and anxiety remained evident across the telling of their story and was palpable within many of the interviews, though many were well past the treatment stage. In fact, in the course of our discussions a number of men expressed surprise at how close their emotions were to the surface, indicating that not unlike the easy triggering of anxieties around their future, although sadness dissipated with time, it could return quickly, set off by other’s struggles with cancer or in the telling of their story. As Earl shared, for him the “emotional moments flowed” months after his treatments ended. “They are more distant now,” he explained, but their presence continued “In the sense that um you know I was telling my story tonight to a complete stranger and I was emotional, so it’s still sensitive.”

In contrast to physical or financial challenges, the source of their own emotional impacts could be difficult to distinguish, particularly amidst a full and complicated life replete with other stressors. As Michael described, “I felt I was in a whirlpool, you know, where I was constantly going around and around…but again this goes back was it cancer, is it divorce, what is this?” Even more, while some men had experienced depression or anxiety before and had networks at hand for support, for many the emotional impacts appeared to be unanticipated in relation to their physiological disease, particularly those enduring beyond the physical assault. While some would eventually integrate the emotional impacts into their assessment of what it meant to be sick, even forming a highly significant element of this definition for many, they were not always initially viewed as core, or as an expected part of the experience of illness. Although Bill
had struggled with depression in the past, he described himself as surprised by the feelings that endured past the initial crisis of his diagnosis and treatment, explaining, “I felt that ah you know everything’s stable…why am I feeling this way? My physical condition is under control, um, it’s been two years since my diagnosis…why am I feeling this way?”

Men with severe or terminal conditions noted that their treatment protocols included standard meetings with a therapist, but for most men the handling of these needs appeared to lay beyond the purview the medical system. As Oscar detailed, he had faith in his “brilliant” health care providers to “take care of the medical,” comfortably accepting this element as fully “out of my hands.” However, he continued to worry over the “psychological effects of it [because] psychologically I don’t know what’s going on (laughing).”

Although many had prioritized independent coping strategies for pre-cancer anxieties, these could be compromised by their condition, particularly those requiring physical exertion. For example, Clint described how the limitations of his illness levelled an untimely blow to his ability to handle stress through cycling, noting that this loss “really hurt” because:

[That] was how I dealt with a hundred things […] that was one of my support systems that would stabilize me because I would just go out for a long bike ride and by the time I would get back I’d forget what was…

Even more, it was not just the process of coping with these impacts that challenged the men; they were also not even sure what kind of help they needed. As Bill shared, he grew “desperate” in realizing that he did not know what was happening and could not do anything on his own to fix it, noting “that’s, I think, where I got with the emotional side […] that I…I can’t reverse this on my own. I need to…I need to help and I didn’t know what kind of help I needed really.”

Many expressed a lack of awareness around either the presence or offerings of cancer support centres as they entered their illness career and only a couple of men noted previous relationships with therapists. While some had access to informed people in their social network (discussed later), a few detailed how those close to them shared their
uncertainty around how to handle emotional impacts. As Brian shared, he and his wife found themselves similarly at a loss in how to manage the depression they experienced as they moved out of the treatment phase, “…We were both, I guess, in spots were we couldn’t…we didn’t…we couldn’t fathom where to even begin to help fix each other or sort of fix ourselves.” In this combination of intense impact and lack of direction on how to respond, emotional struggles could level a challenge exceeding the physical assaults more clearly addressed. As Earl shared, in looking back on his experience, he believed the physical aspects had been the easiest for him, noting:

At the time you wouldn’t have convinced me of that. But when I look back, the easiest was the physical aspect…I think the next then…the psychological aspect was a little bit tougher and the emotional aspect was even tougher still.

A sense of uncertainty around how to handle the medical, physical, financial, and emotional assaults of their illness could linger or take new forms across the course of the illness career as conditions changed, new uncertainties emerged, and efforts at clarity failed. Even more, a sense of preparedness could prove fragile, easily disrupted by side effects that emerged more quickly than doctors had anticipated and advised, treatment extensions delaying a desired return to normal life, a body recovering more slowly than anticipated, or emerging emotional concerns. In this, even as the men learned how to navigate through the multiple assaults of their illness, many were continually challenged to enter new terrain or revisit places they thought were in their past, whether this was in the form of a new physical sign, a shifting government funding regulation affecting their ability to pay for medication, or the resurfacing of emotional pain.

**I feel alone**

Amidst this uncertain future and troubled present, some men emphasized a profound sense of isolation, a self apart from others. Although a few men noted the struggles of physical isolation, a life increasingly lived apart from others as they were forced out of familial and work roles, discussions of isolation more often focused on a more fundamental state of being apart. More than just the strains in relationships amidst anxieties, frustrations and dependencies and beyond the sense of disconnection from others in the day-to day, or the struggles of having friends and family pull away from
them, these men explained how they felt that others could not truly understand what they were experiencing or assist them in a meaningful way. Even in the company of those who loved and care about them, they felt profoundly alone.

This sense of isolation appeared to be founded on two intersecting perceptions. First, although they saw others as impacted by their illness, the men recognized that only they carried the cancer in their body. As Dave shared, receiving a diagnosis of cancer places one in a “very personal” and “unique” situation because “you’re diagnosed with a life threatening disease… nobody in your family is diagnosed with it. […] None of your loved ones have it.”

Second, they described a powerful sense that unless others had experienced cancer themselves, they could not understand this challenge, they could not relate. Speaking to this, Jim argued that regardless of who you are or what you have experienced “You can’t know what it’s like unless you have it.” Personalizing this truth he continued, that “I know that now because I knew people that had it and now I’ve got it and I didn’t know…I had no clue. You know I had no clue what they were thinking, what they were going through….” In fact, many of the men took time to emphasize to me that I could not fully understand their experience. As Dave noted, “I can’t talk to you about cancer because you’ve never had it. Really… I mean I can talk to you [pause] I can…I can discuss the subject of cancer with you but I can’t talk to you about cancer.”

In combination, this recognition of cancer as their burden and as a reality inaccessible to others left many men feeling profoundly alone. As Pete shared, it was a “very lonely feeling” knowing that although he was “gifted with all these…with the family I have and the friends that I have […] in the end I…you know I have to do this myself.” This sense of isolation could be associated with great emotional trauma, particularly for those for whom it endured, without relief, well after their physical healing. In fact, even as they made their way through treatment and returned to daily life this sense of isolation could remain acute. Dan, a man with over 5 years of good health since his treatment, highlighted this when he shared:

And…it just, it was just really, um…I think I felt there just really wasn’t anyone to talk to. I felt alone. Um…and I still…ah…I think at times feel
that way, um…and I think that’s why I struggle with it. [Continues to cry] […] And it…and you feel alone and… you have no one to turn to…and you’re dealing with the fact that you have limited time.

Summary

Releasing a claim of good health amidst the seismic impact of their cancer diagnosis, these men came to understand themselves as ill through the physical, emotional, and social shifts reverberating throughout their lives. Moving toward an uncertain and frightening future, the men described a present way of being that was more restrained and exposed as they struggled to live with a familiar sense of independence and vitality and felt the gaze of others on a body that had lost its transparency. As the vulnerabilities associated with their disease (including the impact of potent medical treatments) infiltrated their daily rhythms and relationships, the men recognized themselves as gravely uncertain about how to respond to the assaults of their illness. This was new and dangerous terrain, the stakes were high, and they were inexperienced. Amidst this disruption, the men could feel profoundly alone, immersed in a new reality they believed others, including those closest to them, could not understand.
Chapter 6

Responding to the disruption

In this chapter discussion shifts from a consideration of how these men perceived and interpreted the assaults of illness to a detailing of how they responded; the commonalities in how they sought to mitigate, modify, and eliminate forces pushing their lives in undesired directions. Discussed first is how their stories emphasized a focus on “getting back,” an orientation toward regaining the life they had known before their diagnosis. Next, I detail how the men positioned themselves as responsible for walking back to normal, acknowledging the value of those around them, but prioritizing this journey as their own. Finally, I detail three strategies of response men engaged as they sought to handle their illness: Fortifying Resources, Maintaining the Familiar, and Getting Through. Although the activities composing these were not separate in the process of daily life, I explore these strategies in three sections to enable conceptual clarity. The threads of response as detailed here will be woven into a theoretical narrative in the Discussion chapter.

Focusing: Getting back to normal

As the assaults of illness disrupted their future and present lives, these men described a desire to return to the life they had known and valued before their diagnosis. For those with a curable prognosis, “getting back” could feel more possible, but even among the men receiving a chronic or terminal diagnosis or who were told that their cancer type and stage carried a high rate of recurrence, the stories emphasized a focus on achieving some degree of stasis or familiar equilibrium amidst so much turmoil, current and anticipated. As Brad, a man diagnosed with terminal condition explained to me, he treasured the moments when he and his wife could be “normal” together, explaining that while they had shared “a lot of tears” finding those moments in which they could be as they had been “just makes it easier to enjoy life.”

In this orientation, many described a focus on “winning,” on “beating” the disease or, at least, not having it “beat” them, positioning cancer as an opponent and evidencing a belief that ‘normal’ could be reclaimed; they could emerge intact. For some, these battle
and sporting metaphors common in cancer discourse fit well with how they positioned themselves as meeting challenges throughout their lives, positioning a desire to ‘win’ as part of their nature. Gerrard highlighted this when he explained, “I’ve always been very competitive. Um, I you know I used to box and wrestle in high school…played football […] and so it’s, you know…it’s…it’s just part of my composition…it’s part of who I am.” Others focused on “fixing it,” wanting it “to be over,” or simply wanting to “feel better,” or “not letting it get the best of me.” In this, some men specifically challenged battle metaphors, the positioning of a winner and loser. Fred explained:

I think once a person begins taking on the whole battle fighting, ah [clock chiming], mentality. ah, there’s a division within the self that happens that begins to weaken ah so there’s a winner and a loser. I’m not a winner, I’m not a loser, I’m a liver.

Even in Fred’s alternate framing, though, emphasis was on minimizing losses and reclaiming their pre-diagnosis way of life, either entirely or nearly so. Driven by this pursuit, the men identified indicators of a successful return to ‘normal,’ explaining that they would know they had returned when they could resume familiar practices: eating steak again, playing a game of hockey or a full round of golf, hiking, taking a long awaited trip, growing in a full beard, or going back to work. Several men specifically highlighted goals focused on completing cancer-related runs/walks or triathlons indicating these as particularly meaningful markers of their successful journey. In this focus, the men emphasized strength and freedom from restraint, a body that was once again powerful, independent, and able to contribute.

Despite this orientation, most men would find that as they walked further on this path they would need to modify this goal as the disruptions levelled by their illness eluded resistance. In the course of moving through this difficult journey many described how valued roles had been significantly troubled or lost, perceptions of the future had fundamentally shifted, physical and cognitive challenges endured, relationships were irreparably adjusted, and across these shifts emotions remained acute. Their life was changing, even as they sought a return to ‘normal.’

Not surprisingly, for men with chronic or terminal conditions, this awareness that life would not again be the same was more difficult to deny. Joseph explained that even
as he sought to live as “normal,” he and his family were forced to do “one-eighty,” accepting life as changed forever after his diagnosis with an aggressive brain tumour. However, even among the men who would survive this disease, as they emerged from treatments and moved back into a life free of medical visits and procedures, some described themselves as facing an altered or “new normal.” As Michael shared, cancer is the “ghost” that never goes away, noting, “[…] life is never the same after you are diagnosed with cancer. It just isn’t.”

**Positioning: This is my journey**

Although many of the men would come to experience a different way of life after cancer, as they sought to reclaim what cancer had disrupted, nearly all the men – single and partnered, gay and straight, young and old, facing treatable, chronic and terminal conditions – emphasized a sense of personal responsibility for navigating their way through this experience. As Michael argued, regardless of who else is in your life, “it is still your journey, it really is.” In walking this treacherous and shifting terrain back to normal, the composition of their paths would vary, but this acceptance of personal responsibility was nearly universal.

As introduced in the previous discussion of isolation, in this framing, the men accepted cancer as their responsibility, at a very physical level. Though they might, as Marc described, be an “unwilling participant,” and even as they accepted that others in their lives were impacted, they recognized that the disease was something they carried. It was their physical body that had to endure the trauma; it was their way of being that was at stake. Earl highlighted this dynamic as he explained:

> I mean it’s…it’s…it’s…it’s me, it’s my body […] it’s on me, not [my wife]. Now does it impact her? Absolutely it does. Right but um I’m the one who has to go through it. I’m the one that has to endure…

As evidenced in Earl’s emphasis on himself as the one “enduring” the condition, this sense of ownership went beyond the basic physicality of the disease as the men evidenced a perception that it was on their backs that the psychological as well the physical burden rested; no one else could carry this load for them. This perspective not only fed a sense of isolation, it also informed how they approached the journey. In this orientation, they
both accepted their own responsibility and diminished the potency of others. As Dave described:

You’re the only one in that situation. Nobody, absolutely nobody…none of the experts, none of the doctors, none of the nurses, none of your friends, relatives… anybody can fix it. The only person that can fix it is you. You’re the one that’s going to ah…you’re the one that has to deal with it. You’re the one that has to, um, accept what you can accept. And you know fight when you have to fight.

For many of the men, ownership of this responsibility was not just perceived as a functional reality of disease, but also as a key element of a successful journey. Some men emphasized caution in relying on others, including medical professionals, asserting that these individuals, although highly skilled and often guided by good intentions, were capable of error. Others focused more directly on the fundamental importance of taking control of your life. Like Jakob, they emphasized that they were not the kind of person who “lets things happen to me.” While a sense of control was less central to some men and others would eventually come to accept that they would need to adapt to a life clearly defined by less of it, the presentation of self as in control was valued, even as some recognized it as a façade. As John explained, he was “inclined to ah [pause]…ah try to put on a good show […] regardless of the circumstances.”

**Others are with me**

As many positioned themselves as leading this charge, the men did not deny that others were involved in the response. First, they recognized that their medical team had a plan. In contrast to the decision-making process around when to engage medical professionals prior to diagnosis, medical support was accepted as critical after they had been informed of their cancer.

Although some men had to make choices about treatments, for most the standard treatment protocol was initiated soon after diagnosis. As will be discussed, this clinical process, defined by prescribed steps and objectives, was one many of the men trusted in, even as they stood ready to challenge it. Brad echoed the comments of others when he detailed a faith in his physician’s guidance, while hinting at a willingness to push back, if required, explaining, “what my Oncologist says is, ah, the most important to me…
I…from that perspective I’m certainly, to date, I’m willing to follow, ah, his protocol.” Notably, the role of physicians was often recognized as focused on the disease, not the broader challenges and consequences associated with illness. As Jack noted, he did not expect his doctor to guide him through all aspects of his condition because “doctors are like car mechanics, they’re just for people.”

Second, as the men detailed their journey, many described how family, friends, even god, walked with them, “keeping track” of them or “monitoring” them, and describing how they recognized others as ready to help “at the drop of the hat” or “without even thinking about it.” As Fred shared, “even when I was having a shitty day…I wasn’t alone.” Within this broader circle, partners were often emphasized, as men in committed relationships described how these women and men stood with them “every step of the way,” and praising partners as offering “unbelievable” levels of physical and emotional support and “doing everything right.” In this, some emphasized that they did not know how they would have survived without this support.

For men who did not have a partner, the absence of this type of support was felt acutely, although some amended this gap by leaning on the support of adult children or certain core friends. Michael, the man going through a divorce at the time of his diagnosis explained how he missed what many of the other men in his prostate support group seemed to have: someone who is simply “there.” In this, he accepted that a partner “can’t make you feel better” or “make it go away,” but, he explained, they are “there” for you. Describing what he lacked since his split with his partner, he echoed the moments of comforting connection emphasized by those who were partnered, sharing, “if I’m having a bad night or something, and he happens to be awake, you know, can you give me a hug? Well, I don’t – that isn’t an option for me, it just isn’t there.”

Beyond this emphasis on the comprehensive support offered by partners, the men described how family and close friends enabled them to navigate the practical challenges of a day-to-day life complicated by acute physical constraints as well as facilitated a sense that they were valued; that others cared about them and their survival. More specifically, they detailed how partners helped them to manage physical limitations and accompanied them to medical appointments, how friends and family spent time with
them (talking, watching movies, hanging out), brought food, offered rides to treatment, and quietly took over chores around the home. They highlighted how communities linked to their religious faith, work, or volunteer associations offered them a sense of connectedness as they moved through their illness. And they described how they received countless notes of sympathy, flowers, and prayers from others, including from those they had known only as acquaintances. One of the younger men described how friends, family, and others in the cancer community surrounded him through Facebook, explaining that when others participated in his virtual events, responded to his status updates, or simply clicked ‘like’ on his postings, he felt surrounded by a community of positive energy.

Further, many men highlighted how close friends and family “checked in” on them, phoning or emailing to inquire how they were doing. Dave, describing a dynamic detailed by many of the men, emphasized a deep appreciation for how a close friend would reach out, noting that although they would often talk hockey, his friend would also take the time to “phone me up…[and ask] how are you doing? That’s all he wants to know…how are you doing? How are you feeling today?” Even as some declined tangible supports (discussed later), they recognized this array of gestures, when sincere, as expressions of caring. As Earl explained, when his siblings took the time to stress that he should not hesitate to ask them for anything he might need, he recognized this was “by extension” a “measure of support.” Similarly, Nico shared that he felt “good” knowing that others took interest in his experience and John noted, succinctly, that these gestures allowed him to feel he was not “entirely alone or without a friend in the world.”

As it often escaped direct reference, it is challenging to specifically characterize the magnitude of this implicit process of accessing support. However, its pervasiveness is evident in the ‘we’ statements many used and it also emerged across the course of the interviews as what many initially portrayed as independent activities later turned out to be those engaged in with the support of a partner, family member or close friend. For example, Brad spoke in detail about his on-going efforts to handle a dispute related to drug payment, mentioning later that his wife had done much of the communication with the insurance company and pharmacist, noting his lack of energy for the task and
characterizing her as the “doer” in the relationship. Similarly, when I asked Marc whether his family had influenced his decision to see his GP for a physical exam (an activity he had described as unnecessary in the past, but which had led to his diagnosis), he replied, “No, no, I thought okay you know it’s my turn, I guess I should go.” However, when I spoke with his wife after our interview (his request), she noted that she had made the initial appointment and encouraged him to go. This pattern was observed across the interviews, and in keeping with the principles of theoretical sampling, I began to anticipate it, to seek it out.

**But this is still my journey.** Even as the men recognized themselves as embedded within a network of expertise, love and support, they prioritized illness as a *their* journey; they were supported by others, yet ultimately responsible for walking through it. Illustrating this, Andrew described himself as a “warrior” leading an “army behind me of Chemotherapy, doctors, nurses and nurse practitioners, emotional supports people, friends, family…everybody…drugs.” Similarly, other men positioned themselves as the “quarterback,” the “sergeant,” and the “co-pilot” seeking to regain the pilot seat, analogies prioritizing a claim of leadership in getting themselves and others (the football team, army, or passengers) through this experience safely, securely, and intact. This was not just about being strong. As Fred shared, a warrior needs to not just be in charge, but also “crafty,” to take in “all the information” and be “at one with what’s going on…being connected to it.” Accordingly, as the men organized a response they sought to ensure that they were sufficiently skilled and resourced to lead the charge back to normal.

**Engaging: Strategies of Response**

As detailed in the discussion on broadening the conceptualization of help seeking, this study integrates a dynamic approach to the study of how men perceive and respond to illness-related needs. In this more inclusive operationalization of help seeking, attention has not been limited to men’s formal requests for clinical help.

Recognizing that processes of soliciting support can be indirect and oriented toward a range of goals, I sought to remain alert to how men subtly and explicitly relied on a variety of others to do something for them and how they drew on these supports in
efforts to build their capacity for handling challenges. I accepted that a man’s decision to engage independent and interactive approaches to handling assaults is not determined by a set of beliefs or individual characteristics, but is a complicated process embedded in a dynamic social context. I considered how a man’s perception and interpretation of situation and self, including his evaluation of the qualities and attributes of potential supports influenced how he built his response with others.

A challenge in this approach is that boundaries are blurry. In contrast to studies focused on formal requests for help, this orientation requires a suspension of practiced judgements of what qualifies as help seeking. Instead, analysis is led by the men’s experiences and research attention is devoted to how they described moving toward and away from others as they sought to handle the challenges of illness. Thus, in working with the interview data, I observed how the men’s stories highlighted three overlapping strategies of navigating the perceived assaults of illness: Fortifying Resources, Maintaining the Familiar, and Getting Through.

As detailed over the following pages, the strategy of Fortifying Resources focused on ensuring sufficient ‘supplies’ for the journey. This pursuit was defined by activities oriented toward developing cognitive and physical capacities as men repaired uncertainties about the nature of their disease, its impacts, and their options and as they strengthened their body through diet, exercise, and other healthy practices. The strategy of Maintaining the Familiar centred on ensuring that they continued to perform in ways consistent with who they felt they were, a process facilitated through efforts to limit exposure of the impacts of illness, retain positions as active and contributing members in their family and community, minimize disruptions to other’s lives, and reassert their sense of self within the health system. Finally, the strategy of Getting Through allowed men to manage the heavy and difficult thoughts and emotions accompanying the assaults of illness, ensuring that they were not pulled under by a powerful undertow of fear, anxiety, and sadness. Engaged in this pursuit, the men’s stories highlighted activities focused on moving away from difficult thoughts and emotions (insulating, trusting, staying present) as well as those moving toward these (showing worry, seeking comrades, finding guidance).
As these men placed the treatment of their disease into the hands of trained and skilled medical staff, these intersecting response strategies allowed them to handle the assaults of their illness: a troubled future, a discordant present, a sense of uncertainty, and feelings of isolation. The men were not uniform in their integration of these, nor did each man engage every activity detailed in the particular strategies. However, even as the composition and content of activities varied across the complexities of individual lives, the overall processes of Fortifying Resources, Maintaining the Familiar, and Getting Through formed a common thread across the stories.

Help seeking: Unspoken, but Present

Consistent with a focus on personal responsibility in ‘getting back’ the men often framed their response efforts as independent. As noted in Chapter 3, with some exceptions related to the use of supports in handling emotional struggles, there was limited reference to “help seeking” as the men described how they handled the assaults of illness. Some even actively rejected this terminology, evidencing a perception of help seeking as an activity engaged only in situations characterized by extreme need and dependence and organized by explicit requests for help.

In the context of a study focused on help seeking, the men’s glossing over of assistance from ‘expected’ aids, steady focus on how they propelled themselves through this process, and resistance to the language of help seeking are important dynamics. These are explored in more detail in the Discussion chapter. However, at this stage it is important to recognize that regardless of how they were framed, a number of the men’s response activities integrated assistance from others. In particular, as the men worked to Fortify Resources and engaged with difficult emotions in the process of Getting Through they evidenced how they turned to others for help in gathering information, initiating healthy behaviours, and handling the uncertainty and emotional pain related to their illness. More specifically, these activities requiring men to draw on the assistance of family, friends, medical staff, and other experts are consistent with indirect, adaptive help seeking processes oriented toward addressing challenges and building capacity.

These foundational or baseline supports (i.e. medical staff, partners, family, friends) were accepted as critical, even essential, as men developed resources and
handled difficult emotions. However, while this often-implicit support network served a valued and comprehensive function, it was not always enough. As will be detailed, these supports were recognized as insufficient as men acknowledged that those around them did not always fully anticipate the nature or quality of their needs during illness and as they observed how some of those they expected to help them struggled with or resisted engagement. Further, many viewed these individuals as ill equipped to help with particular needs, regardless of intentions or desires. The men navigated this reality by not just emphasizing their own resources, but also compensating for gaps by stretching familiar connections in new directions or pursuing those with experiential or medical expertise (beyond the treatment team). These new relationships or manners of interacting with others are often more obvious in the men’s stories, as they required them to go beyond normal interaction patterns: formally pursuing assistance or transgressing familiar ways of engaging others.

Help seeking: Intertwined

In addition to developing an awareness of hidden help seeking processes, as one enters this discussion it is also valuable to consider how the men’s stories highlighted an intimately woven matrix of individual and interactive activities amidst the on-going experience of handling illness. More specifically, practices of drawing on a baseline of support and actively requesting help beyond this foundation ran concurrent to and intersected with strategies focused on coping with physical and emotional shifts and independently managing or mitigating impacts. In the complexity of lived experienced there are few absolute or clear boundaries in this process and, thus, these activities are neither easily nor appropriately isolated in presenting men’s accounts.

Recognition of implicit and explicit help seeking processes as threads in a broader tapestry of illness response, a dynamic acknowledged in the discussion of illness behaviour and the conceptualization of help seeking itself, both remains truer to these men’s experiences and enables consideration of the relative focus on individual and interactive approaches and the ‘play’ amongst these as men responded to the assaults. As detailed next, amidst a shifting array of assaults and diverse compendium of response strategies, an approach men took in one area had implications for those possible in
another. For example, the more individually oriented activities emphasized in Maintaining the Familiar could restrain efforts to open up about difficult thoughts and fears as a method of Getting Through. Alternately, the process of ‘repairing uncertainties’ in the Fortifying Resources strategy could lead some to communities normalizing disclosure around fears (e.g. support groups) as a viable effort in Getting Through.

Thus, what began as individually focused could become interactive as men accepted their initial approach ineffective or as they were led into relationships in the course of individual pursuits. Similarly, what began as interactive could become individual, in absence of what a man perceived as suitable or effective supports. Even more, as acts were engaged, some assaults (or elements of these) would be addressed while others modified, and still others left unabated, at least for a time, a dynamic requiring men to consider alternate approaches or experience unmet needs. Recognizing this complexity, over the next three sections, I detail how the men engaged the strategies of Fortifying Resources, Maintaining the Familiar, and Getting Through, focusing on the activities emphasized within each category, including how men engaged others in efforts.

**Strategy 1: Fortifying Resources**

Amidst a multitude of unknowns regarding what lay ahead and how they should respond to challenges, most of the men described entering their illness with limited knowledge about the medical system, cancer terminology, or their disease. This knowledge gap was emphasized in the course of the interviews, as men highlighting their lack of familiarity with the terms coming at them in the doctor’s office. Arthur spoke for himself and others when he shared, “[I] met the Oncologist…I learned how to spell that word. And ah…ah she explained to me what was involved. I had…I couldn’t spell Chemotherapy very well…I had to learn that word too.”

With some exceptions, even men with medical training or prior exposure to the health system described moving into their illness career with little knowledge about their specific disease. Further, many took care to emphasize the complicated nature of their condition. In combination, these efforts seemed to serve as a way to highlight their role as one embarking on a difficult journey into a foreign land. Similarly, as their physical
form lost its transparency, many of the men described an acute awareness of their body’s limitations, its ‘weak’ spots. In this context, they described efforts to bolster their cognitive and physical defences as they sought to (a) repair the uncertainties around their disease and (b) strengthen their body.

**Repairing my uncertainties**

For many of these men, a core part of taking responsibility for their disease involved researching their condition. As Terry, a retired medical provider, explained, “Yah, I mean you have a certain responsibility for your own care. And, ah, I think it helps…[...] any patient to be somewhat understanding of what they’ve got and…and, um, what they will receive.” Although a couple of men described a preference for limiting the amount of information they took in about their disease, particularly during the course of treatment, most demonstrated a keen interest in learning about their disease, including some men who lamented an inability to gather enough information in situations where their treatment commenced quickly after diagnosis.

Engaging in independent research using the internet or print resources, consulting medical experts, and soliciting guidance from others with a cancer diagnosis, the activity of repairing uncertainties focused on four main learning objectives: (a) understanding my disease, (b) anticipating where I am going, (c) making wise decisions, and (d) resolving impacts. This process appeared to intensify shortly after diagnosis, as men clarified understanding around their condition and prepared for and engaged in treatments, although it could continue well after treatments ended as men handled new assaults emerging across the course of their illness.

Notably, even as they recognized that some questions could not be answered, many men developed extensive knowledge about their disease, building a repository of information related to their cancer and treatment (a file several brought to the interview or referenced throughout our discussion). Although not always initially highlighted in the men’s accounts, as we explored this process, the men detailed how others participated in this process. In particular, partners and close family members and friends were described as assisting or even leading the process of information gathering by attending medical appointments (primarily partners or adult children), performing independent
searches, facilitating connections with experts (those with health training or experience-based knowledge), or referring the men to key information sources.

**Understanding my disease.** One of the first uncertainties the men sought to repair was in regard to the nature of the disease within their body. Although some noted that they had been offered detailed information from their physician in the context of the discussion around their diagnosis, for many men the shock accompanying the news of their cancer had limited their ability to absorb what had been offered. Pete explained, “You know they…they can tell you all kinds of things, but you know when you’re sitting there and you’ve got cancer…yah it becomes all a blur and so…it ah…it’s really hard…it’s really hard to take it all in.” In this context, many of the men moved quickly to explore questions around the cause of their disease, how long it might have been in their bodies, how it functions, and even what it looks like. As Andy explained, immediately following his diagnosis he did a week of research on skin cancer because “I wanna know what I have, what the symptoms could be, what they do to prevent this.”

For many, the Internet and medical providers were prioritized resources in this effort. Often turning first to cancer-specific websites, the men described how they developed detailed understanding of their cancer, obtained familiarity with terminology associated with their disease, and prepared themselves to ask medical providers the ‘right’ questions in order to further develop their knowledge and guide decision-making.

As many praised the detail and accessibility the Internet provided (a resource valued over brochures and pamphlets described as too “vague”), they also recognized the need to use this resource with caution. Clint, a man with an early stage kidney cancer explained that he learned to stay away from Internet resources because they could “fuel the negative,” as he faced a disease that has a dire prognosis at more advanced stages. In addition, the men recognized that these resources could have questionable merit or validity. As Brad noted, he preferred to rely on his physician’s expertise, because “it’s not an area that I know very much about and I know enough about the Internet to know that there’s a lot of very valuable information there but there’s a lot of hokum as well.” In this focus on obtaining high quality information, they praised medical providers who took
time to answer their questions and could quickly become frustrated by those perceived to be ‘holding back’ critical details or providing incomplete or misleading information.

