

An Exploration of Identity in Cancer Patients with Early Malignancies

By

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### **Abstract**

Patient Centered Care (PCC) is an evolving concept, considered to be a component of high quality care. Central to PCC is the consideration that care is enhanced when the unique aspects of a patient's identity are considered when providing medical care. This study sought to better understand the concept of identity in Manitoban cancer patients and how identity is affected through the early stages of diagnosis, decision making and treatment. This was explored using a grounded-theory approach and semi-structured interviews. Data was collected from 18 adult patients with colon, breast, endometrial, lung and prostate cancer using semi-structured interviews generally occurring after initial surgery and before meeting with radiation and medical oncologists to make decisions regarding adjuvant treatments. In addition, 15 adult participants, identified by the patients as either friends or family, were also interviewed. A total of 42 separate interviews were conducted. The findings showed that the participant's identity through the cancer experience could be described using five main concepts: terminal and instrumental values, terminal and instrumental identity, and routine. Data analysis also indicated that a significant source of distress for patients came from an inability to establish a post-diagnosis routine. Based on this finding, recommendations that serve to assist patients with establishing a post-diagnosis routine can be made. These include: placing priority on early notification of appointment times for treatment and clinic visits, and providing information about how different treatment options will affect patient's instrumental identities. By exploring the cancer experience of patients in the social context, this study has forwarded a model of identity that is useful for describing the experience of cancer patients in Manitoba. In addition, it provides a lens with which to guide future research, and presents recommendations that are mindful to the identity of cancer patients - an important consideration in providing PCC.

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**Dedication**

To: G.W., M.T., and B.B.

Always loved.

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## **CHAPTER 1: INTRODUCTION TO THE STUDY AND LITERATURE REVIEW**

### **Introduction**

Patient centered care (PCC) is a relatively new construct that continues to evolve in the literature (Scholl, Zill, Harter, & Dirmaier, 2014). In this model, care occurs in the context of a relationship that the healthcare provider and patient share (Mead & Bower, 2000). Literature from philosophy, psychology and sociology provides a useful framework for interpreting this relationship, and understanding how the patient navigates through it. It can be suggested that a person's identity is a construct of social and personal identities that are informed by a unique set of enduring values (Hitlin, 2003; Perry, 1975). Furthermore, decisions informed by values will result in better patient centered outcomes than decisions not informed by values. This assertion is supported in the literature, as undertaking value clarification exercises during the decision making processes has been shown to result in less long term decisional regret (D. Feldman-Stewart et al., 2012; Stacey et al., 2014).

The importance of making decisions based on values is particularly important in the adjuvant treatment setting. Adjuvant therapy provides no guarantee of preventing cancer re-occurrence. In addition, many adjuvant therapies require a tremendous time commitment from patients and are associated with side effects that can be severe and lifelong (DeVita, Lawrence, & Rosenberg, 2011). In this setting, however, value clarification exercises and the information needed to inform the development (i.e. what patients' values are and how patients' identities are affected by receiving healthcare) are yet to emerge.

This study will explore how the identities of patients are affected by the initial diagnosis and treatment of potentially curable cancer. Specifically, the purpose is to develop a theoretical model using grounded theory that explains and predicts challenges to the identities of individuals

diagnosed with potentially curable malignancies as they go through the process of being diagnosed with malignancy, receiving initial curative treatment and making decisions regarding adjuvant treatments. It focuses primarily on adult cancer patients who have undergone diagnosis and initial curative surgical treatment for their primary cancer and will be considering adjuvant chemotherapy and radiotherapy in Manitoba. The concepts of values and identities, as well as authenticity, will be defined in the literature review.

Guiding research questions to be explored include:

- How do patients perceive their own personal identities, social identities and values?
  - How did the patient's personal and social identities change while undergoing initial treatment?
  - How is the patient considering their values, personal and social identity while making treatment decisions?
- How can treatment be provided that is congruent with a patient's values?
  - What changes in the patient's personal and social identity were desirable and which were undesirable?
  - What would have helped improve the experience of treatment or prevented undesirable changes?

### **Literature Review**

This literature review is intended to accomplish two things. First, to define the concepts of values, authenticity and identity, and establish them as central to PCC. Second, to provide rationale for exploring these concepts in the context of adjuvant treatment decision making. It will begin by exploring aspects of PCC, including its evolution and definition, its contrasts to the biomedical model of care, and its moral and ethical underpinnings. Next, a conceptual framework that connects values, authenticity and identity to PCC will be used as a lens to examine aspects of the PCC literature. Lastly, rationale for using this framework to explore the experiences of patients preparing to undergo adjuvant cancer therapy will be discussed.

### **Understanding Patient Centered Care**

**The Evolution of Patient Centeredness.** PCC is closely related to the concept of autonomy. Autonomy, as understood in contemporary healthcare ethics, evolved from the Age of Enlightenment and the work of the philosophers John Stuart Mills and Immanuel Kant (Wilson, Ingelton, Gott, & Gardiner, 2014). The Age of Enlightenment, which occurred in the 17th and 18th century, brought with it the idea of persons as individuals with rights and freedoms. Two important ideas in relation to the individual and autonomy were those of Immanuel Kant (1724 - 1804) and John Mills (1806 - 1873). Kant suggested that the individual is capable of deciding what is morally right, while Mills suggested that each individual has the right to be free from the interference of others (Wilson et al., 2014). These ideas provide the basis for autonomy, both placing value on the right of the individual to self-determine.

The concept of autonomy has been adopted as a tenant of ethics in western medicine (Page, 2012). Since its first publication in 1978 *The Principles of Biomedical Ethics*, written by Beauchamp and Childress, has provided an ethical framework that includes autonomy, as well as

three other principles: beneficence, non-maleficence and justice (Beauchamp & Childress, 1978/2001). This framework for ethical decision making is taught throughout medical education, with autonomy being promoted as a key principle when making clinical decisions (Page, 2012).

The core principles of patient centered care can be attributed to two authors. The first is Balint, who is credited with being the first to describe the concept of understanding patients as unique beings in the 1950's (Flagg, 2015). While not directly related to autonomy, this concept stresses patients as individuals and not merely recipients of medical care. Second, Gerteis, Edgman-Levitan, Daley & Delbanco (1993) identified seven dimensions relating to PCC which are widely cited and continue to inform the contemporary understandings of PCC: respect for patients; co-ordination and integration of care; information, communication and education; physical comfort; emotional comfort/alleviation of fear and anxiety; involvement of family and friends; and transition and continuity.

Patient centered care has evolved into a model of care that is accepted throughout the world. Based on the work of Gerteis et al. (1993) the Institute of Medicine adopted PCC as one of six aspects of good quality care in 2001, making it one of the first major health organizations to formally recognize the value of PCC (Kitson et al., 2013; Lusk & Fater, 2013). PCC has since been recognized as a healthcare goal by organizations internationally, including in Canada by the Canadian Partnership Against Cancer and The College of Family Physicians of Canada (Bauman, Fardy, & Harris, 2003; Beaulieu, 2013; 2014; McMillan et al., 2013; Millenson, DiGioia, Greenhouse, & Swieskowski, 2013).

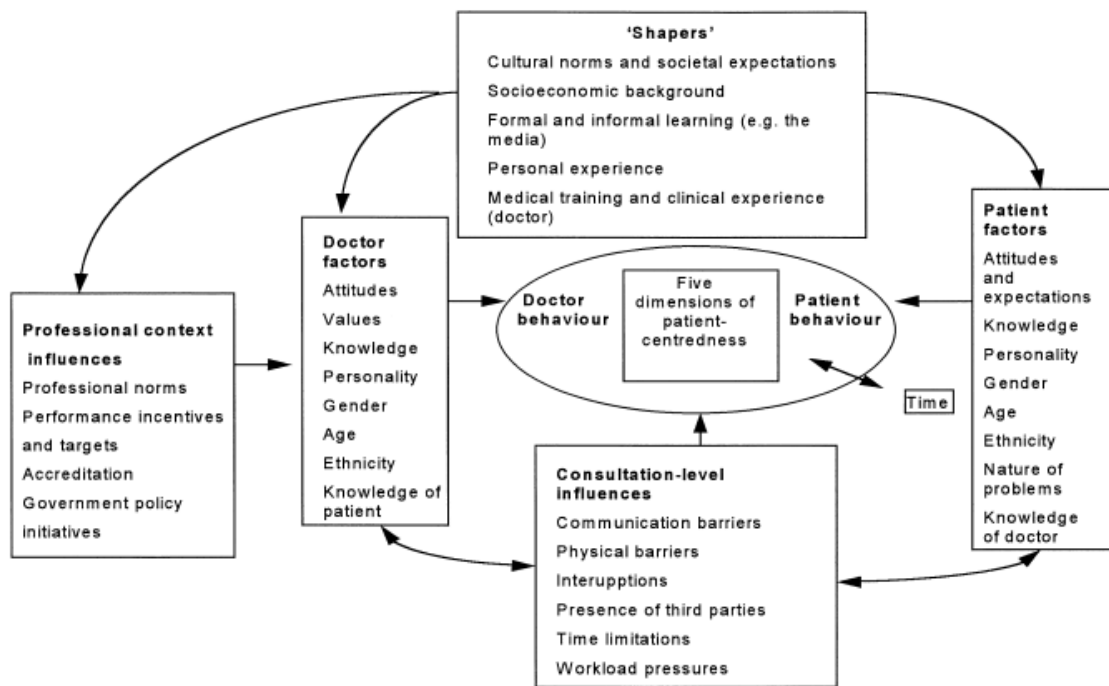
**Defining Patient Centered Care.** A clear consensus of what PCC is does not exist in the literature (Australian Diabetes Educators Association, 2008; Pulvirenti, McMillan, & Lawn, 2011; Scholl et al., 2014). However, common themes have emerged which help to develop a



working definition. PCC often refers to treating the patient as an individual, respecting the patient as a person, considering the patient's point of view and circumstances, forming health practitioner and patient partnerships, and assisting patients with making informed decisions (Bauman et al., 2003; Binnie, 1999; Pelzang, 2010; Redman, 2004; Shaller, 2010). The goals of PCC are generally accepted as helping patients be more informed, reassured, supported, comforted and empowered (Fulford, Ersser, & Hope, 1996; Rogers, Kennedy, Nelson, & Robinson, 2005). Lastly, it is accepted by most proponents of PCC that through achieving these goals, PCC may promote healing and reduce injury and suffering (Nelson & Gordon, 2006).

PCC has been described as a process that occurs within a supportive system (Pelzang, 2010). In the system, several constructs combine to create a patient-centered environment that organizes staff and services around the needs of the patient (N. C. Robinson, 1991; Shaller, 2010). The process model seeks to adopt the patient's perspective and describes a range of activities to do this successfully. These include consideration for the patient's beliefs, values and needs, co-ordinating and integrating care, informing and communicating with the patient, and involving both patient and family in decision making (Gerteis et al., 1993). When considered together, these two models create the environment as well as the perspective necessary for PCC (Pelzang, 2010). Figure 1 provides an illustrative model of the concept of PCC.

The evolution of PCC has been informed by multiple disciplines of health care provision (Kitson et al., 2013). On the health policy level, the Institute of Medicine has demonstrated that PCC is central to improving overall care (*Crossing the quality chasm: a new health system for the 21st century*, 2001; Kitson et al., 2013). In the discipline of medicine, Stewart et al. (2001) have provided insights into improving doctor-patient relationships through communication. They



*Figure 1.* Conceptual model of patient centered care. This model demonstrates interdependence of PCC on both the patient and the doctor (read: healthcare provider) and pays special attention to numerous psycho-social factors for both individuals. In addition, time is indicated as a variable the influences the process of PCC. Note that in this model, PCC is clearly a process which occurs within a context. Adapted from “Patient-centredness: a conceptual framework and review of the empirical literature,” by N. Mead and P. Bower, 2000, *Social Science and Medicine*, Vol. 51, p. 1104.

developed four dimensions of patient-centered communication. These include exploration of the patient's disease and illness experience, understanding the whole patient, finding a common ground for management, incorporation of health promotion and prevention. In addition, they stress the importance of care providers being realistic (Kitson et al., 2013). Lastly, McCormack et al. (2006), provide insight into how PCC pertains specifically to the nursing domain, identifying a framework with four constructs: the (personal) characteristics and attributes of the nurse; the context in which care is delivered; how care is delivered; and the expected outcomes. These examples identify seminal contributions to the practice of PCC as well as important variations in the unique lens that each discipline provides.

### **The Evidence for Patient Centered Care**

As interest and acceptance of the PCC model of care continue to grow, so does the body of evidence regarding care utilizing the processes and systems in keeping with PCC principles (Kitson et al., 2013; Lusk & Fater, 2013; Mead & Bower, 2000). In one review by Kitson et al. (2013), PCC interventions that demonstrated benefit were categorized into three themes: the context in which care is delivered; patient participation and involvement; and the relationship between the patient and the health professional. The following section will use these three themes to explore the PCC literature.

The context in which care is delivered pertains to which definitions of patient centered care are used, how policy translates into practice regarding patients' rights, patients' safety and evidence based practice. This theme highlights resource and knowledge barriers to providing PCC. Lack of resources available to support PCC interventions is a considerable barrier. In one survey study, nurses working on an acute care floor identified time limitations as barriers to addressing patients' anxieties, fears, concerns, and information needs (West, Barron, & Reeves,

2005). Lack of appropriate knowledge of PCC is another barrier. In a case study design, six nursing preceptors demonstrated limited understanding of patient centered care, stating that it was limited to having good manners and respectful etiquette (McCarthy, 2006). These findings reflect the fact that changes at the organizational level, including improved education and increased human resources, are required for delivery of PCC (Brown, McWilliam, & Ward-Griffin, 2006; Buerhaus et al., 2005; Nelson & Gordon, 2006; J. Robinson, Callister, Berry , & Dearing, 2008; N. C. Robinson, 1991).

The theme of patient participation and involvement includes studies focusing on patient participation in care as respected individuals, the care plan being based on the needs of the individual, and the care plan addressing both physical and emotional needs. Shared decision making and patient adherence are central to this theme. Shared decision making, where clinicians review evidence and engage the patient in making a treatment decision together, is thought to promote autonomy, result in ethical healthcare provision and take into account the emotional and physical needs of the patient (Elwyn et al., 2014). The literature suggests that there are important patterns in patient participation and preferences in the shared decision making process. One qualitative study demonstrated that as age increases, patients consider “active participation in decision making” less important compared to receiving information, perception of being in a caring relationship with the healthcare provider and the provider having a “person centered approach” (Bastiaens, Van Royen, Pavlic, Raposo, & Baker, 2007). The importance of shared decision making also changes with disease specific factors. One survey study demonstrated that increasing severity of disease and chronicity of disease were associated with an increased importance of shared decision making (Muller-Engelmann, Keller, Donner-Banzhoff, & Krones, 2011). In addition, the role of shared decision making about conditions requiring urgent

management were considered by patients to be best handled without using the shared decision making approach. On the other hand, decisions about preventative treatments, such as vaccinations, were considered by patients to be best approached through a shared decision making model (Muller-Engelmann et al., 2011).

Patient adherence to prescribed management plans has been demonstrated to be improved through patient centered strategies that focus on education and helping patients understand the importance of taking medications. In one review of interventions that targeted medication adherence sixty studies were examined. Interventions that were included were patient education sessions, decision aids, patient-clinician shared decision making models, case-management interventions, and feedback interventions (Kuntz et al., 2014). This study demonstrated improvements in adherence and patient centered outcome such as patient satisfaction and concordance between patient preference and prescribed regimens.

Literature on the relationship between the patient and the health professional focuses on communication, expertise, and having a genuine clinician-patient relationship. This theme is affected by cultural differences as well as the nuances of the specific disease that is being treated. Different cultural groups have varying definitions of what appropriate and open communication or a genuine clinician-patient relationship means. For instance, one qualitative study comparing interview styles of Italian physicians with those of American physicians demonstrated that while both groups perceived their own style as being patient centered, the American group was more willing to share bad news or to take measures to promote autonomy (Lamiani et al., 2008). Similarly, in a survey study of oncologists, those from western countries were more likely to share bad news and resist family member's requests to withhold bad news from patient's than those from non-western countries (Baile, Lenzi, Parker, Buckman, & Cohen, 2002).