Anticipating where I am going. When I asked the men what this information on their disease enabled for them, many explained that in addition to understanding what was in their body, they wanted to know what was lay ahead. This information was important to preparing themselves and others in their lives for changes. Gerrard explained:

Um I don’t know…I mean when you put it in that context that you know what are you hoping to gain? There’s not a whole lot like…you know once you’ve got your diagnosis and somebody’s telling you, nobody’s told you you’ve got cancer yet but you’re trying to figure out what you know…what they’re sending you to all these specialists for. So for me it was…it…it wasn’t going to change anything but maybe just being prepared. Understanding what you know what could happen and because I have a family…you know, also getting them prepared.

In this, the process of information gathering was positioned as way of smoothing out some of the ripples obscuring a future troubled by the diagnosis or even pre-diagnosis concerns. Although this revised future might be unwelcomed, being able to see ahead could enable the men to regain a sense of control as they were able to get ready, to anticipate and plan for the changes.

For most men, their focus was on anticipating physical impacts, as they sought out information on what side effects might occur due to treatments (e.g. pain, incontinence) as well as odds for survival. Brian, a man facing a poor prognosis related to his Leukemia, explained:

…Ah [pause] this sounds weird…I…I wanted to know how I was going to die if I was going to die. I wanted to know you know this organ fails first…you know all of a sudden this happens… whatever…what the succession was, how quick it would happen…I needed to understand that…for some reason.

In gathering this information, men emphasized the utility of medical providers and, even more, others with cancer. Internet or print resources, when identified, included blogs, medical sites with detailed information on procedures, and journal articles (although as Brian noted, he had to rely on abstracts as he was unable to access full content without a
subscription). Often equipped with the information they had gathered about their disease, the men described how they consulted with their physician, receiving or gathering information on how procedures would be conducted, how other patients had fared, and the possible impacts of the treatments.

Discussions with others with cancer, whether on-line or in person, provided an additional level of knowledge. Describing physicians as often lacking the time or inclination to provide extensive details on side effects and other physical impacts, the men emphasized a strong valuation of learning from those who had experience-based expertise; others who had been there, particularly those who had experienced the same form of cancer. In some cases, men reached out to those within their existing network who had experience with cancer, while some described how they connected to individuals, including strangers, through the facilitation efforts of family or friends, or sought out others through online communities or support groups. A few men, including Marc and Clint, turned primarily toward print or on-line information sources, seeking to learn from others with a similar diagnosis through these less interactive media. Notably, not all the men could find a community of others from whom they could learn, particularly those who had less common forms of cancer. The three men with throat cancer, in particular, all described frustration with not being able to find others with whom to consult.

This process of engagement could come at different stages for the men. Some were eager to anticipate impacts prior to the commencement of treatment and others, feeling that they had enough information relating to this stage, starting to reach out after treatments had concluded and they began to move into a less prescribed stage of their illness career. In either case, while the information allowed the men to more clearly envision and plan for the future and respond in the present, the details they learned could also enhance their fears. As they engaged with individuals at different stages of illness and with different prognoses, they not only heard about possible eventualities, but also witnessed them. Michael described feeling more traumatized coming out of his first prostate support group meeting than he had felt going into it, terrified by the “horrid” stories of physical loss shared by the men in the group. Similarly, Earl spoke to the
impact of a conversation he had with a ‘friend of a friend’ he had met through a family member:

He said you’ll feel like a Mack truck hit you and then backed over you again. [...] and then he told me a little bit about his bladder problems…you know he couldn’t pee and he’d have to…had to go in and have a catheter put in again and all that stuff…so it is kind of like, Holy Jesus, do I want to go through this?  And this was before, um, I had the discussion with the, ah…with the Radiologist right. So having understood what this guy had gone through this surgery thing didn’t look so good. Right?

Far less often, the men spoke of seeking information that would help them anticipate and respond to emotional challenges, relationship impacts, or an onslaught of practical decisions. While more would eventually seek out support in regard to these, Michael, a man going through a divorce, was alone in explicitly identifying a search for information on possible emotional fallout or impacts to his relationships. This dynamic emphasizes a point made earlier: that many of the men did not fully anticipate the severity of emotional and relational impacts in the context of their physical condition. Even more, though, the men described others in their lives, including medical staff, as similarly lacking attention to these potential impacts. Exceptions included men with terminal diagnoses, for whom psychiatric counselling was often part of their treatment protocol. In this silence, it could be easy to assume that emotional impacts were abnormal, of secondary importance, or that there were few resources available for preparing for these impacts. In this, some men described feeling that they were on their own in this area. As Dave noted, though his information gathering allowed him to obtain clarity on the “mechanical or practical” elements, it did not address the emotional impacts: “…on the emotional side or the, ah [pause], I don’t know the ah…the long-term outlook for yourself…it’s something to develop for yourself.”

**Making wise decisions.** Although the protocols for some forms of cancer are fairly rigid, some men faced choices in their treatment. As noted, this point of decision-making could be highly stressful, as the men struggled to make the ‘right’ choice about which protocol to use, where to have their procedures, and even when to cease treatments. As with the process engaged in learning about what lay ahead, the men stressed interactive forms of information gathering.
The Internet proved useful for some men as they gathered details on treatment centres and specialists, but most appeared to prioritize conversations with medical providers, others with cancer, and family members, friends or acquaintances with medical training and knowledge, as they sorted through their options. This latter group proved particularly helpful for those who had access to social networks containing such supports, particularly as not all had contact with others who had experienced a similar form of cancer. For example, John explained that he drew on a number of “medical friends” to gather information on treatment options, Marc relied heavily on a sibling in the medical field, consulting regularly and following up on resources identified, and Jakob described how a friend connected him to a relative trained in radiology from whom he was able to obtained detailed information on radiation treatments. In particular, engagements with ‘experts’ outside the medical team, including those with experience-based knowledge or specific medical training, were emphasized as men detailed how these contacts enabled frank discussion around the side-effects of certain treatments, an element of wise decision-making that they did not always feel was possible from specialists championing a certain procedure.

For some men, this process was a necessity of their condition; they had to make a choice. For others, it was propelled by an unwillingness to simply follow a prescribed treatment. As John emphasized, he was keen to learn “what treatment is appropriate and what’s inappropriate.” In either case, while at times frustrated by a perceived lack of sufficient clarity in their options as well as unwillingness of others, particularly medical professionals, to give them more certain or detailed guidance, this process helped the men narrow down their options and could also bolster their confidence that they were making the right choices. As Jakob detailed, consultation with others in his prostate support group emphasized to him that he was on the right track:

I hadn’t quite made up my mind yet what I wanted to do, but, and so listening to these people talk was very, very helpful. I was sort of almost there and just reinforced for me you know that I was heading in the right direction. I also spoke to a lot of people about, um, who would be the best doctor, ‘cause I…I didn’t take it as a given that the Urologist that I was going to at that time would be the one who would treat me…
This consultation process could continue across the course of their illness, particularly among those who faced on-going treatment decisions.

Handling impacts. Finally, the men were active in repairing uncertainties around how to handle the impacts of their illness. Again, their research appeared to focus on physical side effects and improving odds for survival, although men also explored how to handle emotional and relational struggles accompanying illness.

In this process, the Internet was valued as an avenue for obtaining basic information on drug side effects or developing general knowledge on how to respond to physical impacts, but medical providers, support groups, and others with personal cancer experience were prioritized, particularly in response to acute or complex challenges. Specifically, men described pursuing the guidance of doctors, nursing staff, and pharmacists as they prepared their bodies for treatment and sought to address acute physical challenges emerging in the course of treatment (e.g. pain, bleeding) and enduring limitations (e.g. ED, incontinence). Several also engaged naturopaths, seeking complementary methods of managing disease and caring for their body during treatment.

The advice of others with cancer, including those met on-line, was also emphasized in relation to physical impacts. Not only did these men recognize that medical staff would not address (or were not addressing) all their physical needs in sufficient detail, but they also demonstrated a strong valuation of experience-based expertise. In turning to those who had been there, they found an opportunity to “compare notes” with others in a similar situation as well as obtain tips on response. As Gerrard shared, “you’ve never been through this, you don’t know what to expect and you just want to know, hey I’m getting this is that normal? Are you getting that too? Oh yah…oh okay.” The information gleaned from others with cancer helped the men to gauge whether the impacts they experienced were ‘normal’, a question important to determining an appropriate response, and was used to inform strategies for handling emerging challenges. As John explained, he connected with a support group because he simply wanted to “see what other people’s experiences were and what they were doing for it.”

In handling physical impacts, the timeliness of guidance was emphasized. Although some struggled to obtain quick and useful information from their physician,
others reported more positive experiences, particularly as facilitated by electronic communication. As Jakob detailed, when he had a question about a side effect he would “get on my BlackBerry and email the doctor or some of the nurses” and would get a response that allowed him to “deal with” the challenge. Consistent with this valuation of e-communication, internet-based chat sites proved valuable to those seeking immediate guidance. As Jack noted, although in-person support groups had an important role in relation to emotional dynamics, he valued the opportunity for “instantaneous” feedback offered through his on-line community of others with Lymphoma, enabling him to post a question regarding a physical challenge and receive a response within a couple hours, rather than waiting a month or two for the next support group meeting.

Although few men had described information gathering around anticipated emotional and relational challenges, there was more discussion of how they solicited information on how to handle these non-physical challenges, once they emerged. Most often, the men highlighted how they sought out cancer related classes or support groups to learn how to handle anxieties or care for family. While the distinction is subtle, this process is separated from the latter discussion on how men actively managed anxiety and depression, as the focus here is on the information gathering process (self as learner), not strategies around engaging or disengaging with these feelings. Given the close connection between learning response techniques and engaging them, some of the strategies detailed here will be discussed in more detail in the latter section.

In educating themselves about how to respond to non-physical challenges, the men emphasized interest in learning coping strategies to respond to the anxiety accompanying their illness, an effort engaged at different points in the career, including in the midst of treatment and after it ended. Similar to the process in handling physical impacts, some men described a broad level of consultation with others with cancer to, as Dave explained, “find out about other people’s experiences…what happened to you guys, what did you do?” However, other men sought out cancer support centres to access meditation, yoga, or relaxation classes or took courses on cognitive/emotional intersections and spiritual considerations to develop knowledge and skills around responding to feelings of worry and unease.
For example, Brian solicited the support of an expert in neuro-linguistic programming to help him understand how cancer and chemotherapy impacted his “thinking process.” Nico, a man describing severe insecurity associated with a sense of instability related to his brain tumour, emphasized that he participated in a class about self-esteem to “learn about myself and how I think” and seeking to gain “insight” into how to deal with his condition. Similarly, several men detailed their participation in a course entitled the *Healing Journey*, a seminar focused on providing “psychological and spiritual tools which promote inner harmony, peace and healing” (Healing Journey, 2008). This course, Brad explained, enabled him to learn “skills to appreciate life” and “cope” with challenges. More informally, some described consultation with others with cancer around how to talk with children about the condition. As Gerrard noted, he sought to learn from another man in his support group who spoke about his experience with his son to see if “there were things that you know I could help my daughter with or help her understand.”

Others in the men’s lives would play a key role here as well, identifying sources of information and facilitating connections with support groups other individuals with cancer. As many explained to me, they had not previously been aware of available supports and described how they were “invited,” “encouraged,” or “pushed” to check out a cancer support centre by friends, family, or service providers. As Joseph shared:

I…I’ll be honest with you, I had never heard of [the centre]. And, ah, somebody from church had come here because she had breast cancer and she asked me, ah, probably I don’t know six months later if I had heard of [the centre]? And I said no. Would you like to go? They have…because every Friday they do ah relaxation and visualization. And I said sure. So she brought me up here [pause] and that was it. I was in the door.

As in Joseph’s situation, these (often female) facilitators typically had attended these centres themselves or were close to someone who had.

For some men this effort would be linked with a process of sharing difficult thoughts and feelings related to their cancer, a process discussed later. However, as men obtained information and skills helpful to handling non-physical impacts of their illness some (though not all) would actively resist emotional displays, limiting personal
disclosure and pulling away from others who expressed emotions. Their focus was on obtaining information they could use, techniques they could employ to manage anxiety, and conversations oriented around the expression of fears and sadness (as opposed to the handling of them) could be seen as detracting from this. Brad’s experience highlights this as he explained that while he valued the opportunity to learn how to cope emotionally with the reality of his terminal cancer, he struggled when others in his support group turned the conversation to points of fear and refrained from participating fully in the discussion. As death loomed large for Brad, he explained:

It’s like I don’t want to talk about death, man, let’s talk about anything but. Um… but some people needed that and I… I guess I was there as just to listen, not judge and, you know, I figured if I had something to add then I would add it, if not and hopefully it wasn’t uncomfortable and we’ll get through it as quickly as possible (laughing) and move on to something else.

In this, while some men appreciated an opportunity to talk about experiences and fears amidst the process of repairing uncertainties, for some it was important to find others who had not only experience-based expertise, but also a shared focus on gathering information in absence of emotive sharing. Even more, in this context once they felt they had obtained the information they needed, some could experience the support group as no longer having value for them. As Alfred noted, he grew “fed up” with repetitive information and “bored” with the conversation.

**Strengthening my body**

Among some men, lifestyle factors including sun exposure, smoking, drinking, a diet heavy with meat, and/or participation in stressful home or work dynamics were perceived as key factors in their disease (whether or not this link would be accepted as medically valid). As Oscar shared, he accepted that his “[throat] cancer is entirely due to smoking and drinking. That’s… this answers your “why me” (laughing). Self-inflicted (laughing).” Not all men accepted these practices or conditions as central to their diagnosis and even those who did often gave additional rationales, but this recognition was linked with a belief that lifestyle changes could be helpful. For example, Oscar quit smoking after his throat cancer diagnosis, Andy tried to practice more sun safe behaviours to prevent skin cancer recurrence (noting that his wife had to remind him to
wear sunscreen), Alfred, attributing his prostate cancer to his high level of meat consumption, described how he stepped away from his love of barbequing, and Bill ended a long-term relationship he described as making him deeply unhappy and contributing to his Leukaemia.

Even among men who did not link their cancer to aspects of their lifestyle, there was emphasis on strengthening their physical body amidst these assaults. As noted, their diagnosis could level a powerful blow to their sense of confidence in their health. In this disruption, although one man described a brief detour toward poorer health practices amidst feelings of frustration and anger directed at his body (what he described as an active “self-whipping” in the form of eating whatever he wanted), most men with treatable conditions appeared to lean toward a focus on trying to be more deliberate in caring for their health for the purposes of (a) getting my body through and (b) protecting my body against recurrence. In this orientation, the men positioned themselves as caretakers for a body that they would need to carry them through this disease, and it was their responsibility to prepare it to steer around future challenges. As Jakob explained, “I figured, you know, it’s really not my body’s fault, it’s me. I just wasn’t maybe taking care of it in a way I should have been taking care of it…you know.”

**Getting my body through.** Most often, the men emphasized the role of a strong body in carrying them through treatment and moving into a disease-free state (cure or remission). Some argued, more specifically, that a fit body was key to their survival. John, a man approaching 80 who stressed his continued high level of skill in sports, argued that his survival was directly related to his fitness level: “I’ve had, um, a number of medical people tell me that, um, one of the reasons that they thought I did well is because […] I was in pretty good shape because of having exercised almost all my life…” Similarly, Fred, a man who continued an active exercise regime even while in the hospital, explained that he was granted a treatment typically reserved for younger men because of the “vitality” his medical team saw in him.

Beyond this valuation of pre-cancer fitness levels, men emphasized the importance of exercise and, to a lesser extent diet, throughout treatment. In particular, they detailed how they continued or increased regular exercise regimes right up until the
commencement of therapies and described efforts to maintain activity and avoid foods that might “fuel” cancer throughout treatment. Anticipating the physical trauma of their treatments, these activities were driven by a desire to mitigate impacts as they equipped themselves with the best physical resources they could muster. As Jakob shared, he ramped up his regular walking routine in the time leading up to surgery, determined “to be sure that I’m in the best shape I can be.” Even more, the men demonstrated a focus on resisting a body submerged or lost to the disease. Pete, a man facing a chronic condition, provided a particularly powerful illustration of this process as he positioned his regime of getting out and walking despite the intense weakness in his body following his stem cell transplant as evidence of his persistent faith in his body:

I had to take it slow. Um, when I went…when I…when I would go for walks it would be very short. Um, each time I would try to make it a bit longer. Um, I…I always felt that it was going to come back. Ah I didn’t think that ah…no I hadn’t given up on my body.

Notably, although there was also recognition of the importance of resting during this time, most of these men emphasized staying active, while explaining that it was others, including partners, children, co-workers, or friends, who would draw their attention to the need to take time to rest. As Arthur explained, “I had to be reminded that I was weak and to slow down and stuff and that’s when [my wife] would pull my chain every once in a while.”

**Protecting my body against recurrence.** As the emphasis on fitness prioritized in ‘getting through’ remained relevant for some men after treatment, nutrition considerations and smoking habits were positioned as additionally important in an effort to challenge disease progress and avoid recurrence. Most often, men described how they had fully altered their diet since their diagnosis, particularly in regard to meat consumption. For some, this change was made under the guidance of nutritionists or naturopaths, but more often it was conducted with the support of partners and family. As Marc noted, his family kept an eye on his diet, chastising him when he deviated from healthy choices. Similarly, Arthur explained, with affection, that his wife impacted his choices to eat more healthfully both in the home and away: “[she’s] the cook, she feeds
me, so I eat the chicken, I eat the fish [and]…that’s good and…and so when I travel or go away she’s sitting on my earlobe […] telling me what I can eat and not eat.”

In addition, the majority of men who had smoked before their diagnosis emphasized that they quit, out of choice or under the very clear advisement of their physician. Notably, the one man who continued to smoke had a chronic condition and dismissed the logic that quitting would benefit him. He explained: “What the hell, you got cancer (chuckle) you know people…people (laughing) still walk by and say, you know, you should stop, you’re going to get cancer…got it.” Even those men who did not believe body strengthening would prevent cancer recurrence argued for the value of an active, strong body as central to maintaining health. As Andrew noted, “Doing Yoga isn’t going to protect me from getting cancer, but it keeps me active and healthy.”

In moving into the post-treatment period it was recognized that the intensity of their engagement in health promoting practices, as heightened during the acute period of treatment, could wane as they began to feel the threat of cancer diminish somewhat. Jakob spoke to this, noting the need for vigilance:

…I have to say though since the surgery I have started to relax a little bit and I…and I…I was at the support group last week and we were talking about that and I…I’ve sensed from most people that you know there’s this intense preoccupation with taking care of themselves and then when you get into a point where you know you see…you think you have things under control, you start relaxing a bit. You know you back away from doing all the good things that you were doing. And I think I’m sort of getting at that point and I have to be careful about that.

In this, as the men perceived these practices as providing critical protection against future threats of illness, they could demonstrate a fierce determination to maintain a strong body, even as those around them questioned the wisdom of their efforts. Explaining that his family worried that his post-treatment exercise and diet regime was leaving him too thin, Keith argued that he was determined not to gain weight, as he avidly believed that “exercise and being in shape and fit trumps anything” (his emphasis).
Strategy 2: Maintaining the Familiar

As much in their lives shifted amidst the assaults of their illness and its associated treatments, the men described how they sought to mitigate or limit the extent of change in their own life and the lives of others. These efforts were not conducted in blindness to the realities of the situation; they recognized how life had shifted amidst the assaults of illness. Rather, they oriented toward maintaining valued ways of being and doing. In particular, as the complications of illness constrained their ability to present themselves as independent, vital, and strong, many men sought to continue a way of being they had known prior to their diagnosis and which would be familiar to those around them as well as to themselves. Seeking to hold onto the thread of a ‘normal’ life as much as possible, four main activities were engaged: (a) minimizing exposure, (b) staying in the game, (c) limiting the burden carried by others, and (d) (re)asserting ‘me’.

Minimizing exposure

Recognizing that the news of their condition could soon take on a life of its own as it circulated through their social networks, many of the men sought to get out in front of, or influence the conversation following their diagnosis. Because cancer as a group of diseases carries such a potent and difficult storyline in the consciousness of many, it was important for many of these men to play an active role in shaping the conversation. As noted in the chapter on assaults, the men indicated particular sensitivities around being an object of other’s concern and the associated perception of them as off-putting, weakened, or dying. Responding to this, they detailed a range of techniques oriented toward guiding others’ perceptions regarding the nature and impact of their condition. In particular, many minimized exposure by (a) framing their situation through a control over the timing and content of their disclosure around their diagnosis and managing on-going conversations around the impact and experience of their illness and (b) shielding from view the physical, cognitive and emotional shifts they experienced.

Framing. For many of the men this process began immediately. Starting at the point of initial disclosure, while a minority of men displayed few hesitations in discussing problematic symptoms and/or sharing news of their diagnosis with those close to them, particularly partners, most were guarded in this process. Although some tried to hide the
details of their diagnosis from certain individuals, citing the frailty of elderly parents, children’s inability to understand, fears about impacts to their job, and concerns that others (outside their close circle of family and friends) would just worry, most men described how they sought the ‘right time’ to disclose.

In deciding when to tell others, some men expressed a desire to “regroup” before sharing the news and others wanted to delay disclosure until family, friends, even work colleagues were less occupied with other stressors. However, most men highlighted a preference for waiting until they had a solid understanding of what they were facing. Consistent with the focus on repairing uncertainties around what they were facing and what lay ahead, the stories pointed to a desire to have personal clarity regarding what they faced: diagnosis, prognosis, and treatment plan, before introducing others into this new reality. Gerrard spoke to this as he detailed how he delayed telling his wife about his condition until after he had undergone multiple tests received his official diagnosis of Non-Hodgkin’s Lymphoma. Noting he “took a lot of heat” from his wife for this decision, he explained that he did not want to worry her over “nothing.” Instead, he explained to his wife that he needed to go through it first, because it was a “process” for him:

It’s kind of like A to Z right. I’m now at stage M and I’m just making my way to Z and once I get to Z and they tell me that this is the outcome… then I’ll let you know, but for me…I’ve got to go through it.

Similarly, other men argued that this approach allowed them to protect those they loved from the particularly traumatic period of multiple unknowns, particularly as they recognized that many in their lives had known and loved others who had suffered greatly or died because of a form of cancer. Their own minds were racing with possibilities and they knew others would as well. As Randy shared: “I wasn’t sure what I was going to be going through and I didn’t really want to put anyone else through that…ah, ordeal.” However, intimately linked to this emphasis was a desire to protect themselves from the difficult and worried reactions of others. As Marc described, to guard himself from the anticipated negative reactions of others, he needed to be sure that he had a solid story in hand:
…And I knew [my family] would all think negative, negative and I, ah, usually the way I fight negatives [is with] counter, ah, arguments that are positive and I didn’t have any […] I didn’t know what…what to say, how to defend ah the negatives. So I thought, ah, I won’t be touched by any negative thoughts of anyone else because nobody knows.

In this orientation, the eventual process of disclosure often occurred in organized stages, starting within the family and moving out from there. Although the activity of informing colleagues was often handled independently, men with partners often brought these individuals in earlier and solicited their support in preparing and sharing the story with others in the family, including children and relatives, as well as close friends. As Clint described, once he had met with his specialist and had his “head around” the process, he and his wife sat down with their kids and told them the news nearly three weeks after the diagnosis.

This plan for controlled disclosure was, at times, complicated through the acts of others. In one case, a man described how although he was ready to share the news of his diagnosis with friends and neighbours, his partner initially requested that he not tell others out of preference for keeping family matters private, a desire he attributed to cultural differences (he and his partner were of different ethnicities and cultures of origin). More often, the men described how they were forced into earlier disclosure as others became suspicious in observing frequent medical appointments, physical changes, or shifts in behaviour. As Dan shared, his son learned of his cancer by coming upon a Google search his wife had conducted:

He didn’t realize it was me…but I think he started putting two and two together not long after that with…ah…you know, my surgery, you know, all of a sudden, you know, ah, I wasn’t going to the cottage and, it’s a whole bunch of things sort of, you know, I guess started to, you know, he started to put them together, you know.

It was not just the *timing* of disclosure that many sought to manage, but also the content of conversations. In this, some omitted details they felt could frighten others. As Joseph noted, “my role is not to scare people.” This approach was often used with those lives perceived as more fragile, including children, parents, and others viewed as less able to handle difficult news. For example, Brian explained how he encouraged his parents to
avoid medical websites amidst their mounting fears and Andy detailed how he and his wife let their children know that he was sick, but avoided the word “cancer” because “They’re kids. What do they need worry about that for?” More often, though, men described how they sought to quell others assumptions and fears by controlling how others viewed the situation. Although acknowledging their illness as serious, many introduced their disease to family, friends, and co-workers as something that they did not need to worry about; it was a situation that they would handle, whatever the outcome. Fred’s story illustrates this position shared by many of the men:

The message that I sent out to folks was that I have just been diagnosed with cancer and I want you to understand very clearly...number one I’m not afraid of it...it’s a disease like other diseases and in fact, start from the beginning, don’t talk about cancer, talk about cancers...so it’s not a big dark monster although it has the potential to kill so does Heart Disease, Diabetes...you know ah all these things, um, and I do not have cancer...I do not want you ever to talk to me about having cancer. [...] I am living with cancer but cancer doesn’t have me and I don’t have cancer. It is a disease...I’m living with it and that’s where we started out.

Through this process of framing their condition, they were seeking control over their narrative, even as the ground was shifting beneath their feet. Consistent with a valuation of the appearance of control (regardless of what is actually felt), as discussed earlier, many positioned themselves as “doing fine.” This was important in work settings, as some described how they sought to assure bosses and/or clients that although they might have to take leave, and might look weakened for a time, they were focused on a return. As Dan noted, although he was not expected to live more than two years from diagnosis (a prognosis he denied) he sat down with his staff and explained “now look, I’m gonna look different, um...I’m going to be off for a little while, but, you know, [the company] has guaranteed me my job, so I’ll be coming back.”

More broadly, the men described how they conditioned friends and family to maintain a perception of them as the same person. Andrew described how he let friends know that he would not accept their “pity;” asserting that “I wasn’t broken, I was still a functional person that can function in society.” In constructing this narrative, men were actively campaigning against other storylines associated with a cancer diagnosis in this
society, particularly the association of cancer with death. Anticipating both the physical changes that might come as well as the “grapevine,” Bill emphasized the importance of taking the lead on sharing the news, explaining to his friends, “I wanted you to hear it from me […] and I want you to know that the prognosis is good and that, um, I intend to live a normal life from this point forward.” In this, while many men sought to convince others that they would survive this disease, emphasis on continued competence was maintained even among those who accepted that they might ultimately die from it. Even death was under control. Further, as the men sought control over how others initially perceived them as someone diagnosed with cancer, they also set the tone and boundaries for future conversations around their illness, indicating to others what was appropriate conversation and what was not.

**Shielding.** As they moved into the treatment and post-treatment period, positive framing efforts could continue to be prioritized, though for some men they were increasingly challenging to maintain amidst mounting assaults. As Clint noted, although he tried to remain positive with his kids he “got caught a couple of times,” struggling with intense fear and anguish amidst his illness. Thus, as bodies and minds increasingly weakened and emotions acute, men engaged additional control tactics including avoiding certain forms of contact or exposure (limiting what others saw) and avoiding discussion around certain impacts (limiting what others knew).

First, for some men a period of social withdrawal was described as part of a period of “adjustment,” or a process of coming to terms with their illness. As Michael explained, “I just didn’t want to be with people, I was sort of really started to go into myself.” For others, contact avoidance, including momentary episodes, was a way of limiting the exposure of emotional displays and physical pain or restrictions, particularly during the course of treatments. Speaking first to emotions, while not all men sought to hide their tears, particularly from partners, some did. Clint offered a poignant illustration of his efforts to limit exposure around his family:

> I would do a lot of stuff – like I would sit out back and make sure that they didn’t see me crying and stuff like that, like, I made sure I did that, but a couple of times…ah, during it, they’d catch me crying in bed…and like you
don’t want to show the weakness – my wife’s pretty tough – but you don’t want to show the weakness to your kids, you know.

Similarly, some described measures to limit observations of physical limitations. For example, Brad detailed his reluctance around going away with friends as he struggled with physical weakness and frequent toilet breaks, Jack, struggling with mental confusion, refused to go out again by himself after he found himself unable to cognitively perform a regular errand, and Keith detailed how he removed himself from family meals so others would not witness the tears of pain associated with eating amidst his treatments for throat cancer:

I dreaded meal times because it was more or less I ate in the kitchen [saying to others] go away, just go away. I actually did, I’d be in tears, I would be in tears of pain […] I would finish up and go back to the dining room with them and be back to normal.

Seeking to engage with others in ‘normal’ ways despite intense emotional and physical pain or exhaustion, some men would not just limit what others witnessed, but also invite others to manage the gaze cast on their altered body. For example, Jim explained how he asked friends to “ignore” any weakness he might display: “I tell people that I’m close to…try to ignore it […] if I can’t do something, if we’re [hiking] or something […] if I can do it, I’ll do it…if I can’t, I won’t and don’t worry about it.” In this, some men emphasized an appreciation for those who were willing to support them by ignoring their struggles and treating them as they always had.

More commonly, men sought to control the content of conversations across the course of their illness. While some stressed an approach of complete openness with their partner, explaining as Joseph did that “we don’t have secrets,” other men placed boundaries on the content of their discussions with friends and family, including partners. In this, they detailed how they kept conversations “brief.” As several men noted, this was not about hiding their condition, but was simply a practice of not talking about it. Terry explained: “It’s not that I was secretive but, um, with the exception of a few friends, I didn’t go around talking about myself.”
Some appeared to apply this approach to their illness in general; they simply did not want to talk about any element of it. This could be expressed as a desire to focus away from illness and toward capabilities. John highlights this as he provided an example of a conversation with a close friend who had called to check in on him after surgery, explaining that he had replied to the friend’s queries by changing the subject, “Oh, it’s fine […] do you want to [golf] tomorrow?” However, others stressed that this approach was necessitated because they believed that the reality of what they were experiencing would be too difficult for others to handle and they did not want to “push” the details of their illness on them. As Jack explained:

…People know you have cancer and they know you’re going through Chemo and they’re asking you how you are. Guess what…I feel like shit. I want to puke all over you…I don’t want to be talking to you, you know like I’m fine thank you (chuckle) you know what are you going to say? And you…you can’t be rude because they’re just being nice, you know, they are concerned…

Similarly, Clint shared that he wanted his wife to limit who she told about his cancer because he did not want others to worry, noting that while he appreciated the support, “what’s the point, like how are they going to benefit from, from knowing that you’re dying, right, I don’t see that…”

As evident across the stories, these men emphasized a particular reluctance to get into specifics with family and friends around embarrassing physical challenges and presentations of weakness. Even more, many limited discussions around what they were feeling. Although some men emphasized that they were fully open with their partners, many described how they avoided speaking in detail about the intense fears and sadness occupying their minds over this time, or at least did so sparingly. Beyond efforts to protect others from “stress” or manage these emotions (processes detailed later), attempts to limit evidence of difficult emotions was linked to concerns that these displays would disrupt others’ expectations of them. As Nico explained, he had “always been a pretty positive person” and worried that letting his friends in on the “negative” aspects of his feelings around his brain tumour would not only bring them down, but also show a very different and unwelcomed side of himself, as someone who is “unsure and doubtful.”
From the moment of disclosure and across the course of their illness career, these strategies of limiting exposure provided the men an opportunity to control how others viewed them, allowing them to work through their emotional or physical disruption beyond the gaze of others. As they framed conversations and kept others from witnessing threatening moments (tears, a weak body) they were enabled to, at least partially, maintain the appearance of ‘normal’, to keep their preferred narrative of self largely in tact, despite the mounting disruptions to it. As Randy explained, “you don’t really want to advertise it. You don’t want to…you don’t want to be treated differently.” As will be detailed in the later section on Getting Through some men would dismantle these boundaries, particularly in company of others with cancer.

**Staying in the game**

In addition to managing exposure, many of the men described how they sought to minimize the disruptions threatening to overtake their lives by continuing to engage in regular activities, or by ‘staying in the game’, as much as possible. In this, although they accepted they might have to slow their pace, they emphasized the value of (a) avoiding inactivity and (b) continuing to contribute. This practice of remaining “a part of society,” as Micky described, often focused around handling the threats to a familiar sense of vitality.

**Avoiding inactivity.** The men’s stories emphasized discomfort with inactivity, a sense of struggle with the loss (or threat of loss) of normal routines that had previously organized their lives. They described dangers in “staying in,” “sitting at home” or becoming isolated. As Keith noted, “Ah…I didn’t shut myself away, I tried to be as normal as I could.” Consistent with an orientation associating illness with restrictions to normal functioning, an inability to remain active in the home, at work, and in their community was associated with a way of being that had been overtaken by illness. Joseph spoke for others when he explained that “you’ve got to get on with living and part of living is doing. And doing is getting out.”

In avoiding inactivity, some focused on continuing involvement in pre-cancer activities, while others were forced to establish replacement activities, pursuits modified or sought out to fit shifting capacities. Beyond providing opportunities for distraction
(discussed later), involvement in these activities appeared to offer the men a sense that they were not significantly impaired and they valued those in their lives who supported them in this pursuit. As Terry explained, although he had to pause involvements for a time, his abilities to continue working out, attending sporting events, and maintaining involvement in the music activities he loved were each important aspects of life lived “as usual.” Similarly, Fred described how a practice of continuing daily exercises while in the hospital was an important part of “normalizing the abnormal.”

More specifically, through these activities the men could feel vital, even as their physical body was under assault. As Joseph detailed in reference to his involvement in percussion activities at the cancer centre, “I still go out and I still hit things.” Even as they recognized that they might not able to maintain the same degree of involvement in these pursuits, maintenance of the effort was important. As Jim described, although he knew he would not be able to make use of his membership with a sports club, he purchased the pass anyway. Notably, these activities could offer valued interpersonal connections, but the men rarely focused explicitly on the opportunity this involvement afforded to stay engaged socially.

**Continuing to contribute.** The men’s stories highlighted how they valued not just activity, but also an opportunity to maintain a sense of self as a *contributor* at work, at home, and in their community. Many of those who were employed at the time of their diagnosis shared how they sought to maintain an active work role, continuing to contribute as an employee either on site or virtually despite the physical, cognitive, and emotional challenges they faced. Several emphasized how they continued working through the course of their chemotherapy treatments and Bill, a man who experienced significant depression in relation to his diagnosis, asserted, “I went to work every day. I didn’t lose any time because of my little moods.” Men forced to take a leave from work emphasized the importance of returning quickly and expressed gratitude for employers who demonstrated continued support for them during the leave. As Dan noted, part of keeping life ‘normal’ was getting back to work as soon as possible after his treatments ended. In these descriptions, while some noted concern with job security amidst an
extended leave from work, emphasis was more often on being someone who continued to contribute.

For some men, a return to work would be significantly delayed or not possible. These men, in particular, emphasized the value of finding alternate avenues of contributing at home and in the community. In this focus, they described how they “stayed busy” around the house, not just ensuring that they continued to complete their chores, but also taking on additional projects (e.g. repairs, renovations), and increasing their role in activities they had not previously led, including cleaning and/or meal preparation. In the absence of being able to work, these activities enabled the men to feel like they were still serving an instrumental role in their families, even as one man gently mocked himself as becoming a “Suzy homemaker.” Nico, a man who spoke a great deal about his struggles with being away from work, explained:

I can’t sit around. I feel like I’m useless just sitting around, you know what I mean? That’s why I do things around the house trying to get things done and you know and ah trying to reno…start renovating just by doing stuff and you know, um, just keeping myself busy.

Similarly, men described how they became more active in their community, taking on roles as athletics coaches or becoming more active contributors in social organizations. Andrew, a man who blogged about his experience, saw this as not just a way to sort through his thoughts and feelings around illness, but also as a work-replacement:

It gave me a project to do throughout my cancer treatment so I felt like I had something to do. An obligation in a way but I…it was an important obligation. So instead of having a job to go to [clears throat] I had my blog to write.

Later in the process, some detailed how they sought out roles with cancer organizations, serving as facilitators, leaders, peer supports or drivers. Several moved into an even more public arena, speaking at events or writing up their experience to be shared in cancer-related magazines or newsletters. In describing these new roles men highlighted an appreciation of opportunities to put their experience-based expertise to use as well as find new venues to apply their skills. For example, Michael emphasized that because he had been “through all these various stages” he could assist others in the path
and Cheef, forced into early retirement by his cancer, stressed how he could bring his work-related business acumen to the operation of the local cancer centre.

In taking on these new roles, the men expressed appreciation for those recognizing them as critical contributors, as mentors to others with cancer as they emphasized encounters in which health professionals, family, and friends sought out their guidance, encouraged them to directly support others, or viewed them as role models. For example, with a quiet sense of pride Bill detailed how he had been invited to facilitate a cancer support group and Chris shared how his grandchildren saw him as a role model for their mother, currently handling a cancer diagnosis, explaining “and, of course, they were all saying, ‘you’re going to be like grandpa’ and get over this for her kids and everything.” These engagements not only provided an opportunity to ‘give back’ or share their story, but they also emboldened a sense of self as a valued contributor within the broader network of those experiencing cancer.

As noted, in these pursuits, many men acknowledged that they needed to scale back their involvement in certain activities in order to accommodate a compromised body. But this was not always an easy transition. Not only were they worried about the burden placed on others if they failed to complete certain tasks (discussed next), but their altered body was unfamiliar and some pushed too hard, at least initially, trying to almost force a sense of vitality in this effort to ‘stay in the game’. As Gerrard noted, he decided to complete a major home project in the days before his treatments commenced, explaining that he was not ready to give in, “I wasn’t going to let this thing beat me. It was kind of like screw you I’m…I’m…I’m punching back.” Instead, this pursuit resulted in an emergency hospitalization as his body was too greatly compromised.

Limiting Disruption to Others

As the men sought to maintain consistency in their own lives, efforts to manage exposure and remain active contributors were closely joined by an orientation toward limiting disruption in the lives of others. In this, the men emphasized the importance of: (a) avoiding impositions and (b) getting my affairs in order. These strategies appeared important to handling the threat to independence and sustaining vitality as a provider and protector, even in the event of their death.
Avoiding impositions. As noted in the chapter on assaults, the threat to a sense of self as independent was particularly acute for many of the men and asking others to take over activities could feel like “giving in” to their illness, as Joseph explained. This orientation was not absolute, but stories from men prioritizing an independent self or who explained that they were used to, and valued, handling things on their own, highlighted a discomfort around ‘imposing’ on others, both practically and emotionally. First, as Terry explained, although it was “comforting” to be cared for, he did not want to be a “nuisance,” or one requiring others to go “out of their way” to help him. Similarly, Justin, a single man who spoke at length about how he struggled to care for his practical needs after his surgery explained that he found it “very hard” to ask for help because, “you know, um, [pause] you feel like, um…you know that you’re, um, imposing.”

In this context, the men detailed how they sought to manage treatments on their own so that friends and family members would not have to miss work, how they avoided family, social, and work activities where they felt they would be a “drag,” slowing down the group, or how they restrained themselves from asking others to help with practical items. As Andrew shared, although he was unable to keep up with his cleaning and laundry throughout his treatments, he resisted asking friends for help, explaining, “I’m not a slave to anyone and no one’s a slave to me.” Notably, as I explored this with the men it was not uncommon for them to reflect on how they never considered asking for help from others, a dynamic noted earlier in relation to familial supports, but also extending to the broader social network. Even more, some emphasized that they never felt they were in a position of truly needing help. As Dave noted, he “wasn’t looking for help […] I just wanted to fix it,” and Jim explained that while he knew others would come to his aid if he needed it, he felt he would need to “get pretty desperate before I get to that point.”

Avoidance of these impositions was not just practiced in regard to asking for help, but also engaged as the men responded to offerings of practical supports. Although some evidenced appreciation of selected supports offered across their illness, accepting help with tasks they were physically unable to complete (e.g. transportation to appointments, household chores), there was a clear sense that certain forms of assistance were not
welcomed. Specifically, they described discomfort with supports perceived as unnecessary, beyond normal patterns of exchange, or which they anticipated would be difficult to “pay back.” In this, some men directly rejected offers of help, emphasizing that they were capable of handling their challenges. For example, Jim shared how he informed those around him that he would not look kindly on offers of support, “Like I…I make it very clear that I don’t like that.” Similarly, although Randy reluctantly accepted his neighbour’s decision to mow his lawn and shovel his sidewalk, he re-donated a food basket that had been given to his family by a local charity organization because “We…we were never in the position that we really needed that. You know, it’s nice to be thought of, but we didn’t really want it and we weren’t expecting it so…”

For some men, these offerings appeared to level a direct blow to their sense of competence as it highlighted their limits. As Jack described, when others “came out of the woodwork” to offer meals and other supports, he felt like he was being treated like a “sick dog,” explaining, “you know, you go and buy him a treat which you never usually do but you shouldn’t give him the treat because the dog is sick […] you just…you want to be left alone…you don’t want all this attention…” Although less commonly emphasized, others explicitly noted concerns with their ability to balance out the support received. For example, despite the intensity of his physical needs after his Leukaemia treatments, Brian described himself as initially reluctant to accept the offerings of support from friends, explaining, “I was worried about, well, if, you know, a hundred of my friends help me out then do all of a sudden I owe a hundred people favours when I’m better? You know? And (chuckle) I didn’t want that.” Brian eventually came to accept this support as necessary, but continued to struggle with concerns around giving back.

As the men detailed an absence of needs requiring intervention and a resistance to certain offerings, focus was often on these patterns in regard to extra-familiar supports. They continued to make use of practical support from partners and children and other family members, though this was not often explicitly described nor viewed as an *imposition*, a pattern consistent with an orientation to these persons as providing ‘normal’ or expected levels of support. However, they did evidence sensitivity around *emotional* impositions, particularly in the family (and beyond).
Recognizing that those close to them carried a great deal of stress already, some men detailed how they sought to keep others away from the extraordinary depths of their emotional pain, trying to avoid “burdening” others with their pain. As Dan explained, he avoided talking with his wife about his fears and sadness because “I didn’t want to add to what was already on her plate…and, and try and have her deal with my emotions…when she’s probably got enough of her own to deal with.” Similarly, Dave, a single man, explained that although he wanted to discuss some “deeper emotional things” with his adult children, he picked up cues of discomfort from them and “decided not to because it was too much of a burden on them.”

In these discussions, the fear was not just that emotional expression was an imposition that would increase the load carried by others, but that the heaviness of this weight would fundamentally disable them, a condition at odds with a prioritized position as protector of others. Clint offered a powerful illustration of this as he explained that while his wife was “strong” he worried that she would be pushed too far by his pain and “collapse.” This was an unacceptable scenario for him as he valued his role as one who “kept the family going.” He explained:

I had to be strong […] regardless of my outcome, because tomorrow all the other three people are getting up [laughs]. You know what I mean? …So um…but yeah, I’m…as far as showing emotion and all that, I wasn’t…it was more for keeping the family stable.

**Getting my affairs in order.** As part of this process of limiting the burden on others, the men detailed how they not only sought to avoid imposing on others in the present, but also took steps to limit the practical and financial burden others would face in the future, as work income was lost and fears of incapacitation loomed. As noted, although facing a variety of prognoses, at the moment of diagnosis there was a nearly universal fear of critical impairments in the course of treatment, as well as death. In this, Brian noted, it was important to “anticipate as much as you can beforehand” and emphasis was placed on “getting my affairs in order.”

In this orientation, the men spoke of funeral planning and, even more, preparation of Wills. As Dave explained, “The Will was a reaction…getting everything ready
because I mean, shit, the next thing...the way I figured it is okay you’ve got cancer, you’re going to be dead. Get it all straightened out...” Closely associated with this legal process were efforts organized around making certain that finances were in a sufficient state to carry themselves and/or their family through the treatment period, as well as cushion loved ones after their death. For some men, this meant ensuring that they continued to bring in money. Given only a couple years to live, Dan described how he sought to “do everything I can and, and, earn as much money and make sure that all of these things are taken care of.” For others, it meant limiting expenses and making wise decisions about investments. As Jack noted, in the face of his chronic and terminal condition and limited employment opportunities, he was petitioning his wife to downsize their home in order to “conserve” what funds they had. Similarly, Dave detailed how he sought to reduce his expenses so that more money could be secured for his children after he died.

Beyond economics, some men described how they sought to prepare others to take over their roles at work and at home. For example, Jim emphasized the importance of making a gradual transition out of his management role, detailing the importance of preparing his staff and protecting his company around the departure. Jack brought a similar spirit to his roles within the home as he described teaching his wife and children to take over his chores, explaining that although he found it painful to be releasing ownership of valued tasks, he worried over the burden his family would bear if he did not teach them:

You’re worried that, you know, um, the car won’t be taken in to get the oil changed. Not because they’re not capable of doing it, but because you’ve always done it and they’ve just never done it before or don’t like doing it so you always did it […] Well you know what, you better learn because I may not be around for a long time so you know you’re going to have to do this sometime so let’s…you know get looking at this or you know if a fuse blows in the fuse box, well come with me and I’ll show you how to change this…

(Re)asserting ‘me’

As the men sought to organize their lives in a way that minimized disruptions to normal ways of being, they were simultaneously required to function in a medical system
obligating them to relinquish significant control over their bodies. In entering into relationship with health professionals, they were positioned as ‘patients’ and subjected to an other-directed process that pushed and pulled them in directions that were often unwelcomed and increasingly disparate from normal. Although many accepted the value in giving their bodies over to medical staff charged with treating their disease, the stories highlighted efforts to sustain a valued self. In this, they sought to protect their voice amidst a cacophony of expectations of who they were and what they should do, as put forth by health providers, family, and friends.

More specifically, in this engagement, the men described a process of negotiating how much of themselves they would yield. While some used the language of self-advocacy, the spirit of this attitude oriented toward a goal more fundamental than ensuring that they remained active and attentive in all aspects of their care. Rather, as they (a) challenged others to recognize their individuality and (b) drew boundaries in their care, many demonstrated to others that they would not simply follow the path of patient as laid out; they would not fully release familiar ways of being. Instead, they would move through this experience in a manner allowing them hold on, as much as possible, to the person they were. Thus, part of maintaining a familiar life could include asserting and reasserting a sense of self amidst the heavy power of the medical system. As Fred argued, “if you are not in charge of it, if you are just the subject of the experiment, if you’re just the patient in the equation, then you have lost power all ready.” Not all men bristled so strongly at the positioning as ‘patient,’ but there was a common desire to remain as much more.

**Emphasizing my individuality.** In a system focused on their disease, it could be easy for the men to feel that who they were was less a concern than was the disease growing within their body, particularly as some encountered providers they perceived as insensitive to the urgency and nature of their needs. Sufficient time and attention from physicians enabled not only information gathering processes, but also perceptions of respect. Likewise a lack of this engagement could be perceived as an indication that they were not valued, not distinctly important. As Dave explained, while his oncologist gave
him ample time to explore questions, he felt like he was simply on a “production line” at his general practitioner’s office.

Many men identified positive experiences in the medical system, but there was recognition that they could be easily lost within it. As many lamented the threat in being positioned as “just another patient,” this power dynamic could be challenging to confront. In response, some described how they sought to nurture in themselves an attitude of individuality. As Joseph noted, he refused to be just another brain tumour “statistic,” explaining that “You’ve got to look at yourself that way you know you’re a person…you’re an individual…you have all these feelings and emotions. Statistics don’t look at that stuff at all (laughing).” Similarly, as Fred powerfully argued, “I am the person at the centre of this. Ah, I am not the patient, I have a name, I have a personality and I will celebrate it and live it to my last breath.”

This orientation led some men to engage in more interactive strategies as well, seeking to challenge those who might diminish their sense of individuality. In this, men detailed how they explored different ways to navigate the medical system, demanding procedures or refusing to wait for diagnostics, petitioning the government or battling insurance companies for better drug coverage, and, in some cases, severing relationships with health providers viewed as insensitive to their needs as an individual. As Alfred explained, when his urologist treated him “roughly” by tossing him a book on prostate cancer rather than engaging in respectful discussion he chose to cease his own participation in the relationship: “So I just stopped [going to him] (laughing).”

Alfred had the luxury of time that enabled him to pursue an alternate provider. Others, including those constrained from exploring other options, described how they sought to shift attitudes within the course of treatment, as they challenged their physicians to adopt an approach that felt more respectful. For Fred, a man with significant professional experience in the health system, this meant directly telling his doctor that he was doing a “piss poor” job, while for Jakob, who was more of an outsider in this world, this involved employing a more indirect strategy. Describing how his doctor spent limited time with him and brought little sensitivity to the interaction, Jakob decided to “disrupt his procedure.” He explained:
I’d go in there with this challenge to keep him longer than three…than two minutes you know. It was like a game I was playing with him, you know, because […] it was very hard to get him longer than two minutes because he’d be standing up ready to go out, you know, um…and I wouldn’t…I wouldn’t get up as quickly as he did (laughing).

For some men this process of emphasizing their individuality was a comfortable mode of interaction, but others noted that these activities moved them outside their “comfort zone.” Pete’s experience highlights this. Describing his cancer type as one rendered invisible as it mainly affects the elderly, Pete evidenced a sense that he, too, was disregarded, unseen, as he found the government unwilling to pay for the treatment he required. This positioning drew him into drug advocacy activities, leading him to engage in a way with others that was entirely new for him. A soft-spoken man, Pete detailed his work rallying others and engaging with politicians and explained: “[…] I’m not that kind of person (laughing). So it…it was ah…it was very…I…I was really out of my league doing this thing but I…you know I just felt I had to do it.” In this, the process of maintaining individuality could require extraordinary efforts, including the performance of an emphasized way of being, engaged to reclaim a sense of individuality.

**Drawing boundaries.** The men’s stories also emphasized how they sought to establish boundaries in how they would live and die. Participation in the medical system required some compromise if they were to eliminate their disease, but interventions were not accepted without question. In fact, although many of the men appeared unlikely to resist treatments recognized as essential, their stories evidenced a willingness to challenge or even refuse procedures across the course of treatment perceived as pushing them *too far* from familiar ways of being and doing, too far from their valued sense of self. In this, part of asserting their self was saying ‘no’.

For example, although feeding tubes are often a standard part of treatment for throat cancer, Keith refused the procedure when it threatened to keep him from participating in a critical family event. Dan pushed back against a pain medication that left him too drowsy to drive, explaining how he immediately phoned up the clinic and demanded that he stop the medication and that “we do something else.” In particular, a number of the men evidenced discomfort with pills, valuing a way of living that was
“drug free” and describing how they sought to limit the use of more optional medication. As Earl explained, he chose not to fill his prescription for pain medication after surgery because he is “not a pill taker by nature.”

Men facing more severe prognoses could carry this approach into the process of decision making around end of life decisions. As Brian shared, although his family strongly resisted his choice, he decided not to have a risky procedure, preferring death to a life of continued suffering that it might yield. Though he did not end up needing to enact this choice, he explained:

For me…there’s a point where I would say […] fine if it’s taking it, if it’s taking me over, it’s taking me over and I would rather you know die quicker than prolong and be in agony. And a lot of people don’t understand that.

Even as the men made concessions to a body increasingly constrained by disease and treatments, the activity of drawing boundaries evidenced a determination to preserve, even in pieces, a valued identity as one unrestrained: someone who is a valued member of the family, who is independently mobile, and who can manage his body without on-going medical assistance. As disease progressed and options diminished, men could enter a paradoxical space in which choosing death over life was the last avenue available to “assert me;” to preserve a sense of self. As Brian argued, a life in which the cancer was “taking over” was one that was not worth living. Notably, these decisions challenged a defining of ‘successful’ treatment as patient compliance to treatment standards or the pursuit of survival, at all costs.

For Dan, Cheef, and Earl their choices meant greater pain, and for Brian it threatened a quicker death. In all cases, this process of drawing boundaries evidenced that physical comfort or even continued existence was at times less important than maintaining a valued identity, a way of living they recognized as normal. Accommodations would be necessary, but they were not accepted without question. The medical system can at times push individuals toward life at all costs, and these men (and others) pushed back as they championed and asserted themselves.
Strategy 3: Getting Through

As discussed in Chapter 5, for many of these men the emotional strains accompanying illness felt overwhelming as they struggled with feelings of isolation and faced a frighteningly troubled future and uncomfortably discordant present. They could build thick binders of detailed information on their disease, work toward a stronger, more trustworthy body, and pull together the threads of a ‘normal’ life, continuing to do much of what they had done before the diagnosis, but in most cases these activities were insufficient to quell the fear, anxiety, and despair illness wrought. Even as the strategies of Fortifying Resources and Maintaining the Familiar helped men to resist or limit the disruptive impact of cancer in their bodies and social lives, uncertainties remained, shifts continued, and losses were acute amidst the power of the assaults. Life was not normal, the threats to self were significant, and this was a painful reality to negotiate.

The strategy of Getting Through centred on managing this internal turmoil, on handling the intensity of emotional pain the men experienced amidst fear of death, physical and social restriction, sadness over personal and familial disruption, and more that persisted, even after treatment ended. As the heaviness of these feelings of disquiet and anguish threatened to pull them under, they described a diversity of approaches aimed at keeping themselves afloat. The most common were individual efforts focused on restricting the infiltration or influence of the emotions some feared would erode the strength and focus they needed to ‘get back’ to normal, particularly during treatments. These activities, including (a) insulating, (b) trusting, and (c) staying present, enabled men to create distance from their pain. These were efforts men sought to enable on their own, though others in their lives could facilitate or inhibit these approaches.

Although individual efforts at restricting the penetration of emotions were pervasive, many also described how they engaged with these struggles through (d) showing worry, (e) finding comrades, and (f) seeking guidance. In this, although focus remained on diminishing the immobilizing power of fear and sadness, these difficult thoughts and feelings were managed by moving toward them, not away. Even more, although ‘showing worry’ included activities that could be independent (crying), these processes most often required interpersonal connection. These efforts could be pursued
informally, as men shared openly with selected friends, family, and others with cancer about their concerns or challenges, and they were also facilitated through formal efforts, as some participated in cancer support groups and/or consulted with therapists. Notably, although some men specifically sought out these opportunities, others moved into a process of engagement while in pursuit of learning goals. In other words, they might have joined a group to learn about their illness or develop skills for handling impacts, but once engaged in the setting they could experience opportunities to share about what they were feeling.

Although the six activities comprising the strategy of Getting Through could pull men in different directions, they were not either/or processes. Some men focused almost exclusively on forms of restriction, efforts particularly emphasized during the treatment period, but many men engaged both approaches across the course of their illness career, not just distancing themselves from emotional pain, but also choosing to engage with difficult feelings at particular points, in certain situations and with selected supports. Notably, although for some men the engagement activities could initially feel less natural than those focused on restricting emotions, men able to pursue this path, even with one or two trusted allies, had access to a broader complement of resources. Even more, the engagement process could offer unique benefits that the restriction processes did not appear to supply. In particular, as these activities helped facilitate management of day-to-day anxieties and feelings of isolation they also enabled an opportunity to reduce a sense of isolation and to manage the work of healing and moving forward amidst a disrupted life.

**Insulating**

One of the most common strategies the men employed to manage difficult thoughts and emotions was to distance or insulate themselves from negative thoughts and fears. There were a variety of approaches comprising this broader effort. At the early stages of their illness career, a few men practiced denial, refusing to let in the possibility of death, despite the oncologist’s clear assertions. Alternately, some turned their attention elsewhere, immersing themselves in work and home obligations, reading, watching movies, or coaching sports teams. For example, Dave devoted his attention to
watching films while Dan described how his continued participation as a coach gave him “one…place where I didn’t have worry about…what was going on,” as he used the needs of his team as a distraction from his own. In these efforts, some men detailed how others supported them in this process, offering books to read, arranging retreats, and engaging in conversations around other interests. Gerrard spoke to this, detailing how he and a friend (with a chronic disease that was not cancer related) would get together to watch movies, he explained, “so we’d plug some movies in the VCR and ah we’d sit and for the afternoon and we’d chat and watch movies and things like that. But we’d never really talked [about the cancer].”

Others used humour, as they sought to lessen the weight of fears. As Brad explained, he and his wife shared “a bizarre sense of humour” and sought refuge from the harsh reality of his terminal diagnosis by making jokes about his impending death, “like I said, this year for Christmas I’d, ah…I’d like a family, ah, photos. And ah she said oh you think you’ll make it? […] Um…just for us, ah, that’s actually, um…just better than being all serious about it.”

More commonly, though, the men detailed how they chose to limit the time spent thinking about their challenges and fears, explaining that since they were unable to change their situation they did not perceive any value in devoting much thought to it, or at least not for very long. Jim, wondering if this was a “male thing,” explained, “There’s not a damn thing you can do about it anyway so you might as well ignore it.” In this, some could be dismissive of those they perceived as devoting too much “attention to their own problems,” as Terry described, allowing the impacts of the cancer to dominate their lives and arguing that this practice could contribute to “self-fulfilling prophecies.” Similarly, Jakob detailed his appreciation for friends who took steps to distract him, keeping him from getting too “self absorbed.”

These insulation efforts were often accompanied by the refrain: “it is what it is.” For some men, particularly those with terminal or chronic conditions, this could be further nuanced by a depersonalization of death or an assertion that “everyone’s going to die,” whether it is by cancer, a heart attack or a car accident. As Richard, a man given less than year to live at his diagnosis, argued, “There is only one thing for all of us that’s
guaranteed: it’s death.” Although in some ways these assertions suggested acceptance of a difficult position, even their impending death, it was not a whole hearted one. Rather, it appeared to be an acceptance in the face of no other options, a movement away from pain, rather toward equanimity. Jim illustrated this when he explained: “[It] is what it is. You know and I…I know that’s kind of a cop out in a way…[...] But I don’t know what else you do. You could drive yourself nuts about it.”

Amidst this process of distancing themselves from difficult thoughts, many specifically detailed how they sought to move away from emotional expression. “So, it was, buck up and suck it up,” Dan noted, drawing on a phrase his wife uses. In this, some men emphasized a valuation of stoicism and discomfort with fear and sadness, beyond the context of their disease. As Gerrard shared, he had long recognized emotions as a “weakness” and pulled back from his own tears and those of his wife, arguing “all hell breaks loose when you start to cry.” Similarly, John who presented himself as “stoic,” distinguished himself from those with “poor” coping mechanisms, describing how they “collapse pretty readily.” Other men described themselves as normally ‘emotional’, but viewed this orientation as a threat to their focus on getting back, particularly during the treatment period. As Keith shared, although he had always worn his emotions “on his sleeve” he felt he “had to throttle that back throughout just because I had the tunnel vision, you got to do this you got to get by it.” He had to become “numb.”

The practice of avoiding emotional ‘drag’ through distancing was also evident in how men engaged others. Emphasizing the challenge of having the grief of others around them, some men noted their appreciation of health providers, family, and friend who supported their focus by “hiding” or sidestepping emotions. Further, men shared how they actively moved away from others’ expressions of pain, seeking to keep others from creating gaps in their own insulation. Brian spoke to this in regard to his relationship with his parents, who were struggling with his illness. Explaining that he would get “depressed” after spending time with them, he began to “minimize” contact. Similarly, Terry shared how he ceased involvement in an online chat group because the content left him feeling down:
I thought this is depressing…hearing people talk about all their problems and some were nasty problems. And, ah, they were having a lot more problems than I was and it was making me, ah, not depressed, but feeling, um, sad for them but, um, it also ah occupied my time of thinking…over…over dwelling upon what I had and I thought skip it, I signed off of that and never went back.

In its many shades, the strategy of insulating the self was engaged by many men across their illness career, including in the handling of lingering fears of their cancers return.

**Trusting**

In addition to creating space, or insulation, between themselves and their fear and sadness, the men described how they sought to limit the influence of these forces by practicing trust. What is unique about trust as a sub-theme is that while it did not operate completely apart from the facts of their experience it was not entirely dependent on them either. More particularly, it could rise above them. Trust allowed the men to manage concerns by displacing fears with a confidence in the power of forces accepted as more powerful, whether this was (a) a general belief in their eventual survival (i.e. staying positive), (b) a specific faith in those perceived to have more influence (i.e. trusting those with influence), or (c) a basic assurance in their own strength to make it through, whatever the odds (i.e. believing in myself).

**Staying positive.** As the men struggled to manage difficult emotions, their stories highlighted a perceived value in staying positive. Present even among some with chronic or terminal conditions, a sense of trust that they would be all right as they focused on promising outcomes was often positioned as critical to the process of getting back. As Keith asserted: “Attitude is everything […] you don’t have to be strong, but you have to have a good attitude.”