An example of disease specific factors that affect the patient-clinician relationship is found in a mixed methods study of stroke patients. Following a stroke, communication can be impaired, and health care providers may be perceived by patients as struggling to communicate in a “patient centered way”. In this instance, providing meaningful and respectful communication requires emphasis on working with family members in addition to the patient (Lawrence & Kinn, 2012).

In addition to literature focusing on the cultural and disease context that affects the relationship between the patient and the health care provider, evidence for specific interventions that improve the patient centeredness of the clinical consultation exists in the literature. The Cochrane Database provides level 1 evidence for these interventions (Dwamena et al., 2012). A total of 21 trials were included in the most recent update, all of which included specific training for healthcare providers. Seven of these provided additional education for patients. Positive effects were found in measures of clarifying patients’ concerns and beliefs, communicating about treatment options, levels of empathy, and patients’ perception of providers’ attentiveness.

Although a body of evidence is growing that demonstrates benefits for PCC interventions, the Cochrane review highlights one of the challenges in gaining support for PCC interventions: interventions that are patient centered may result in statistically significant negative biomedical outcomes (Dwamena et al., 2012). For instance, in a randomized controlled trial of diabetic patients included in the Cochrane review, patients (n=522) were randomized between a care group that had received PCC specific training to encourage communication and one that had not (Kinmonth, Woodcock, Griffin, Spiegel, & Campbell, 1998). At the end of one year follow up, the PCC specific measures were improved in the intervention group, including better communication (OR 2.8; 95% CI 1.8 – 4.3), greater treatment satisfaction (OR 1.6; 95%

CI 1.1 – 2.5) and wellbeing. However, the intervention group also had significantly higher BMIs (mean difference = 2.0; 95% CI 0.3 – 3.8), and triglyceride concentrations (mean difference = 0.4 mmol/l; 95% CI 0.07 – 0.73 mmol/l). These situations, where the priorities of the biomedical model are seemingly at odds with those of the PCC model of care, represent an important challenge for the future of healthcare provision.

### **The Biomedical Model of Care and the Patient Centered Model**

The challenge that arises when traditional biomedical outcomes are at odds with those of the patient centered model is important. Some suggest that the increased focus on patient autonomy and patient centeredness in contemporary medicine has resulted in the medical expertise of healthcare professionals being devalued, and that the “pendulum” needs to swing back towards a more paternal ideal of care (Quill & Brody, 1996). Alternatively, resolution to the potential conflict between the traditional biomedical approach to care and the patient centered model can be found by viewing patient centeredness in one of two ways. The first is as a moral imperative, whose goals simply trump those of the traditional biomedical model. Alternatively, by understanding PCC as part of an important evolution of contemporary medical practice, the goals of PCC and the biomedical model can be viewed as ultimately complementary.

As a moral imperative, it has been suggested that the conflict between the biomedical and patient centered model of care may be related to the fact that PCC did not evolve from a concrete rationale, but through clinical efforts to achieve better patient-physician communication as opposed to an ethical or moral approach (Duggan, Geller, Cooper, & Beach, 2006). In other words, the question “why patient centered care?” has not been adequately addressed. The answer to this question, which justifies PCC as a moral concept, comes from three general approaches to moral theory: consequentialist, deontological and virtue-based (Duggan et al., 2006).

Duggan et al. (2006) describes these three moral frameworks as a spectrum, ranging from actions to outcomes. Consequentialist moral theories define actions as right or wrong based on whether they have outcomes that are considered desirable or undesirable, respectively (Duggan et al., 2006). Deontological moral theories on the other hand are not concerned with the outcomes of actions, but whether the action itself is “right” such as telling the truth, even if a negative outcome may result (Duggan et al., 2006). Virtue theory lies in-between deontological and consequentialist moral theory, with actions and outcomes being evaluated based on the underlying attitudes and beliefs that motivated the actions and outcomes (Duggan et al., 2006).

Consequentialist rationale for PCC is found in studies that show positive outcomes for PCC interventions. For instance, PCC interventions have been associated with an increase in patient satisfaction, trust and functional status (Duggan et al., 2006). Patient-centered approaches, by respecting the individual, are considered morally good on deontological grounds, as it is considered morally good to respect the individual (Duggan et al., 2006). From a virtue-ethics perspective, one cannot be patient-centered without the underlying beliefs that each patient is unique and that the preferences of the individual should be acknowledged and respected. Therefore, some suggest, that to pursue patient-centeredness is morally good (Duggan et al., 2006). Understanding PCC as a moral imperative is useful. This viewpoint provides a simplistic directive in instances when biomedical outcomes are in clear conflict with ethical and decidedly PCC principles such as autonomy. However, because of the complex nature of clinical practice, it is challenging to categorize actions, outcomes and intentions of medical practitioners, or their patients for that matter, as morally right or wrong.

What is perhaps more constructive than applying moral philosophy to prioritize healthcare outcomes, is understanding how PCC and the biomedical model fit within the current



context of medical history and evidence based practice. PCC can be seen as a movement that adds important “human” context to the science heavy focus that has developed in western medicine. Historically, the humanities, religion, established practices, authorities’ opinions and previous experience guided medical practice (Raabe-Meyer, Kaiser, & Bauersfeld, 2010; Vrdoljak, 2012). However, since the mid-19<sup>th</sup> century with advances in scientific method, chemistry, biology and physics have evolved to form the basis of modern medicine (Raabe-Meyer et al., 2010). This evolution, guided by a positivistic worldview, has culminated in the widespread adoption of the principles of evidence based practice (EBP) (Raabe-Meyer et al., 2010; Vrdoljak, 2012).

Proponents of EBP assert that EBP provides superior medical outcomes, improved efficiency of care and, when practiced correctly, can be tailored to the individual needs of the patient (Vrdoljak, 2012). EBP aims to incorporate practices which are based on evidence through the development of practices guidelines which are based on scientific evidence, and through ongoing auditing and dissemination of the outcomes of practice changes (Melnik & Fineout-Overholt, 2011). These principles have been standardized. For instance, the Registered Nurses’ Association of Ontario (RNAO) has established standards for the development, presentation, incorporation and evaluation of practice guidelines (Registered Nurses' Association of Ontario, 2006). This formalization encapsulates both the adoption of scientific evidence into practice, and a rigor for evaluating and reporting the effects of a practice change intervention in keeping with scientific method.

The movement to evidence based practice stands in stark contrast from many non-western medical traditions. Many of these traditions, often referred to in western medical practice as complementary or alternative, remain rooted in worldviews that exist outside of

Eurocentric concept of science (Zollman & Vickers, 1999). Attempts to link these therapies to western medical practice has led to a growing body of evidence regarding complementary and alternative medicine (CAM). In fact, the Cochrane Library contains over 5000 CAM related articles, suggesting that a body of evidence is certainly emerging regarding these therapies (Ezzo et al., 2002). Despite the growing body of evidence, CAM therapies remain largely separated from western medical practice, as there is little education on CAM therapies in traditional western-medical education and many mainstream practitioners are unsure how to embrace CAM therapies in their practices (Cowen & Cyr, 2015; Ezzo et al., 2002; Giordano, Boatwright, Stapleton, & Huff, 2002).

Even though there is uncertainty regarding the incorporation of CAM use into practice by practitioners of western medicine, there is a high uptake of CAM therapies by the public. Prevalence of CAM use has been demonstrated to be as high as 70% in some adult populations (Richardson, Sanders, Palmer, Greisinger, & Singletary, 2000), and greater than 80% in some pediatric populations (Tuncel et al., 2014). However, there is evidence that only a small proportion of CAM users report its use to their physicians, with reporting rates being as low as 41% in one study (Chrystal, Allan, Forgeson, & Isaacs, 2003).

The high rate of CAM use suggests that complementary and alternative healing practices offer something that western medicine does not provide. Surveys of CAM users indicate that CAM therapies are appealing because they address aspects of the human experience that are not explained by the traditional biomedical model of health. CAM use has been linked to desire to for personal control (Hedderson et al., 2004), a need for a spiritual component in care (Montazeri, Sajadian, Ebrahimi, Haghighat, & Harirchi, 2007), belief in the paranormal and mistrust of science (Clobert, Saroglou, & Van Pachterbeke, 2015). These findings certainly

suggest that for most people, the experience of being unwell raises concern that are not completely addressed by the contemporary healthcare system.

Recognizing that many people utilize CAM therapies to meet unmet aspects of the illness experience is important. Perhaps widespread acceptance of PCC suggests that, like CAM, PCC may be addressing aspects of the illness experience that have been ignored with advances in other areas of medical practice.

### **Defining Individual Identity as a Fundamental Unit of Patient Centered Care**

One feature distinguishing PCC from the biomedical model is the recognition of the relationship between healthcare providers and patient as central to care. For instance, from the nursing perspective, the attributes of the nurse are considered part of the four construct framework of PCC (McCormack & McCane, 2006). The frameworks offered from the discipline of medicine also consider the important role of the care provider, focusing on alliances, common ground, and distribution of power (Mead & Bower, 2000; Stewart, 2001). Because relationships are central to the PCC model of care, understanding how individuals relate to themselves and others provides insight into patient centeredness.

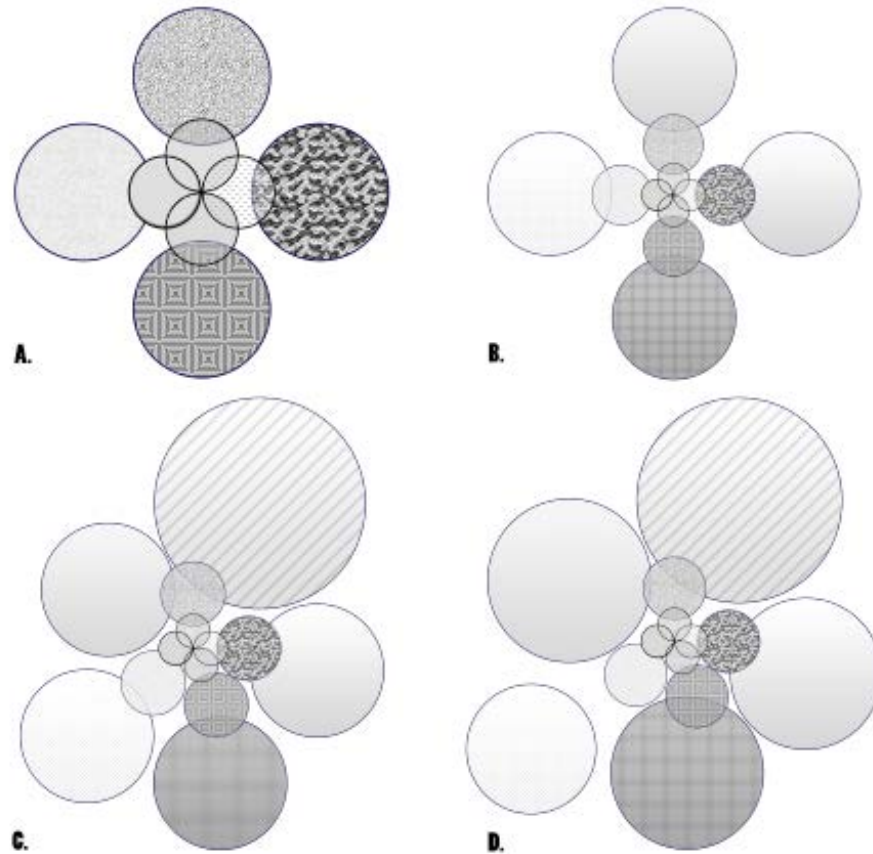
This section presents a model of identity useful for exploring the relationships that patients have with themselves and the people they interact with. In it, the concepts of social self, social identity, personal identity, values and authenticity will be defined. How these concepts are structured to define a person's identity and affected by time will also be discussed. This model draws from philosophical, sociological and psychological theories (Heiney, 2014; Hitlin, 2003; Hogg, Terry, & White, 1995; Perry, 1975; Trenton, 1999) and provides a lens for critiquing existing literature as well as a theoretical basis with which to advance a research agenda. To

further clarify this model, Figure 2 provides a graphical representation and an illustrative scenario is included in Appendix A.

A person's identity can be viewed as a sum of two sub-identities: the personal self and the social self. Personal self is made up of an individual's values which are situated at the core of the individual and their personal identity (Hitlin, 2003; Hogg et al., 1995). Values inform both the social and personal self. Examples of values include benevolence, security, tradition, achievement and hedonism. According to Schwartz, values can be described as "desirable trans-situational goals, varying in importance, that serve as guiding principles in the life of a person or other social entity" (as cited in Hitlin, 2003, p. 119). Values develop in social context, from culturally symbolic material. They are based on feelings and are emotion laden. According to Hitlin (2003) values fulfill five criteria: they are concepts or beliefs; they pertain to desirable end states or behaviors; they transcend specific situations; they guide selection of evaluation of behavior or events; and they are ordered by relative importance. An individual's values are identified by the ego as not influenced externally - they are intrinsic to the self and endure over time (Hitlin, 2003). Individuals become committed to the personal and social identities which best enable the expression of their values (Hitlin, 2003).

Like values, personal identities have several components (Hitlin, 2003). Examples of personal identities include volunteer, parent, student, laborer and professional. The concept of personal identity is similar to that used by authors who have described the "ideal self" (Turner, 2013) - these are the identities that are most closely based on an individual's values. Like values, personal identities transcend specific situations and guide evaluation of behavior and events. Personal identities are also similar to values in that individuals have multiple personal

identities. However, unlike values which co-exist in an enduring hierarchical fashion, personal identities



*Figure 2.* Representation of the model of identity synthesized in the literature review. A. The personal self, made up of the individual's core values at the center with personal identities connected to those individual values. B. The addition of the social group identity, as indicated by the outer circles, creates areas of overlap with personal identity. These overlapping areas are the social individual's social identity. C. Integration occurs when a new social identity is achieved without loss of a previous social identity. D. Adaptation occurs when the addition of a new social identity results in loss of a previous social identity.

are dynamic, are enacted based on the situation in which individuals find themselves, and tend to change more rapidly over time (Turner, 2013). Figure 2.a is a visual representation of the components of the personal self.

Unlike the personal self, which is intimate to the individual, the social self exists in a space that is evident to other individuals (See Figure 2.b). Identity theory describes the concept of the social self and its interactions with personal identity and social group identity (Hitlin, 2003). Like personal identity and personal values, identity theory suggests that the aspects of the social self are divided into two discrete components, social identities and social group identities. Social identities, or “role identities” as used in identity theory, are the social roles that individuals participate in as members of the societal group that they identify with. For instance, a person may have several different social identities such as “a mother, a wife, a daughter, a social worker and a blood donor ” (Hogg et al., 1995, p. 256). This is the aspect of identity where a healthcare provider and patient are in direct interaction. Social group identity refers to the larger social grouping which an individual is identified as a member of (Hitlin, 2003). Examples of social group identities include being a member of a group of friends, an employee at a certain organization or member of a sports team.

Two important socio-cognitive processes occur in social groups: categorization and self-enhancement (Hitlin, 2003). These processes are motivated by the normative values of the members of the group. Categorization is the process by which specific perceptions and actions develop into the stereotypical group norm. Through the self-enhancement process, categorization occurs in such a way to value those members of the group which embody the stereotypical group norm. Through these processes, the group evaluates those within the group in a more favorable

way than those outside of the group. In a similar manner, within the group, a hierarchy of evaluation develops favoring those closest to the group norm.

In the model being presented here, the distinction between personal identity and social identity is important. While identity theories fail to make a clear distinction between the two, this model identifies a distinct and an important difference (Hitlin, 2003). Personal identity is influenced by values, while social identity can be influenced as much by personal values as by social group identity. This is because the social identity taken on by an individual as part of their social group identity may include values and behaviors that do not fit with all of the personal identities of an individual.

Why individuals choose social identities that do not fit with their personal identities is explained by exploring the hierarchy of values that an individual has. Central to the models of identity theory and social identity theory is the concept of symbolic interactionism (Hitlin, 2003; Hogg et al., 1995; Turner, 2013). Symbolic interactionism is a term used to indicate that meaning and importance of concepts change when they interact or are in the presence of other objects (Charmaz, 2006).

In both identity theory and social identity theory, symbolic interactionism is used to describe how choices are made between identities. According to identity theory, an individual will choose which social identity is expressed in any given social situation based on how it relates to one's personal self, or how it relates to any combination of one's values (Hitlin, 2003; Hogg et al., 1995; Turner, 2013). In social identity theory, a group will evaluate the activity of its members or other groups based on how the activity in question relates to the normative group values (Hitlin, 2003; Hogg et al., 1995). Individuals choose social identities that maintain personal identities based on how their personal identities are linked to their value hierarchy.

Individuals prefer social identities that allow them to integrate their personal identities with their social roles (Freire, 1974/2013, 1970/2014; Lincoln, Travers, Ackers, & Wilkinson, 2002). Taking on a social identity that allows maintenance of personal identities, and honoring of the connected personal values, results in authenticity (Freire, 1970/2014). However, in some circumstances, the social identities available to an individual allow the values to be honored, but may compromise personal identities. This is challenging for the self, and the self must find a resolution in order to achieve stability. This can be done by either adopting new personal identities or finding an alternative social identity (Lincoln et al., 2002) which can be achieved through the concepts of integration and adaptation. These two concepts are illustrated graphically in Figures 2.c and 2.d respectively. Referring to Appendix A.0 and A.1 and the illustrative case of Jan further clarifies the model being forwarded here.

### **Identity and Time**

An important characteristic of this model is how a person's identity is connected through time. The first documented hypothesis on how time relates to identity came from John Locke in the 1600's (Perry, 1975). Locke suggested that personal identity was related to continued existence over time, implying that the continuity of the body was all that is necessary for persistent identity (Locke & Winkler, 1689/1996). Others have expanded on this idea, suggesting that the identity of the individual is related to continuity of memory (Little, Paul, Jordens, & Sayers, 2002; Perry, 1975). In the model proposed from the literature review, values are seen as the moniker of a person's identity, not memory.

Support for identity being dependent on values, not memory, comes from Alzheimer's disease (AD). AD is characterized by progressive impairment of cognition, function and behavior (Herrmann, Gauthier, & Lysy, 2007). A cardinal feature of AD is progressive memory loss.



Specifically, declarative memory, which describes memory for facts and events is lost while procedural memory and motor learning are spared until late in the disease (Markowitsch & Staniloiu, 2012). Despite the impact on memory that AD has on those diagnosed, a sense of “self” endures throughout the disease. This was demonstrated by Shell (2015) through qualitative research exploring happiness in those living with AD. Security, belonging, peace and freedom all emerged as important values in the study. Other qualitative data in this population demonstrates that patients may desire to return to activities previously enjoyed before being limited by disease. This suggests a desire to return to previous social and personal identities that better reflect the individuals inner values in spite of memory loss (Clare, Rowlands, Bruce, Surr, & Downs, 2008). Refer to Appendix A.2 for further clarification of the relation of identity to values and memory.

In summary, values are a component of a person’s identity that transcend time, situational context and even memory. Therefore, if the individual and their relationships are central to PCC, and values function as the core of an individual’s identity, then the values of the individual as they pertain to his/her identity must exist as a central aspect of PCC.

### **Exploring The PCC literature: A Focus on Values, Identity and Authenticity**

The model of identity suggested by the literature review provides an important tool for interpreting the PCC literature. It offers contextualization for both the qualitative and quantitative evidence that currently exists regarding the decision making process and suggests opportunities for further exploration. The following review will begin by exploring the shared decision making literature, applying the concept of identity as it evolved from the literature as an interpretive guide.

Decision aids are a tool that is used in the shared decision making process. They are thought to help patients understand the pros and cons of treatment (Edwards et al., 2004). The

Cochrane review entitled *Decision aids for people facing health treatment or screening decisions* (Stacey et al., 2014) provides a comprehensive and up to date review of decision aids. In the most recent review, a total of 115 randomized controlled trials were included. The findings of the review demonstrated that use of a decision aid was associated with an increased proportion of accurate risk perception (RR 1.82; 95% CI 1.52 to 2.16), as well as lower decisional conflict related to feeling uninformed (Mean difference -7.26 of 100; 95% CI -9.73 to -4.78). Decision aids also reduced the proportion of people who were passive in decision making (RR 0.66; 95% CI 0.53 to 0.81), and those who were unable to make a decision (RR 0.59; 95% CI 0.47 to 0.72). In addition, decision aids contributed to increased patient satisfaction with the intervention. These all can be considered positive outcomes that suggest an improvement in patient centeredness with the use of decision aids.

The Cochrane review also demonstrated interesting findings with respect to patient values. While decision aids were defined in the review as interventions designed to provide “a) information on the options and outcomes relevant to a person’s health status and b) implicit methods to clarify values” (Stacey et al., 2014, p. 8), explicit value clarification exercises were only included in some of the interventions studied. Specifically, when value clarification exercises were included in the patient decision aid, a higher proportion of patients were able to choose options that were congruent with their values (RR 1.51; 95% CI 1.17 to 1.96; n=18). These results demonstrate a positive effect when explicit value clarification is incorporated into the intervention studied.

In the studies included in the Cochrane review, explicit value clarification exercises did not place the patient within the context of their own personal identity. For instance, in a decision aid for bowel cancer screening, S. K. Smith et al. (2010b) included a value clarification exercise

(S. K. Smith et al., 2010a) with questions focused on the risks false positives, risks of screening, interest in performing the test at home, and how the increased risk of dying of cancer without screening affects their screening preference. The model of identity presented here suggests that broadening the scope of values explored to focus on a patient's personal and social identities may result in increased patient centeredness. For instance, one question reads: "Your risk of dying from bowel cancer over the next 10 years without screening is about 2 in 1000. How does this make you feel about screening?" (S. K. Smith et al., 2010a, p. 1) The ability of this question to aid in values clarification may be enhanced by including reflection on how this risk affects aspects of self, such as one's personal identity as a parent or provider. A more appropriate alternative question may be: "Your risk of not being alive in the next ten years because you have died from bowel cancer is approximately 2 in 1000. This means that there is a 2 in 1000 chance you will not be around for your family in ten years because of bowel cancer. This risk may be decreased by bowel cancer screening. How does this make you feel about screening?" While this question is certainly more abrupt than the one provided by S. K. Smith et al. (2010b), the question clarifies what is at stake for both the personal and social identity of the patient, facilitating a clear decision. Of the decision aids with accessible value clarification exercises included in the Cochrane analysis (Arterburn et al., 2011; Mathieu et al., 2007; Stacey et al., 2014; Trevena, Irwig, & Barratt, 2008; Wakefield et al., 2008) this was a consistent pattern. The value clarification exercises asked for reflection from the patient, but did not place that reflection in the context of the patient's own identity.

Another observation from the value clarification exercises was a somewhat limited and vague scope of value inquiry. In the study by S. K. Smith et al. (2010b), value clarification was limited to understanding how the patient felt about being diagnosed with cancer and their own

risk of dying. But, as has been suggested in this paper, the social identities people have are important to a person's identity and authenticity. Eliciting the opinions of those in a person's social group, such as family members, may help a patient understand what the "normative behavior" of their social group, and help them maintain their identity. An approach fitting with this would be to expand the clarification exercise to include how a patient's loved ones feel about the patient getting screened.

Another approach was for the value clarification exercise to be directed by the patient. For instance, S. K. Smith et al. (2010a) included a few blank lines for the patient to write down any feelings they had about colon cancer screening. Mathieu et al. (2007) took a different approach, focusing on key statistics related to screening and providing a structure for patients to reflect on these statistics. One challenge with these open ended approaches is that the patient may limit the exploration of their values and identity, not considering aspects of their identity that could be negatively affected by a decision to forego or undergo screening.

One of the reasons for avoiding personal context in the studies included in the Cochrane Review (Stacey et al., 2014) may have been because the studies which had explicit value clarification exercises were largely focused on screening interventions. While it is difficult to prove, perhaps screening was not considered to be enough of a high stakes endeavor to challenge otherwise healthy individuals with directed questions about their mortality. For instance, one study reported that only 0.2% of fecal occult blood tests yielded malignancy, this represents a number needed to screen of 500 to detect a single cancer (McDonald, Tomlins, Smith, & Harmston, 2013). For a single individual, the consequences of not thoroughly exploring how screening may affect personal identity are relatively small. Screening tests are often short, minimally invasive procedures, generally done no more often than on a yearly basis, with a low

risks of negative outcomes (Herman, 2006). But what about when the stakes are higher? The situation where a patient is forced to make decisions about adjuvant therapy provides an example of an instance where exploring values and identity, or the failure to do so, might have major consequences.

By definition, adjuvant therapy is offered to cancer patients when all signs of cancer have been removed through a curative surgery, but a significant risk of recurrence remains. The choice to receive adjuvant therapy is a complicated one. Undergoing treatment provides no guarantee that a cancer will not re-occur. Alternatively, not taking treatment does not guarantee that a cancer will re-occur (DeVita et al., 2011). Second, many adjuvant treatments are well known for their side-effects. For instance, side effects of chemotherapies are fatigue, nausea, vomiting, increased risk of infection, cardiac dysfunction, gastro-intestinal side-effects, neuropathy, nephropathy and hair and skin changes are all commonly cited side effects for many of the agents used in contemporary chemotherapy regimens. Some of these side effects may resolve after the completion of chemotherapy, while others may persist lifelong (DeVita et al., 2011). Lastly, the total duration of adjuvant treatments may be months, or even years. This means that the acute side effects of these treatments may persist in some form until treatment is completed.

In addition to the side effects, other factors influence the impact of adjuvant treatment on a person's life. For instance, there is a tremendous time commitment required while receiving chemotherapy. Patients may be required to have frequent visits to healthcare providers, sometimes on a weekly basis (DeVita et al., 2011). In addition, many individuals are unable to work during treatment, and some do not return to work for significant periods of time, if ever (Hedayati et al., 2013). Given the side effects and overall impact on an individual's life it is easy to speculate about the many ways in which adjuvant treatments could affect one's identity.

Despite the importance and complexity of making decisions about adjuvant therapy, there is only limited evidence supporting the importance of value clarification in the cancer treatment decision making process, and this evidence does not include the adjuvant treatment setting. In a recent review and systematic analysis of 14 decision aids for localized prostate cancer, only one study had an explicit values clarification exercise (Violette et al., 2015). This study randomized patients making decisions about curative treatment for localized prostate cancer to either the control arm, which received a decision aid, or the intervention arm, which received the decision aid in addition to a specific values clarification tool (D. Feldman-Stewart et al., 2012). While no differences were found in decisional conflict scores between the two groups, decisional regret scores did differ. What is interesting about this finding is that at the initial follow up period of 3 months the regret scores did not differ. However, at 1 year, decisional regret scores began to separate, with less decisional regret being demonstrated in the intervention group (mean difference = 1.3 at 1 year,  $p < 0.05$ ). The authors suggest that, unlike in previous studies which included a value clarification exercise but did not show a benefit in decisional regret, their study demonstrated a positive effect of the intervention because follow up was longer. This phenomenon was explained using Svenson's Differentiation and Consolidation theory (D. Feldman-Stewart et al., 2012). According to D. Feldman-Stewart et al. (2012), this theory suggests that two process goals exist for each decision: to limit the cognitive dissonance that is felt while making a decision, and to decrease post-decisional regret. The findings of D. Feldman-Stewart et al. (2012) certainly suggest that value clarification exercises helps to limit decisional regret consistent with the Diff Con theory, in addition, they also support the model that has been developed through this literature review.

Implicit in the model proposed in this paper is that values are less dynamic than attitudes or beliefs. The decisional regret scale utilized by D. Feldman-Stewart et al. (2012) is helpful for exploring this assertion. The decisional regret scale used by D. Feldman-Stewart et al. (2012) tool consists of 5 items which ask: 1) whether regret was felt to be present, 2) whether the decision was right for the patient, 3) whether the same decision would be made again in the same circumstances, 4) whether the decision was a wise one and 5) whether the decision had resulted in harm. Each item is scored using a 5 point Likert scale ranging from strongly agree to strongly disagree (Brehaut et al., 2003). These questions reflect attitudes and beliefs about past decisions, and if measured over time reflect the consistency of a decision with an individual's identity. The fact that there was less decisional regret detected after one year in the intervention arm suggests that the process of value clarification enables patients to base decision making on core aspects of their identity. At the same time, patients who did not have the opportunity to use the value clarification exercise may have based their decision on transient attitudes and beliefs about the treatment, as opposed to an effort to make the decision most consistent with their values. Please refer to Appendix A.3 for the corresponding illustrative scenario.

### **Advancing Value Clarification for Adjuvant Treatment Decision Making**

Although the rationale for value clarification in the adjuvant setting is strong, value clarification is an area of research that is just starting to evolve as evidenced by the small number of studies found in the literature. In addition to the studies mentioned above, only one other study with an explicit value clarification tool for determining surgical treatment for breast cancer could be found (Goel, Sawka, Thiel, Gort, & O'Connor, 2001). While patient preferences for information sharing and decision making preferences have been addressed throughout the literature (Deb Feldman-Stewart et al., 2013; Johnson, 2011; Vogel, Bengel, & Helmes, 2007;

Wengstrom, Aapro, Leto di Priolo, Cannon, & Georgiou, 2007), specific explorations of values and how they relate to personal and social identity do not appear to be evident in the literature. The model of identity presented here suggests that exploring this area is key to providing patient centered care.

Patients preparing to make adjuvant treatment decisions are in a unique position to reflect on the past and look forward to the future. By definition they have already had considerable exposure to the healthcare system, as this type of contact would have occurred during initial diagnosis and removal of the primary malignancy (DeVita et al., 2011). Individuals in this position would be able to reflect on how receiving a diagnosis of cancer and receiving, in many cases, a surgical intervention, affected their identity and fit with their values (Lee et al., 2015; Lehto, Helander, Taari, & Aromaa, 2014). In addition, these individuals will be considering future treatment, and be weighing the information they have about the treatment against their attitudes and beliefs of what a desirable outcome is. These characteristics make this population an important group to explore values and identity with.

To summarize, at the center of PCC is the concept of the individual (Mead & Bower, 2000). The individual can be described using a model of identity that includes values as well as personal and social identity (Hitlin, 2003). Values exist at the center of the model, and inform all aspects of an individuals' identity. When an individual is able to maintain personal and social identities that are consistent with their values, authenticity is achieved (Freire, 1974/2013, 1970/2014; Hitlin, 2003; Starr, 2008). Evidence exists that when patients are provided with tools to help them clarify their values in the setting of a treatment decision, they are less likely to regret their decisions in the long term (D. Feldman-Stewart et al., 2012). Exploration of the concept of values and personal and social identity is limited in the cancer treatment setting, and



patients considering adjuvant therapy are an important and unique population in which to study these concepts. The aim of this study is to explore, using grounded theory, how patients' identities and values have been impacted by their experience with diagnosis and treatment, and may be affected by further adjuvant treatment.

## **CHAPTER 2: GROUNDED THEORY AND METHODOLOGY**

### **Grounded Theory and The Constructivist Worldview**

Because the focus of this study is on understanding the experience of the individual, a constructivist worldview serves the research agenda best. This is because the ontology and epistemology of the constructivist worldview are congruent with the model of individual identity forwarded in this proposal (John W. Creswell & Plano Clark, 2010). As is central to PCC, constructivist ontology identifies that each individual has a unique reality. This ontology is in keeping with the model of identity that has been forwarded above, in that each individual's identity is made up of a variety of unique identities that place the individual in a unique place in reality, with a unique perspective.