Although promoted as essential, some men also spoke to the challenge in sustaining this orientation across the course of their illness. As Gerrard shared, despite his best efforts, his ability to maintain this focus was at times successful only superficial:

We are human beings…there…you know…ah, you know, I think there’s always doubt and there’s always some um [pause] you know um doubt I guess…second-guessing…is that the right? […] It’s…it’s…it’s hard not…it’s hard not to go through something like that and think you
know...be positive all the time. I mean you...you definitely put on that face for other people but in your heart of hearts, you know the stuff that you keep close to your chest...the stuff that no one else sees...you go, hey God...I wonder.

In this challenging pursuit, men emphasized how others, partners, family, friends, and others with cancer, enabled this approach, strengthening their focus as they struggled with negativity. For example, Earl shared how his family offered examples of how others had survived cancer, assuring him that he would be “fine” and should “hang in there,” Bill detailed how his cancer support group peers assured him he would eventually “feel better,” Brian described how his wife would “feed positive into me,” and Jakob noted how his wife, a “positive person,” would “kick my butt. I mean right out of bed [laughing]” (his emphasis) when he felt sorry for himself.

Alternately, this effort could be disabled or complicated by the responses of others, particularly those who engaged with the men as weakened or dying. As Randy shared, as he struggled to keep his own powerful fears at bay, he had to resist those of others who he found greeting him with what he interpreted as surprise at his continued survival. He explained, “I’m trying to battle this and try and keep a positive attitude and every chance when someone or someone has a chance they knock me down a peg.”

**Trusting those with influence.** Many men also spoke to a need to trust in others perceived as yielding critical influence over the situation: medical providers and, for some, god. As noted, the men recognized that their medical team had a plan and many chose to place their trust in this even as some sought multiple opinions and were ready to push back against their physician’s advice. As Dave explained, “You’ve got to believe in the system.”

In this, it was not uncommon for the men to stress the skills of the health team, describing their specialist as among the best. However, even those with tempered assessments of medical providers described how they reduced the weight of their own burden by placing trust in those trained for the task. Arthur explained, “I’m sure there’s thousands of doctors like him but this one was okay with me and ah...anyway, I didn’t have to do any thinking. I only had to show up at the hospital and present my body.”
Notably, while some struggled with abrupt and insensitive medical providers, for some engagement with medical providers offering direct, specific and “no nonsense” information appeared to support a sense of confidence that they were in capable hands. Similarly, men with strong religious faith emphasized a trust in an omnipotent God, a power they placed above the medical team. Fred offered a particularly powerful illustration of this dynamic as he described an experience in which he was taken into the ER for a high fever:

I said to the Oncologist you seem more concerned about [this fever] than I am. And she said well why’s that? Well, I said, perhaps it’s perception…you’re looking at it scientifically and [saying] you’re burning up and I can’t explain it and I’m saying, yes I recognize you are not in control, but that’s not a concern for me because as far as I’m concerned it’s the finger of God burning the hell out of this damn disease (laughing).

Believing in myself. Although less often explicitly discussed in this way, some men also spoke of a trust in themselves. In this, some spoke generally of their willingness to follow their internal compass, while others spoke specifically of how past experiences handling difficult situations had enabled them with a sense of trust that they would be able to handle the struggles faced across their illness. For example, Chris shared how a physical trauma as a child had left him visibly scarred, teaching him how to be a “fighter,” Micky described how a variety of hardships across his life, including experiences of abuse and poverty, had left him confident that even although he might reach the bottom, “you can always go back up!” and Michael noted how the extensive “work” he had done on himself gave him the confidence to “allow myself to go with whatever it is I need to do and knowing that I’m going to be fine with doing that.”

Further, in this process of finding trust in the self, some of the men moved beyond their own experiences as they considered the struggles of others in their lives and found some security in recognizing how others had successfully moved through hardship. Keith drew inspiration from his wife’s process of dealing with her cancer, explaining how he sought to model his journey on hers, noting that she was “very, very strong” and saying to himself, “that’s what you have to do” and Andrew described looking to his father for inspiration, explaining:
[When] things got really, really hard for me…like during the transplant and I couldn’t get out of bed for you know days on end and they couldn’t break a…a fever that I had for like five days and, um, you know things were breaking down in my body like my…you know I had incontinence […] all kinds of crazy things…um I said to myself, if my father can get through [internment during war] and survive, and witness the death of his parents and sister in front of his face and turn out to be such an amazing, wonderful human being still…then I can do the same. [Pause].

In nurturing this faith in self, these men demonstrated a specific appreciation of those who supported them, without question. They highlighted how health providers respected their requests for additional tests or saw value in their decisions around how to respond to physical or emotional challenges. They expressed thankfulness for friends or peers who were supportive, but not “preachy,” and they emphasized how family members demonstrated their commitment to support whatever decision they made. As Earl shared, he appreciated his wife’s willingness to follow his lead, though they would both be impacted by his choices related to prostate treatment:

[She] was kind of like, well what are you most comfortable with? You’re the one who has to go through it…not in, ah, well it’s your problem…it’s your decision, your problem, you live with it…it’s kind of like honey, it’s…what’s…what do you want to do?”

In contrast, some men expressed frustration with being “second guessed” or “questioned” as they held tightly to whatever degree of confidence they carried in their ability to get back.

**Staying present**

Closely associated with the process of insulating themselves from negative thoughts and feelings and practicing trust, the men described efforts to manage emotions by focusing their attention on the present. They detailed how they took their illness “day by day,” and “[dealing] with it as I go along.” Often facilitated by an undefined process of mental control, this effort could also be supported through practices of meditation, yoga, and relaxation techniques often learned through classes at a cancer support centre.

For many men, these were new approaches to handling stress, moving them outside their comfort zone. As Pete explained, “Yoga is not…to me, it was something
guys don’t do.” However, for men engaging in the practices, there was an appreciation of techniques enabling them to achieve emotional peace, “calming, soothing, and relaxing” them by bringing focus back to the present. Illustrating this, Arthur explained that although he believed it sounded “corny,” he found benefit in breathing, noting, “You’re hearing that from a guy that didn’t believe in all that stuff,” but “I do…I’ll sit in that chair and…and just breathe and when I say breathe… acknowledging and knowing that you’re breathing. And I find that somewhat relaxing.”

Beyond these techniques for decreasing anxiety in the moment, they emphasized the value of a more general practice of focusing on what is known. Fear is non-productive, some explained, as they described efforts to dispense with “what if” scenarios. More than choosing to not think about what they perceived as beyond their control (a strategy of insulating), amidst the vast uncertainties and contingencies comprising an uncertain future many focused on what was directly in front of them: what they could see, could touch. Arthur’s sharing illustrated this well:

[Fear] is not fact, so I can’t deal with it…if it’s a truth or it’s fact then I can deal with it but you know if somebody tells me, you flunked the blood test, okay I can deal with that. But if…if I’m thinking geez, I’ve got a colonoscopy coming up and they…they may find a tumour in there, well I can’t deal with that.

Oscar described this as going into “survival mode,” Brian framed it as “rolling with the punches,” and Arthur positioned it as a “pragmatic” approach. However described, in this focus the men’s attention was directed on doing “what I have to do,” reducing the multitude of possible tasks down to a more manageable set of critical activities perceived as key to getting better. Although he struggled to achieve this approach in his own experience, Clint detailed the value of this orientation, while also demonstrating how it integrated insulation activities:

[There] is some real benefit to being about to just…take a bit of the emotion out and go, okay, here we go, what’re we doing for that, what’re we doing. Closer to the date of the operation you definitely get into that mode, because there are steps you have to follow, cause there’re steps you have to do after all of that…
Oriented this way, the men detailed how they broke a lengthy process into smaller pieces, checking off accomplishments one at a time. Arthur offered a particularly tangible analogy in likening his chemotherapy rounds to the innings of a baseball game (a game, he acknowledged, that had gone into extra innings): “I considered it, you know, when I look back on it, a bit of a game and that going through the Chemotherapy well, you know it’s…it’s the innings…I…I had 12 innings (laughing) and…and I got through them.” Although this approach was emphasized amidst the treatment phase as the men’s lives were often tightly organized by the treatment regime, elements could be maintained after treatments concluded.

For some men this approach offered more than the opportunity to limit the overwhelming burden of the feared unknown. They also viewed it as a way to find moments of pleasure amidst so much pain. As Richard shared, although death hung heavy in his thoughts, when he focused on each day, his mood improved: “…I don’t know, it’s…in the now, to be in a conversation, an interview, it’s…I’m enjoying it, you know, that moment. So, the more I can be in the right moment, I find that…the better I feel, you know.” Similarly, Micky described how he sought to “Enjoy the butterfly, enjoy the flower, look at the sky and how beautiful it is. Just enjoy being.” Notably, these moments of peace could also be nuanced by some bitter undertones, as evident in Jack’s story of sharing a drink and smoke with a friend sharing a terminal diagnosis:

I’m looking at [my friend] saying […] guess what, let’s have a big fat joint and a glass of scotch because you know what, it’s not going to hurt us is it? And he’s killing himself laughing and he’s saying, yah you’re right, let’s…we might as well enjoy an afternoon.

**Showing worry**

In Steinbeck’s *Grapes of Wrath* (1939), Muley explains to the preacher Casy that he fears he might be a bit “touched,” affected by the loss and isolation with which he has been struggling since being driven off his family farm. Casy responds with a simple suggestion: “Yes, you should talk. Sometimes a sad man can talk the sadness right out through his mouth” (p. 72). Like Muley, most of the men expressed a desire to “tell their story,” to “vent,” “express,” or “release” thoughts and feelings troubling them amidst the
trauma of losing so much and fearing more to come. Concerned with “festering” emotions, many valued opportunity to “show worry”

Although the men’s experiences were also coloured by anger and frustration, focus here was on expression of fears, anxieties, and sadness as linked to losses and uncertainties. Further, a willingness to release these emotions through crying, particularly in private, was distinct from a practice of open communication around their struggles. Many men acknowledged “teary” times. However, this expression of pain was often framed as a release over which they had little control. For example, Earl identified himself as an “emotional slob” unable to restrain emotions and Pete argued, “If I’m going to cry about this cancer (laughing) I need to cry about this cancer.” In contrast, the process of putting words to emotional turmoil, of talking openly about feelings and acknowledging their struggles was a more deliberately chosen act and is the focus of this section.

The men used a variety of approaches to showing worry. While Michael facilitated this through journaling (as well as conversation with friends) and Andrew through photography, most often the men detailed how they valued having someone they could trust and who was willing to hear them. In this, there was no expectation that others would resolve their difficulties. In fact, as Andy noted, he did not care whether or not the other person listened to every detail, noting:

You don’t have to say anything. Don’t even have to listen if you don’t want. Just sit there going “hmmm, hmmm…yeah, really, okay.” And then, as long as you do that. Put an ipod on, I don’t care […] pick up the phone and walk away. Probably, I wouldn’t know it. Every now and then, pick up the phone, “yeah, yeah, yeah” put the phone down again and walk away. You think you’re talking to somebody. And that’s what you need.

What was important was the opportunity to let down their guard and not have to contain within them the intensity of what they were experiencing. As Pete shared: “it just helps to have a sounding board you know. Um, to…to get it out (laughing), to get it out.”

As alluded to in Pete’s comment, this release was often positioned as therapeutic. “The more I share,” Richard explained, “the better I feel.” Similarly, Bill shared a common sentiment when he explained that letting others know what he was experiencing
not only made him feel “more comfortable,” but that it was also “good therapy.” As we explored the nature of this “medicine,” as Dan termed it, the men explained that telling their story to others helped them to acknowledge the pain they were feeling, a process that could also allow it to feel more real. In this, they could move toward “acceptance,” toward a sense of “closure.” As Michael described:

> What I have learned from people that are diagnosed with cancer is the fact that the cancer is sort of out there, like in other words, it isn’t being owned. […] So, in telling my story it is owning that, that part of me that I have to deal with, which I do believe is part of, of the healing.

This need and the process of showing worry could continue for years after their treatments ended as the men continued to make sense of the disruption the assaults of illness had levelled in their lives. However, even among those who saw value in showing worry, this practice was not always easy, particularly among men with little experience with this form of expression. As Nico explained, although he was trying to open up with others, he still struggled to let his emotions out: “I mean I can well up but somehow the tears just don’t come (laughing) you know what I mean? And ah that’s been…you know that’s been ah bit of a challenge.”

In selecting witnesses to their pain, many of those in relationships explained that they maintained a fully open dialogue with their partners. Although Brad felt that he and his wife were unique in that they “know everything about each other,” others echoed this sentiment, emphasizing, like Pete, that they would “not hold anything back” from their partner, including tears as well as verbal expression of fears and sadness. As Earl noted, although he might feel the need to be “macho” with his buddies, he was not ashamed to express emotions with his wife, given their level of connection. Similarly, Brian described the relief in letting down the “façade” of stoicism with his wife, explaining that while he might still keep a wall up with others in his life, he found it “really helpful” to share what he was feeling with his partner.

However, even among men who practiced openness with their partners (or even adult children), a concern with overwhelming trusted supports with the intensity of their emotions, particularly as these persons were seen to be struggling with their own pain associated with the illness, led some men to emphasize the need for extra-familial
supports. Dan shared a common sentiment when he stressed the importance of protecting his partner and children from the intensity of his anxiety and depression by seeking someone outside the family to talk with, explaining “I think it’s gotta be outside the family, I don’t think it can be within. Um…because I think that just puts too much pressure on, um, your spouse or, you know, your kids.”

Beyond the partnership, men prioritized supports including those individuals with whom they had a solid and trusted relationship and/or a practice of helping each other, qualities often overlapping. For John, it was key that the friend with whom he shared openly had “the admirable quality of being discrete,” while others described how they turned to those with whom they had shared a solid friendship over many years and knew them well, including close friends who might live a great geographical distance. For example, Clint opened up to several high school buddies with whom he had managed an on-going friendship through email and Jakob sought out a friend he had known since university, well over three decades previous, explaining that they had shared so much of their lives with each other during their schooling and had continued to share this “bond” since then, despite residing at separate ends of the country.

These relationships, typically with male friends (though not always), were often also defined by a practice of a mutual support. This might be a new area of concern in the friendship, but the process of support was often an existing component of the relationship. As Andrew shared, he turned to his best friend because “we have each other’s back.” These individuals had proven their trustworthiness and their ability to maintain connection across a range of challenges.

Given these conditions, not all the men were able to find appropriate supports within their existing social network. Some, like Dan, did not feel they had the “right” kind of friends. As he explained, although he had many friends, he lacked “that real one friend that I’ve been really tight with” leaving him feeling that he had no one to whom he could turn. For others, their initial efforts at disclosing around emotional pain were rejected by those presenting a lack of interest or ability to engage in this way. More specifically, they detailed how family or friends sent clear messages diminishing their needs or conveying expectations that they would handle the trauma on their own. As
Micky shared, his friends “didn’t really want to hear about it” expecting him to “just, you know, go do your surgery and – hey…come back strong…” and Clint shared how he had reached out to a family friend for “sympathy,” only to feel struck hard by the man’s response of “it is what it is,” explaining, “And I thought that was kind of harsh when he left, really…right [laughing], so he left the door and I went, it is what it is…fuck, I know that [laughing].”

Further, many of the men described others as uncomfortable with emotional expression or uncertain around how to respond. They shared how friends and family “stayed away,” kept discussions “superficial,” and/or limited the content of conversation. Dave shared a common experience when he described how his son “put up boundaries,” indicating that although he would do “anything” for his father, including sitting with him while he cried, he did not want to talk about the emotional pain. Positioning this pattern as more common among his male friends, Michael asserted, “Like in other words, I don’t think they mean to pull back or mean to be distant, it’s just the fact, what do we say?”

This dynamic could be particularly challenging later in the illness career, as the physical traumas passed and emotional turmoil endured. As Justin described, he felt pressured to be “all right,” after his surgery was complete, describing how one friend kept insisting, “You’re all right now, aren’t you?” to which he would respond:

…Well I’ve had the cancer surgery but no, I’m not all right. And um…[and then] he would say basically the same thing again… Well, you’re all right now? And I would say no, I’m not all right. I’m you know…just because I don’t have the cancer, I’m not all right I mean…my whole life…my life has changed, you know?

Partners and trusted friends were prioritized, but for men lacking supportive individuals or who wanted to extend their network, there was often a willingness to also turn to persons not previously part of their life. For a few men, therapists were included in this circle. As Dave shared, he was motivated to make an appointment with the psychologist affiliated with his treatment centre because “I got to say things to him that I didn’t say to my kids or anybody else.”

More often, though, the men emphasized opportunities in opening up with others who had directly experienced cancer, anticipating that those who had an intimate
familiarity with this experience would be more able to handle the intensity of the experience. They did not have to protect these others from pain and could feel safer in letting down their guard. As Clint explained, he chose to talk to someone who had been there because “I knew he could handle it, that he wasn’t going to, like I wasn’t going to call someone who was going to go off…” (his emphasis). Even more, with these individuals, the conversation could go deeper; it could be more honest. As Andrew noted, “you can reach a different level with expression and ah…you know yah you can…you relate on a different level than you can relate to other people.”

Even as some found opportunities to talk with others in the context of a support group, the activity of describing their experiences could be constrained by the quantity of others in the room sharing this need. As Richard lamented, in a room of over 15 individuals, he only had a few minutes to speak. Further, not all support groups were structured to enable this practice. As Pete shared, he was disappointed to find that his support centre did not offer more opportunities for one-on-one discussions, explaining that with sessions focused on education or discussions of treatment, “[…] you might briefly talk to people ah about their…their ah…how they’re doing. But, ah, you don’t really sit down over coffee or something like that and just run through it all.”

Given this challenge, some men emphasized the value of conversations outside this room. In particular, several highlighted the opportunities in having close friends who had also been diagnosed with cancer, a pairing of qualities perceived as particularly valuable. As Dave shared, although his friend had experienced a less severe prognosis, “he’s got the experience…he has the emotion.” In combination with their shared love of “messing around with old cars,” these qualities allowed Dave to be comfortable opening up to his friend, explaining, “I can talk to him…he’s the…actually the only guy that I can talk to.” Whether facilitated through groups or one-on-one, this community of others with cancer could prove particularly important as men began the process of opening up about the challenges of their experience. As Brad noted, although he had grown “less self-conscious” in discussions regarding his cancer and its impacts, he had valued the opportunity to share in the context of his support group at earlier stages.
As men struggled with on-going shifts, the process of showing worry could continue well after treatments ended. In fact, several men directly attributed part of their decision to participate in this study as motivated by a desire to share their story. As Dave shared, “Well, even coming and sitting here talking with you, eh,” part of the reason is that “it, ah, you know gives me some sort of closure on what’s going on to a certain extent.” Further, this strategy appeared to factor into decisions to take on roles as supports to others with cancer, serving as peer-support or as mentors. As Oscar noted, “I think you get more from helping other people than you get from helping yourself (laughing). It seems to help even more if you know you just…just share your experience with somebody.” Similarly, Jakob explained:

[If I’m] talking to somebody about Prostate Cancer I’m getting something out of it. So you know even if they get nothing out of it…I hope that wouldn’t be the case, but I know that I’d get something out of it.

Finding comrades

Although the process of showing worry could be engaged with a diversity of trusted others, the men highlighted the particular value of finding others who could empathize with their experience. They detailed how they were drawn to the company of those “in the same boat,” “on the same journey,” or in the same “club;” others with whom they shared the “bond” of a life assaulted by cancer. Although these supports are highlighted in the previous discussions on showing worry and in the subsequent one on seeking guiding, the role of comrades extended beyond provision of a willing ear or the offering of sage advice. Rather, as the men shared their experiences with those who had endured hardship or “had been there,” they were finding a community of fellow wounded travellers on what felt like a painfully lonely journey.

In this association, the men emphasized feeling comforted as they spent time with others who understood their feelings. As Bill shared, in the company of others who had experienced cancer he did not need to explain himself; they “had been where I was, where I am kind of thing…they understood.” In this connection, the men described feeling less abnormal as they recognized that they were not the only one feeling “crazy” or struggling with fear. Even more, they could “feel better,” about themselves and their
situation, as Dave detailed, and break through some of the isolation that accompanied their condition. Brian explained:

You feel very isolated and you’re by yourself and all of a sudden now you realize someone else out there is at least going through the same thing you are. I don’t know if I can describe why that’s comforting other than just to know that you’re not alone is [pause] is just somehow comforting.

Among some men the significance of this companionship was realized as they pursued other goals, emerging as an unanticipated opportunity encountered in the process of seeking information or guidance through support group meetings or as they moved into new areas of conversation with friends who had also experienced cancer. However, other men actively pursued this sense of connection, either through reading about others’ experiences or engaging directly with those on a similar path. For example, although Clint was reluctant to attend in-person cancer support group meetings, he sought out books detailing the stories of others who had experienced kidney cancer, seeking to find those with whom he could relate. Similarly, Marc’s combing of online ‘blogs’ by others with colorectal cancer provided useful information and offered him a sense of connection, of normalcy. Describing one of these blogs, he explained:

[The guy] unfortunately died, but he went through 90 percent the same thing as me and, um, so it was kind of neat because this guy [clicking on computer mouse] had, um …must have been a super techie ah guy and he was hooked up at the hospital with his computers. He was always researching things and he was being …similar...see?

Other men adopted more interactive approaches. For example, Dave sought out a cancer support group in the pursuit of “compassion,” describing a sense of “comfort in numbers” and Andy, frustrated by family and friends who failed to offer a level of support he believed was appropriate, shared how he turned to a cancer support agency, anticipating that others in a similar situation would not turn him away. Although he worried that these individuals, mostly older and enduring more extreme treatments, would not recognize his non-melanoma skin cancer as sufficiently worthy, he recalled feeling welcomed in, his fears understood. He explained:
I feel like everyone’s probably [voice drops and gets quick] thinking why is he here, but ah, the one guy, actually come up to me and he goes, “so, are you with somebody?” And I says, no, no, I got it. And he goes, “you got skin cancer?” Like my age, he’s looking at me, like, my God. And I says, well it’s only basal cell. And he says, “it doesn’t matter, it’s skin cancer.”

Not all the men would seek out or access these comrades. Some were unsure where to go to find those who shared their experience and some perceived few resources available to them. For example, although more than five years post treatment for neck cancer, Dan lamented an absence of a support community for men that was not focused on prostate cancer. In some situations, services did exist and informed friends, family, and health providers would help link the men to support groups or arranging meetings with others with cancer.

Regardless of how the men reached these persons, those who did achieve a sense of connection with others on a similar path could access a critical opportunity to feel ‘normal’ during a time when little felt familiar. Even more, through this companionship they could access opportunities to engage with transparency; they did not need to protect those who shared their burden and had access to a process of “mutual caring,” or “mutual support,” as Earl emphasized. Thus, this dynamic flows into the following discussion of how men sought guidance. Although their networks of support would extend beyond others with a cancer diagnosis, this community remained distinctly important for many of the men across their illness career and beyond.

**Seeking guidance**

As the process of ‘showing worry’ helped the men to acknowledge their struggle amidst the assaults of their illness and the activity of finding comrades allowed them to feel included within a broader community, some men described how they also turned to others in search of guidance around how to handle the challenges of a life characterized by loss and uncertainty: seeking advice on how to live with cancer and beyond cancer. In contrast to the process of learning tips or techniques for responding to anxiety, as detailed in the context of repairing uncertainties, the efforts detailed here brought men into an interactive relationship with supports. They did not just listen; they also disclosed.
Opening up about what they were feeling, explicitly acknowledging these as struggles, the men sought the counsel of others who had been there.

Through this engagement, the men’s stories evidenced how they pursued specific advice on handling day-to-day emotional and relational challenges related to their illness. Andrew illustrated this process as he described how anxieties around impending treatments and traumas associated with a partner who was not only unable to support him, but was also abusive, brought him to a cancer support centre, “sobbing” and pleading to the receptionist that “I have cancer…I’m getting Chemo…starting Chemo tomorrow and my girlfriend just beat me up.”

As Andrew’s experience highlights solicitation during a crisis, others demonstrated how the process could be integrated into a broader approach. As Jakob detailed, he learned to just “lay it out there,” recognizing that “the more open I was and willing to be with people that I talked to, as long as it didn’t make them uncomfortable, the better off I would be because I’d get more information.” Even more, amidst their uncertainty, the men sought out the “wisdom” of others that might help them navigate the path ahead or re-envision a future troubled by their diagnosis and the changes it wrought in their lives. As Dave shared, he had never gone through an experience like this and valued the opportunity to learn from others who had so that he could better “plan my own future.” Similarly Michael longed to glimpse the “light at the end of the tunnel,” and Jakob longed to be told that his diagnosis did not signal “the end of the world.”

In turning to others for guidance around navigating a life with cancer, including the more fundamental questions around what lay ahead for them, the men drew on a range of supports in this process. Again, others with cancer proved key. Consistent with the expectation that those who had not been there could not understand their experience, they prioritized learning from others who had experienced cancer, whether in the context of a cancer support group or more informally. Justin argued a point made by nearly all the men I met when he asserted, “you can’t say I know how you feel when until…until you’ve had cancer yourself.”

As men engaged with others who shared the journey or, even more, were further ahead on the path, they emphasized opportunities to find hope or much needed
“reassurance.” As Bill shared, through engagement with his support group his confidence in his own ability to move through his emotional pain was strengthened, explaining, “Well, these people have coped with everything that I’m coping with and they’re still alive.” Similarly, in reflecting on his own needs, Gerrard argued that the fear overwhelming those entering this experience can be significantly soothed by witnessing those who can say, “I’ve been there…I’ve been through the treatment and I’m okay. I’m five years cancer free.” This dynamic could be particularly powerful for men who witnessed the survivorship of those with worse prognoses. As Arthur noted, “I guess from a selfish point of view just sitting there realizing I don’t have too much to worry about given what stories I’m hearing of others, you know?”

Although personal experience was emphasized as the men sought guidance, some also accepted the value of surrogates. For example, Randy trusted the wisdom of a health provider who had lost her partner to cancer, explaining that while she might not know his experience perfectly, “she knew exactly what my wife was going through…had an idea what I was going through and…and an idea what the kids were going through.” Similarly, Clint turned to a friend he knew who had “suffered” in his life, trusting that he would be able to offer useful advice.

Further, not all guidance men sought during this time required a personal understanding of cancer. For Jakob, struggles in his relationship required support from those who knew him and his wife, and other men evidenced an appreciation of the expertise, objectivity, and safety of therapists when soliciting guidance through frank conversations around emotions. Although a few men had existing relationships with a therapist, most who turned to these supports initiated the relationships because of their illness. Some, like Joseph, positioned engagement with a therapist as a check in, to “basically say…what am I doing, can I be doing something better” while others described extensive engagement. Randy, a reserved man who spoke sparingly with family and friends about his struggles explained that had been in treatment for depression for nearly two years after being connected to this resource by a trusted health provider.

As evident in Randy’s experience, others played an important role in directing men toward these supports, whether in structuring this as part of treatment or by
identifying resources and encouraging the men to take action on emotional struggles. Notably, the influence of others appeared to be most welcomed among men who already recognized themselves as struggling, but who were unsure how to handle the pain. For example, although Andrew had a difficult relationship with his girlfriend, she helped him to seek out guidance of a psychiatrist, noting that she was the “first” to suggest that he was depressed and needed help, noting that her comment helped him see his situation more clearly, “And I said, you know, maybe you’re right because I am walking down the street every so often on a regular basis and I’ll start spontaneously crying.”

Lest this support selection process seem tidy, the men’s stories illustrated how their evaluation of suitable supports followed complicated intersections of expertise, experience, and identity. For example, Dan argued that while a psychiatrist might “give you some direction” he believed their lack of personal experience with cancer disabled them from offering real help. More often, the men argued that while a cancer diagnosis was important in terms credibility, this was not always sufficient. As the assaults of illness threaded through the complexity of personal biography, they detailed limitations in the potential for guidance related to differing identities and relationship statuses, prognoses, positions on the illness career, goals, impacts, and more.

For example, Andrew, a young, single man without children explained that while others he met were “worried about feeding their kids and I’m worried about feeding myself,” Jim, a man with a solid financial base, struggled to relate with those facing economic challenges, wanting to focus on other areas of concern. Richard lamented that he had not met another gay man with cancer at his support centre, and several men with rare cancer types described a struggle to find others who shared their diagnosis. This collection of differences might be less critical in the context of soliciting information related to coping with physical side effects or learning relaxation techniques, but could be more disruptive to the process of engaging with others around their intimate thoughts and fears in the process of seeking guidance.

Further, there were challenging diversities in regard to cancer stage or severity. Brian pulled back from peers with cancer who did not appreciate his focus on quality of life over continued survival and Clint refused to attend kidney cancer support meetings
because he was reluctant to be around those facing a more severe prognosis, explaining, “I shouldn’t be there because I’m the lucky one, so far, I am the lucky one so far, right?” Others felt constrained by an environment of competitiveness around the severity of their condition. Although not pervasive across the stories, this dynamic could frustrate attempts to talk openly about struggles as the men felt a need to justify the quality of their pain. As Joseph described, he tried to speak “carefully” in a room where individuals with “so many losses” sought to “build up their self-esteem again” by positioning their cancer as worse than that of others.

Finally, some men struggled with the reticence of other men to both attend support groups and talk openly about their struggles. First, many of the men with non-prostate cancers identified themselves as one of the only men in their support groups. Most did not interpret a support person’s sex as a barrier to obtaining guidance as they explained that they shared much in common with female peers and even emphasized an appreciation of the diversity of perspectives co-ed sessions offered. As Gerard explained, nearly all the women in his group had breast cancer and he admired several for their wisdom and felt what they shared to “really resonate” with him, a man with non-Hodgkin’s lymphoma. Similarly, Michael noted that the women with breast cancer he met “were feeling very similar to what I was feeling.”

However, this dynamic had its challenges. As Brad noted, in this sex imbalance “all the references are references pertaining to women” and Dave argued that he would be “a hell of a lot better off if we had a situation where a guy could say all right…here’s 14 other guys that are in the same position I’m in, I want to go talk to them.” Instead, he described how in an absence of other men willing to attend support groups, to talk about “cancer” as opposed to “hockey” or “fishing” he contented himself with the company of women willing to participate in the groups.