The constructivist epistemology also fits with the PCC model as a whole. In the constructivist worldview, and in PCC, emphasis is put on learning through closeness with the study participant or patient, and is accomplished through engaging in the individual's own space (John W. Creswell & Plano Clark, 2010; Scholl et al., 2014). The model of identity presented in the literature review also fits with the constructivist epistemological approach, and informs the research methodology. For instance, as the social identity taken on by a patient may be different in a foreign research space than in their own home the researcher must determine which social identity they want to connect with in their research.

Grounded theory as a methodology, serves the research objectives in this study well from a purely exploratory standpoint and from a knowledge translation perspective. From an exploratory standpoint, grounded theory evolved from a perceived need to generate new lenses to explore social phenomena (Charmaz, 2006; Glaser & Strauss, 1967/1999). Grounded theory takes its roots in palliative care research in the 1960's (Charmaz, 2006). Its pioneers, Glaser and

Straus, were sociologists that were concerned with the emphasis on theory verification that existed in the field of sociology. They developed methodologies for systematically analyzing a wide range of data in order to generate new theories. This is in contrast to deducing testable hypotheses from existing theories (Glaser & Strauss, 1967/1999). Theories generated through grounded theory can demonstrate the causes and conditions under which social processes emerge and the consequences of these process. Establishing and further defining a working theory of how the aspects of individual identity interact with the experience of cancer diagnosis is clearly desirable from a patient centered care perspective because it provides a novel lens to understand the patient experience.

Describing phenomena, is not unique to grounded theory as other qualitative methods including ethnography, narrative research and phenomenology are well suited to provide rich and detailed descriptions of cultural, social, shared social experiences and phenomena (J. W. Creswell, 2014). Where grounded theory differs from these methodologies, is in its ability to generate theories which predict outcomes (J. W. Creswell, 2014). Because of the predictive and descriptive power of theories generated using grounded theory, the resultant theory is expected to have knowledge translation implications. This is because the theories generated using this methodology can provide a lens with which to evaluate existing processes of healthcare delivery within a social context, enabling predictions of how changes within the social processes will affect outcomes. In other words, grounded theory provides a methodology to not only describe phenomena in a manner that is in keeping with the lived experience of the research participants, but it also provides a tool to direct change.

## **Methods**

### **Ethical and Administrative Considerations**

Approval was obtained from the Health Research Ethics Board (HREB) at the University of Manitoba as well as the Research Resource Impact Committee at Cancer Care Manitoba (RRIC). As this research aimed to involve all peoples in Manitoba, including indigenous populations, letters of support were obtained from groups representing the Indigenous populations in Manitoba (i.e. Assembly of Manitoba Chiefs, Manitoba Metis Federation and Manitoba Inuit Association, in keeping with the principles outlined in the University of Manitoba's Framework for Research Engagement with First Nation, Metis, and Inuit Peoples (University of Manitoba, 2015). In addition, because this research program involved activities throughout Manitoba, additional approval was obtained from the various health regions within Manitoba (Winnipeg Regional Health Authority, Interlake-Eastern Regional Health Authority, Prairie Mountain Regional Health Authority and the Northern Regional Health Authority). To protect the identity of study participants, all identifying data was separated from de-identified study data through the use of two sets of password protected encrypted USB keys.

### **Setting**

Because of its diverse population, Manitoba provided an ideal setting for exploring identity. Manitoba contains both urban and rural communities, in addition to many remote and geographically isolated communities. In addition, the Manitoba population consists of three distinct indigenous populations, namely, First Nations, Metis and Inuit, each of which have many distinct cultures and ways of life (Government of Manitoba, 2001). Manitoba is also home to many recently immigrated populations from all over the world. In fact, in 2012 Manitoba received the second largest number of immigrants in Canada. While the majority of immigrants

to Manitoba come from Asia and the Pacific, the immigrant population is diverse with representatives from all over the world (Government of Manitoba, 2013). This incredible diversity is ideal for providing the participants to inform a deeper understanding of the individual and a new perspective on what it means to provide patient centered care that truly celebrates the uniqueness of the individual.

Data collection took place between January 2016 and October 2016. Theoretical sampling was for data collection in this study in keeping with grounded theory research (Charmaz, 2006; J. W. Creswell, 2014). Data collection concluded when theoretical saturation was achieved and additional data did not contribute to the understanding of the emerging theory (Charmaz, 2006).

### **Recruitment and Sampling**

Recruitment was limited to patients that were 18 years or older with recently diagnosed cancers of the colon, rectum, lung, pancreas, endometrial, cervical, prostate and breast cancers. This study did not include patients that were known to have metastatic disease or those that had already been evaluated for and consented to chemotherapy or radiotherapy for treatment of a recently diagnosed malignancy. Because patient flow through cancer services in Manitoba varies somewhat by disease site group, the recruitment strategies and timing of the interviews differed between disease site groups in three different ways. Patients with breast, lung and colon malignancies were recruited directly by nursing staff over the phone at the same time that consultations for appointments with medical oncology and radiation oncology specialists were being booked. The referrals nurses for these disease sites invited patients to participate and, for those that were willing, obtained consent over the phone to be contacted by researcher as well as

to have their CancerCare Manitoba electronic health record reviewed. Interviews for these patients took place prior to meeting with the medical or radiation oncologists.

The second way in which patients were recruited involved the gyne-one patients, included those with ovarian, endometrial and cervical cancer. In Manitoba, gyne-oncology patients, receive chemotherapy directly from their gyne-oncology surgical specialist. The gyne-oncologists were responsible for recruiting and obtaining consent from patients to be contacted by the researcher as well as to have their electronic health record reviewed. This process took place when initial diagnostic biopsies were available, prior to undergoing surgery. Interviews with these patients took place prior to initial surgery.

The third way in which patients were recruited involved those patients with prostate cancer. These patients had previously received an initial curative procedure and were being referred to radiation oncology for additional treatments. At the time of referral, they were provided a letter providing information about the study, and contact information for the investigator, with the interview taking place prior to meeting with the radiation oncologist. No records were kept of the number of patients that were initially approached by clinic or referrals staff or the number of interview letters that were distributed to patients.

Once a patient was identified as being interested in participating in the study, they were contacted by the researcher. Once consent for review of electronic health information was obtained, either through the referrals nurses, the gyne-oncologists or over the phone for patients who contacted the researcher directly, a brief chart review was completed. This processes involved obtaining available staging information, timing of upcoming appointments, and the patients contact information. Then complete details of the study were reviewed with the patients over the phone. If patients were interested in participating an interview was then set up. The

interviews themselves took place in the patients homes when possible. Family and friends of patients were included in the study (referred to as secondary participants), if both the patient participant (primary participant) and the secondary participant consent (and legal guardian of the secondary participant if appropriate). Short follow-up interviews following a decision about chemotherapy or radiation therapy were also conducted when possible, these interviews took place over the phone and involved only the primary participant.

In total, 34 patients agreed to be contacted by the primary investigator or contacted the investigator directly after receiving a letter of invitation. Of these patients, after a telephone discussion about the full details of the study, 18 were eligible for an interview based on willingness to proceed and the logistics of carrying out the interview before a consultation with a specialist to discuss chemotherapy or radiotherapy was scheduled. Twelve of these primary participants had at least one friend or family member that was willing to be involved in the study, with two participants recruiting two secondary participants. This resulted in a total of thirty-three participants (18 primary participants, 15 secondary participants). These interviews were conducted separately, with the exception of three. In two instances, couples choose to be interviewed together. In another instance, a mother/daughter pair choose to be interviewed together. In addition, a pair of sisters wished to be interviewed together, while the interview with their mother, who was the primary participant, was conducted separately. This resulted in a total of 29 initial interviews. Thirteen follow-up interviews were conducted with primary participants, as two primary participants were unable to be reached for follow-up and three of the participants were scheduled to have their interviews after it had been determined that data saturation had been achieved. In total, this process resulted in a total of 42 interviews being conducted. The

characteristics of the sampled population are presented in Table 1 and Table 2 for primary participants and secondary participants, respectively.

### **Development and Evolution of the Interview Guide**

For both the primary and secondary participants, the initial interview included reviewing the study information and the consent form, and completing a demographics questionnaire. Then, an interview was carried out with the primary participant, using an interview guide designed specifically for the primary participants. Following this, usually immediately after primary participant interview, the interview with the secondary participant was carried out. The interview guides were modified slightly throughout the study to explore certain themes as they emerged in keeping with accepted data analysis procedures in grounded theory. The interview guides were designed to generate a 45 – 60 minute interview for primary participants and 15 – 20 minute interview for the secondary participants. In most cases that involved secondary participants, the interviews with each participant were done separately, however, in some instances that primary participants indicated that they wanted to do the interview with the secondary participant. This was also the case in some of the interviews with the secondary participant, where they indicated that they wanted to conduct the interview with the primary participant present. Whether additional participants were present for any given interview was recorded, interviews were transcribed to indicate which participant was speaking, and the interviews were conducted in such a way to encourage open discourse and sharing between all participants present.

The initial interview guides themselves were structured to explore the concepts of values, and personal and social identity as defined by the literature review, along with reflections on how the diagnosis of cancer and subsequent treatment had affected these concepts. The initial interview guide is presented in Appendix C. As data analysis progressed and the theory emerged



Table 1

*Demographic Profile of Primary Participants*

Patient ID	Age	Gender	Type	Rural (Y/N)	Driving Distance Round Trip to Cancer Center (Minutes)*	Education	Marital Status	Employment
1	52	Female	Breast	Urban	30	Finished Post-Secondary	Married/Common Law	Part-Time**
2	65	Female	Breast	Rural	280	Finished High School	Married/Common Law	Part-Time**
3	36	Female	Breast	Urban	50	Finished Post-Secondary	Never Married	Part-Time**
4	41	Female	Breast	Urban	100	Partial Post-Secondary	Married/Common Law	On Medical Leave
5	44	Female	Breast	Rural	95	Finished Post-Secondary	Married/Common Law	Full-Time**
6	59	Female	Breast	Rural	255	Partial High School	Married/Common Law	Retired
7	69	Male	Lung	Urban	280	Finished High School	Married/Common Law	Retired
8	79	Female	Lung	Urban	50	Finished High School	Widowed	Retired
9	67	Female	Gynecologic	Rural	70	Finished Post-Secondary	Married/Common Law	Part-Time
10	52	Female	Breast	Urban	60	Finished Post-Secondary	Married/Common Law	On Medical Leave
11	56	Male	Breast	Urban	20	Finished High School	Never Married	On Medical Leave
12	57	Female	Colon	Urban	55	Finished Post-Secondary	Married/Common Law	Part-Time**
13	49	Female	Breast	Urban	70	Finished High School	Never Married	On Medical Leave
14	62	Female	Breast	Urban	40	Finished Post-Secondary	Widowed	On Medical Leave
15	62	Female	Gynecologic	Urban	60	Finished Post-Secondary	Widowed	Full-Time

16	64	Male	Prostate	Urban	40	Finished Post-Secondary	Married/Common Law	Full-Time
17	33	Female	Breast	Rural	160	Partial Post-Secondary	Married/Common Law	Retired
18	51	Female	Breast	Urban	35	Finished High School	Married/Common Law	Part-Time**

\* Average distance from downtown Winnipeg used instead of postal code to protect confidentiality of participants as a number of the rural participants came from very small communities. This is an indicator of the amount of travel time required for out of town participants to attend consultations with medical oncologists, and, except for those that are assessed in Brandon MB, radiation oncology. Calculation based on Google Map estimates and rounded to nearest five minutes.

\*\* Despite indicating on the demographics questionnaire that they were working full-time or part-time, these participants indicated in the context of the interview that they were not attending work for medical reasons.

Table 2

*Demographic Profile of Secondary Participants*

Secondary ID*	Age	Gender	Education	Relationship	Duration of Relationship (Years)
1.1	65	Male	Finished Post-Secondary	Spouse/Partner	Not Completed
2.1	58	Male	Finished High School	Spouse/Partner	38
2.2	55	Female	Partial Post-Secondary	Friend	10
3.1	40	Male	Finished Post-Secondary	Spouse/Partner	3
4.1	18	Female	Finished High School	Daughter	18
6.1	70	Male	Partial High School	Spouse/Partner	19
6.2	42	Female	Partial Post-Secondary	Friend	16
7.1	66	Female	Finished High School	Spouse/Partner	47
8.1	45	Female	Finished Post-Secondary	Daughter	45
12.1	58	Male	Finished High School	Spouse/Partner	32
14.1	35	Female	Finished Post-Secondary	Other - Daughter-In-Law	16
16.1	62	Female	Finished Post-Secondary	Spouse/Partner	47
17.1	65	Male	Partial Post-Secondary	Spouse/Partner	50
18.1	20	Female	Partial Post-Secondary	Daughter	20
18.2	22	Female	Partial Post-Secondary	Daughter	22

\* Syntax for secondary ID is "primary ID"."secondary participant ID"

from the data, subsequent revisions to the interview guide were created. These are attached in Appendixes D – K.

### **Data Analysis**

The process of coding began after the initial interview had been completed and was carried out as described by Charmaz (2006). First the interview was transcribed by the researcher then the transcriptions were deconstructed and coded as segments that have an identifiable meaning. From the codes that emerged from the data, data from the individual interviews was grouped and linked to generate theoretical concepts. Initially, open coding was carried out with the participant's statements being reviewed and labeled on a paragraph-by-paragraph basis. Next, focused coding was used to make comparisons across interviews and to develop higher-level categories. Lastly, as the theory began to emerge from the data, theoretical coding was used to explore and define the interactions between the emerging concepts. Memoing and diagramming was used throughout the study to help clarify emerging concepts. Of note is that no dedicated coding software was used as part of this study.

In keeping with a grounded theory approach, data was analyzed through an iterative process called constant comparison that began with the initial interview (Charmaz, 2006). The process of constant comparison “generates successively abstract concepts and theories” by beginning the data analysis process as soon as data begins to be collected, instead of delaying analysis until all data has been collected. In this study constant comparison involved the ongoing analysis of data, categories, and concepts between the established data and interview transcripts (Charmaz, 2006).

The processes of constant comparison lead to the interview guide evolving throughout the study, it also informed the sampling strategy throughout the study, in keeping with theoretical

sampling (Charmaz, 2006). As the study went on the interview guide was modified as aspects of the theory became clear to focus on aspects of the evolving theory that were less clear. This processes lead to several modifications to the interview guide, with the most notable change being questions surrounding relationships with doctors and questions exploring previous experiences with cancer being added to the primary participant's interview guide.

Practically speaking, initial interviews were carried out with the primary participants whenever possible. Logically and ethically it seemed better to collect data that seemed redundant at the time then to miss the opportunity to uncover a new perspective or an important challenge to the evolving theory. Where theoretical sampling was utilized to exclude potential participants was with regards to interviews with the follow-up interviews with primary participants and the interviews with secondary participants. The follow-up interviews were initially intended to better understand the experience of meeting with the oncology consultant for discussion of chemotherapy and/or radiation. It quickly became clear that what was important to participants at the time of these interviews was issues regarding expectations and, from the standpoint of the evolving theory, issues regarding decision making. When these themes were saturated and it was determined no additional themes were emerging from the follow up interviews, they were discontinued.

Regarding secondary participants, in many cases primary participants were very agreeable to having friends and family interviewed. However, in some cases, especially towards the end of the study, these interviews were not adding to the evolving theory in a substantial way. Therefore, towards the end of the study interviews were limited to those secondary participants that offered a unique perspective. The decision to undertake a secondary interview was made when the primary participant described a dynamic in the relationship that had not been

previously described in other primary-secondary participant dyads or if the secondary participant clearly represented a demographic such as age or relationship with the primary participants that had not been previously explored.

### **Data Validity and Reliability and Researcher Bias**

Several strategies for ensuring valid and reliable results were utilized in this study in keeping with published recommendations (J. W. Creswell, 2014). Verification of the data is inherent to the study methodology and was ongoing through constant comparison. As this project was carried out as part of a master's thesis study, auditing of coded transcripts by the thesis supervisor occurred as part of the supervisor/mentorship process. Lastly, reliability was addressed through the extensive use of memoing throughout data collection and data analysis, functioning as an ongoing narrative as the study evolved.