Second, even among those men who attended prostate cancer support groups comprised mainly of other men, some shared how they struggled in an environment where information dominated and few others were willing to practice openness about their feelings. As Jakob explained, it was not until a speaker failed to show up for a monthly meeting that he found an opportunity to “relate to everybody personally,” as the
time was filled with the men talking about experiences, rather than hearing from a speaker. And Michael shared how he was frustrated by peers who were “not very good with their feelings,” describing how the other men in his group shut down his invitations to talk about emotions, arguing that they were “not feeling anything.”

Summary

As these men described how they sought to handle the assaults of illness, their stories emphasized a sense of personal responsibility in managing their illness. Although recognizing others as integral to the process of recovery, many sought to lead themselves through this experience as they engaged three broad strategies of response comprised of a blend of coping efforts and indirect and direct help seeking activities. Although presented as distinct, many of the activities comprising these strategies were interwoven as the men sought to handle a complex range of shifting challenges over the course of their illness career.

The first strategy, Fortifying Resources, included efforts to develop the cognitive and physical resources important to combating disease. Although some of this work could be engaged independently, the men often relied on a combination of support persons, including those with medical knowledge and/or personal cancer experience, and close family and friends to assist them in developing disease-related knowledge and skills and to enable efforts oriented toward strengthening their body. The second strategy, Maintaining the Familiar, was a more independent process. Although others could facilitate or inhibit these efforts to hold onto a ‘normal’ way of life, the men often drew on their own resources as they sought to minimize exposure related to the impacts of illness, remain active contributors, limit the burden placed on others, and reassert a sense of individuality with a health system focused on their disease.

Finally, the strategy of Getting Through allowed the men to manage the difficult thoughts and emotions infusing a life increasingly unfamiliar and uncomfortable. The activities within this strategy included individual coping efforts allowing the men to resist feelings of anxiety, fear, and despair as well as interactive activities, moving them to engage with selected others (e.g. peers with cancer, family or close friends, therapists) as they acknowledged struggles and asked to be heard, included, and/or led by others
through this challenging experience. Some men would emphasize efforts to limit emotional engagement, particularly during the treatment phase, but many would engage a combination of activities over the course of their illness. Next, these patterns of response are integrated with the findings on how men perceived needs (Chapter 5) in the presentation of a substantive theory of men’s help seeking during a cancer experience.
Chapter 7

A substantive theory of men’s help seeking across a cancer experience

Over the previous two chapters, I have detailed how the men in this study perceived and interpreted the impacts of illness and how they sought to respond to these assaults. In this Discussion chapter I provide a synthesis of these findings through a presentation of a grounded, substantive theory of men’s help seeking across a cancer experience, from the point of diagnosis and into the post treatment period. As I weave these data together into a broad, theoretical story, I remain cognizant of the tremendous diversity among the men sharing their experience with me. In addition to the particulars of their disease form and stage, each man brought to his experience an evolving narrative, that on-going story of who he is, what he does, and who he hoped to be; a story built across countless experiences. Each man was embedded in a particular social network and moved through his day with a distinct cadence.

As outlined in Chapter 3, as these men described themselves, some emphasized their loyalty and kindness while others noted that they were bull-headed and abrasive. Some stressed a devotion to faith, others to social justice. Some were “social butterflies,” others loners. Some said they were laid back, while others described themselves as anxious, driven, and goal focused. Some said they were “emotional” and others emphasized discomfort with tears. Some were classical music devotees, others preferred electronica. Some loved sports, others photography, and still others enjoyed quiet conversations around books and ideas. Nearly all the men identified as helpers. As an individual works with others to build a story of self, he is not easily reduced to a set of social placements, ‘critical’ experiences, or preferred pastimes. His biography is nuanced, intricate, and contextualized.

Across these complexities in disease and self, the specific needs associated with illness varied, as did the compendium of responses the men engaged. The commonalities underlying these stories were all the more significant in light of these diversities. As will be detailed, among these men, illness represented a disruption to a valued self. Expectations for who they would be and familiar ways engaging with family and
community in the present were destabilized by a diagnosis powerfully associated with death and which threatened to move each man into an uncomfortable and stigmatized way of being. Struggling to live as they had, the men recognized the risk of appearing ‘less than’ who they had been. In handling this disruption, many initially oriented to resistance. Preferring who they were to who they feared they might become, they sought a return to ‘normal’. Despite these intentions, as they moved through their illness career, most recognized their lives as shifting further from the familiar. Although some changes would be temporary, others would endure, restricting their ability to reclaim the life they had known. Feeling altered, the men were challenged to adapt their story of self to accommodate these shifts.

Rather than cataloguing needs and responsive actions, the theory of help seeking detailed here describes how these men turned to others for help in navigating the identity dilemmas posed in a life assaulted by cancer. Recognizing cancer as a “biographical disruption” (Bury, 1982) in the lives of these men, I draw on a metaphor offered by Halifax (2008), to describe two distinct processes of soliciting support amidst this experience of destabilization: help seeking with a strong back and help seeking with a soft front. Resistance to vulnerability defines the first, as the men turned to medical providers, friends, family, and others with cancer for help in protecting a body and self, efforts focusing on pushing back against the disruption and reclaiming a familiar way of being. Recognition of vulnerability defines the second, as many also solicited the support of others as they sought to handle the shifts they experienced, acknowledging the disorientation and pain in this disruption and reworking who they were amidst the losses levelled by illness.

Each of these processes could be critical in handling a disrupted life, but they were distinct experiences. Specifically, amidst an unwelcomed disruption to a familiar narrative of self, help seeking oriented toward securing the self (strong back) was largely unproblematic, particularly as it allowed the men to draw on expected supports (e.g. medical staff, partners) and demonstrate their strength, resilience, and commitment to battling an insidious opponent. In contrast, solicitation of help in efforts to recognize loss and adapt their narrative of self (soft front) would prove to be a more complicated
process, as many of these men were challenged to evidence their vulnerability amidst the assaults of cancer and stretch or expand their existing support network. Those men able to engage both processes had an opportunity to ensure some consistency in self while also recognizing how illness was altering who they were. In outlining this theory, I first describe the particulars of this identity disruption before detailing the processes of help seeking with a strong back and with a soft front.

Moving into this presentation, it is important to briefly revisit the aim and structure of this theoretical work, to ensure clarity around what this theory aims to be and what it does not. As detailed in Chapter 3, grounded theory can be generated within the structure of both positivist and interpretivist traditions (Charmaz, 2006). In the former context, objectivist grounded theories are characterized by a focus on questions of who, why, and when as they pursue models enabling predictions and explanations of behaviour. These theories identify core variables and can be used to examine empirical occurrences, even transitioned into quantitative frameworks.

In contrast, this study has oriented toward the development of constructivist grounded theory, a process guided by an interpretivist approach. Rather than predicting men’s acts or proposing a definitive explanation for their behaviours amidst illness, my goal has been to enable insight and enhance an understanding of how men with cancer experience help seeking. As I acknowledge myself as part of this process, accept multiple realities, and recognize meanings as indeterminate, this theory moves beyond description to explanation, yet remains grounded in the complexity of lived experience. Focused on patterns in how men perceived and interpreted needs and supports and built responsive acts within a powerful social environment (Charmaz, 2006), contradictions and ambiguity are worked into the structure of this theoretical story, rather than positioned as conflicting patterns or negative cases in an otherwise “orderly” process (Daly, 2007; Dupuis, 1999). In all of this, I seek to present a theory that is necessarily “incomplete” while providing a “[portrait] of culture in action” (Daly, 2003, p. 781).

Feeling disrupted (the problem)

Charmaz (1994) observed that the threat of death “shakes men to their very core. Within moments or brief hours, the disruptive crisis removes them from their most valued
identities to that of patient, possibly of dying patient” (p. 271). In the wake of the shock accompanying their cancer diagnosis, the men in this study glimpsed mortality and came to understand themselves as ill in the context of tangible shifts reverberating in their lives. Amidst the biological and social sequela accompanying the progression of their disease and the treatments targeted at eliminating its force, the men’s stories highlighted how many came to experience life in a different way.

The body they trusted in, that they had long accepted as healthy, lost its transparency and became problematic. The future they had populated with intentions for their family, work, and leisure dissolved or was marred by fears of death or severe impairment. Their ‘free’ movement through daily life was complicated by treatment protocols, pain and exhaustion, and a loss of passion disabling their ability to do what they had done and engage with others as they had. Less certain of the future and restricted in the present, they described a profound isolation and grave and disquieting uncertainty amidst a life increasingly unfamiliar, uncomfortable, and insecure.

These embodied shifts were experienced in relationship. Across their illness, the men recognized the risks and realities in how illness adjusted others’ perceptions of them (or how others might look upon them). As bodies absorbed the impact of disease and its therapies and the rhythm and content of life dramatically changed, the men recognized themselves as different: as unfamiliar, weakened, even dying through the eyes of those around them. Friends, family, health providers and others responded to them in new ways, accommodating and caring for them, pulling away, reducing them to their disease, and/or taking over roles that had been theirs. As these patterns varied in nature, degree, and timing across the realities of each man’s disease, life and social network, nearly all evidenced a sense that life was growing distant from normal.

A controlled performance of self is at the core of one’s ability to claim and accept identity attributions. As Stone (1970) argued, identity is worked out across situations, as an individual communicates where he has been, where he is now, and where he is going. Among these men, illness made problematic their appearance and their present and future movement in the social world. To use Mead’s terminology, these shifts represented a threat to the ‘me’; a loss of whom these men were, as recognized through the eyes of
others, a presentation of self built over a history of gestures and responses, a way of being influenced by a variety of social scripts.

Thus, as a man experienced illness as an unanticipated, unwelcomed, and disorienting interruption in the narrative he was building with others, the risk he faced was not just biological death, but an inability to be who he wanted to be and believed he needed to be in the context of his life and relationships. As Kelly and Field (1996) argued, as serious illness compromises an individual’s body, it challenges his ability to perform socially, familiar self-conceptions and identities are destabilized. This on-going problematic situation was propelled by continually emergent physical and social shifts (felt and feared), informed by the reactions and responses of others (participants in the definitional dialogue), and made palpable through emotional infusions of fear, frustration, and sadness. A sense of disruption is a common reality of those facing severe or chronic illness. In fact, scholars in the social constructionist tradition have long accepted that illness can unsettle identity, or operate as a “turning point” (Strauss, 1969) in conceptualizing the self. As Frank (1995) argued, the ill body “sets in motion the need for new stories.”

Among the leading voices in developing this awareness, Bury (1982) described chronic illness as a “biographical disruption.” Drawing on Gidden’s (1979) broader concept of the “critical situation,” Bury theorized how illness disrupts “structures of everyday life and the forms of knowledge which underpin them” as individuals move into a space of intense familiarity with great suffering (p. 169). Bury’s work aligns well with Charmaz’s (1983) concept of loss of self, discussed earlier, in highlighting how biological disease metastasizes into the social lives of individuals, infecting both the practice of daily life and the future one imagines. Both theories, influenced by symbolic interactionist concepts and built through engagement with those living with illness, are recognized as critically shifting how researchers have come to understand lay experiences of illness (Lawton, 2003). Notably, even as some debate the positioning of cancer as a chronic illness, there is recognition that cancer is associated with a biographical disruption (Mathieson & Stam, 1995; Tritter & Calnan, 2002).
In fleshing out the nature of this disruption, Bury, Charmaz and others described illness as a challenge to a familiar “unity” of body and self. More specifically, Bury (1982) argued that illness brings bodily states into consciousness, forces individuals to engage with a degree of pain and anguish typically held at a distance from the self, drives a re-imagining of the anticipated future, and compromises normal patterns of reciprocity and support. In this process, he argued, a sense of uncertainty is potent as the “explanatory frameworks” one draws on in understanding personal and relational experiences are disrupted. In this disarray individuals are challenged to evaluate “what is going on” and reconsider “taken for granted” identities (Charmaz, 1995). More specifically, Charmaz (1994) has explained that individuals can experience “identity dilemmas” as illness compromises valued roles, qualities, and abilities.

As individuals move further from the familiar, limitations in functioning and a sense of embarrassment related to new ways of being alter normal patterns of relationship (Bury, 1982) and can contribute to a sense of alienation as one struggles to communicate his new reality (Little, Jordens, Paul, Montgomery & Philipson, 1998). As Bury (1991) argued, individuals are in “situations of risk.” As they struggle with disrupted definitions, they cannot be sure that those around them will share the interpretations they are developing. Aligned with assumptions in a symbolic interactionist perspective, this work enhances awareness of how illness can function as a ‘problem’, or disruption to practiced situational definitions and manners of self-presentation.

**Filtering the meaning of the disruption (the context)**

In accepting illness as a ‘problem’, it is recognized that the presence, impact, and nature of a biographical disruption is filtered through, or contextualized, by qualities of illness and identity, as one draws on a range of possible meanings in the process of making sense of what is happening. Among the filters relevant to these men, disease type and gender appeared key.

First, in addition to a diversity of meanings built in regard to the losses in certain ways of being, it is accepted that different diseases types carry different meanings, which influence how individuals view themselves. Specific to this study, beyond stigmas associated with certain forms of cancer associated with unhealthy lifestyle practices (e.g.
lung cancer, smoking) or located in parts of the body less comfortably acknowledged (e.g. prostate, colon), cancer as a group of diseases is accepted as stigmatized in its association with undesired physical change (emaciation, hair loss), suffering and death (Muzzin, Anderson, Figueredo & Gudelis, 1994). This stigma may be most evident in how cancer tends to be spoken of as a singular condition, rather than a vast collection of diseases, some of which pose limited risks to individual well-being and others which are nearly always fatal.

It is recognized that conditions recognized as temporary can be less disruptive to self, as the ill person and those around him anticipate a return to health, while chronic conditions can level a more “substantial” impact as one comes to recognize enduring effects (Kelly & Field, 1996). However, regardless of the specifics of their prognoses, each of these men (and many others in their lives) responded to their cancer diagnosis with an almost universal and intense fear of death. This response illustrates the stigma of cancer, the power of the socially dominant characterization of this group of diseases. Many of the men, and those close to them, would develop more nuanced understandings of their conditions, but being positioned as one living with cancer, often initially interpreted as dying with cancer, was a fearsome label.

Second, although less explored in Bury’s original theory, others have emphasized how the presence and impact of biographical disruptions can be differently experienced according to the particular threads of personal and social identity weaving together a life. For example, older individuals might come to expect certain conditions, reducing the shock of diagnosis and those with prior exposure to suffering whether through illness, a particular event, or a lifetime built in hardship might have already achieved an intimate familiarity with the quality of pain levelled by illness, moderating the shock of loss (see Faircloth, Boylstein, Rittman, Young & Gubrium, 2004; Lawton, 2003, Williams, 2000). As Williams (2000) argued, a healthy body is not always as taken for granted as Bury’s concept might imply.

Although this is a worthy reminder in working with this concept, there was little evidence that the men in this study were already living with “biographical uncertainty” (Williams, 2000) in regard to their health when they received their cancer diagnosis. One
man, an octogenarian, noted that given his age he was less surprised by his disease, but the vast majority of these men indicated that they had neither anticipated a cancer diagnosis, nor the assaults that would define a life lived with illness. Even as some men recognized that others “had it worse,” and many would eventually come to understand that none are ‘safe’ from disease, cancer was not dismissed as a “normal hardship” (see Sinding & Wiernikowski, 2008). This pattern might have been different among a sample of men experienced with serious illness, but for those in this study, men who defined themselves as ‘healthy’ prior to their diagnosis, cancer appeared to be a significant and unanticipated turn in their life, a disruption to how they lived and to a future anticipated.

Specific to the men’s social location as gendered beings, research has demonstrated how severe or chronic illness can take on different meanings in relation to how men and women present and experience their bodies in the context of social life. Recognizing gender as an organizing force in Western society, this research demonstrates how physical and social losses associated with illness, including shifts in capacities related to physical abilities, bodily appearance, and role performance can trouble valued elements of identity as it challenges comfortable ways of being a man. As discussed, although other identities might be more or less obvious across a given situation, directives related to gender competence are particularly potent in daily life as gender, linked to one’s sex category, is always in play; one is rarely without an understanding of how gender should be performed in a single interaction. Even more, in the context of physical illness, attention is intensified on the body, the site from which gender performances are propelled and the reference point on which they are judged.

Charmaz (1994), Watson (2000), and Robertson (2007) are among those who have critically informed awareness of how illness can disrupt a man’s sense of self. In detailing these dynamics, Charmaz (1994) argued that as men are assumed to be active, strong, autonomous and brave problem solvers, illness can present core identity dilemmas including passivity (vs. activity), sub ordinance (vs. dominance), dependence (vs. independence), and acknowledgement of emotions (vs. preservation of a public persona). Each choice, she argued, carries physical and social costs, as men seek to sustain a familiar way of being or make identity claims amidst the mounting losses of illness.
Watson (2000) discusses this dynamic with particular attention to how these ways of being are integrated into role performances. In this, he detailed how men, in assessing health and illness, tend to focus on their ability to function in ‘normal’ social ways (pragmatic embodiment); as a father, worker, or husband, a social point of concentration contrasting with a medical focus on biological processes (visceral embodiment).

Expanding on Watson’s work, Robertson (2007) argued that although role performance is important to how men perceive health and illness, they are also attuned to the physiological functioning of their body, particularly as they experience the visceral reality of disease through exhaustion, pain, and other subjective assessments (experiential embodiment). Even more, these considerations of both the experience and functionality of “‘real’, ‘fleshy’ bodies” that might or might not be in “working order” are made within a social context, as men seek to present an “acceptable” male body in form and movement (p. 91). Reintegrating biological and discursive, Robertson has emphasized how a continued ‘normative’ association of male bodies with action and strength (as opposed to passivity and weakness) is an embodied reality with which men must contend amidst illness, an awareness emphasized by researchers examining how the physical costs of cancer can trouble ‘embodied masculinities’ (e.g. Kelley, 2009; Oliffe, 2006).

These explorations of how illness can compromise ‘normal’ ways of being a man emphasize consideration of the scripts from which men are drawing as they work to demonstrate to others that they are who they claim to be. Notably, gender competence can adopt a variety of appearances, varying across intersections of personal and social identity, time and place. Yet, in 21st century Western society core elements are emphasized for men and others prioritized for women, regardless of how closely individuals choose to follow them.

As introduced earlier, Connell (1995) and Connell and Messerschmidt (2005) identified a social dynamic organized around a socially prioritized, or hegemonic, masculinity. Although few men can meet the criteria provided through this reference point, performances are evaluated in the shadow of this ideal type, defined in comparison to what is agreed upon as most normal. Settled into the shared consciousness and discourse, infusing institutional and social dynamics, the power of this directive remains
even as individual men engage other ways of being a man (i.e. masculinities), even as their performance is influenced by the intersection of a diversity of identity-related scripts related to age, race, religion, disability, sexual identity, and more and as they work with others to perform across a range of contexts.

Recognizing this dynamic, I asked the men to respond to the Western hegemonic ideal, or notion that men are to perform as emotionally reserved, self-reliant, controlled, and strong. Regardless of their age, race, country of birth, sexual or gender identity, whether they perceived the source of this script as biological, individual, or societal, and whether or not they sought to adhere to it, questioned the logic of the directive, decried elements of it as a tired and ineffective approach, or distanced themselves through word and act, each man recognized its force.

In fact, as these men accepted this prioritized positioning as more ‘normal’ than other ways of being a man, they often responded with a simple “yep” to my queries around whether this directive had been experienced in the context of their own life. The pervasive awareness of these expectations, even as distinct from the conscious practices of daily life, emphasizes the enduring power of these messages, a pattern observed by others examining men’s health. As persons saturated in the social patterning of Western society, these scripts appeared sedimented into an understanding of what was natural; what it meant to live as a ‘normal’ man. As Brian had shared, this was a way of being had been “bred” into him.

**Becoming less than me (the threat)**

As illness shifted how these men presented themselves to others in the present and future, it threatened ‘who’ they were. All would struggle in this disruption, describing a life “turned upside down” by cancer, and feeling the sting of a stigmatized disease. However, this unsettling of familiar ways of being, a common challenge in illness, was additionally coloured by understandings of how ‘best’ to perform as a man, a partner, a father, a friend, an employee, gendered patterns of being built over a lifetime of experiences and embedded in the relationships and structures comprising their daily lives. In this, the social manifestation of the visceral agony of a body and mind corrupted by disease and difficult treatments was additionally filtered through how tightly each man
held to powerful and pervasive scripts organizing a performance as a competent man amidst an onslaught of physical, social, and emotional assaults.

Gender is socially “inscribed” on the body, but agency remains (Robertson, 2006). Each man had a complex, evolving self-concept informed by a diversity of intersecting ways of being associated with a range of social locations and personal experiences (undoubtedly including prior biographical disruptions) influencing how he engaged with a dominant masculine ideal. Before cancer, his presentation of self was informed by other social scripts (e.g. gay or gender queer men, religious men) and influenced by experiences compromising his ability to perform in ways aligning with the dominant ideal (e.g. poverty, disability, addiction) or which allowed him to rest more easily on a solid sense of self amidst destabilization (accomplishments, psycho-therapy). Although all men were familiar with the culturally prioritized way of being a man, some had significant practice transgressing social norms positioning men as strong, stoic, and self-reliant.

As the men made sense of the assaults of illness, these identity positions and experiences could broaden the path of gender performance, even moderate the acuity of threats experienced amidst an illness compromising physical and social lives. Men who had found a degree of comfort in offering alternate displays of masculinity were less restricted in what they perceived as a valid way of being a man and those close to them knew them to deviate from dominant scripts; they could present as weakened, scared, and in a position of dependency without this threatening their status as a competent man. This positioning would also come into play as they sought to respond to the assaults of illness, a pattern discussed later.

However, most men evidenced how they sought to comply, at least in part, with the socially dominant ideal of masculine competence. They might have deviated from the script before and they might challenge the logic of its prescriptions, particularly amidst their new reality, but they still felt its pull in their lives. As illustrated in Chapter 5, some spoke directly to how an inability to perform in accordance with this model, or “the making of man,” could level a threat to their sense of personal value. However, even among men who spoke less directly to how the assaults of illness challenged their sense
of masculinity, or who actively discounted the ‘gender stuff’ in describing their experience, the stories evidenced gender-infused expectations for a successful way of being. Specifically, the men were attuned to threats limiting their ability to perform as an independent and vital force in their families and communities as partners, parents, friends and employees, and as they demonstrated significant discomfort in being looked upon as physically, cognitively, or emotionally weakened.

These patterns resonate with those observed by Charmaz and others, discussed above, and empirical research on men’s illness accounts (e.g. Chapple & Ziebland, 2002; Kelley, 2009; O’Brien et al., 2005; Oliffe, 2006; Robertson, 2006). Even more, emphasis on presenting as one who is strong, independent and unrestrained, as one who does for others (as opposed to with others) starkly contrasts with performance standards associated with subordinate masculinities and femininities including compliance, connectedness, and acknowledgement of physical and emotional vulnerability. Thus, even as the broad assaults the men identified (i.e. troubled future, discordant present, sense of isolation, uncertainty) aligned with biographical challenges reported by men and women with cancer (Little, Jordens, Paul, Montgomery & Philipson, 1998), the quality or nature of these shifts was filtered by gendered expectations. Simply, gendered scripts and structures prepared the men to notice certain shifts and to interpret them in particular ways.

Researchers examining men’s help seeking have recognized the stigma of failing to perform as a competent man (Addis & Mahalik, 2003; Mahalik, Good & Englar-Carlson, 2003), a “blemish of individual character” in Goffman’s (1963) framework. As cancer struck at the heart of the active, strong, and self-reliant man, an embodied identity, these men recognized illness as pushing them toward a way of being in which emotions outgrow efforts to manage them and bodies and minds functioned in ways beyond control, becoming transparent and so weak as to disable an ability to perform in expected and valued ways, leaving them unable to care for others and increasingly dependent on family and friends. Given the severity of their disease, there might be allowance of temporary shifts acknowledged among selected companions and during active treatment, particularly physical and emotional realities perceived as expected: pain, frustration, and
anger. But threats intensified as the men experienced explicit or enduring ways of being positioning them not only as different in others’ eyes, but also as incompetent.

Close on the heels of an inadequate performance is the fear of rejection. For the majority of men measuring themselves against a culturally idealized image of masculinity, the disruption of illness was infused with the threat of shame: troubled egos and disrupted pride as men who are not enough in the eyes of others. As Micky shared, the weight of these expectations could press “heavily on your emotional psyche” making it difficult to “move forward” amidst the assaults of cancer. They could come to accept past ways of being as neither possible nor entirely beneficial, but even as the men argued that they had “nothing to be ashamed of” they described how illness left them feeling not just different, but less than: “like shit,” “embarrassed,” taken “down a notch,” “useless,” “incapacitated,” like a “burden,” or a “fifth wheel.” Health researchers use the term ‘vulnerable’ to label communities or individuals at risk for health concerns (Rogers, 1997). But these men evidenced a sense of vulnerability that was more consistent with the definition of the word: susceptible to wounding. Illness was not just the uncontrolled proliferation of cancer cells in the body. As cancer compromised familiar definitions of situation and self, the men were at risk for physical, emotional, and social injury in the present and future.

Handling the disruption

Not all stories brought forth through illness are those of self-change (Frank, 1993). Although a biographical disruption presents opportunity for an edited narrative, it does not automatically lead to an altered sense of self, particularly in situations where illness does not result in enduring or visible physical shifts (see Kelly & Field, 1996). Amidst the disruption of illness, Charmaz (1995) detailed how men and women with severe or chronic illness can choose to ignore or minimize realities of their condition (denying identity shifts), struggle against or reconcile themselves to illness as they acknowledge shifts but resist or work around them, and also embrace these changes, adapting a sense of self that includes the realities of their illness. Notably, these are not either/or choices as one can engage a variety of responses and even claim contradictory identities amidst an ever-evolving experience of illness (Charmaz, 1995).
More specifically, Charmaz (1994) described how a man, awakened to the possibility of his death, can view this as a discrete event, believing that once he is past this crisis he will return to a familiar way of being. Further, an outpouring of support from those around him can help to “crystallize” this sense of an enduring self. However, amidst the significant losses associated with illness a man can also begin to recognize the lasting impacts of his condition, particularly the uncertainty it brings into his life. Acknowledging this force, a man might perceive disease as an enemy, ally, intruder, and opportunity, depending on his context. But in all cases he is challenged to make sense of who he is amidst the disruption. In this process, Charmaz argued, men tend to orient efforts to ‘preserving’ the self: to holding onto who they were before illness as they seek a coherence across their past, present and future selves, even as that self is dissolving.

**Retaining (and Adapting) Self**

As illustrated in the discussion that follows, the men participating in this study moved into their illness career with an orientation toward resisting identity change. In the course of their journey, though, some would come to recognize themselves as altered in both temporary and more permanent ways. These patterns echo much of what Charmaz observed.

However, as demonstrated here, this process of working through identity dilemmas was intimately associated with the help seeking process. More specifically, amidst the biographical disruption posed by illness, these men turned to others to assist them in the often-concurrent processes of identity protection and adaptation. Thus, more than the specific physiological or psychological impacts the men experienced, their process of help seeking was informed by efforts to resist and adapt to threats to who they were (i.e. how they lived).

As help seeking enabled this identity work, the purpose, process, and experience of soliciting support varied greatly depending on whether the men sought to secure their narrative or whether they worked to acknowledge and adapt to an altered way of being amidst the disruption. In describing this dynamic, I draw on the metaphor of strong back/soft front to illustrate how men worked with others in walking through the biographical disruption of illness.
Moving Through Illness with a Strong Back and Soft Front

Anthropologist, hospice care provider, and Zen teacher Joan Halifax (2008) argued that in times of great suffering individuals can find benefit in carrying themselves with both a “strong back” and a “soft front.” As Halifax described, a strong back allows one to “uphold” the self amidst chaos and to continue moving forward despite the tremendous sense of disorientation and discomfort brought on by grief, a lack of knowing, and a sense of despair. Reflecting on Halifax’s work, Bein (2008) explained that a strong back keeps one on course, providing a “foundation” as he enters “the unknown and uncertain – the places where suffering exists and the ways out are not yet illumined” (p. 15). This is strength defined as composure, not as force.

A soft front is the counter balance. Established on the secure base of a strong back, a soft front allows one to move toward vulnerability, enabling an individual to open up to things “as they are;” to be “touched” by the pain, uncertainty, and the vast fear that accompanies times of great struggle and loss. One might imagine these processes, equally and distinctly valuable, as the nested circles of the taijitu (or yin yang). Although a balance is difficult to achieve, in the relationship between fearlessness and vulnerability, Halifax argued, an individual is able to meet the difficult realities surfacing during times of loss without being disabled by them.

I was introduced to this metaphor in context of a meditation course held during the time I was conducting the analysis presented here. As our instructor challenged us to nurture this balance in our own lives, I was immediately struck by how this intimate duality helped me to make sense of the dynamics I was observing across these men’s stories. Most centrally, I had been struggling to reconcile the different ways the men were carrying themselves as they moved toward and away from others in their lives, how they demonstrated great comfort in asking for certain forms of help even as they strongly resisted others. Even more, I was challenged by the diversities in these movements across the group as well as the trajectories of change within a single life. Although Halifax has focused her work on guiding the efforts of therapists as they engage with terminally ill clients, her metaphor had broader relevance as I considered how these men walked this very personal journey through illness.
Notably, the men did not frame their experience in this way. They were not explicitly seeking to nurture this relationship, nor did their accounts evidence an achieved integration of fearless equanimity and a compassionate vulnerability, or a state of spiritual balance, as outlined by Halifax. However, as I worked with their stories, reflecting on the energies with which they shared these as we sat together, the spirit of this stance was evident. As they described how they moved through the disruption of cancer, I witnessed how many sought to pull themselves into a composed carriage, emphasizing their efforts to remain ‘rooted’, controlled, and steady in who they were as change swirled around them: keeping a “strong back.” I also observed how many men cautiously and bravely moved into a space of engaging with their pain, seeking to make sense of changes as they acknowledged their uncertainty, fear, and despair and opening up to others around their vulnerability amidst the chaos of illness: engaging a “soft front.”