As qualitative research involves heavy dependency on the researcher's skill and perspective, some have suggested it is important to provide background on the researcher as part of qualitative reports (J. W. Creswell, 2014; Tong, Sainsbury, & Craig, 2007). In this case, all research was carried out by a white male in his mid-early 30's as part of a master thesis project. The researcher is also a practicing physician that holds a bachelor's degree in biochemistry, a medical doctorate, and has completed three years of specialty training in internal medicine, two years of specialty training in medical oncology and holds certifications in both Internal Medicine and Medical Oncology from the Royal College of Physicians and Surgeons of Canada. These credentials were indicated to the study participants at multiple points throughout the study including: in all of the consent forms which were signed by the study participants including those to be contacted by the researcher; the letter of invitation to participate in the study which prostate cancer patients received; at the time of setting up the initial interview over the phone; and prior

to initiating recording at the time of the interview. It was also made clear that participation in the study would not affect the healthcare delivery for the patients. Furthermore, the researcher was not involved in the care of the patients, either prior to study enrolment or during study participation. No participants were known to the researcher prior to study enrolment.

This study represents the researcher's first qualitative research study, although formal training in qualitative methodology did occur as part the researcher's master's coursework. This research was motivated by anecdotal clinical experiences that the researcher had while in training where patients expressed decisional regret regarding adjuvant treatments that they had taken. Several identified that if they had a better understanding of the effect that treatment would have on their function they would have considered alternative options.

It is certainly possible that the prior education and experiences of the researcher may have affected both data collection and data analysis. Clearly, undertaking graduate studies in order to find a resolution to a specific clinical concern implies a critique of existing processes in healthcare delivery and a personal investment in finding a solution. Identifying the researcher as a physician to the participants may have certainly altered how the participants shared information about their experience with healthcare providers. However, after data analysis concluded, it was clear that a broad spectrum of experiences and opinions of healthcare providers was shared, suggesting that any tendencies that the participants had to color how they described their experience and their healthcare providers in data sharing perhaps balanced itself out.

One other aspect of this study, that poses important questions regarding both the validity of the findings and professionalism of the researcher is with regards to the possibility of this study to be viewed by some as an audit or an expose. There were definite instances throughout the study where participants expressed dissatisfaction with the healthcare system or specific

providers. When participants indicated they were looking for a response to their negative experiences the researcher provided responses that were guided by an overarching effort to address the processes that lead to the negative experience, expectations of the professional conduct of physicians - i.e. avoiding being freely and unfairly critical of colleagues (McDaniel et al., 2013) - and an effort to not influence care or the relationship between the participants and the treating physicians by acting as an observer.

The general strategy for handling these instances included validation of the emotion the participant was experiencing, identifying the aspect of the experience that was challenging for the participant without making a judgement statement about the reported behavior of any of the healthcare providers and then moving on to the next question. Responding appropriately to these participant concerns was certainly challenging, but a conscious effort to avoid sharing personal judgements that the researcher had about the reported negative experiences was made. When these negative participant experiences were reflected on during data analysis, after the transcripts had been de-identified, understanding the processes that lead to the negative experience for the patient was the focus. However, many of the participant's stories and experiences were certainly emotional. Every effort was made to rigorously analyze the data throughout the coding processes, and through reflection during memoing. However, biases are inherent in qualitative research as the researcher becomes the instrument of interpretation (Charmaz, 2006). Therefore, the reader should be aware of the researchers aforementioned perspective.



## CHAPTER 3: FINDINGS

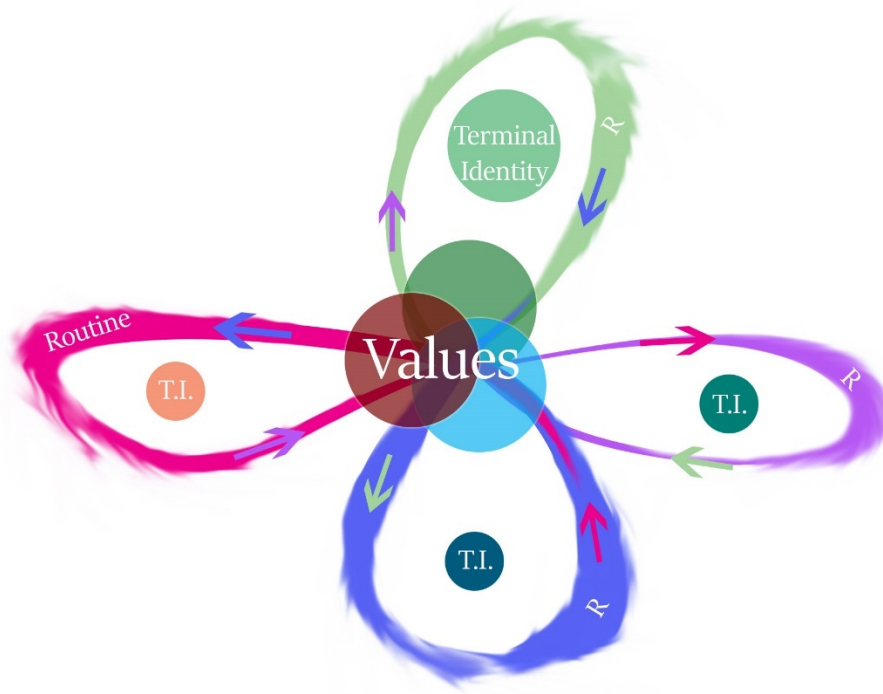
### Evolution and Validation of the Emerging Model

Using the theory of identity synthesized in the literature as a base, it was possible to use the data collected to further refine a model of individual identity. This model was modified to include the following concepts: *terminal* and *instrumental values*, *terminal* and *instrumental identities*, and the *concept of routine*. This revised model was found to reflect the lived experience of the participants better than the model derived from the literature review, in part because it was derived directly from the data collected from the participants. The model that emerged from the data analysis is illustrated in Figure 3.

The following section will be divided into five subsections. The first three will define and demonstrate how the data collected supports the concepts of 1) terminal and instrumental values 2) terminal and instrumental identity and 3) routine. The fourth subsection will provide a summary of the completed model. These first four subsections will draw on interview content that is not directly related to the cancer experience or involved reflection on the pre-diagnosis identity of the participants. The fifth sub-section will use the data collected to examine how the cancer experience, including the initial interview, affected the five concepts of identity used in this model.

### Conceptualizing Identity: Learning from Life Before Cancer

**Terminal and Instrumental Values.** The participants demonstrated that values form a central part of individual identity. In keeping with the literature, values were shown to be motivating factors that existed in an identifiable hierarchy. When the primary participants were asked what they valued, two types of responses emerged. In one type, responses uniformly included references to things in which they invested energy into, these types of things are defined



*Figure 3.* Representation of the model of identity obtained through data analysis. The components of the model are as follows: 1) Values exist as the core of identity. Terminal values represent recognizable non-abstract objectives that the individual wants to establish or maintain. In the data these were things such as family, friends and employment. Instrumental values are the rubric by which individuals evaluate their own instrumental identities and the instrumental identities of those they interact with. 2) Terminal identities (T.I.) exist as the social expression of terminal values. In the data, these emerged as specific groups of friends, relationships with spouses, roles as parents and employees. 3) Routine (R) is the method by which the individuals maintain their various terminal identities. This includes utilizing aspects different aspects of instrumental identity over time.

in this model as *terminal values*. This term was chosen in part because achieving and maintaining these things can be seen as achievable and measureable. These included employment, family and friendships. In the other type of response, personal qualities were referenced, these included, but were not limited to, loyalty, authenticity, helping-others, friendliness and honesty, these behaviors or ways of acting are known in this model as *instrumental values*. The term *instrumental value* was chosen in part, because these are valued ways of being or engaging in a processes, but, in and of themselves, do not have an objectively measurable end result. Of note, is that the terms terminal and instrumental values have been used in previous work on values, notably by Rokeach (1973). A more in depth discussion of the influence of Rokeach's work on this study follows in Chapter 4.

Two kinds of interview questions lead to the clarification of the role of values in this model. Questions asking what things the participant valued most lead to responses that identified terminal values and the hierarchy of their terminal values. Typical responses included "My wife, for sure. Above all else. Then there's my two daughters and their families. That's the most important thing in my life" (Patient 7). In this response, the participant clearly establishes his wife as the most important thing in his hierarchy of terminal values, followed by his children. For responses that identified important instrumental values, the presence of a value hierarchy was not as clear. When asked about values another respondent states several instrumental values, but did not establish a clear hierarchy between them. "Integrity. Yah. Big time. And the other one is justice. Fair. Fairness" (Patient 9). Whether the participants could have produced a clear hierarchy between her stated instrumental values was not clearly established in the data as the usefulness of this in the emerging model was not evident.

When the primary participants were asked about their goals for the future, or about plans that had been made prior to cancer diagnosis, what emerged were goals and plans closely linked to work and relationships, primarily with family and friends. In other words, the goals for the participants were closely linked to what they had identified as their terminal values, establishing terminal values as motivating factors. A clear example of this comes from one participant who was diagnosed with breast cancer and who was employed as a music teacher. When asked about her important values she gave the following reply:

Having a strong relationship with my children and my husband. My children always come first. I am passionate about my work. I feel very fortunate that I have a career where I want to go to work every day. (Patient 1)

When asked about goals for the future, her response was closely tied to her statement about what she valued:

I'm definitely working on the clarinet. That's a huge goal. To be able to play well enough that I could play it with [the students] and not be embarrassed about it. I do play with the [students] a lot, they need that help. They get scared and they don't want to play. So sometimes if I play along with them it really helps.... I hope to have grandchildren. I wouldn't call that a goal, but I can see myself enjoying that. (Patient 1)

What is especially notable is that in cases where participants were asked to share their values and offered only instrumental values, their goals were focused on family, friends or work. For instance,

one participant offered the instrumental value of honesty and having a straightforward attitude towards life, but when asked about goals for the future he stated “I work for [...], I am on a work furlough thing, and my goal would be to get back to work there part-time. And I have talked, my boss is very supportive of that” (Patient 11). The importance of this statement is that despite stating the importance of honesty and a straightforward attitude, participants base their goals on their terminal values.

**Instrumental and Terminal Identities.** The term terminal identity described the roles and relationships that the participants hold in their lives. Instrumental identity describes the collection of skills and tools they used to maintain their terminal identities. These concepts present a simplification to the model of identity synthesized from the literature review. In the literature review, the terms personal identity and social identity were used. However, what emerged from the literature was that in practice, both primary and secondary participants were able to consistently agree on the skills and tools that the primary participant brought to the terminal identity that was shared between the two individuals. While personal identity may be a useful theoretical concept, from the interviews it was not one that was clearly evident in the data collected.

Participants were able to clearly identify what terminal identities they held in their lives. For instance, when asked about who she was to other people, one participant offered the following statement:

Well, to other people I am a wife, a mother, a daughter, a friend, a supervisor, an engineer. It's a lot of things. I am a volunteer. I do a lot of volunteer things with different committees. (Patient 5)

The participant is articulating what identities she has established in her life, clarifying her terminal identities. When describing herself in general terms the participant offered a detailed description of herself:

... I am quiet, dedicated, very practical, quite a perfectionist, very detailed and very reliable. That's the main kind of things. I'm a little bit on the shy side. That sort of has gone away. The longer I'm in the work force [...] you gain the ability [...] to talk to people you don't know very well. But it's not my tendency. (Patient 5)

This description applies to a general understanding of the instrumental identities she uses to maintain her various terminal identities. When asked directly about the kind of person she is at work, the participant described herself as determined, creative, motivated, assertive.

I'm the one that they would usually give the projects too that are quite hard that take a lot of determination, because they know I'll find a way to get it done. Because I'm always thinking of different avenues and ways to do things differently or another angle to try and explore and I'm usually pretty good at making those things ticks. So I can think of ways to do what will advance my project or initiative and stuff, and I stand behind my staff very much so they tend to like working with me, and my supervisors like me because I am reliable and get stuff done. But I don't hesitate to say if I think they are on the wrong track either. (Patient 5)

When describing how she carried out her role as mother, the participant used a different set of adjectives.

I'm definitely the organizer and keep things on track. My husband is quite laid back and I'm more, I don't have as much patience, I'm more forceful. I want to get everything done. But his, it helps to moderate some of my personality characteristics. But I'm lots of fun, and energetic, and get them doing things. (Patient 5)

The distinction between this participant's description of her instrumental identities in general and specifically in the different roles is important to the theory that is emerging here. She is able to take on different identities in different circumstances in order to meet the demands of her various roles. At the same time, she is aware of a central core-identity suggesting that the different identities of the participants are linked by a central identity that informs the identity the participants take on in individual roles. This is consistent with the idea that the participants have a central set of both instrumental and terminal values. When the participant's description of herself in her roles at work and with her family were contrasted with how she described her relationships with her friends, the importance of values in shaping the participant's global identity and what characteristics they bring to each of their social identities is emphasized:

As time has gone by, I'm probably a little bit more passive with my friendships now, just because I'm so busy with my family and work. [...] I'm probably more of a follower than a leader in the friendship side of things because you can't control everything and there is only so many hours in a day. (Patient 5)

Here, the participant establishes that family and work are her biggest priorities, and in her relationships with her friends she is more likely to be a follower than to invest the energy to be a leader, which is in contrast to her roles at home and at work.

A deeper characterization of the concepts of terminal and instrumental identities come from the examples where a primary participant was associated with two secondary participants. These instances allow for an understanding of who the participant is to multiple people, further illuminating the concept of instrumental identities. It is clear that the participants employed multiple instrumental identities to maintain their different terminal identities. Some of the instrumental identities contained aspects that were clearly shared amongst their different terminal identities, while others were stated to be present only in certain terminal identities. One series of interviews included separate interviews with a primary participant, her husband and a person she described as her best friend as secondary participants. In these interviews, the primary participant described herself as a wife, a friend, a grandparent, and a worker. She also described her instrumental identities in each of these roles. In general, she described herself as a good person who speaks her mind, stands up for herself, helps people and looks to the future. The primary participant also described the instrumental identities that she brought to her various terminal identities, including those with her husband and her best friend. In the interviews with the secondary participants, both her husband and her best friend were asked to describe the primary participant. Their responses demonstrated that the instrumental identity that the primary participants brought to specific terminal identities were identifiable to the secondary participants. When asked to describe herself as a wife, the primary participant described herself in terms of being someone that focuses on the future.



It's changed a little bit over the last few years. But not because of the cancer. I don't know whether it it's an age thing.... He's kind of gone negative.... So just leave it. Move onto something else because you're never going to be able to fix it. So just forget it, *move on, move past it*. But sometimes he has a hard time doing that. (Patient 6)

When her husband was interviewed separately as a secondary participant, he described her in terms similar to how she described herself:

Very strong person, *she's got a positive attitude*. She's always happy and smiling. When she was diagnosed she said right off the bat, I'm having my breast removed. That's it. Done. It was harder on me then it was on her. But with her, she's strong.... Ever since being married to her she's always been heads up, let's go. (Secondary 6.1)

When asked to describe her friendships, the participants defined distinct terminal identities between her groups of friends. Additionally, she identified that she utilizes different instrumental identities with her different groups of friends. Speaking of the friends she has around where she lives:

Around here, I'm more of a lighter, we don't get into deep conversations. Like if I've got personal stuff I don't go over there and discuss it with them. I stop in for coffee and we'll get together or go out for a meal with them, or get together and have a little party. It's more, I don't really get into telling them anything really serious.... People tell me lots, because

you've told me something doesn't mean I'm going to go over there and repeat the whole conversation. They tend to tell me quite a bit... But there are certain people that if I want everybody to know, then there are a couple people I will tell. Because the whole area will know before supper time. (Patient 6)

This is in contrast to her relationship with her best friend, in which she described her instrumental identity in different terms:

Then I have my girlfriend down in ..., and her and I are really close.... That's the one that I do, that I would probably confide in the most. She would be the one that probably knows the most about me. I don't tell people a whole lot. (Patient 6)

When her girlfriend was interviewed and when asked to describe the primary participant, she did so by saying "Passionate, caring, positive, very strong minded and strong willed.... Just a really close friend that I can pretty much tell anything too. We respect each other very well" (Secondary 6.2). In doing so she identified the general characteristics that the primary participant stated were part of her instrumental identity. In addition, she identified the openness that the primary participant had identified as being an aspect of the instrumental identity that the primary participant brought to their shared relationship.

Being able to define boundaries between terminal identities, in this case between the relationships with different friends, and recognizing that there are different combinations of instrumental identities used in each of these identities suggests that certain aspects of a person's identity are only evoked based on the relationship they are currently engaging in. Other primary

participants gave additional examples of the different instrumental identities they brought to their friendships. For instance, one participant, who had terminal identities including a father, a veteran, and a husband stated that he had several different distinct instrumental identities that he brought to his friendships. In one group of relationships, with a group of friends that he had served in the army with, he described how he handled himself as being distinct from those that he wasn't in the military with. "Yah, the military guys, we talk the way we always talk when we were in the military. That's just one different group. But with other ones that are civilian background, I'm different with them" (Patient 7). He described how he and his military friends behaved as "chucking [expletive]" (Patient 7) at each other when he was describing how he and his other friends interacted, he agreed that it could be described as fairly subdued. He thought that the uniqueness of the instrumental identity he expressed with his military friends was part of connecting to the identity that they shared as a group while they were enlisted. He described it as "just hashing the good old days in some way or another" (Patient 7).

During data analysis, four themes emerged which were important to the conceptualization of the model and instrumental identity in particular. These included the concepts of body (or health), spirituality (or faith) and knowledge. Why these themes were important in the evolution of the model and how they were eventually understood to fit into the model will now be discussed. During data analysis, the themes of body and health and spirituality were challenging to conceptualize in the model that was emerging. This was because they seemed to fit with multiple concepts including terminal values, terminal identity and instrumental identity. This was because some stated that they valued their health in a way that was consistent with their terminal values or terminal identities of family, friends or even employment. For instance, one participant described her values by stating "Faith comes first, and then health, [sic] value my family"

(Patient 15). Another stated that the most important thing to her was “To have a long life” (Patient 14), suggesting that maintaining health was an important value for her. While another participant stated her “spirituality” (patient 2) was something that she valued. Furthermore, returning to pre-cancer diagnosis health was stated as an important goal, one participant stated “I just want to get this all fixed up and get things back the way they were. I just want to [athletic activity] my four times a week next year and be well enough to do that” (Patient 12). Despite these statements, eventually both spirituality and body were seen as components of instrumental identity. The reasons for this are that themes of body and spirituality consistently fit with the concept of instrumental identity. Both body and spirituality can be demonstrated to have had an important impact on the terminal identities that individuals maintained as well as how they carried out their instrumental identities. Without a body none of the individuals could have established or maintained their terminal identities. In addition, many of the participants established terminal identities which, although defined by athletics – i.e. curling, baseball, aqua size, karate - helped maintain long lasting friendships. Regarding spirituality, when the participant said she valued her faith because “... it helped me get through [my first husbands] death and I think it’s helping me right now” (Patient 2). She also wondered if her faith helped her maintain her current instrumental identity of being a caregiver to her chronically ill husband as part of her terminal identity as a wife.

Knowledge, which in some cases came from past experiences, emerged as a critical part of the participant’s instrumental identities. However, knowledge was initially challenging to fit into the model because the theme existed in the model in two capacities. It appeared to be something that could enhance existing instrumental identities, and also as an instrumental identity in itself. Participants articulated that they were able to gain knowledge from their own

experiences and the experiences of others. One participant stated that she developed her instrumental identity as a mother from difficult experiences with her own mother “This is going to sound rude, but I try to be the opposite of my mother.... Not to say she was a bad mother, but she could have done things better” (Patient 4). Another participant shared an example of how she exchanges knowledge with a friend about a shared hobby as part of her instrumental identity in their relationship “we are always ‘I can’t get this? Do you know how’” (Patient 1)? These examples are important because they demonstrate two aspects of the importance of knowledge. The first, as evident in the first example, is that knowledge helps individuals enhance their instrumental identities. This participant used her knowledge, gained from past experience, to create an instrumental identity that was more desirable than her mother’s was. The second example demonstrates that gaining knowledge can itself be an aspect of instrumental identity that an individual’s uses to maintain terminal identities. This is because, in this example, the terminal identity that the participant had with her friend involved the activity of learning about their hobby.

To summarize the constructs of terminal identity and instrumental identity define who individuals are to other people as well as the specific skills and attributes they use to maintain their terminal identities. These are connected to terminal values because the participants value having certain terminal identities, such as employment, family and friends. In order to maintain these terminal identities, they utilize instrumental identities. These instrumental identities consist of sets of skills and ways of being that are utilized to maintain a connection with the desired terminal identities. Linking these concepts together creates a snapshot of who the participants are, or were at the time of the interview. The next sub-section will examine how the individuals maintain their terminal identities over time.

**Routine.** As the concepts of terminal and instrumental identity emerged from the data, it became clear that there was a concept that enabled an individual to be able to maintain different identities in different roles. The entity is described in this model using the term routine. An individual's routine allows them to maintain various terminal identities, while not participating in all identities at once. It assumes that to stabilize an individual's identity, different terminal identities will need more or less active participation. From the data collected, it was evident that every participant had a routine which, prior to the cancer diagnosis, they had engaged in to maintain their identity. The routine of the individuals allowed them to maintain their terminal identities in their work, their relationships, and their roles as parents and grandparents.

From the data collected, it was clear that routines have both regular and intermittent aspects. A concise example of a regular routine came from one primary participant, who gave the following response when asked about her work week:

I tend to get up really early, go to work every day. Try to go walk or exercise, make supper, run around with the kids, do their stuff, they're really involved in lots of things. Maybe around nine [or] ten, sit down for an hour, talk with my husband, watch a show or whatever. Monday to Friday, it's busy, it's a rat race, there's lots of stuff going on. It's fun. Get together with friends and family on the weekend. (Patient 5)

In her response she identifies maintaining her terminal identities as a parent, an employee, and in her relationships with her husband and her friend and family. While this participant identified how her terminal identities were maintained in a regular, repetitive manner, participants also identified terminal identities that were maintained through intermittent attention. The examples of terminal

identities maintained in an intermittent manner were those in long-established friendships and those as grandparents. The role of being a grandparent is one that changed over time for one participant, and was affected by her relationship with her daughter:

My grandkids, actually, my son's two girls, they used to come up here and stay all summer with me. Now they are going to be fifteen and seventeen, they don't come up here anymore. But they have a little guy, I am going to be going down and babysitting him at the end of the month because they're going away for the weekend. I try to help them out whenever they ask. My daughter has two boys and I don't see them as much; we had a bit of a falling out a few years ago, we're back on good terms now. It's just the way things work, I don't see her as much as I see my own son. (Patient 6)

In the same way that being a grandparent for this primary participant is an intermittent part of her routine, several participants described aspects of their routines where terminal identities, which they described as close friendships, were maintained through intermittent participation. One primary participant described a person that she maintained a relationship with in terms of being her best friend, in addition she stated that "She's very open and honest and a very caring person. And I can tell her anything" (Patient 10). Despite the relationship being important to the primary participant, interactions with her friend were occurred irregularly. She described the frequency of the interaction as a "little bit here and there" (Patient 10). She added that her friend "has her own things going on in her life. But yah, we're keeping in touch and being there when we need to" (Patient 10).

One aspect of routine that emerged from the data was that individuals shape their routines in order to help them achieve goals for the future. In other words, individuals form their routines around the same basic motivators as they form their goals – their terminal values. For example, for one participant, the reason why she went to work was to support the needs of her family. She said “Well, we all have jobs for the very same reason. We all have people to support and lives to live and mortgages, loans to pay” (Patient 4). When asked about how she develops her goals for the future she said “we just sort of acquire them as we go. There might be something I like, or my husband likes or the kids like. We don’t really make plans for future endeavors we just plan them as we go” (Patient 4). While this response doesn’t fit clearly with the model that emerged, it is important to note the use of the pronoun *we* referred to her family, and that when asked, the participant stated that her values were “family, friends, job” (Patient 4). What also fits with the model is that the major goal that she had established with her family was to take a family vacation in the upcoming months.

In summary, the participants each had a unique routine that allowed them to maintain their terminal identities. Some of the terminal identities required regular participation, like those of maintaining a job, a marriage and being a parent of dependent children. Others, like being a grandparent or maintaining established friendships, did not require regular participation. Regardless of the pattern of participation, the participant’s routine was how the participants maintained the terminal identities which were a vital part of their individual identity. Additionally, the routines allowed the individuals to achieve future goals which were related to their terminal values.

**Summarizing the Model of Identity.** In the preceding section a model of individual identity was defined. In this model individual identity was defined as a construct of several



concepts, unique to the individual. These concepts included terminal and instrumental values, terminal and instrumental identities and routine. Terminal values were identified as clearly achievable objectives that were desirable to the individual. In the study, the participants stated these to be family, friends and work. Instrumental values were ways of being or conducting processes that the participant defined as desirable. These included, but were not limited to, integrity, honesty, compassion and helping others. Terminal identities were defined societal roles that the participants engaged in to obtain the things that existed as terminal values for them. These included roles as spouses, parents, grandparents, friends, best-friends and employees. Instrumental identities were defined as the tools, skills and unique personality characteristics that each participant used to maintain their terminal identities. The participants described many instrumental identities including honesty, helpfulness, friendliness and positivity. The concepts of body, faith, knowledge and past experiences are also considered to be aspects of instrumental identity of the participants in this model.

### **Individual Identity and the Effect of the Cancer Experience**

**The Effect of the Cancer Experience on Values.** The data collected suggested that in some cases, the diagnosis of cancer caused participants to become aware of the hierarchy of their terminal values. However, as one participant indicated, this wasn't necessarily an intentional process. When asked in the follow-up interview whether she had thought about her values in the way that they were discussed in the primary interview she said "Not really, I never really thought about them before. I think it's something that is just sort of unconscious and just sort of, you are kind of auto-pilot" (Patient 5). However, later on in the interview she suggested that since diagnosis, she had been re-evaluating what was important to her, and that the initial interview had in-fact helped her to have a more concrete awareness about what was important to her.

You know I think that reflection does help you keep your focus and your eye on what is important to you and what your values are. Like you know, especially when you are going through a difficult time, like this, I think it's even more important. I can see myself as a person over this last five or six months, just with more perspective and kind of trying to slow things down and focus what's really important, instead of all of the business that just seems to take up daily life.... I think after we talked it was just kind of facts and thoughts were more concrete instead of just, I think it takes longer for someone to do self-reflection and really defining your values when you are going through cancer without having a discussion like that is more focused on thinking about that and articulating what they are. (Patient 5)

Other participants gave powerful examples of how their cancer experience was affecting their values and what they hoped to accomplish in the future. One participant that had been diagnosed with lung cancer described shaping his goals around spending time with his wife:

I definitely rethink what I want to do now. Well, I want to go on a trip with my wife now, somewhere this year.... Spending time with her. Quality time.... That is why I live and breathe. That is why I get out of bed in the morning. (Patient 7)

In contrast to the increased awareness of the participant's terminal value hierarchy, it was not clear that the participant's actual terminal or instrumental values had undergone any significant change as a result of their cancer experience. For instance, the goals of the participants for the future

seemed to have been established prior to the diagnosis, with the notable exceptions of now needing to get through treatment. Typical responses to questions about goals for the future included:

Next three months? Well, we were hoping to go on a family vacation. That was a goal of ours this year. But now I am likely to be undergoing chemotherapy and radiation... so that is going to be put on the back burner. So my goal for the next three months is to get healthy enough again so that we can do that vacation.... So my goal is to just get healthy enough so that I can continue to travel and do the things that I want to do. (Patient 18)

Another participant, who had recently started a new job stated that her goals for the next three months were “To get healthy. Get back to work” (Patient 13). Because of the connection between goals and values, it can be inferred that although the cancer diagnosis affected the participant’s ability to accomplish their goals, it did not significantly change their terminal values.

**Instrumental Identity in Pre-established Terminal Identities.** The data demonstrated that the cancer experience had varying effects on the instrumental identities that both the primary and secondary participants utilized to maintain their terminal identities. In some cases, attempts to maintain the primary participant’s pre-cancer instrumental identities in certain terminal identities were undertaken by the primary participants. In other cases, significant changes occurred as evidenced by the data collected from both primary and secondary participants. This did not necessarily translate uniformly across all like terminal identities. In other words, not all spousal, parental or friendship relationships were altered in the same way by the cancer experience.

In relationships between spouses, supportive adjustments to terminal identities included behaviors such as spending time with the participant in the post-operative period, taking over functions generally performed by the primary participant, attending appointments, helping to collect information and spending time talking about the diagnosis and being sensitive to the effects of the cancer experience on sexuality. An example comes from one secondary participant who stated “It used to be that she would just do everything around the house, because I work a lot.... It was obvious post-surgery what she could and couldn’t do, so I just did it” (Secondary 1.1). He also indicated that changes had occurred in terms of sexuality, suggesting that as a partner he had altered what he had anticipated sexually from his relationship with his wife.

She’s been peri-menopausal for a couple of years, and that effects relations. Being diagnosed didn’t help. She’s going to be doing chemo, losing her hair, her self-image is going to be under attack, and I’ve already started combatting that. She’s not going to see anything different in me in how I see her, and I think that’s probably the most critical thing a spouse can do, is to say, yah, you’re still my woman. Sex itself, I believe that when someone is ill, any instigation has to be in the hands of the person that is not feeling well. You can entice, but you can’t insist. (Secondary 1.1)

While this was one of the few instances in the collected data where sexual activity was directly addressed, it identifies sexuality as an important instrumental identity that is affected by the cancer experience. In addition, it demonstrates a spouse providing support while the primary participant isn’t able to maintain an aspect of their pre-cancer instrumental identity.

The changes that occurred to the instrumental identities that the primary participants used to maintain their terminal identities as parents depended on the dynamics of the relationships with their children. In the data collected, the secondary participants who were children were either living at home with the primary participant and either finishing high school or attending university, or were grown and had children of their own. It was evident from the interviews with the secondary participants who were younger and still living at home that their mothers had maintained roles as supports for them. One secondary participant, who was living at home and finishing high school, described the role her mom played in her life as a friend, a mentor and a protector. When asked how the diagnosis and subsequent lumpectomy had affected her relationship with her mom she indicated that there had not been significant change in the instrumental identities that her mother used to maintain her terminal identity as a mother. She said “In terms of our relationship and the way we function with one another, nothing has changed really. I don’t treat her as if she’s sickly. She doesn’t get any special treatment” (Secondary 4.1). When asked specifically about whether she had spent time talking about the diagnosis with her mom or if the relationship had changed to one where she provided emotional support to her mom she responded that it was “pretty much the same. Even if I wanted them to be different, I wanted her to talk about it she probably wouldn’t. It would be on her terms” (Secondary 4.1). In this relationship, the primary participant maintained her role as the supportive mother with the direction of support being maintained from mother to daughter. This is in contrast to another set of interviewees. Unlike the previous mother daughter pair, where the primary participant had undergone a lumpectomy, in the following example the primary participant had undergone double mastectomy with reconstruction. Whereas in the previous example the primary participant did not rely on her daughter for support, in the next

example the primary participant relied heavily on her two daughters for physical care while she was recovering. One daughter described the extensive support that the two provided at home.

... when she was home it was constantly helping her get in and out of bed because she didn't have the muscle strength. Draining her tubes, keeping everything sterilized, there was a lot of you know, making sure her medication was taken, her blood thinners, making sure she was constantly comfortable, heat on her, bandages changed a lot, there was a lot of recording that they wanted you to do in terms of her drainage tubes, how much blood was going down over the days, so making a diary of that. Just making sure she had everything she needed to be comfortable. (Secondary 18.1)

The other daughter described the support they provided during her recovery in her post-op period immediately after the surgery, while she was still in the hospital.