Each of these processes of help seeking, evident across the men’s stories, facilitated important identity work; there was value in working with others to maintain elements of the self while also acknowledging a familiar way of being as profoundly unsettled. However, in (a) moving the men toward distinct goals and (b) requiring different presentations of self, the process of help seeking functioned very differently depending on whether men emphasized their strong back or their soft front. Specifically, as the men moved energies into a strong back, focus was on gathering supports that facilitated their efforts to retain or reclaim who they were as they performed as one composed and calm. Alternately, in engaging their soft front, the men sought out others who could help them make sense of who they were becoming amidst so much change, as they acknowledged the emotional acuity accompanying a disrupted life.

Over the next section, I present these processes in detail, illustrating how help seeking amidst diagnosed illness functioned with a strong back and with a soft front, a discussion integrating the response strategies of Fortifying Resources, Maintaining the Familiar, and Getting Through, as outlined in Chapter 6. Following this overview, I describe three broad patterns in how men engaged these help seeking processes; how they carried themselves.
“Getting back to normal:” Soliciting support with a strong back. As these men leaned into their strong back, they emphasized activities allowing them to resist the disruptive force of their illness and sustain practiced ways of being. In seeking to hold onto who they were, each of the three strategies of response would come into play, as would decisions to selectively accept supports offered. Most centrally to the help seeking process, the Fortifying Resources strategy (i.e. repairing uncertainties and strengthening their bodies) allowed men to develop the cognitive and physical resources perceived as key to defending themselves against disease. This process was led by an assumption that if they could understand their condition, anticipate its impacts, make the ‘right’ decisions, and ensure a strong body through a healthier lifestyle (nutrition, exercise, avoidance of carcinogens) they could mitigate the short and long-term impact of illness. As will be detailed, although efforts linked with Maintaining the Familiar and the independent Getting Through activities were not help seeking, these strategies enabled a process of soliciting support with a strong back, allowing men to remain consistent, composed and focused as they gathered the resources to combat disease and move back to normal.

In this framing, battle lines were clear as disease and self stood in opposition. This was help seeking as one not yielding to disease, as one taking responsibility for the situation and responding with strength, independence, vitality, and composure. In turning to others for assistance, the men admitted to gaps in their knowledge about their disease and its impacts as well as deficiencies in their physical body. However, any discomfort in these admissions was counteracted by a combination of forces. First, in defining their condition as severe and complex (a pattern carried into the interview setting), the men recognized themselves as seriously ill and their foe as vicious and insidious, directly challenging expectations that they could enter this experience with detailed knowledge about this powerful opponent. Second, in emphasizing their management of the activity of assembling key resources, the men demonstrated their self-reliance and resourcefulness in identifying goals for learning and physical development, a performance aligning with masculine ideals. Third, as they selectively accepted help from those offering medical and practical care important to carrying their body through this physical trauma, the men were demonstrating a commitment to moving back to a
position of strength, on building a body and mind capable of ‘defeating’ their disease and securing their self.

Although they relied on selected others for care and assistance, this process was oriented toward the solicitation and acceptance of the temporary support required for a body enduring a confined period of intense physical constraints. Even as these efforts challenged men to enter terrain less familiar (e.g. yoga or meditation classes, attending cancer support group sessions to gather information), focus remained on their leadership in protecting the self against a difficult foe. In this, help seeking with a strong back was more akin to carrying out a project plan than submitting to the direction of others. Faced with a critical challenge, they needed to identify and access the ‘right’ resources to meet objectives organized toward a goal of regaining normal.

Not only did these efforts orient men toward a defence of self, when combined with Maintaining the Familiar and independent Getting Through activities this strategy could enable a performance of self that did not drift too far from normal. More specifically, as men engaged the Fortification activities they could continue to present as controlled, active, even strong, as they limited what others knew about their condition (minimizing exposure), continued in valued roles or found suitable replacements (staying in the game), ensured that others did not take on responsibilities outside their normal scope (limiting others’ burden), and pushed back against those positioning them in unfamiliar or limited ways (reasserting ‘me’). Similarly, although anger and frustration might be acceptable in this resistance, Getting Through activities of insulating, trusting, and staying present helped men to shut out or create distance from the sadness, fear, and anxiety emphasizing their disorientation and sense of loss, emotions perceived as particularly threatening to their ability to perform with fearlessness amidst illness.

Through these processes the men were able to suppress and manage evidence they feared would position them as altered and vulnerable, even as they acknowledged the difficult work they had to do in handling illness. In both focus and performance, help seeking with a strong back was consistent with a prioritized presentation of masculine competence, an alignment important to many. Further, it allowed the men to assure themselves and others that although they needed help in responding to the significant
physical, cognitive, and emotional shifts experienced and threatened in illness, they were
holding firm. In other words, amidst the seismic disruption to their body they were still
the person they had been, and they would emerge, intact and victorious. Notably, amidst
the intensity of this disruption some men acknowledged their performance as including
superficial displays of strength and surety. However, the intention was that this
temporary façade would eventually feel more honest as they worked back to normal.

As help seeking with a strong back oriented the men toward certain activities and
manners of performance it also informed which supports they prioritized. In particular,
as they sought to limit the infiltration of assaults and perform in a manner consistent with
their pre-diagnosis ways of being, they moved toward those they perceived as useful and
appropriate. First, in repairing uncertainties around their condition, they emphasized
persons who had already assembled the information they required, including medical
providers, acquaintances with health knowledge, and others with cancer, both within and
outside of cancer support groups. In turning to those expected to know more than they
did (by virtue of their medical training or lived experience) the men could adopt the
position of student, taking an active, responsible, and focused skill-building position
important to ‘mining’ the knowledge held by these ‘experts’.

Second, as they drew on the support (solicited and offered) of persons they
perceived as appropriately charged with their care (i.e. health providers, partners, family,
or close friends), the men were able to obtain many of the medical and practical supports
important to Fortifying Resources without deviating from ‘normal’ practice. More
specifically, the involvement of the medical team was accepted as a necessary part of the
treatment of serious disease. Although not always comfortable, the roles of physician and
patient were relatively prescribed as the men were automatically moved into the medical
system following their diagnosis. They could manage this relationship to reassert their
independence, as necessary, but to fully reject the care of their medical team would be to
fail to meet the obligations detailed for the patient role.

Further, although the workload of partners and selected family and friends often
increased amidst the period of active treatment, these individuals continued in expected
roles as physical and emotional care providers. In maintaining this relational positioning,
their support was less problematic. As Gerrard explained, his wife did what “you’d expect somebody that, you know, loves you, cares you…wants to…you know wants to be there by your side. Um, making sure that you know your pains in the night kind of go away […]”. Similarly, when describing the support offered by friends Arthur noted they, “didn’t do anything more than they would normally do when I was healthy you know,” affectionately detailing how they continued to “call or come around or harass me…[...] we’d go for lunch and that kind of thing [...].”

The assistance these individuals provided was not always flawless, sufficient, or easily welcomed. However, these support persons often did not need to be asked for help as the men sought to fortify body and mind; the support dynamic was built into the nature of the relationship and was nearly unremarkable in its omnipresence. In particular, as this support was perceived as consistent with the nature of the relationship, the men did not have to significantly adjust how they engaged with these persons, but could position themselves as taking advantage of resources both available and appropriate to the task. As Pete described, because he and his wife were a “unit” it would have been odd to ask her for help; when he required support, she just did it. Similarly, Earl explained that due to the “closeness” with his siblings, he “never contemplated” asking for their support. Further, the men could allow others to anticipate their needs, relying on physicians, family and friends to “monitor” them and take actions to facilitate transmission of support whether that be connections, information, or guidance toward a healthier lifestyle (e.g. partner altering meals they prepared, encouraging the man to wear sunscreen, exercise or rest).

In this process, few men explicitly referred to the activities of Fortifying Resources as help seeking, though they were composed of the essential elements of this process: an identified need addressed (even in part) with the support from others. Certainly, these men valued and explicitly praised the care delivered by health providers, partners, other family, and friends, and the assistance of those with cancer-specific knowledge or experience. However, as combined with a composed, stoic and steady ‘masculine’ performance and a focus on building personal capacity, the accessing of useful and appropriate supports in the service of battling their disease allowed men to
comfortably side step recognition of their vulnerability, both within themselves and as evidenced to others. Further, this was a process others were prepared to support (within limits) as medical staff were trained for this work, partners often socialized for caretaking, particularly as it followed expected gendered patterns, and others with cancer recognized the men as part of their community. Thus, even as the process and focus of help seeking with a strong back was composed of efforts both deliberate and difficult, it was largely unproblematic.

Although the presence of this help seeking process was barely acknowledged, it became obvious in situations where others did not respond as expected. Specifically, men described frustration with support persons they saw as insufficiently fulfilling the responsibilities and roles expected of them based on their relationship, including health providers, family, friends, and others with cancer who failed to anticipate or respond to practical needs, who delayed, withheld, or provided incomplete information, who offered inadequate medical care, or who responded in a way positioning the man as physically, cognitively, or emotionally compromised. These responses both restricted a man’s efforts to smoothly obtain the resources important to protecting himself against the assaults of illness and threatened his performance of continued competence.

This affront was particularly problematic as many struggled to handle their own emotions and continue a familiar way of being in spite of the severe assaults of illness. Given their often-tenuous grasp on normal, those challenging a man’s performance could easily trouble it. To protect themselves, some men would terminate or restrict a problematic connection or seek out alternate supports when one proved dangerous. Alternately, some would adjust dynamics within a relationship, pushing back against those who positioned them in undesirable ways by rejecting offerings viewed as unnecessary, “(re)asserting me,” or seeking to modify others’ perceptions. In this latter response, a man might take time to emphasize the high degree of trauma his disease had levelled while simultaneously demonstrating his fortitude and justifying the appropriateness of his request for informational or practical support. Or, as Michael explained, as men in his support group shared their “war wounds,” they were not just
evidencing the severity of their condition (and rationale for being there); they were also emphasizing their masculinity.

In soliciting and accepting help with a strong back the men sought to resist the tide of disorienting and difficult assaults. By protecting their body and a valued way of being against enduring change, they were protecting themselves. Others played a key role, not just through the tangible offerings they offered or provided upon request, but also as they reaffirmed the men’s value through expressions of caring (e.g. cards, flowers), their willingness to facilitate his efforts, and their commitment to who he had been and believed he would be again. This process was rarely smooth and many would find it insufficient amidst the intensity of the challenges they faced, but in this orientation the men were able to hold onto some degree of continuity of self in the present, and regain a sense of control over a future troubled by a tangible possibility of death and restriction. Through this process men could emerge from illness with a body more robust, a knowledge base positioning them as ‘experts’ on their disease (and thus able to educate others about screening, medical options, physical coping), and a sense of confidence in their value and their ability to move through challenge. In this, help seeking with a strong back not only allowed the men to resist identity shifts, but could also facilitate an enhancement of self.

“The more I share, the better I feel:” Soliciting support with a soft front.
Even as they held tightly to their trusted story, in the tumult of illness ‘normal’ shifted further from grasp and most of the men came to accept their life as altered in enduring ways. Often most apparent after treatment had concluded and expectations of a return were not realized, many men turned to others, seeking to sort through the impacts and meanings of this disruption. In contrast to the more independent Getting Through efforts oriented toward a distancing from emotions perceived as threats to efforts to hold onto normal (i.e. insulating, trusting, focusing on the present), interactive activities comprising this broader strategy allowed the men to spend time with losses, to express the emotional pain accompanying shifts, and to try to make sense of what these meant in terms of who they were and how they related with others. Beyond expression of sadness and fear through private tears, men who engaged their soft front as they showed worry, sought out
comrades, and solicited guidance brought their disorientation and loss into an interactive space. In recognizing how illness had shattered practiced expectations and ways of being, they found an opportunity to acknowledge the disruption they experienced and rebuild a coherent narrative.

Whereas help seeking with a strong back allowed the men to build resources and maintain identity claims as they emphasized on-going strength and stoicism in a fight against a great foe, help seeking with a soft front required that they accept their vulnerability. Whether they expressed their challenges with specificity or simply placed themselves amongst others also battered by an experience with cancer, in this emotionally infused process, the men were letting others know that illness was disrupting core ways of being and knowing, including the troubling of valued roles infused with expectations for how to be a competent man. They were acknowledging that, even for a time, their narrative was unclear, off course, and shifting in uncertain and uncomfortable directions and they were not sure how to move forward in this chaos: they were not emerging from this battle unscathed.

In contrast with the often-unproblematic process of help seeking with a strong back, the activities associated with soliciting support with a soft front were often more explicitly recognized as “help seeking,” as men both acknowledged their vulnerability and often required a degree or manner of support that exceeded or moved beyond the functioning of regular support systems. Even more, this performance conflicted with a presentation of masculinity prioritizing male stoicism, control, and self-reliance. Aligned with Scott and Lyman (1968) descriptions of how individuals offer “accounts” for behaviours they perceive as unanticipated or deviant, these actions were often contextualized by explanations, a rationalization process evident across the interviews, as well as in the content the men shared.

Although the men might emphasize the severity of their illness as they described how they solicited or accepted help from others in gathering information about how to handle their disease or in acting to heal or strengthen their bodies, few appeared to view this behaviour as inappropriate for men with cancer. In contrast, as they recognized a willingness to bring a discordant and troubled self into public view as problematic, even
amidst serious illness, our discussions often spanned two levels: a detailing of what they did and an explanation for why they did it. Seeking to legitimize their decision to present as one needing to be heard, understood, and led by others in restructuring a disrupted life many came prepared with accounts (a) highlighting other aspects of their broader self that positioned them as different from other men, (b) emphasizing their situational context as they argued that emotional expression was an inescapable part of the challenges they faced, or (c) reframing their behaviour as helping others.

First, some men explained that they were “different” from other men in regard to how they handled struggles. Consistent with patterns already noted, these men emphasized that while they recognized expectations of men as stoic and reserved, they drew on other elements of their broader narrative of self in a way allowing them to speak openly around difficult feelings. Some broadly attributed this way of being to their psychological “make up,” for better or worse, describing themselves as leaning toward emotional expression as linked to their personality or as modelled by their father. Others described how they had learned alternate ways to handle these struggles, whether by observing women in their lives (friends, partners, colleagues), engaging in therapy, or in recovering from addiction, abuse, or depression. A few linked their expressiveness to their sexual or gender identity, explaining that as these ways of being had positioned them as an outsider, they were released from some of the rules outlined by the dominant scripts for men, and some noted that in the context of their faith community this type of sharing was common, expected, and formalized. Finally, some men explained that with age and accomplishments came a reduced pressure to perform or prove oneself as competent through stoicism.

Second, even if they were not fully comfortable with expressing emotions or giving voice to struggles before their diagnosis, some men described this as an unavoidable part of the cancer experience, arguing that cancer “brings out” emotions even in men who do not typically respond to pain in this way. Consistent with this, men who described themselves as usually “stoic” or not very “emotional” described a shift in the course of their illness. Even more, many argued that the intensity of their experience left them with few options as they emphasized the acute risks faced in not opening up,
explaining that they would “spontaneously combust” if they tried to keep struggles inside or explicitly describing themselves as suicidal amidst the intense and enduring emotional pain. Although this process shared similarities to the rationalizations accompanying solicitation or acceptance of help for practical needs during active treatment, this was about exposing themselves as struggling not just as a body, but also as a self.

Finally, many explained that their decision to speak openly was motivated by a desire to help others with cancer, a process they admitted also provided benefit to themselves. Actively dismissing concerns about confidentiality and assuring me that they had “no secrets” with this, many argued that in speaking “openly” they could help “save” others from the pain they had endured. Even more, they could “give back” the help they had received. As noted above, help seeking with a strong back often moved men into a position of helping others as they employed the expertise they developed around their disease to encourage others to participate in cancer screening or offering advice on medical options and navigating physical impacts. However, by assuming the position of a helper, the men could also find a freedom to talk openly about their struggles, to “pour your heart out” as they moved beyond discussions of the medical aspects of their experience to share how cancer had troubled valued ways of being. Where disclosure for one’s self could be problematic, sharing for the aid of others was often viewed as more acceptable, aligning with a social prioritization of men as protectors as helpers or protectors.

Although equipped with justifications for their openness, many still took great care in selecting supports. Not only did they recognize that social prohibitions made this behaviour less expected for men, at a broad level, but they also understood that those close to them held images of them that could be disrupted by this expression. More specifically, others in their lives knew them as a certain kind of father, partner, friend, and employee and carried expectations for how they would handle crisis, assessments heavily infused with gendered patterns. In putting words to their feelings of disorientation and vulnerability amidst illness, the men risked breaking a mutual ‘trust’ in the continuity of self and worried that others might re-evaluate the connection, moving away or even rejecting an altered self. Although needing to disclose how cancer was
troubling familiar ways of being, the men sought to care for the integrity of these relationships.

Depending on the intensity or focus of their struggle and the nature and quality of their intimate relationship, some men felt secure ‘showing worry’ with a partner. Similarly, men who were single or who sought to protect their intimate relationship from presentations of self that felt too disparate from normal turned to those outside this relationship, including close friends or family members who knew them well and with whom they had experience sharing struggles. Consistent with the characterization of these supports as appropriate in the previous section, the disclosure of fear, sadness and disorientation could fall within the parameters of the existing relationship. Further, there was less risk of ‘losing face’ with those who knew their ‘back stage’ self and had made a commitment to them to remain connected across life’s challenges. However, when neither the connection with family members or friends was viewed as capable of withstanding the intensity of what they had to say, some men turned to outsiders, including therapists or others with cancer, individuals made ‘safe’ by virtue of their relational distance, shared circumstances, and/or obligation to create a protected space for disclosure.

In pursuit of comrades and guidance, the men were often challenged to move beyond those within their existing social network. In this, while sharing a diagnosis of cancer with another person might be sufficient to enabling a sense of connectedness, the process of seeking guidance often oriented the men toward supports who had a particular type of expertise based on experience or training (selected others with cancer, therapists). This emphasis on ‘utility’ echoes the focus on these types of supports in help seeking with a strong back. However, as the men disclosed difficult thoughts and emotions and struggled to make sense of the ‘bigger’ questions about the self these support persons also had to be safe and aligned. Thus, as men turned to guides to lead them through an unfamiliar world, they sought out those who understood the experience of cancer, who would not reject them, and with whom they could relate as an individual with a multitude of identities and experiences.
Although one person did not need to meet all these criteria, supports equipped with the right set of attributes and experiences could be challenging to access, particularly for men who were less comfortable with formal cancer programs. Even more, men struggling with the process of help seeking with a soft front could be reliant on others to ‘open doors’ to this expression, to invite discussion around concerns as they indicated through word and act that they were safe (e.g. “checking in” through genuine inquiries about how they were). Thus, as family, friends, health providers, and others with cancer reached out to them, some men would be led into engagement, though not all would walk through these doors.

Alternately, others who the men perceived as demonstrating discomfort with this expression or who indicated that they did not expect the man to present as compromised or altered could inhibit the men’s efforts. Moving cautiously and viewing themselves through the eyes of others, even the smallest gesture could be perceived as a warning that their disclosure of vulnerability would be labelled as transgressive and their disoriented or altered self would be rejected. In this, even men willing to engage others in the work of acknowledging and adapting to change could encounter an absence of venues available for this sharing or find potential supports held back by their own discomfort, including in the context of cancer support groups.

Not all of the men in this study moved into a ‘new normal’ across their illness career and even some who did recognize life as altered continued to reject or resist these shifts. However, the men who were able to show worry could find relief from the heavy work of upholding a façade of normality as they let others know that amidst the gravity of assaults faced, they were struggling, even changing. In this disclosure, they were not seeking advice, but asking for others to witness and be sensitive to this profound experience of disruption. Those seeking comrades could find a sense of connectedness or belonging in a community of those who understood, implicitly, what cancer had wrought in their lives. Amongst those sharing a cancer diagnosis, they could feel normal again. This was not the normal they had known prior to diagnosis, but an adjusted one in which the pain of loss, the uncertainty of ways of being were common realities. Finally, those seeking guidance could move beyond information gathering for the purpose of sustaining
an increasingly fragile self and learn how to refashion whom they were (and would be) amidst a life disrupted by cancer, asking to be socialized into this new reality.

Men who were willing to engage help seeking with a soft front and able to find others who would meet them in this space had an opportunity to acknowledge the disquieting shifts in how they lived as well as work on rebuilding a coherent sense of self. This could set them on a new path, and one that could take time to work out. As I met with these men, many had considered how cancer had altered them. In making meaning of this adjusted self, some emphasized positive interpretations. Stressing their thankfulness for survival, in spite of the costs, they described how the experience had led them to a new and valued way of being as they practiced thankfulness for what they had, focused more on relationships (over work or material goods), or felt a heightened confidence born of a successful journey through a challenging time.

Others detailed an adjusted state marked by discomfort and regret as they described themselves as “dialled back,” unsteady amidst a lost sense of control, and uncomfortably mortal. In this complicated transition, a new self was not labelled as simply better or worse, but carried shades of difference. Some resigned themselves to living amidst the complexity, as many continued to struggle to find coherence after their treatment ended. Although they might value elements of what they learned along the way, and might be thankful for their life, they might also long for who they had been, preferring the man who had been more independent, stronger, and more vital. In this, help seeking with a soft front neither ensured an easy transition nor promised a place of peace and comfort, but could be an important element in navigating this bumpy road.

**Patterns of carriage.** In Chapters 5 and 6 I detailed a range of themes present across diverse experiences. The theoretical story, as presented in this chapter, wove these pieces together to inform a deeper appreciation of ‘what is happening here’. As this substantive theory has been built through engagement with men’s lived experiences, it is helpful to take it back to the lives contributing to its formation; to see how this broad story lends insight into the twists and turns of lived experiences and the complicated story of self. In this process, it is clear that even as a cancer diagnosed forced these men to
walk a common journey, the activity of engaging help seeking with a strong back and with a soft front took on a range of appearances.

Again, if the reader brings to mind a taijitu, she can imagine how the concentration of these processes differed over the course of a single illness career and across the individual lives informing this theory. As indicated in the preceding discussion, the side representing help seeking with a strong back was fully engaged for most men across the course of their illness. However, the degree and timing with which men leaned into help seeking with a soft front varied. To illustrate this diversity, I briefly detail three broad patterns of carriage evidenced in these stories, drawing again on the men’s words to describe these processes. Notably, these are not presented as true forms, I do not position any of these as more ‘correct’ than the others, and I do not offer percentages indicating how many men congregated around a particular pattern (as focused on theory development, this sample was not selected for probabilistic generalizability). Rather, these are offered as illustrations of how a diverse group of men can engage different patterns of help seeking amidst the disruption of cancer.

**Pattern 1.** Some men appeared to rely almost exclusively on strategies oriented around help seeking with a strong back; their soft front was nearly invisible across the entirety of their communicated experience. In both the context of our interview and in the stories they told, these men sustained a relentless focus on how they battled back against their disease. Even as cancer compromised their body, disrupting their ability to sustain regular activities, and requiring them to lean on medical staff, family, friends, and others with cancer, they emphasized how they organized the contributions from these supports and described how the help they solicited or accepted allowed them to retain a focus on their goal of return. They might attend cancer support meetings, but this was to exchange information on their disease, not to share their experience.

These men were the central characters in their story as they emphasized their steady and stoic leadership in gathering information, making key decisions, and obtaining care important to controlling or eradicating cancer. As one man detailed, he arranged a meeting with his oncology team, and told them, “I am the quarterback and you are the players and I am calling the friggin’ shots.” He took a similar approach with his family,
describing how he sought to ensure that they were “handling” his cancer all right, anticipating their struggles as disruptive to his path.

In this organization, some men actively rejected any suggestion that they struggled emotionally, assuring me, as did one man, that my apparent search for “deep reactions” in his experience would not yield fruit. For others, this element was simply not a part of their story, except as they emphasized their coping skills. As one man argued, “you really have to depend on your own, um…ah coping mechanisms to…to get you through […] the whole thing. And some people have very poor ones. They…they collapse pretty readily and others ah…they can adopt a more stoic attitude.” He indicated that he fell into the latter category. In the context of the interview, these men often presented themselves as fully recovered from their illness. Cancer might have emphasized to them what was important in life, but they did not recognize illness as having altered who they were. As one man shared, “This is a bump in the road […] it reinforces who you are and that you’re not going to live forever and…and things happen for a reason.”

**Pattern 2.** A second group of men appeared to engage a balance in help seeking with a strong back and with a soft front across their illness career. Consistent with those in the first pattern, these individuals sought information and leaned toward supports they believed could help them sustain or regain a familiar life. But they also described how they quickly moved into a process of turning to others to share their fears, anxieties, and struggles in being diagnosed with cancer and experiencing an illness that assaulted both their present and future self.

These were often the men who drew on the first process of justification as outlined earlier: they identified themselves as “different” from other men, or less driven to be complicit with a culturally idealized masculinity. In this identification they did not need to delay help seeking until their condition grew severe or rationalize their actions as important to helping others. Their repertoire of response strategies already included a practice of moving toward others during times of crisis; help seeking with a soft front was part of regular practice. As one man noted, he responded to challenges in cancer as he did across life, reflecting, “You know, if I ever had a problem and wanted to talk to
someone, I would talk about it.” These men were also central characters in their story, but the cast of others around them was more apparent, acting with them, not just for them.

Consistent with their experience in opening up about challenges, these men often had networks of support in place before diagnosis that provided a regular venue in which to share struggles. This included men emphasizing a close and honest relationship with a partner that permitted disclosure around their sense of disorientation (those emphasizing how they shared “everything” with their partner), and it included single and partnered men drawing on supports beyond an intimate partner, including friends who “have your back,” therapists, and organized support communities. As one man shared, when he received his diagnosis he simply reengaged a therapist who had been working with him on other challenges, noting “So (chuckle) you know I just turned around and went…started going back (laughing) and ah…we…he opened the file.”

Similarly, others turned to church communities, drawing on small groups or prayer networks, while one man, a recovering alcoholic described how his AA group provided him a weekly venue to talk about his feeling, noting that “even though it’s…you know cancer is not part of the program, you can express your feelings.” As they experienced significant shifts, the disruption levelled by illness might exceed the threshold of existing relationships, but the activity of disclosure was familiar. Whether these men returned to normal or encountered a new normal at the end of their journey, they valued working through the pain of their condition with others.

Pattern 3. Finally, some men’s stories gathered around a third pattern. Similar to those in the first group, these individuals emphasized their own leadership and sought to move through this temporary trial by “shutting off” difficult emotions and “keeping focused on getting better.” However, in contrast to those employing this as single strategy (the first group), these men were triggered to engage help seeking with a soft front as they found that a return to ‘normal’ was not possible, a painful realization often apparent after treatment ended and losses remained. As one man shared, before cancer he had believed that life’s challenges were overcome through focused commitment, a way of living affirmed as he found success in striving for goals, achieving them, and moving on to the next pursuit. Understandably, he entered illness with this orientation, believing
that if he carefully followed the protocol he would be rewarded with health. But in this experience he learned that regardless of his commitment and perseverance, “there is no present in the end.” Others echoed this. These men began this journey as solo characters, but would come to recognize that they could not go it alone; a larger cast was necessary.

These men, like those in the second group, acknowledged the disruption levelled by their cancer. However, unlike those who moved almost immediately into help seeking with a soft front amidst this recognition, men in this group delayed this engagement until they were able to convince themselves and others of the necessity of opening up. This timing would vary from a few days to several years, but in all cases it was carefully considered. Specifically, these men drew on the latter two justification patterns detailed above, waiting to engage help seeking with a soft front until they could demonstrate that they had no other choice or were able to frame this with the goal of helping others (an acceptable masculine endeavour). They did not move into this experience positioning themselves as significantly different from other men in handling and expressing vulnerability, and they evidenced concern in presenting as insufficiently masculine, adopting behaviours associated with a subordinated masculinity. In this they did not always know how to do this work and could feel uncomfortable in the performance of it.

Inexperienced in the nature and quality of this engagement, these men often lacked an existing support network practiced in this exchange and could struggle to find suitable supports. Similarly to the second group, men in relationships might turn to partners, but as they required more extreme justifications for their communication (e.g. if this cancer “doesn’t kill me probably this depression will”), the intensity of the pending discussion could be interpreted as too heavy for their partner, particularly as it disrupted pre-cancer patterns of interaction. Propelled by a need for support, these men might eventually reach out to a trusted friend, therapist, or cancer support group, but as they journeyed into unfamiliar terrain, their movements were cautious and easily disrupted by those challenging the appropriateness of their acts. In this, while some found increasing comfort as they stretched the boundaries of how to be an acceptable man, many would continue to explain their response, to reassert their masculinity. As one man noted, he was “not a tree hugger,” he just practiced openness to help others. Struggling, delaying
action, and lacking both comfort with disclosure and an existing network for this support, these men appeared to be at particular risk for unmet needs, a dynamic that could leave them isolated and struggling.

**Restricted soft fronts.** As evident across these men’s stories, soft fronts were less anticipated, less welcomed, and often less comfortable than strong backs. This more limited and/or delayed engagement of help seeking with a soft front is not explained by an absence of a profound sense of vulnerability during their illness career. As illustrated in the assaults the men perceived, from the moment of diagnosis these men experienced cancer as a powerful and often emotion-infused blow to self that often remained palpable well after treatment ended. Rather, I argue that three social forces functioned to emphasize help seeking with a strong front over the equally valuable process of help seeking with a soft front. These included: (a) seeking a return, (b) resisting vulnerability, and (c) fearing rejection. Notably, although some of these patterns include elements common among those living with cancer, focus is on how these forces are emphasized for men in Western societies.

**Seeking a return.** As detailed, although few men had preconceived ideas for how they would move through illness, many focused on “getting back to normal.” Thus oriented, cancer was recognized as a physical opponent requiring timely, skilled medical intervention. However, many acknowledged that the task they faced was broader. As medical “mechanics” handled their disease, the men sought to sustain (or regain) a familiar story. Accepting responsibility in moving through this experience (others are with me, but this is my path), they were determined to prevent their disease from “overtaking” them. Separating self from disease, most neither anticipated nor invited an altered identity, particularly a way of being perceived as limited and shameful and which threatened their legitimacy as a father, a partner, a worker and a friend.

The nature of their disease appeared to fuel this pursuit. First, unlike those diagnosed with conditions more clearly chronic (e.g. multiple sclerosis, rheumatoid arthritis) a number of these men had a strong chance for the removal of their disease, with limited enduring physical impairments. Once they had shaken off the initial fear of death
rendered in the shock of their initial diagnosis, these men had good reason to believe life could return to normal.