Sometimes I felt helpless because she was in a lot of pain or discomfort and there is not much you can do about her, about her. But tell her it's going to be okay and you know the nurses are on their way and get more medication and stuff. But yah, we just did the best that we could I think, each day was a little better. (Secondary 18.2)

The secondary participants indicated that the cancer experience significantly affected their mother's ability to continue to maintain her usual parental instrumental identity. They also identified that providing support for their mom was an unusual experience.

As the days have gone on and she's gotten stronger, were she's getting into the routine of 'how's your school going' - the normal mom stuff. But it was, when she was just recovering it was a little odd for us to be in the position where it was a reverse role. Where we were taking care of her as oppose to her taking care of us. (Secondary 18.2)

In this case it is clear that the primary participant was not able to maintain the usual aspects of her instrumental identity that she used to maintain her terminal identity as a mother during the post-operative period. However, upon returning to her pre-operative level of function, she re-initiated the instrumental identities she used to maintain her role as a mother.

In the case of a pair of mother-daughter interviewees, where the secondary participant was older, married with children of her own, it was clear that *seeking* emotional support was part of the instrumental identity that the primary participant utilized in maintaining the terminal identity. In this case, the secondary participant described her mother in terms of being positive and upbeat, however, in the last few months she has required more emotional support.

She has been more down then she typically would be.... Well, she'll say it. She'll say 'I'm struggling a little bit this weekend or today, but I'm feeling better now'. And or, 'I just want to talk to people and I want to talk to you, more then I might normally [...]'. Again, not that she's a typically depressed type of person at all, but just the fact that she even said something makes me think that she's struggling with worry about what to do and how things will unfold and how she'll handle things, herself. (Secondary 8.1)

When directly asked how the diagnosis affected her relationship with her mom, the secondary participant stated that she was “finding that she is more emotionally dependent on me then she has been in the past” (Secondary 8.1). Unlike the previous two examples, in this case the daughter was no longer a dependent to her mother and gave evidence of providing emotional support and clearly identified that providing emotional support to her mother was now part of the instrumental identity she used to maintain her terminal identity as a daughter.

An important aspect of instrumental identity that primary participants brought to their relationships with their families was wanting to protect their children and their spouses. When one primary participant described how he has been getting through his cancer experience, he described an important aspect of his terminal identity with his adult children, he said “I keep positive for the kids” (Patient 7). A different participant shared the experience of telling her adult children about the diagnosis.

My kids didn't take it well. They, in fact I was more concerned about them then myself. They didn't take it well. But with time, between diagnosis and now I think they are living with it.... the first few days I had to talk, I actually talked to them. And I tried to assure them, I told them that we have to face whatever is coming. (Patient 15)

This example shows how the primary participant had to offer support when she, herself was the one with the diagnosis. Another participant focused on the importance of maintaining a normal life for her young child:



[I] try not to worry the kids too much about any of this. Because until you know certain things there is no point in worrying about it and stuff. I think for them, keeping things as normal as possible keeps them happier. (Patient 5)

Other participants explained that they limited communication with their spouses about their diagnosis, because they knew it would upset them.

Communicating about the cancer experience with others was identified as an important aspect of coping with the stress and anxiety of the cancer experience for the primary participants. However, multiple instances exemplified that in some cases communication regarding the cancer diagnosis in families can be non-existent. One primary participant described the rationale for not telling her family about the cancer diagnosis because of the cultural stigma associated with the cancer diagnosis. “In China, people know, they have heard the words cancer. They will run away very fast. They don’t want to hear it again. They’re thinking it’s bad luck” (Patient 6). This led to her keeping the diagnosis from her parents, despite undergoing a lumpectomy and preparing to face decisions regarding chemotherapy. Another participant preparing to undergo surgery for a diagnosed, but not yet staged gynecological cancer, described not telling her husband, but leaving him a hidden note in case something went wrong with the surgery.

I left him a little letter. Well sealed, so I hope he doesn’t open it. Just in case it goes all wrong with surgery.... Eventually they have to go through my papers if I don’t survive. (Patient 9)

The rationale for not discussing the diagnosis in this case was wanting to protect her family from worrying. While these were extreme examples, other participants reported limiting communication around the cancer diagnosis in order to decrease stress for partners, one participant stating “I can talk to my husband, but he can only take so much” (Secondary 8.1).

Communication was an aspect of instrumental identity that was not only altered in families, it was also altered in friendships. Relationships described as ‘close’ friendships were noted to become a significant source of support for the primary participant’s cancer experience. Important distinctions were made between close friends and other friendships in terms of sharing. One participant described different styles in communication between her close friends and the friends that she had made in her neighborhood.

Around here ... we don’t get into deep conversations. Like if I’ve got personal stuff I don’t go over there and discuss it with them. I stop in for coffee and we’ll get together and go out for a meal with them, or get together and have a little party. It’s more, I don’t really get into telling them anything serious. I mean they all know I have cancer, and we talk about that, but I don’t know, I don’t, you know you have your close friend that you tell everything to.... (Patient 6)

The phrase ‘close’ recurred throughout the data collected in reference to friendships. It referred to friendships that were longstanding and where communication occurred in an open fashion. One participant described these elements when she stated:

I have a girlfriend in [...], we have been friends for years. And miles apart, we're close in that we can pick up the phone, and she is probably my closest confidant that I would probably share the good, the bad, the ugly, so she would probably be my closest friend, whereas my girlfriends [that I see regularly], they are there to support me but I might not tell them my deepest thoughts and secrets, you know? (Patient 18)

While the effects of the cancer experience on communication as an aspect of instrumental identity varied from participant to participant, generally, whether from close friends or family, the primary participants were able to establish a source of emotional support.

While some changes in instrumental identities occurred that were evidenced by objective changes in communication and accomplished tasks, other changes emerged in the data that pertained more to *how* tasks were carried out by the primary participant. For instance, one of the secondary participants was dependent on his wife, who was the primary participant. He had a chronic neurodegenerative disorder and was essentially wheel chair bound. He noticed that she was having a hard time coping with the diagnosis because she was more likely to get upset with him:

She gets agitated. Like I said, and she will take it out. Mood swings. She'll say "why can't you do it?" well I couldn't do it before? So how can I do it know? So it's my fault. (Secondary 2.1)

The primary participant herself, perhaps aware of the challenge she was facing described herself as “resentful” (Patient 2) for needing to care for her husband. In this example, while the specific tasks of caring for her husband were not compromised how she carried them out was.

Other participant felt that important aspects of the instrumental identities they used to maintain their terminal identities as employees were compromised. Except in one case that was complicated by a pre-existing history of chronic disease, no participant reported loss of employment or their position at work because of the cancer diagnosis. However, many reported that the cancer identity had affected aspects of the instrumental identity they used at work. One participant indicated that she took pride in not taking sick days, and now was needing to be away. She was attempting to overcome this by anticipating working from home and going to work in-between adjuvant treatments. Another participant who had recently started a new job and that the diagnosis, and need to take time away, was interfering with her ability to establish herself as the only female member in an all-male workplace.

The last major change that was identified with respect to pre-existing instrumental identities was with respect to the primary participant’s bodies. The data collected suggested that the participants faced multiple losses regarding their bodies and how to use their bodies in their pre-existing terminal identities. One change was overcoming a loss of connection and control with their own body and physical health. One participant articulated this experience:

Sometimes I wake up and it’s like, hey, do I really have it? K, now that I have had the operation do I still have cancer? If they’ve cut it, they’ve taken the breast off, does that mean I still have cancer? Or do I not have cancer? (Patient 6)

Other participants expressed that they were no longer aware of when they were healthy or felt that they were in control of their health. When one participant was asked how she would know when she was healthy, she replied “When the doctor tells me I am healthy” (Patient 13). Secondary participants also recognized the challenge that the diagnosis brought to the primary participants. One secondary participant spoke of recognizing the loss of control her mother was experiencing over her own body. When was asked what she thought the hardest part of the cancer experience had been for her mother she replied “the loss of control over her own self, [over her] body” (Secondary 8.1).

Changes that had occurred or were expected to occur as part of the cancer experience also emerged as a challenge for many of the participants. These changes were important because they identified the body as a vital interface for communication and interaction, a function critical to maintaining the participant’s various terminal identities. This can be articulated by first examining how one primary participant, who described herself as someone that is “friendly to everybody” and “loves to help people” (Patient 13), expressed that she recognized that the changes she was expecting with her breast cancer chemotherapy, specifically hair loss, would identify her as a sick person to others and would likely change how she would interact with others:

... you look sickly. You don’t look healthy. People stereotype, they categorize, they don’t see the big picture. They just look at you and automatically, they just look at you and have an opinion which is wrong, but it happens all the time. And like I said, I am a people person, so I probably wouldn’t want to go out very much. I don’t know. It’s all kind of sinking in right now. (Patient 13)

This participant's suggestion that changes in her physical appearance might cause her to become more isolated was supported by others participants. Two secondary participants who were sisters discussed what they had learned from a friend's mom who had gone through chemotherapy for breast cancer. The first sisters spoke about the experience of going out in public without a wig after her friend's mom had lost her hair from chemo:

My friend would say to her "mom let's go out?" and [her mom would say] "oh I need my wig on." She wouldn't go out without it, but then there comes a point when you kind of reach that stage where you can put on a scarf or something and people look at you and, I think that will be the hardest part [for my mom], will be those stares that she will get. Like why is everyone looking at me like I'm an alien? I am no different, I feel no different, my personality hasn't changed but people are looking at me so differently. (Secondary 18.2)

Importantly, her sister added what her initial reactions are when she see's someone in public that looks like they're going through chemotherapy. "I think she has to remember that if that was her looking at someone, what she feels. For me, that's sadness, but then I feel so great that they are out, and I feel happy for them" (Secondary 18.1). The importance of these statements is tied to the fact that so many of the participants described themselves as being generally "friendly", "happy", "positive" or "upbeat". In this case, by connecting the stated general instrumental identity that the primary participant had in this example of being a "friendly" and "helpful person" in their various terminal identities with the expected reactions of others to the expected changes in physical appearance, it is easy to see how profound the impact of hair loss and other signs of illness are to

the participant's ability to utilize their instrumental identities, and maintain their identity, in day-to-day interactions.

To summarize this section focusing on instrumental identity, it was evident from the data collected that the cancer experience affected the instrumental identities that the participants used to maintain their terminal identities in a number of ways. In some cases, primary participants were unable to maintain aspects of a terminal identity in certain relationships, resulting in some sort of compensation from the other individuals in the relationship. This occurred most obviously in familial identities, where the primary participant's ability to carry out usual roles was affected during the peri-operative period. The effect of the cancer experience on communication was also significant. Participants limited communication in multiple ways in order to protect their spouses, children and friends. Additionally, the data suggested that primary participants were aware of who they could rely on for emotional support, and that different participants were able to find varying levels of emotional support in their various terminal identities. Lastly, participants identified important changes to their ability to use their bodies as an aspect of their various instrumental identities. This was related to a feeling of loss of control over their body and their health as well as the knowledge of how other people perceive people with visible signs of cancer.

**Terminal Identity and the Cancer Experience.** Although the instrumental identities that the participants used to maintain their terminal identities were affected by the cancer experience; there did not appear to be any loss of terminal identities to the primary participants. At the time that the interviews were carried out, no primary participant reported the actual loss of their role as a parental figure, their relationship with a spouse or partner, or the ending of friendships. However, what did emerge was evidence that the diagnosis of cancer was associated with the primary participants gaining a new terminal identity. This new terminal identity will be referred to

here as the *cancer identity*. This terminal identity, along with the various aspects of the instrumental identities that the primary participants used to maintain this identity, will now be explored.

The new terminal identity that the participants gained shared many of the same characteristics of other common terminal identities which the primary participants maintained. First, just as others can clearly identify when someone becomes a new parent, spouse, friend or employee, the cancer identity was clearly identifiable to both primary and secondary participants. One secondary participant identified the addition of the terminal identity saying “She’s not just my mom anymore, she’s my mom with cancer” (Secondary 4.1). Primary participants also recognized that a change in their identity had occurred. The primary participant in this dyad described her new identity in terms of how she will be known to be people at her work:

I don’t think the feeling of identity will be the same. I’m still going to feel like I’m different, I guess. We can say different. We can say new.... I’m not going to be known as that bubbly girl that works in the office. I’m going to be known as, she is the one who has breast cancer.  
(Patient 4)

Second, just as the primary participants valued their terminal identities as parents, spouses, friends and employees, the new identities were valued. This appeared to be because, at least in part, of an underlying belief that this identity was needed to maintain an important aspect of many of the individual’s other instrumental identities – the body.

Evidence that participating in the cancer identity is directly linked to maintenance of the body, which includes preserving both physical and mental function, comes from both primary and



secondary participants. Some participants identified that since receiving the diagnosis, and associated terminal identity, their goals had become linked to their health “I think at this point in my life, my goals are fairly limited right now. They’re kind of focused on where my health goes” (Patient 11). Later in the interview he described the shift in his priorities:

But when you get told something like, ‘you have cancer,’ it’s really a wakeup call to your own participation in your health. It’s just, I better get my shit together. So it’s just been a real wake up call to just make it important.

Other participants identified the importance of maintaining a functional body, despite the potential drawbacks of participating in the cancer identity. Regarding the expected side-effects of chemotherapy, one participant stated:

Some people lose hair, but that’s the worst. Not having hair, I don’t think is the worst thing. I had a grandmother who had very thin hair. As long as you are healthy enough and you are able to function and are able to enjoy life. (Secondary 12.1)

Primary participant’s expectations that maintaining the cancer identity would result in restored or prolonged health, and in doing so served to protect their ability to maintain their other terminal identities, is one of the most important aspects to the cancer identity. This expectation seemed to be pivotal in forming the instrumental identities which the participants used to maintain their cancer identity.

Hope and faith in the healthcare system, including the treating physicians and available technology, were important aspects of the instrumental identities that the primary participants used to maintain their cancer identities. Hope and faith emerged as one of the major reasons why the primary participants relied on the medical system to provide care for their cancer diagnosis. Primary participants were able to trust and take the recommendations of their physicians because they believed that their health was a priority for the physicians. One participant remarked “If the doctor says do this it’s not because he’s trying to, you know, whatever, you - he’s looking out for your health” (Secondary 12.1). Trust in the training system of physicians and confidence in Canada’s healthcare system also helped the participants trust the people providing their care. One participant exemplified this by sharing how he found confidence in his treating surgeon, even without clearly understanding the certification system for physicians.

So I walked in thinking that this person is educated. Spent ten years learning to be a doctor, sort of had faith in the system or whatever.... I guess in my mind I just built up a case that this person has been doing these procedures, they have experiences at it, they know what they’re doing and uhm, and I back up the logic that we are so luck to live in Canada and have a high standard of healthcare in all areas.... And I guess it extends to the confidence in meeting a person, they have gone to being certified by the [University of Manitoba] or whatever [the] system is. We have confidence in that system, so that is foremost in my mind. (Patient 11)

Other sources of faith and hope came from a belief in advances in technology. One participant explained that she didn't think she was going to die, in part because of understanding that her stage II breast cancer had a good prognosis and in part because of the current state of technology.

I think anyone else going through cancer, we all have the same thoughts. You think death.

I never once thought I was going to die. With the technology we have today and my cancer is stage two, so never once thought death. (Patient 4)

Hope and faith in the treating physicians, the healthcare system and technology of instrumental identity that was pivotal in shaping the cancer experience for the primary participants by providing the motivation to engage with conventional medical treatment. However, hope and faith in the healthcare system were not the only motivating factors.