Second, and more comprehensively, as many drew on “struggle language” common in cancer discourse (Seale, 2001), they referenced societal narratives of illness and cancer, more specifically, calling them to “outdistance mortality” (Frank, 1995). As detailed in the literature review, restitution stories are the preferred narrative of illness in contemporary Western society where “medical heroism” is praised. Seeking ‘good news’ stories of health, many expect illness to follow an organized path, contained by a beginning and an end (Remen, 1996). And those with cancer are expected to perform their own heroism in offering a disciplined body to medical care to defeat disease through both medical compliance and a force of will (Seale, 2002).

Considering gendered aspects of this popular discourse, Seale (2002) noted that media accounts often emphasize men’s abilities to emerge from the experience “unchanged,” as they position a cancer diagnosis as a “test” of a man’s “pre-existing character.” Even more, as restitution stories “conceal the agony” of illness, rendering silent chaos stories that acknowledge the vulnerability and sense of impotence often accompanying this experience (Frank, 1995), a cleansing away of the intimate devastation of illness can be particularly acute for men. As Seale (2002) explained, although popular accounts of cancer often detail how women “labour” through the fears and pain central to this experience, such stories tend to be silent on men’s emotional experience, positioning men as less “thrown” or “ruffled” by cancer.

This was not just rhetoric. As men aligned with others who had experienced cancer (and distinguished themselves from those who had not), these messages offered direction on how to navigate an uncertain path, including what to expect. Unfamiliar with a life affected by serious illness and oriented toward a return to normal life, it was not surprising that as these men entered this experience many did not fully anticipate their vulnerability as they focused on winning the ‘fight’, ‘fixing’ the problem, or engaging their foe with the prudence of a warrior. In moderation, this could be a powerful framework for the men (and for those who loved them) as it propelled help seeking with a strong back, enabling men to draw on formal and informal supports to block or mitigate
assaults while holding onto coherence in self amidst chaos. However, this focus on a return provided little space to consider the possibility that normal might not be regained.

**Resisting vulnerability.** The orientation toward a return to normal intersects with the second hurdle men faced: resistance to vulnerability. Regardless of one’s intentions, a sense of vulnerability is a nearly inescapable part of the disorientation and loss amidst life-threatening illness. As Frank noted (1995), although the “Phoenix does not mourn what lies in the ashes,” human illness “always returns to mourning” (p. 136). This painful truth is core to Halifax’s metaphor and was palpable in the stories men offered and in how they shared them.

Although all with cancer encounter the challenge to ‘fight’ their disease, this call to arms can be emphasized for men as it aligns with masculine ideals of determination, grit, and courage (Oliffe, 2006), a positioning accompanied by a rejection of physical or emotional weakness. In this framing, it is not surprising that many perceived vulnerability as dangerous amidst battle. Even men who might normally be comfortable as more “emotional” during times of good health sought to resist their vulnerability as they took control, pushed themselves to maintain practiced ways of being despite significant discomfort, and strictly managed engagement with emotions that might emphasize their fears and felt losses. For men believing there was space for only one victor in the war between cancer and self, acknowledgment of disorientation and loss stood in conflict with the goal of defeating the enemy (i.e. eradicating disease) and regaining normal. In this stance, it was not safe to acknowledge and engage with the painful reality of their disruption, let alone share these stories and have them heard by others.

Not all the shifts these men experienced were evidence that normality could not be regained. Further, there could be benefit in temporary efforts to resist a powerful sense of vulnerability, particularly as the men sought to get through the difficult treatment period. However, for those acknowledging a new normal, cancer had insidiously shifted from a distinct foe forcing them to navigate a detour in their story, to a force infusing their sense of self. Many could not fully reclaim their pre-cancer self. In this reality, those men who actively resisted an acknowledgement of their vulnerability risked mistaking a strong back with what Halifax has termed a “defended front,” a guarded and
more fragile stance motivated by fear or the desire to “conceal” doubt or pain. To borrow a popular (and problematic) phrase, in “manning up” to illness, men could position their vulnerability as fully inconsistent with their strength, rather than balancing a focus on rootedness with a recognition of the difficult struggle amidst disruption.

**Fearing rejection.** Even as many came to accept their own vulnerability, the extensive ‘justifications’ offered regarding help seeking with a soft front highlighted how many men felt restrained in bringing their struggles to others. More specifically, in the course of the interviews, men detailed an extensive awareness of gendered prohibitions restricting open communication regarding emotional struggles, describing how social codes complicated their abilities to disclose what they felt, or how they recognized this as a constraint for men in general. In describing these pressures, many emphasized that men clearly experienced emotional pain, but relative to women, were less likely to express it. In particular, some described women as more comfortable with emotions or emphasized that their training as a man had included the lesson that “it’s not manly to show your feelings”: they had learned to control expressions of fear and sadness, to resist “PDE’s” or “Public Display’s of Emotions,” even as some questioned the logic in this directive.

These arguments were often emphasized by the assertion that relative to women, men are more inclined to believe they can (and should) handle challenges on their own. Some described self-reliance as part of male “biological wiring” as others noted social pressures, describing it as part of the “aura of manhood,” and arguing that men are expected to “take care of it” and to do so “quietly,” adopting an “I can do this myself attitude.” Either way, they positioned men as particularly reluctant to talk about their vulnerability, interpreting this as a feminine approach to handling struggles and one that did not come naturally to men, a construction also observed in popular accounts of men with cancer. As Seale (2002) noted, relative to women, men with cancer are more often portrayed as “hard working,” “strong,” and “stoic.” Tears might be unavoidable, but choosing to put words to one’s expression of vulnerability or asking to be heard or guided by others was less expected and less comfortable. Thus, as a directive toward self-reliance was less disruptive to help seeking focused on resisting or denying vulnerability, it was often acute amidst the process of handling identity disorientation and adaptation.
Amidst these social discourses, not only was identity adaptation unwelcomed and vulnerability dangerous, but also the process of handling these challenges carried social risk. Recognizing men as ‘normally’ self-reliant and ‘normally’ emotionally reserved, the men were aware that others (friends, family, the researcher) could view openness around fear and sadness amidst the disorientation of illness as unexpected, even deviant male behaviour. Thus, even men with little regard for social pressures pushing them toward quiet and private coping took time to explain their acts, arguing for other models for being a man, emphasizing the severity of their condition, and emphasizing how they were helping others. These ‘accounts’ were important as men negotiated deviations from masculine ideals (i.e. different kind of man or as one lacking other options) or reframed their acts as aligned with the idealized scripts (helping others).

Even as men came to accept the value in reaching out, social prohibitions against expressions of vulnerability were reinforced as many found themselves standing alone, as one of few men in their support group or as engaged in open communication beyond medical aspects of their experience, and as they encountered potential supports (health professionals, family, and friends) who were unwilling to participate in this process. Men could accept that even ‘warriors’ need to connect with others about their struggles, but they also recognized this behaviour as unexpected among men. Not all felt equally bound by this social pressure, but for the many who did, even in part, the stigma of failing to perform as a competent man that coloured the threat of the identity disruption levelled by their illness also critically complicated their ability to solicit other’s help in handling it. Many perceived this social patterning as limiting.

Summary

As emphasized throughout this dissertation, identity is a social project. Individuals are ‘how’ they are with others, as they make claims and invite attributions by presenting themselves to others through word and act. Life with cancer complicated this process as it thrust these men into new ways of being. Their bodies were altered, their days were comprised of new situations and their performance of self was complicated by experienced and feared physical, cognitive, and emotional shifts that altered relationship
patterns and made it difficult to offer a presentation of self that was both consistent with the past and organized by a clear vision of the future.

In navigating the terrain of this disruption, men could lean into strong backs as they drew on the support of family, friends, health providers, peers with cancer, and others to sustain a grasp on a familiar way of being, and they could engage soft fronts as they turned to others to help them acknowledge and rework what no longer fit amidst the realities of unstoppable change. In Halifax’s construction, the intermingling of a strong back and soft front enables the “brave, tender ground” on which to engage suffering (p. 17); in this balance, neither stance reigns and a blended carriage is valuable in moving through disruptive experiences.

Amidst expectations of men as strong, active, and stoic leaders, strong backs were quickly engaged. As men struggled against the chaos of illness, soliciting the support of others in protecting their narrative was critical. Using Hewitt’s (1989) identity framework, holding onto this story of who they were would help men navigate the on-going problematic situations experienced in the day-to-day of life with cancer. In particular, a sense of self as distinct from others (personal identity) and reference to group norms for men and cancer patients (social identities) provided valuable direction to men and their supports as they were challenged to handle a new, and unclear role as one living with illness. Further, as Charmaz (1994) argued, a determination to ‘preserve’ the self can help one maintain hope amidst dire circumstances.

As efforts to Fortify cognitive and physical resources were accompanied by Maintaining the Familiar and independent Getting Through efforts, these activities did not require men to justify their actions or rework identity claims and were rarely acknowledged as ‘help seeking’, despite the fact that men were drawing on others to assist them in the difficult work of retaining or regaining practiced and valued ways of being and doing. Men might have to remind others of the viciousness of their opponent as they reached out for assistance, but help seeking with a strong back was accepted as a challenging, reasonable, and responsible approach for a man handling a devastating and deadly disease, an orientation reinforced by expectations that the ill ‘battle’ back against cancer (Seale, 2002). In this process, men’s acts smoothly aligned with masculine ideals,
even allowing men to *emphasize* themselves as strong and composed warriors.

However, as illness disrupted present and future ways of being and as struggles persisted well after physical traumas had abated, a pre-cancer narrative was difficult to maintain and many of the men were challenged to consider how elements of their story were shifting, particularly their ability to offer a competent male performance. Acknowledging disruption and adapting the self to incorporate the realities of illness, Charmaz (1995) has argued, enables honest closeness with loved ones. And expressing these struggles is critical in this adaption process (see Bury, 1991). Recognizing the loss and pain wrought by cancer can be a solitary process (i.e. facilitated through reflection, reading, journaling, etc.), but the identity work accompanying this profound, embodied disruption requires engagement with others.

Unfortunately, strong backs and soft fronts are not equally welcomed for men in Western societies. As many men struggled to anticipate and justify the need to engage others in handling the feelings of vulnerability and disorientation that accompanied their experience, discomfort and isolation could flourish in the space between the self that was known before cancer and a shifted one that felt increasingly true. Even more, in working to hold onto who they were (or reclaim that familiar self), these men were challenged to prop up a ‘life as usual’, a practice demanding careful and continual management of self and others that was not only taxing to self and detrimental to relationships, but which could also restrict their ability to engage in the work of adapting their narrative. Help seeking with a strong back was important, particularly in the earlier stages of illness, but as an *independent* strategy, practiced without the balance of help seeking with a soft front, it could falter amidst mounting and persistent shifts away from normal.

Alternately, the men able to combine a commitment to how they remained constant (help seeking with a strong back) with a degree of openness around their sense of vulnerability amidst so much change (help seeking with a soft front) had an opportunity to make sense of the shifts experienced in a life disrupted by cancer. Working with selected others, they could acknowledge how they were being physically, cognitively, and emotionally altered by their illness experience and, as necessary, renegotiate with others what it meant to be a competent partner, father, work, friend (and
more), identity work that could critically challenge or adjust the gender assumptions infusing these ways of being. Although not easy and often not perfect, this interactive process of realignment could be critical to rebuilding a coherent sense of self that was familiar to the men and to others, a process also important to diminishing feelings of isolation. For men feeling altered by their illness, an inability to engage this work could be devastating, leaving them alone and struggling amidst an uncomfortable narrative lacking integrity well after disease has passed.
Part 3: Concluding (and Continuing)
Chapter 8

Some Conclusions

As researchers seek to understand the experience of illness, there is value in considering how individuals make meaning of a day-to-day life lived “with and in spite of illness,” attending to meanings, context, and strategies of adaptation (Conrad, 1987, p. 4). This is the approach taken in this study. Although a growing body of research has explored why men do or do not seek clinical help when facing signs and symptoms of disease, limited attention has been devoted to how men are navigating needs and supports in the course of diagnosed illness. To help address this gap, this study oriented around two intersecting questions. The first considered how men with cancer perceive, interpret, and understand needs and sources of support during their illness and the second focused on how men work with others to address these needs.

As evident in these research questions and as detailed throughout the literature review and discussion of results, this study was organized around a broad conceptualization of help seeking. Although the term ‘help seeking’ is often linked to formal, direct requests for help, it is not limited to these. Further, as I observed resistance to this terminology in the course of the interviews, the language of “supports” and “challenges” allowed me to explore an array of activities these men engaged as they worked with others to respond to the assaults of illness. In this, although the men did not identify a great deal of “help seeking,” they provided numerous accounts of how they turned to others for their help in addressing a range of needs across this experience. These interactive activities of accessing support, processes at the heart of help seeking, would have gone unobserved had I relied on a definition of help seeking that was inattentive to this process as often informal and indirect.

Through the primary lens of symbolic interactionism, these research questions facilitated a study of meaning making related to this process of identifying needs and accessing supports. Rather than anticipating or cataloguing men’s needs or seeking to predict whether or not they would take selected actions, this study prioritized men’s perspectives. To understand how they responded in the course of illness, I examined how these men worked with others to define their experience of cancer and how they
perceived and presented themselves within this process. In this focus on matters of identity, my analysis accepted that the narrative of self that the men brought into this experience informed what they noticed as relevant, how they interpreted these elements, and how they worked with others to build acts. Even more, I acknowledged that the dynamic, embodied story of self could continue to evolve as men were challenged by an illness that severely troubles practiced ways of being.

Thus oriented, I met with thirty men who agreed to lead me through their experience. My research questions were quickly infused with the richness of the men’s lived experience. As each man presented a distinct story, the complexity of his experience was not just a product of the intersections of his social identities, but was filtered through a complex composition of self built over countless interactive events and informed by multiple social worlds.

Researchers look for patterns. In adopting a constructivist grounded theory methodology, I accepted the task of identifying common undercurrents infusing how these men defined illness and how they positioned themselves within it. In contrast to studies that profile and predict behaviour based on individual variables, I met with each man, exploring his experience and examining his story in relation to the others, moving across diversities in pursuit of commonalities in how these men made sense of situation and self. Seeking analytic generalizability, these shared processes were then worked into an integrated composition enabling a broad understanding of how men with cancer experience help seeking. Like a Chuck Close painting\(^1\), this is an image clarified in taking a few paces back, though it is composed, fully and essentially, of individual complexities that become stunningly visible in taking a few steps forward. Thus, broad patterns should be accepted with care and respect to the diversities within each individual life.

Holding onto my research questions and methodological goals as guides, I allowed myself to follow the terrain of the men’s experiences. Further, I maintained a practice of reflexivity, continually examining my role in the research process and challenging myself to spend time in the complexity of each man’s story, allowing space to witness contingencies I had not anticipated and resist the commonalities I could too quickly

\(^1\) [http://www.nga.gov/fcgi-bin/tinfo_f?object=69637](http://www.nga.gov/fcgi-bin/tinfo_f?object=69637)
assume. In particular, even as I prioritized a focus on gender in the development of this study, I sought to be cautious in how I engaged this lens.

A challenge in studies on gendered patterns is to resist the simple story. This temptation is acute in the context of a domain of study that has long emphasized masculinity as a ‘barrier’ to help seeking. Even more, it is facilitated by the propagation of assumed ‘truths’ about men and health prevalent in popular discourse (Oliffe, 2007). The broad integration of these assumptions was evident in a near perfect unanimity in how friends, health providers, and academics responded to the topic of my dissertation: “Oh [laughing], men don’t seek help, right?” Notably, given the relational nature of gender, this response was not just about men. In positioning men in this way, the accompanying, often implicit assumption was that women are ‘better’ at health. In particular, women were smoothly accepted as natural nurture/ nagggers who care for bodies (their own and those of others), and as comfortable in asking for medical help and pressuring men to do the same.

In accepting human lives as deeply and often unconsciously influenced by social forces organizing men and women as essentially distinct, it is easy to strip gender of its true complexity, leaning on comfortable stereotypes and blinding research to the dynamic nature of gender as both a located performance and part of a complex, integrated sense of self infused by a range of social locations and experiences. As Connell (2005) observed:

In many practical situations the language of ‘masculine’ and ‘feminine’ raises few doubts. We base a great deal of talk and action on this contrast. But the same terms, on logical examination, waiver like the Danube mist. They prove remarkably elusive and difficult to define (p. 3).

There is comfort in the polarity of women and men and the assumptions defining these locations, but gender is not so simple in day-to-day life.

A persistent positioning of men as ignorant or disinterested in health is criticized as incorrect, unproductive, and simplistic (Robertson, 2006; Smith et al., 2008). These assumptions deny men’s agency, burden women as responsible for health, obscure more complex (and often far more interesting) processes, and they are inconsistent with a contemporary understanding of gender that rejects dyadic and static categorizations of men and women. Thus, in moving beyond a deterministic approach in the study of men
and help seeking, integrating a broad view of help seeking, and practicing reflexivity and care in exploring men’s perceptions, interpretations, and actions, I challenged myself to be surprised by how each man thought and behaved. I accepted the influence of gendered scripts, but recognized these not as prescriptions, but as powerful guides, meshing with other directives informing how men made sense of situation and self amidst illness and how this meaning making influenced the actions they built with others.

In all of this, I sought to seize the opportunities for understanding that each man enabled as he shared his story, while also recognizing the limits in my ability to fully comprehend his experience. In this study I functioned as an outsider, less because of my social positioning, and more because of my health history. The men recognized this, I accepted it, and we continued on, willing to enter into an imperfect process focused on building understanding.

The product of this process has been detailed across the previous chapters as I detailed how men perceived the challenges of illness, what they did in response, and how these processes can be integrated into a story of men’s help seeking during cancer. In concluding this journey (for now), it is important to consider how this study fits into the broader, on-going discussion of how men handle needs in illness, the focus of the next section detailing how these findings integrate with prior research. Following this, I discuss the scope of this study and offer recommendations relevant to the research community as well as those directly supporting men with cancer.

**Key Findings Integrated with Previous Research**

This study offers a substantive theory of how men with cancer experience help seeking. In contrast to a heavy focus on prostate or testicular cancer in much of the work on men’s cancer experiences, this research includes voices of men with a range of cancer types. Even more, as I engaged a comprehensive conceptualization of help seeking I did not limit study to clinical help seeking, but devoted attention to formal and informal help seeking processes men engaged throughout their illness career. On this base, this study considered identity (dynamic, embodied, and intimately linked to context), not as a variable in whether a man asks for help, but as a social force woven into how he perceives and responds to challenges amidst illness. Thus structured, this theoretical
work recognizes how illness destabilizes the self and describes how help seeking can function as both a way of maintaining and reworking identity claims.

The findings offered by this study can be considered in relation to several bodies of literature. First is research focused on men’s health-related help seeking. As detailed in the literature review, this body of work has largely focused on men’s perceptions and acts during the period leading to an initial clinical visit. As I integrated a dynamic approach to the study of help seeking, my focus included activities beyond this early point of decision-making. In this scope, it quickly became clear that pre- and post-diagnosis processes of soliciting support are distinct (a point made by Robertson, 2007) and that for men experiencing a range of signs and symptoms leading up to their diagnosis, including an absence of perceived bodily shifts, an examination of common patterns required that I focus theoretical work on the period after men learned of their cancer. Although help seeking prior to diagnosis is not integrated into the substantive theory, in the summary section of Chapter 4 I have offered reflections on how these men’s perceptions and actions during this period align or differ from previous research.

In focusing on help seeking beyond the point of diagnosis, the findings engage with two additional bodies of literature. The first is the literature considering what men are doing during their cancer experience, including the study of the needs they perceive and prioritize and how they address these, a body of work introduced in the sections on ‘why cancer’ and included in the discussion of the expanded conceptualization of help seeking. Although this literature is not always explicitly framed as a study of men’s help seeking, it is relevant as it considers how men handle perceived challenges during illness. The second literature includes research on how illness can disrupt identity. This work, including key identity challenges in men and research on ‘embodied masculinities’ was detailed in the context of a symbolic interactionist perspective and referenced in the Discussion chapter as I introduced the ‘biographical disruption’ concept.

Given these points of connection, the findings built through this study are examined in relation to these additional bodies of work, with discussion organized around how this theoretical work challenges and enhances current understanding related to: (a) how men perceive illness, (b) how they respond to needs, and (c) how men handle
identity in the context of their illness.

**Perceiving Illness**

As introduced in Chapter 7, as these men emphasized how cancer troubled an anticipated future, made their present discordant, and left them feeling isolated and disquietingly uncertain, their descriptions of a destabilized self resonated with theoretical work characterizing illness as a biographical disruption or an identity ‘turning point’ (Bury, 1982; Charmaz, 1983). Even more, in describing how illness challenged their ability to present as one who is independent, vital, and physically robust, the specific elements of this struggle aligned with descriptions of how illness can level particular threats to male identities as organized around ideals of autonomy, activity, and power (Chapple & Ziebland, 2002; Charmaz, 1994; Kelley, 2009; McVittie & Willock, 2006; Oliffe, 2006; Robertson, 2007; Watson, 2000). Consistent with this, for these men illness threatened not just an altered self, but also a self that was ‘less than’ it should be.

As the findings here align with those observed in previous work, they also challenge research to recognize diversities and to consider male bodies more fully. First, these shifts were not equally threatening. These men shared a common focus on certain ways of being as more valued, but limitations could be less stigmatizing for men who had experience deviating from dominant masculine ideals as they drew on other scripts (sexual/ gender identity, religion) or who entered this experience recognizing a wider path of male expression as influenced by a life challenging them to try other ways of being (e.g. traumas, work experience, etc.).

Further, the evaluation of threats could vary depending on the context, as men recognized certain ways of being as more or less problematic depending on who stood as witness. Even more, as the severity of these challenges intensified or diminished over the course of illness, the evaluation of who was a ‘safe’ witness could change. Recognition of this variability aligns with social constructionist demands for increased attention to identity intersectionality and greater consideration of situational context in the study of men’s health behaviours, while extending this call into the examination of how men perceive and interpret needs during illness.
Second, although some of the work on identity threats among men with illness is inclusive of a range of diseases, much of the literature examining men’s ‘embodied’ experience of illness has focused on the lives of men with prostate cancer. This research offers critical value in understanding “how masculinities […] are mediated by illness experiences” altering both the structure and functioning of the body (Oliffe, 2006, p. 428). However, impacts to sexual functioning are disproportionately emphasized when attention is limited to this cancer type.

As demonstrated in this study, a threat to a man’s sense of vitality is inclusive of sexual impairments and/or loss of sexual desire, but it is not limited to these. As these men experienced a range of physical shifts leading them to reconsider themselves as a social object, they struggled to present as one who was ‘potent’ in diversity of ways: as a man who contributes and has a meaningful impact in the home, the community, and the workplace. Consistent with Robertson’s (2007) arguments, disruptions to a man’s embodied sense of self as strong and active can take a variety of forms in the context of a diversity of cancer types. This awareness is important to recognizing the gendered experience of cancer as not limited to diseases particular to the male sex. Other impacts should not be minimized through a lack of attention.

**Responding to Illness**

As their cancer diagnosis delivered a thundering recognition of their mortality these men released a long-held claim of ‘good health’ and medical supports were accepted as essential and engaged universally and with little hesitation as men were immersed into the health system. This pattern is consistent with Robertson’s (2007) observations that men can recognize clinical help seeking as a legitimate practice amidst illness. Even more, this medical compliance as combined with a sense of personal responsibility in handling their illness aligns with Robertson’s (2006) argument that men can experience a “moral obligation” to discipline their body back into proper functioning. This directive, it should be noted, might be even less problematic in a Canadian context than in nations lacking a universal health system. In most cases, these men did not have to consider the financial burden of their treatment, apart from select medications.

However, the story did not end there. For men experiencing illness as a
biographical disruption, the needs associated with cancer extended far beyond clinical
treatment of disease. As Micky shared, “the other needs to deal with are…to me, I think,
more important than the medical needs. The medical needs will happen, as need be.” In
other words, a vulnerable body set them on this path, but a vulnerable social self was
engaged in the response. Existing research on men’s acts during an experience of cancer
does not always integrate explicit attention to these matters of identity, particularly
identity as a dynamic, embodied, and situated process. But it is valuable to consider how
men’s engagement of ‘strong backs’ and ‘soft fronts’ has been evidenced in previous
research. Notably, as previous work has not examined these as complementary
processes, they appear distinct in the following section.

**Emphasizing strong backs.** Most of the current work on how men navigate
cancer provides similar evidence regarding activities I described as help seeking with a
strong back. In particular, as noted in the literature review, previous research has detailed
men’s efforts to build cancer-related knowledge (Bottorff et al., 2008; Breau & Norman,
2003; Oliffe et al., 2008; Seale et al., 2006) and enhance physical status (Gray et al.,
2000; Kelley, 2009; Oliffe, Davison, Pickles & Mroz, 2009), adaptive help seeking
activities aligned with the efforts described by men in this study and which comprise the
Fortifying Resources strategy. Further, much of this existing work acknowledges the role
of female partners and cancer support groups (online and in person), patterns again
consistent with those observed in this study.

As evident here, though, the support circle can be broader. Partners (female and
male) and support groups were important, but these men described how they also drew on
the critical assistance of friends, adult children, extended family, and ‘friends of friends’
with medical knowledge and/or cancer experience as they sought to fortify their
understanding and their body. Even more, men prioritized certain supports depending on
the nature of the need. For example, although others with cancer were perceived as
helpful in anticipating what was coming, medical providers were recognized as key
resources as men sought to understand their disease. Further, partners and
complementary health providers (e.g. naturopaths) were accepted as valuable and
appropriate supports in work to enhance physical resources through diet, exercise, and
general physical care, a finding aligned with patterns observed by others (e.g. Mroz, Chapman, Oliffe & Bottorff, 2011; Oliffe, Davison, Pickles & Mroz, 2009, Rose et al., 2000). Notably, these evaluations could be modified depending on the availability of prioritized resources.

Moving beyond the Fortifying Resources strategy, others have documented men’s pursuit of a ‘normal’ life (Gray et al., 2000; McCaughan & McKenna, 2007). This pattern has been observed in the ill more generally (Bury, 2001), but is consistent with an emphasis on strong and active male bodies as signs of normal, healthy functioning (Robertson, 2007). More specifically, the activities detailed as part of Maintaining the Familiar and the independent Getting Through efforts align with research describing how men with cancer can limit disclosure around their illness and associated limits, reassure others that all will be fine, avoid requests for help, sustain regular relationship dynamics and roles (Gray et al, 2000; Kelley, 2009), and manage difficult feelings through withdrawal and humour (Chapple & Ziebland, 2004; Moynihan, 1998; Oliffe, Ogrodniczuk, Bottorff, Hislop & Halpin, 2009). As much of the existing research in this area focuses on men with prostate or testicular cancer, this study has highlighted these patterns among men with a variety of cancer types while also introducing a detailed range of related activities.

**Minimizing soft fronts.** Existing research has recognized help seeking for mental health issues as particularly stigmatized amidst expectations of men as controlled and stoic (Addis & Mahlik, 2003; Barbee et al., 1993; Galdas et al., 2005; Moller-Leimkuhler, 2002; O’Brien et al., 2005; Oliffe, Ogrodniczuk, Bottorff, Johnson & Hoyak, 2010). Although men are acknowledged as experiencing significant and enduring emotional pain during a cancer experience (Goldzweig et al., 2009; Pudrovsk a, 2009; Rieker, Edbril & Garnick, 1985), research has documented men’s reticence in communicating about these challenges, with some exceptions made with intimate partners (Gray et al., 2000; Kelley, 2009; O’Brien et al., 2011; Moynihan, 1998). These patterns align with those observed in this study, as many men struggled to engage interactive efforts in the strategy of Getting Through (i.e. showing worry, finding comrades, seeking guidance).
However, this study enhances understanding in two key ways. First, as consistent with an appreciation of lived experience of masculinities, not all men in this study were equally restrained from this form of help seeking. In particular, men with existing support networks including partners, therapists, close friends, and religious or social organizations practiced in these types of discussions could more easily access others with whom they could open up about their vulnerability. Further, men could justify their engagement, highlighting a sense of ‘difference’ from other men, the severity of their condition, and/or a desire to help others. This pattern shares similarities with those arguing that men can draw on other aspects of their identity to legitimize help seeking that deviates from masculine ideals (e.g. O’Brien et al., 2005; Galdas et al., 2007; Robertson, 2003) and aligns with Addis and Mahalik’s (2003) assertions that men are more likely to ask for help if their peers are supportive and if they perceive their challenge as ‘normal’ given the circumstances. However, these findings extend current understandings by detailing a range of justifications and illustrating how assessments evolve over the illness career.

Second, as men described how medical staff, friends, children, extended family, and others with cancer could both facilitate engagement with their vulnerability and pull them away from discussions of emotional turmoil, this study has highlighted and provided detail on bi-directional forces both enabling and restricting engagement with vulnerability. In reference to enabling forces, this study recognizes the influence of those beyond a marital partnership and also offers more specific insight into this dynamic in the context of how men navigate this engagement over the course of illness and in the context of particular needs.

Further, this study draws attention to how this process can be restricted by others in a man’s life who are also referencing social expectations emphasizing male stoicism and control. Existing research has described cancer support groups used by men as prioritizing information exchange over personal sharing (Bottorff et al., 2009; Breau & Norman, 2003; Seale et al., 2006; Volkers, 1999), it has recognized how practitioners can fail to anticipate men’s emotional needs (e.g. Moller-Leimkuhler, 2002), and it has been argued that health resources targeted at men can reinforce hegemonic masculine ideals as
they ignore men’s vulnerability as bodies and selves (Kelley, 2009; Gray et al., 2002). Consistent with these patterns, as men in this study noted a plentiful supply of resources focused on their disease, many described others as less prepared for, and less comfortable with, assisting them in handling emotional issues, a dynamic that could reinforce a perception that these needs were abnormal for men or best handled alone. In highlighting how these forces at the institutional and interpersonal level can critically challenge men’s ability to engage emotional supports, this study challenges an orientation that might ‘blame’ men as solely responsible for a breakdown in this form of help seeking.

**Handling Identity Disruption**

As this study aligns with and extends previous research considering how men make sense of serious illness, including cancer, and how they handle challenges during a cancer experience, it also offers an opportunity to understand how the help seeking process influences identity work in the context of a biographical disruption. In particular, this theoretical work lends insight into Charmaz’s (1994, 1995) observation that men can take an “all or nothing” approach to identity work amidst illness; to “give up” when unable to maintain a past, preferred identity.

More specifically, Charmaz has argued that women tend to show greater resilience amidst chronic illness, adapting to the experience in ways allowing renewal of self. In contrast, as men focused on reclaiming a pre-cancer way of being, she asserted that illness could have positive impacts as others rallied around them to affirm their pre-illness identity (as valued men, fathers, partners, employees, etc.) but it could also be linked with a diminished sense of self as men experience a life that is increasingly severed from ‘normal’.

Although emphasizing men as less likely than women to adapt their identity in relation to illness, Charmaz did not deny men could. And researchers examining illness as a disruption to embodied masculinities have detailed how men can adjust or reformulate gender performance (within social limits), as they accommodate limitations levelled by their illness (e.g. Chapple & Ziebland, 2002; Gray et al., 2002, Oliffe, 2006; Riessman, 2003; Robertson, 2006). Consistent with this scholarship on identity and illness, the study detailed here accepts identity as dynamic, embodied, and interactive.
On this common ground, it enhances the existing dialogue by demonstrating how help seeking can be engaged in ways allowing men to resist and adapt a self that has been destabilized by cancer and considers the impact of a lack of balance in this effort.

Facilitating resistance. Aligned with Charmaz’s (1994) argument that men tend to use strategies of control (“timing, pacing, staging”) to present a public self as unchanged, this study evidenced how men engaged help seeking with a strong back to emphasize their independence, strength, and vitality both in the focus and process of obtaining supports amidst illness. As men sought help to fortify their cognitive and physical resources, these activities were not in conflict with a dominant masculine script. In fact, as combined with Maintaining the Familiar activities and independent Getting Through efforts, they allowed men to adhere to masculine ideals of control, leadership, strength, and stoicism. Even more, resources acquired could help men compensate for losses they were unable to stem. For example, they might not be able to continue working for pay, but they could experience a degree of continuity in taking on a new role at the cancer centre, in the community, or at home, integrating familiar ways of being with new expertise.

This pattern directly challenges a common positioning of help seeking as ‘essentially’ in opposition to masculine ideals, including arguments that in order to engage help seeking men must negotiate an identity deviating from hegemonic scripts (e.g. McVittie & Willock, 2006). That might be necessary in engaging help seeking with a soft front, but it is less true for help seeking with a strong back. Others have made this point. As noted, Robertson (2003, 2007) argued that the clear distinction men tend to make between health and illness allows them to draw on hegemonic values (not deviate from them) to recognize help seeking as a reasonable and rational choice in the context of a health risk, accepting serious illness as a legitimate reason for moving toward the ‘should care’ side of the “don’t care/ should care” dilemma.

Further, O’Brien and colleagues (2005) asserted that depending on a man’s broader identity composition and disease type, he might evaluate clinical help seeking as a legitimate activity during periods of good health and in illness and use it as a strategy to ‘preserve’ or ‘restore’ a prioritized masculine presentation as one who is strong,
contributing, and virile. Similarly, researchers have described how men draw on masculine ideals of knowledge and control to position themselves as “lay experts” and “legitimate users” of medicine (Farrimond, 2011; Noone & Stephens, 2008). These assertions resonate with the argument that in a society valuing health, a drive toward ‘healthiness’ is not always disruptive to hegemonic ideals, but can be a way for men to demonstrate power, control, and even self-reliance (Crawford, 1994; Farrimond, 2011; Pietila, 2008). For men in this study, as help seeking with a strong back enabled resistance to the emotional and physical vulnerability posed by cancer, this process could function as a way for men to demonstrate, even emphasize, masculine competence.

Facilitating adaptation. However, many of these men also (eventually) engaged help seeking with a soft front in efforts to acknowledge and rework a disrupted self. Even as previous research has recognized identity adaptation among men with cancer as possible, limited attention has been devoted to how men are working with others to navigate this shift. In discussions of men renegotiating masculinities in the context of health and illness, scholars have hinted at the value of ‘models’ for men (Kelley, 2009), trusting relationship with health providers (Kelley, 2009), discussing losses with partners (Oliffe, 2006) or telling illness stories more broadly (Riessman, 2003) and finding ‘safe’ environments that include others who will appreciate or understand an altered way of being (O’Brien, Hunt & Hart, 2009).

As the interactive Getting Through activities detailed in help seeking with a soft front align with these considerations, this research extends understanding as it illustrates how men turned to others for help in acknowledging threats and reworking a self destabilized by cancer, including asking others to witness their pain, to include them in a community of others sharing this experience, and to be guided by others. Further, in drawing attention to the justification process accompanying this process of help seeking, this research evidenced how men can be challenged to both negotiate deviations and renegotiate alliances with dominant masculine scripts to engage this process. In contrast to the ease with which help seeking with a strong back was positioned as a ‘reasonable’ male response in the context of serious illness, the ‘accounts’ men offered for help seeking with a soft front explicitly recognized expressions of vulnerability as deviant and
required men to distance themselves from dominant masculine ideals, adjust their construction of what it meant to be a competent man, or reframe their behaviour.

**Differently enabled.** As help seeking is accepted as a tool in both resisting and enabling identity adaptation, this study has highlighted how social norms discouraging male vulnerability can compromise the interactive process important to adapting the self. More specifically, in terms of identity work amidst a biographical disruption, this gendered dynamic indicates that while men can often comfortably turn to others ready to assist them in maintaining or recapturing who they *were*, they are often more challenged to engage and access supports willing to help them recognize losses and work through who they are *becoming*.

In this, the “all or nothing” dynamic Charmaz (1994) observed could be as much a consequence of discomfort in male *expressions of* how illness destabilizes the self as it is about resistance to the disruption itself. Further, as evidenced here, this is a bidirectional challenge. Both men and potential supports (individual and institutional, formal and informal) can be challenged by expectations of male stoicism and continuity in the face of illness. In this space, men unable to justify and effectively engage help seeking with soft front when experiencing a disrupted self can be forced to maintain a fictional identity (Charmaz, 1995) and experience the painful isolation of a growing chasm between the self that was and the self that is.

**Considering Scope**

I have chosen not to title this section as ‘limitations’, although that is how it is typically presented. In this, I do not seek to suggest that this study is without methodological and analytic gaps. That is not the case. This study included some voices and it omitted others. It explored certain processes and left others less examined. These matters of circumstance, analytic choice, and conditions related to the examination of social reality mean that although this study offers some clarity, important questions and uncertainties remain. This is an appropriate condition of a substantive theory presented as generative, rather than definitive (Daly, 2007).
Thus, although it is critical to consider how this study is limited, a consideration of scope recognizes that this research does not stand alone, nor are understandings generated here offered as final or static. This study is located within a broader process of knowledge generation around the phenomenon of men’s help seeking and these considerations do not just identify gaps, but can also propel additional avenues of research and/or ensure caution in how findings are used, matters explored in the Recommendations. In this spirit, I detail several methodological and analytic considerations of scope, including (a) recognition that certain voices are emphasized in this study, (b) findings illustrate broad patterns, not individual particularities, (c) focus is on meanings, not outcomes (d) findings are built on the men’s point of view, and (e) theory is built of subjective interpretations (not facts).

**Certain Voices are Emphasized**

First, the substantive theory offered here was constructed through the conversations with men who were willing to talk with me about their experience. Recruited through support centres, most (although not all) of these men had taken steps to engage with others about their cancer in a more formal way before our interview. Many did not begin their journey with an orientation of openness around all aspects of their experience, and some remained guarded in the interview, but all were willing to talk about their cancer and this was core to developing an awareness of men’s perceptions, interpretations, understandings and actions over time.

Further, with few exceptions this study was built through the participation of able-bodied, Caucasian Canadian-born men without a history of illness. Those who were immigrants had been in Canada well over a decade and all but one was of European descent. Although the men’s biographies were far from uniform as participants claimed a range of ages, interests, family statuses, occupational and educational experiences, personal economic realities, sexual or gender identities, and life events, different patterns might have been noted in a sample of men recruited through avenues not associated with formal support networks or if the study had included men with disabilities, who had a history of serious illness, or the voices of men from a wider range of racial and ethnic backgrounds, including recent immigrants from non-Western nations.
Focus is on Broad Patterns, Not Individual Particularities

In exploring men’s shared experiences, this theoretical story does not offer a detailed analysis on individual particularities. Although I sought to emphasize the presence of diversities throughout the findings and included discussion on how men drew on particular aspects of their biography and situational context in explaining their interpretations and acts, I do not compare men according to their demographics. Further, in contrast to existing work on prostate or testicular cancer, I do not detail how certain cancer forms or treatments levelled particular threats to how men perceived and performed a valued self. Similarly, as I integrate some consideration of disease prognosis, I do not offer extensive detail on how men with chronic or terminal conditions might differ from those with more treatable cancers, and I did not distinguish between men at different stages of ‘recovery’ from their disease at the time of the interview.

Consistent with the process and focus of constructivist grounded theory I examined meanings and pursued common themes on the path to developing a substantive theory capable of lending insight into powerful undercurrents in how men perceive, interpret, and respond to needs across an experience of cancer. Through the integration of a range of voices, this study enabled an understanding of shared patterns in help seeking among men claiming diverse personal and social locations and contexts, and among men experiencing a variety of cancer types, prognoses, and stages. However, in emphasizing the common story, this study does not offer specifics on why individual men carried themselves in particular ways.

Emphasis is on Process, not Outcomes

Although much of the existing research on men’s help seeking takes a deficit perspective in asking why some men are not good at asking for clinical support, this study examined how men make sense of needs and supports and work with others to handle challenges over the course of their illness career. In this approach, focus has been placed on the process of help seeking, not outcomes of these activities. Certainly, I argued that men can use help seeking to facilitate different forms of identity work (i.e. resistance and adaptation to change) and that there is evidence that men achieving some degree of balance in help seeking with a strong back and with a soft front had access to a
broader range of resources that could be important to handling an array of challenges posed by a disrupted sense of self. However, I did not collect information on whether or which compositions of help seeking processes resulted in ‘successful’ resolution of challenges, nor is there sufficient data to reflect on the outcomes of the identity work.

**Focus on Men’s Point of View**

Help seeking is an interactive process engaging both seekers and helpers. However, as I focused in on the men’s subjective experience, their descriptions were not complemented by the perspectives of others who were intimately woven into this process (e.g. health practitioners, partners, children, friends, etc.). In this dynamic, as I enquired about what the men noticed, what they thought, what they did, and how they worked with others, the men could choose to highlight or deemphasize events or relationships. They could attribute the acts of others to themselves and they could step over aspects of their story they did not wish to bring to light or which simply seemed less important or memorable given their constructions of the events.

**Theory Built of Interpretations**

This theoretical story is built on what Bury (2001) described as ‘factions’. As the men described their experiences through the lens of their own subjectivity, the stories they shared were not received as “true” accounts of an illness experience, but as narratives inextricably entwined in the “social fabric” of these men’s lives and their presentation of self within the interview (Bury, 2001). As a participant, I also brought subjectivity to the stories as I designed the research, guided the discussions, sorted through transcripts, and pieced the theory together.

These interpretations of a complicated experience were on-going as the men reflected on their past in the context of the present and as I continually reengaged with their stories over the course of an analytic process continuing even as I write these final pages. In accepting facts and values as intertwined, an on-going process of reflexivity helped foster my awareness of the assumptions informing my interpretations and those of the men I interviewed (Charmaz, 2006). However, as I accept knowledge as located, I
acknowledge that a different group of men working with a different researcher are likely to have produced a differently textured theoretical story.

**Recommendations**

In efforts to expand and apply findings developed through this study, recommendations are offered regarding (a) the study of men’s help seeking, (b) the development and refinement of this theoretical work, and (c) efforts to move theory toward practice.

**Studying men’s help seeking**

There is value in widening the scope of research on men’s health-related help seeking. Specifically, there is a need to (a) integrate a broader conceptualization of the core concept of help seeking and to (b) consider the experiences of men experiencing a diversity of disease types.

**Integrate a broader conceptualization of help seeking.** There is value in considering how men move toward an initial clinical visit in the context of problematic signs and symptoms. However, this narrow focus is insufficient in efforts to build a comprehensive understanding of the broader phenomenon of men’s help seeking as it occurs across time and in the context of a variety of social interactions. In broadening the conceptualization of this key concept, research focus can move beyond a study of individual characteristics toward a consideration of a subjective, interactive and on-going process of identifying challenges and negotiating support.

More specifically, as detailed in the literature review, integration of a dynamic and inclusive approach to help seeking can enable researchers to consider what challenges men perceive during an illness career, how they interpret these, how they engage informal and formal supports, employ a variety of help seeking strategies, and adopt a range of approaches to obtain help. Further, there is opportunity to understand how this process evolves as men integrate learning from a range of help seeking experiences. Included in this expanded view is the value of using the term ‘help seeking’ with care. A narrow association of this term with explicit and formal requests for help (accompanied by a position of dependence) is apparent not only among researchers, but
also among the participants in this study. Researchers need to be sensitive to the weight of this language and make efforts to ensure that a reliance on familiar definitions does not inhibit an examination of how men are engaging in processes of soliciting support.

**Examine a broader range of disease types.** As noted throughout this study, much of the existing work on men’s help seeking and illness response focuses on men with prostate cancer. Again, there is value in exploring the qualities of this embodied experience, particularly given the high rates of this cancer type. However, there is a need to also consider how men with a diversity of cancer types, prognoses, and stages experience help seeking (in addition to these processes in other forms of severe or chronic illness). This study offers some understanding, but other voices must join the discussion and work against an implicit assumption that men’s health is limited to diseases of male anatomy. The gendered experience of illness is broader and research must be prepared to inform services inclusive of men with many forms of cancer.

**Developing this theoretical work**

This generative theory can continue to evolve as research is devoted to the study of (a) the experiences of a broader diversity of men (b) caregiver perspectives, (c) critical turning points, (d) outcomes of different help seeking patterns, and (e) help seeking process in other substantive areas. This is not a complete list, but a sampling of possible future directions.

**Engage a broader range of voices.** In pursuit of analytic generalizability, I examined men’s experiences as embedded within a broad social dynamic (Charmaz, 2006). As evidenced in the diversity contained in this study, variations in a man’s personal biography and context influence the points of social vulnerability a man notices in the course of illness, the degree to which he accepts these as stigmatizing, and how comfortably a man engages a balance of help seeking with a strong back and a soft front. Further, scholarship on ‘biographical disruptions’ has evidenced that severe or chronic illness is not always destabilizing to the self, as older men, men with a history of illness or other hardship can come to anticipate a loss of good health.

In further developing the substantive theory presented here, attention to more
voices will both nuance this work and enable consideration of how (and whether) this theoretical story lends insight into a broader range of men’s experiences. In addition to a need to hear from a more ethnically and racially diverse group of men, particularly men from non-Western nations, recognition of masculinities as influenced by social and personal identities carried into a diversity of situations can propel research focused on the experiences of men with disabilities, men with a history of trauma related to illness or other critical life events, and men with different self construction strategies (as detailed by Hewitt, 1989).

**Consider caregiver perspectives.** In relation to the impact of help seeking processes, there is value in considering perspectives of key support persons working with men. This study offered detailed information on what men noticed and how they positioned themselves in this journey, but given the bi-directional nature of help seeking and evidence that others can facilitate and/or inhibit forms of help seeking, there is value in complementing this understanding with a study of how those providing care make sense of the process. There is some research on the experience of wives or adult children acting as caregivers, but given the range of supports on which men draw (including that not all men have female partners or children) future work can expand attention to also include male partners, close friends, others with cancer, health providers, or others key in a man’s experience with a specific focus on help seeking processes.

**Examine turning points toward help seeking with a soft front.** While they moved quickly into help seeking with a strong back, many men evidenced significant hesitancy in engaging help seeking with a soft front. Given this dynamic, there is value in considering turning points in how men move into the latter process, exploring in greater detail how they perceive and interpret challenges related to identity destabilization and how they move toward others to solicit related assistance. These efforts could draw on learning from research focused on men’s feelings of destabilization, including literature specifically examining men’s help seeking related to mental health challenges (e.g. Moller-Leimkuhler, 2002; Oliffe et al., 2010), and should be attentive to a range of forces at play, including a man’s personal history and resources, particular needs, and his relational and situational context.

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Among a range of additional theoretical lenses that might assist in this effort, research could draw on resilience theory to organize a study of how engagement of help seeking with a soft front is influenced by protective processes (or “assets”). Although often conceptualized as a trait, recognition of resilience as a process enabling individuals to sustain well-being could facilitate a focused study of how a man’s personal biography (i.e. values, sense of purpose) intersect with community and institutional level forces (Masten & Obradovic, 2006; Rutter, 1999; Schoon, 2006) informing how he perceives available supports and engages this often more challenging form of help seeking. This orientation, consistent with the social determinants of health model, would offer a valuable framework for considering the intersecting internal and external forces influencing how men respond to feelings of disruption. In addition, as contrasted with a deficits model, efforts to “map” assets offer a more positive approach to exploring related facilitators and barriers within a community or institution (Morgan & Ziglio, 2007).

Further, as this study evidenced the influence of bi-directional forces in men’s ability to engage help seeking with a soft front, future work could draw on attachment theory (Bowlby 1969, 1973) to explore this process as influenced by expectations and qualities of help seekers and care providers. Through this lens, research could examine dynamics in specific support relationships, enhancing understanding around the relational bond between men and those evidenced as key in help seeking with a soft front (i.e. partners, adult children, close friends, and others with cancer) and considering how relationships are experienced as ‘safe’ (or not). Work by Barbee and colleagues on interactive coping might be particularly valuable in sensitizing this research, given their focus on help seeking dyads related to emotional challenges (e.g. Barbee & Cunningham, 1995). Overall, this understanding could help deepen an understanding of how some men experience unmet needs even as part of an intimate dyad and draw attention to dynamics enabling this support connection within the context of other critical relationships.

**Explore consequences of help seeking processes.** Although I have argued that complementary strategies of help seeking with a strong back and help seeking with a soft front are linked to the different forms of identity work, I did not specifically examine the consequences of these processes. Recognizing three broad patterns in how men managed
In particular, research can explore long-term experiences of men evidencing different balances of help seeking; how do men reflect on the effectiveness of their strategies and how are they managing on-going challenges? Similarly, future work can be devoted to the examination of how a man’s comfort and skill in these forms of help seeking develop through this experience and are carried into future events. More fundamentally, there is value in examining in greater detail how men who do engage help seeking with a soft front renegotiate their identity as they engage in the interactive activities in Getting Through (i.e. showing worry, finding comrades, obtaining guidance). I collected some information on how men perceived their ‘self’ after cancer in relation to the ‘self’ they recognized before, but this dynamic is worthy of more explicit attention, including considerations of the adaptation process and identifying patterns and particularities in how men are modifying personal narratives.

**Examine men’s help seeking in other substantive areas.** Finally, there is value in considering men’s help seeking across other identity disruptions, including a troubling of valued ways of being as related of marital dissolution, loss of a loved one, retirement, or other major life events. This process of developing multiple substantive theories in a diversity of conditions is important to moving toward a formal theory (or theories) of men’s help seeking that can lend insight into this process across a range of challenges (Charmaz, 2006; Strauss and Corbin, 1998).

**Moving theory to practice**

In the course of this study, I drew on sensitizing concepts orienting me in the examination of how men experience help seeking. Through engagement with men living this experience, I built a substantive theory that can enhance understanding of how men make sense of needs and challenges and work with others to address these. Consistent with the pragmatism of symbolic interactionism, this process oriented to the development of *useful* knowledge relevant to men with cancer, medical and psychosocial health providers, and informal networks supporting men. Thus, beyond efforts to enhance
research on men’s help seeking and refine the theory offered here, it is necessary to consider what help seeking with a strong back/soft front means in terms of developing and delivering supports for men living with cancer, including a consideration of policy implications. In other words, this study examined meanings of help seeking and future efforts must consider how an understanding of these dynamics informs practice.

In moving theory to practice, it is critical to continue to engage with men with cancer as well as supports working to enhance services for men: to integrate the perspective of those who respond to this theory through the lens of experience. To this end, I will present this theoretical work to cancer support centre staff and to practitioners at conferences, and I will conduct focus groups with men with cancer. These efforts are important to soliciting feedback on the theory (i.e. does it resonate), identifying additional areas of research, and aiding the development of relevant and specific recommendations informed by existing efforts and sensitive to the practical realities of those seeking to support men. Given the critical value of this pending process, I do not offer detailed recommendations for supports with the framework of this dissertation. However, I do identify key areas of exploration as informed by this substantive theory, with focus on (a) supporting strong backs and (b) supporting soft fronts. These identified pathways will give rise to key questions brought to stakeholders.

**Supporting strong backs.** Although most of the men quickly engaged help seeking with a strong back, there is value in exploring how care providers can enhance their support for men engaged in this process. Practically, the findings on how men sought to repair uncertainties, strengthen their bodies, and limit the infiltration of emotional pain can inform formal support services as they audit their existing resources and consider how to enhance these offerings with attention to content, timing, and delivery of resources. Similarly, among informal supports, these findings can be useful in attuning individuals to the type of resources men seek and alerting them to a possibility that men might rely on them in gathering information (including referrals), adopt lifestyle changes across their illness, and/or enable distractions from difficult emotions.

More fundamentally, recognition of these efforts (combined with Maintaining the Familiar) as important to resisting threats of identity destabilization can enable valuable
sensitivity as support persons engage with men. In particular, although there is often strong approval of men’s efforts to gather information, this framework of help seeking with a strong back supports appreciation of the rationale behind these activities, including related efforts that some might view as problematic (i.e. separation from difficult emotions, efforts to build physical resources, and/or seek to maintain a degree of normalcy). More specifically, this awareness can help push back against assumptions of men as simply stoic or stubborn toward a difficult reality.

Even more, recognition of these efforts as identity work can inform the framing and development of informal and formal strategies enabling men to engage these valuable processes. For example, as specifics are worked out with stakeholders, this awareness can inform how stress-reduction programs are positioned and marketed, and it can drive efforts encouraging men to replace lost roles or apply their existing skills in new areas (including within the cancer support system itself), that offer exercise supports before, during, and after treatment and that facilitate connections with nutritionists/naturopaths. Further, as help seeking with a strong back is framed as part of complementary process balanced with help seeking with a soft front, men and their supports can become alert to the risk of exclusively promoting resistance strategies. These approaches, while effective in many regards, can sustain and even emphasize assumptions that men’s experiences of vulnerability should be resisted or hidden.

Supporting soft fronts. As emphasized in the presentation of this theory, both help seeking with a strong back and with a soft front can enable valuable identity work in the context of cancer as a biographical disruption. However, as informed by the experiences of men in this study, achievement of this balance will likely require an increased emphasis on soft fronts.

Again, starting with the practical guidance, findings highlighting men’s valuation of opportunities to show worry, find comrades, and obtain guidance on how to live a life with and beyond cancer can be used to inform the development and structuring of formal programs. In particular, as service providers in the medical and psychosocial support system review existing resources and services, this information can be used to consider whether offerings anticipate these needs and enable these opportunities across an illness
career, with attention to the qualities of supports the men noted as particularly relevant (i.e. safe, useful). Informally, this awareness can encourage friends, family, and other supports to engage a sincere practice of ‘checking in’, anticipating these needs and creating opportunities for men to talk candidly about their struggles (beyond the medical) and/or facilitate connections with others with relevant skills or experience.

As practical considerations are worked out in consultation with stakeholders, recognition of the role of help seeking with a soft front as important to acknowledging and adapting to the identity disruption often levelled by cancer can critically inform how supports perceive and engage with men at a more fundamental level. Specifically, rather than assuming that feelings of distress are absent from men’s experiences, secondary to medical needs, or that men simply prefer not to talk about these aspects of their illness, awareness of both the need for and value of this process as men negotiate a ‘new normal’ can propel efforts to normalize men’s emotions, develop relevant support networks, and establish safe environments for engagement.

In this orientation, stigmas related to male expressions of vulnerability are acknowledged, but not accepted as absolute. Although men should not be pressured to engage, supports can help men and those around them anticipate these struggles. Further, in recognizing how men can be challenged to navigate stubborn social prohibitions, efforts sensitive to a justification process can help men legitimize engagement, including efforts that help men accept the gravity of their condition and structure opportunities combining help seeking with help provision. Finally, in accepting that this challenge is not exclusive to men, efforts can be devoted to educating support persons about how to manage their own discomfort in engaging with men in these challenges.
Appendix A

Sample Recruitment Materials (e-posters and print post cards)

ARE YOU A MAN WHO HAS BEEN DIAGNOSED WITH CANCER?

WE WANT TO HEAR WHAT YOU HAVE TO SAY

We are looking for volunteers to take part in a study of how men experience cancer.

Your participation will involve 1 interview for approximately 1.5 hours and the meeting will take place at a location of your choice. In appreciation of your time, you will receive a gift valued at $15.

As a participant, you will be asked to talk about your experience from when you first noticed the signs and symptoms of illness or received a diagnosis of cancer. All information you share will be treated as strictly confidential.

For more information, or to volunteer, please contact:
Lisa Wenger, PhD Candidate
Department of Family Relations and Human Development, University of Guelph
Email: lwenger@uoguelph.ca / Phone: (519) 824-4120, ext. 56382

Or
Dr. Kerry Daly, Dean (advisor)
College of Social and Applied Human Sciences, University of Guelph
Email: kdaly@uoguelph.ca / Phone: (519) 824-4120 ext. 52400

This study has been reviewed by, and received ethics clearance through, the University of Guelph Ethics Research Board (REB# 10JN020).
Appendix B
Early Interview Guide
(Note: Questions used as broad guide to what to explore – not asked as written or always in this order)

<table>
<thead>
<tr>
<th>Tell me about yourself (spend time here)</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Family comp, age, cancer, occupation, education, family doctor, time in Canada, other)</td>
</tr>
<tr>
<td><strong>Prompt:</strong> How would someone close to you describe you?</td>
</tr>
</tbody>
</table>

So, recently you’ve been dealing with a cancer diagnosis…

<table>
<thead>
<tr>
<th>Walk me through your experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Possible prompt: Why you? How do you make sense of the fact that this experience happened to you?)</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Problems</th>
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<tbody>
<tr>
<td><strong>How did you first come to notice something was going on?</strong></td>
</tr>
<tr>
<td>(Sensations, thoughts, activities, body, others)</td>
</tr>
<tr>
<td><strong>Critical events along the way</strong></td>
</tr>
<tr>
<td>(Sensations, thoughts, activities, body, others)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Definitions</th>
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<tbody>
<tr>
<td><strong>What were you thinking at the time?</strong></td>
</tr>
<tr>
<td>(Needs, supports, health, illness)</td>
</tr>
<tr>
<td><strong>What were you feeling at the time?</strong></td>
</tr>
<tr>
<td>(Needs, supports, health, illness)</td>
</tr>
<tr>
<td>Past experiences / Interactions with others / Societal messages</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Acts</th>
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<tbody>
<tr>
<td><strong>How did you decide what to do?</strong></td>
</tr>
<tr>
<td>(What did you see as necessary, possible, preferable)</td>
</tr>
<tr>
<td>Past experiences / Interactions with others / Societal messages</td>
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<tr>
<th>Identity</th>
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<tbody>
<tr>
<td><strong>How did you view yourself – then, now?</strong></td>
</tr>
<tr>
<td>(Expectations, Evaluation of self)</td>
</tr>
<tr>
<td><strong>How did others view you – then, now?</strong></td>
</tr>
<tr>
<td>(Expectations, Responses)</td>
</tr>
<tr>
<td><strong>How do you think you compare with other men in this situation – then, now?</strong></td>
</tr>
<tr>
<td>(Within your social network, more broadly)</td>
</tr>
</tbody>
</table>

Closing questions:
- Do you have any advice for other men facing cancer?
- Is there anything you would like to ask me?
- Preferred pseudonym
- Still comfortable with consent? Willing to connect again, if necessary?
Appendix C
Later Interview Guide
(Note: Questions used as broad guide to what to explore – not asked as written or always in this order)

1. Introduction of self
   a. Demographic piece (see sheet), Critical pieces of ‘me’

2. What was going through your mind when you first noticed symptoms?

3. How did you respond to these?
   a. Probes: Look stuff up, ignore, explain away, worry, talk with someone, etc.

4. What went through your mind (thoughts/feelings) when you were diagnosed?

5. How did you respond to the diagnosis (think, feel, do about it)?
   a. What were your thoughts/feelings about the present, the future?
   b. Did you know what to expect?
   c. How did you want to respond?
   d. What were worried about/not worried about?
   e. How did others respond (friends, family, etc.)?

6. If you experienced uncertainty due to the diagnosis...
   a. How did you cope with this?
   b. When did you start to feel like you had a grip back on your life?

7. What sort of challenges were you facing over this time?

8. How did you respond to these?
   a. Consider individual coping (activities, being alone, distractions)

9. How did you engage with others?
   a. Who did you connect with? Who did you avoid?
   b. What did you want from them?
   c. How did they interact with you?
   d. How do you think they saw you during that time?

10. What was offered to you?

11. What was it like for you to ask for their support?

12. How effective were these supports? What worked? What was missing?

13. This study is about men and help seeking – would you say that there were any defining moments for you as you dealt with challenges throughout this experience? (Incl. how this changed over time)

14. How do you make sense of this happening to you? (Why me?)

15. How has this experience impacted how you see yourself?

16. What do you think of arguments that men are expected to be stoic, reserved, self-reliant, independent, etc.?

17. Advice for other men?
Interview Date: ______ Location: ____________

Cancer Type:

Treatment (Check all that apply)

☐ Surgery
☐ Hormone
☐ Chemotherapy
☐ Radiation
☐ Medication
☐ Other:

Prognosis:

Age:

Marital status:

☐ Single
☐ Married
☐ Divorced/ Separated
☐ Widowed

Children?

☐ No
☐ Yes  Number:   Ages:

Had a family doctor at time of diagnosis?

☐ No
☐ Yes

Education level

☐ Less than high school
☐ High school
☐ College/ Certificate
☐ University
☐ Post-graduate

Occupation:

☐ Retired, What was past work?
☐ Employed PT
☐ Employed FT
☐ Disability
References


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