In addition to hope and faith in the healthcare system existing as an aspect of instrumental identity that promotes relying on the healthcare system for management of cancer, evidence emerged that for some, engaging in the healthcare system existed as the only option while for others the choice was less straightforward. One primary participant described her rationale for pursuing adjuvant breast cancer treatment in terms of it being necessary to regain her pre-cancer health. When asked about her goals for the next year she said "To get better, health wise, which is why I have agreed to do both radio and chemotherapy. Not that there is a whole lot of choice there, but if you want to get better, you have to" (Patient 1). Another participant demonstrated that the choice to utilize the healthcare system to manage her cancer involved being pressured to choose between western medical treatments and alternative therapies. When asked how she was determining what, if any, treatment she would take she said:

I think for me - I will probably do what the doctor says although I will research it. And like, I have explored other alternatives, homeopathic? Homopathic? I am considering that too. The bottom line is that I am going to do whatever is going to prolong my life, but I might lean towards a less critical treatment if chemo is going to knock the [expletive] out of me I might refuse it. (Patient 13)

In the follow-up interview it became evident that she had experienced pressure both for and against taking chemotherapy:

It was a hard decision. Uhm. I was torn. I had to talk to a lot of different people before I actually went through with it.... Because some people were telling me that it's chemo that is going to kill me. It's chemo that is going to cause the cancer, it's chemo. [Cancer] is not going to kill you. And then other people were telling me no, you have a great and huge positives by doing chemo. You'll live longer, it will cure you, you'll be good. (Patient 13)

She stated that she was able to make up her mind by talking to her close relative, who was a physician, and that was what helped her make up her mind. In addition to demonstrating that response to societal pressure was an aspect of the participant's instrumental identity that shaped their cancer experience, this example also demonstrates that for some, hope and faith in the healthcare system may not be automatic. If not for her conversation with her relative, it is plausible the participant in this example may have chosen to put her faith and hope in therapy outside of the

conventional healthcare system. What is clear, is that her decision to take treatment was not an easy one, involving external pressures both for and against alternative therapies.

Responding to the expectations of the primary participant's friends and family to "fight" or "battle" cancer emerged as an important aspect of instrumental identity for some of the primary participants. Some participants defined this as going along with recommendations of the treating physicians. When one participant was asked if she felt there was an expectation to fight cancer she replied "Yes, from everyone around me" (Patient 4). Further support for this observation came from one primary participants husband when he indicated his expectations of his wife saying "She's going to fight it. She's going to beat it" (Secondary 6.1). This statement is important for two reasons, in addition to clearly stating the secondary participant's expectation of his wife to "fight" it also touches on an important aspect of what it meant for the primary participants to "fight" cancer.

Several participants early on in the study used the terms "fight cancer" and this term, along with the term "battle cancer", was explored in more detail in subsequent interviews. Not all participants choose to describe their cancer experience in term of a fight or a battle. For instance, when one patient asked if the term "fighting cancer" meant anything to her, her response suggested that "fighting" had not been part of her experience.

Well you know, I don't really feel like I'm fighting cancer. I guess because I was never sick. I had not, I wasn't feeling sick. I found the cancer or whatever, and they cut it out. And my only sickness was the healing from the mastectomy. But you know, I don't really feel like I'm fighting it because I was never really sick. (Patient 6)

Another participant didn't like the term because, as she said "I think that it implies that there is some kind of demon or some monster. I don't see it that way. I see [cancer] as something that needs to be worked through" (Secondary 8.1). Despite the specific terminology of "fighting" or "battling" not being included in all the participants experience, for those that used them, the terms appeared to encapsulate the activities that made up the instrumental identities that the participants used to maintain their cancer identity. While not all the participants used the terms fight or battle to describe their experience, the behaviors and attitudes associated with fighting or battling emerged as present both in those that described themselves using these terms and in those that didn't.

Fighting and battling cancer was described as including several activities. These included keeping a positive attitude, protecting others, taking treatment, becoming educated about cancer and exploring different treatment options. Keeping a positive attitude emerged as an important aspect of the instrumental identity of participants in maintaining their cancer identity. This was because it was an important part of how the participants approached other aspects of their instrumental identity. When one participant was asked what it means to fight cancer he responded "Well trying to beat it. You don't want it the other way around" (Patient 7). When asked to clarify what fighting meant he suggested that it meant taking things one day at a time and trying to be positive for himself and for other people:

Day by day. For me it's day by day. I keep positive for the kids.... Cause when I told my one daughter there was a spot [on my lung]... there was a lot of crying going on. And I get all choked up because I am very emotional, sentimental type guy. But I'm just going to take it one day at a time. (Patient 7)

Keeping positive was also an important tool for dealing with the uncertainty of treatment options. When asked about what it meant to fight cancer, one participant described waiting for treatment decisions from her oncologist

Well, I think mentally you can fight it too. You can be positive about it .... I'll wait and see what [the oncologist] has to say, and I'll evaluate what he wants to do for me. Then we'll take it from there. I don't know what he is going to say. Right now I am optimistic, and maybe he won't give me the worst thing that I am expecting.... [which is] chemo. (Patient 8)

Keeping positive was also seen as an important part of the cancer experience for participants who did not endorse the terms fight or battle. One such participant stated that key elements for going through the cancer experience were “staying positive and working as best you can with your medical provider to stay healthy...” (Secondary 8.1).

In contrast to the emphasis that many participants placed on staying positive, some also clarified the perceived risks of not having a positive attitude. Some participants described being able to avoid their mind going to “dark places” by working to stay positive. When one participant was asked to describe what battling or fighting cancer meant to her she said “... part of it is just to keep your head out of that dark place where you think the worst” (Patient 12). Other participants added further defined what the “dark place” was. One participant described how scheduling inconsistencies lead her mind to a “dark place”, an experience that was traumatic enough that it motivated her to be part of this study. When asked why she agreed to be part of the study her response was:

Because I found the waiting between appointments and stuff like that is quiet stressful and that maybe nobody said that. Like they tell you at this appointment ... that you'll hear from somebody to set up that appointment. And then you wait to set up the appointment, and even just a few days can be really stressful, and then you get going in your mind to a dark place that you think, well, whoa, it must be bad, it must be worse than I thought, or worse than they lead me to believe because it seems to be taking a while to set this up.... It's just like they say four to six weeks and the first day of the four weeks you say, okay, I should hear something and it may take a little bit longer than that like even just getting to the four weeks is a long time. (Patient 12)

Interestingly, while some participants identified working to stay positive as a strategy for keeping their minds from going to the "dark place", others stated that their belief in a higher power helped them to stay positive. One participant stated, that in order to avoid the 'dark place' she put stress on her faith and the belief "that the battle is not mine. It's gods battle" (Patient 15).

At first, the term "dark place" seemed both ominous and abstract. However, when the various contexts of how the participants used the term "dark" were explored, a concrete understanding of what the "dark place" was emerged. First, participants described being "in the dark" (Patient 3, Patient 13, Secondary 3.1) as a general state of not knowing what to expect with their treatment or their cancer. For instance, in a follow up interview with one participant, she described her state at the time of the initial interview as being "in the dark" (Patient 3). She said "well, before we were talking about my treatments, and at that time I was in the dark. I really don't know what is going on for my treatment" (Patient 3). Her partner described being in the dark in a



similar way, relating it to being handed from one specialist to another with his mother who previously passed away from cancer, and now with his girlfriend who was diagnosed with breast cancer “You go to a doctor that says ‘I am your surgery doctor’ they do their part and then they move the person down the line. And that you kept completely in the dark, and you don’t know what is going on” (Secondary 3.1). However, when a social worker explained to him what was going on he described a great sense of relief “I was so grateful for her. I wanted to go out and basically buy a present for her... to show our appreciation.... Because it was the first time in two situations that I’ve been through where I actually knew what was going on” (Secondary 3.1). The experience of being “in the dark” then is illuminated as being an experience where the participants were unclear about what to expect in the future, and the “dark place” is perhaps a state of mind where the participants felt they were unable to be optimistic about what to expect or what the outcomes of their treatment would be.

Another important aspect of the instrumental identity of the participants was gathering information about their diagnosis and what was expected to happen with treatment. Gathering information was important for two main reasons. First, it informed the expectations that the participants had. Second, it helped them to maintain their cancer identity as well as their other terminal identities. Information largely came from past personal experiences, healthcare professionals, friends and family. How the participants gathered information and the effect of information on the participants will be explored next.

Many of the participants had either previous personal experiences or had received information about the cancer experience of others that affected their cancer experience. One participant’s expectations were affected by the loss of her husband to cancer one year ago to metastatic liver cancer from an unknown primary. This participant stated she did not have any

other personal cancer experiences to draw from, as only distant relatives had been diagnosed with cancer in her family and she did not have friends or other people that were close to her that had been diagnosed. When asked what the hardest part of her cancer experience had been she stated “I think the hardest part is that you are reliving the last year. We just had this thing last year, and it’s like turning the second page and hearing the same story” (Patient 15). When asked if she thought the same thing would happen to her that happened to her husband she simply said “Well, it might. Who knows” (Patient 15). Past experience clearly impacted the expectations of many participants, making it challenging to be positive. The effect of past experiences was also evident to the secondary participant’s, one reflected on his wife’s experience shortly after diagnosis “uhm, when she was diagnosed she was really scared. She was concerned about her dad. I believe her dad died at 65, and she thought she was not going to see 66” (Secondary 2.2).

Other participants were able to draw on previous cancer experiences to stay optimistic, despite having two previous cancer experience that ended with the death of someone that she knew. One participant who had been diagnosed with colon cancer described two instances that shaped her expectations of her cancer experience. On one hand, her friend had passed away from metastatic colon cancer within several months of being diagnosed, just months before the participant herself was diagnosed. On the other hand, she also described the experience that her grandmother had with cancer, being diagnosed twice with colon cancer and living for twenty years. This caused a significant amount of distress and anxiety, and was compounded by the fact that participant’s daughter had recently gotten engaged and she didn’t want her treatment or her death to interfere with the wedding, however she chose to base her expectations on what had happened with grandmother:

And you have to concentrate on keeping your head on straight. Like, that was the biggest thing that I found was hard was to keep from going to the worst case scenario. And I guess it's just that the people closest to me, like yes, it took my grandmother longer, but she eventually died of it too. You know, so. You need to think of, my first thing was, I have got to be well enough to get to the wedding. And then. [other daughter] is not married yet either, I'd like to make it to that one too, whenever it may be. (Patient 12)

Many participants also described gathering information from people that they did not know well, but that had had previous personal experiences with cancer. In some cases, connecting with these people occurred through the healthcare system, in other cases the connections were made independently. Regardless of how the connections were made, being able to talk to someone about their experience was seen as helpful. When one participant was asked if she knew anyone that was diagnosed with cancer she described being connected with someone through the social worker at the cancer center. She described her experience of being connected with someone that that had gone through what she was going through as follows:

I [did] meet one person. She is very nice.... it happened seven years ago. She was 29 years old. She had breast cancer. Stage 3. After she got treatment her hair came back very well. After she had two kids.... [she shared] her experience with me, and she just wanted to encourage me. And I am so happy with what she did for me. And that's the reason I came here. I think I can help somebody. We can fight cancer together. (Patient 6)

This participant's experience with talking to other people with personal cancer experience was presented as uniformly positive by the participant. However, it is important to question what happens if this participant's experience does not result in the same positive outcome that the person she was put in contact with had?

Another participant described meeting someone for the first time and having an experience that was not entirely positive. For her, the meeting led to expectations that weren't met. This participant described meeting a friend's brother's wife for the first time who had previously undergone a double mastectomy with reconstruction involving an abdominal flap.

And I don't even know her, that was the first time meeting her. And we got to talking, and she was telling me that she had a double. And I had just had mine a couple of weeks earlier. And she was 'like you want to see?' 'Yah okay, if it doesn't bother you.' So we get up and [are] heading off to the other room, and they're like, 'where are you going?' and I'm like 'we're going to the bathroom to make out, okay?' (Patient 6)

When the participant was asked how she felt about the interaction she said it was "good in a way" (Patient 6). However, learning about the procedure led the participant to adjusting her expectations. She shared her initial reaction to learning about the procedure and how it helped her be optimistic "... they do it using stomach material. Okay what!? Free tummy tuck!? There might be an upside to this after all" (Patient 6). But when the participant met with the plastic surgeon, she learned that the procedure wasn't an option because the participant had relative contraindications to the procedure. The participant expressed her disappointment. "Then it was like, yank. Nope. You don't get that. It was like 'really?' I got kind of pissy about that. I was really

pissy” (Patient 6). The participant then described her reaction to her husband when he asked if she was relieved that she wasn’t going to have any more surgery “And I looked at him and said, what do I have to be happy about? I said, tell me, what do I have to be happy about? I still have the cancer, I don’t get the tummy tuck, so tell me what the hell do I have to be happy about” (Patient 56)? The participant then described the processes of working to stay positive despite being let down by not being eligible for the surgery. “.... and then after a couple of days, it’s kind of like, well, I don’t get the tummy tuck, but the healing time will be about half. So, my healing time is cut in half... Then I’ll get to go to the greenhouse. So okay, there is a little bonus there. So we’ll kind of pick the good things” (Patient 6). This participants story underscores the challenge of information gathering for participants, as for many of the participants, expectations are set based on the information that is gathered from their own experiences and from those of others. For this participant, unmet expectations left her recovering from a loss, needing to adjust her goals for the future and having to work to be positive.

The internet also provided an important source of information for participants. How the participants incorporated the internet into the instrumental identity they used to maintain their cancer identity varied. Some participants expressed some hesitation towards using the internet sharing either personal concerns, or concerns that had come from friends or family. Some participants described staying away from the internet to avoid misinformation, primarily relying “on the doctors, the people how are trained for this kind of thing” (Patient 11) for information. Some stated they relied on a list of websites that had been given to them by their healthcare providers or that they had been told by the doctors to “stay off the internet” (Patient 13). Others described needing to be critical of the content but indicated that it was an important source. For those that did use it, the internet was used mainly to explore topics that they had questions about

or weren't fully explained to them and learn about what to expect from their cancer experience. One participant described using the internet as a main source of information about her cancer. She shared an experience where she was left wondering about specific detail of her breast cancer pathology, and relied on the internet to help her understand more.

... when I met with my surgeon and she explained to me about being a triple negative, I said is that a good thing? And she said not necessarily and she kind of moved on to something else. And I thought okay, she doesn't want to talk about that so then I had to investigate that on my own with regards to treatment and recurrence and things like that.  
(Patient 10)

Another participant's experience illustrates the ambivalence that exists towards the internet due to the need to understand expectations, in this case in terms of prognosis, and the fear of becoming misinformed:

... I looked it up on the internet, to see the mortality, and she said "mom, you don't look anything up on the internet" but I said I didn't know, I needed to know, what is the worst case scenario here? (Patient 12)

Interestingly, this desire to clarify her prognosis was due in part to receiving information she had perceived as conflicting from her surgeon and her gastroenterologist. "The gastroenterologist said, 'it's early'. And the surgeon said, 'it looks like something that you probably had for four or five

years', to me that doesn't seem early" (Patient 12). She continued, expressing how she was unclear about the stage of cancer and needed to learn more in order to understand what to expect:

Nobody has ever said curable. Nobody has ever said like stage one, stage two.... That nobody said that this isn't a death sentence or shouldn't be a death sentence, nobody said that. That is why I looked it up.... They just kept saying early, and I didn't know what early was. And I didn't know that I wanted to know until I had surgery. Like when you are sitting there you don't know what you want to know. So you should almost get two free phone calls. (Patient 12)

She went on to state that she determined that her colon cancer was likely stage two, and that based on what she had read on the internet she had the expectation that she would likely survive "in the neighborhood of ten years" (Patient 12).

In addition to using the internet for finding information to help participants manage their expectations, and clarify questions about their specific cancers, participants used the internet to find ways of augmenting their medical care. One participant described finding out about ways to change her dietary routine to make her body more alkaline and therefore less hospitable to the cancer. She said "I go onto the internet and they tell you that cancer flourishes in the acidic body environment, so rather take foods that make your body more alkaline" (Participant 15). Based on the information on the internet she changed her diet to include more fruits and vegetables and she decreased her intake of meat. Participants also reported learning about complimentary strategies from their friends and family, indicating that anything they could do to improve the outcome of their cancer experience was important.

In addition to gathering information from past experiences, the internet and from other individuals that had experienced cancer first hand, participants reported receiving pamphlets directly from their healthcare providers. Unlike the internet and their personal experiences and the experiences of others, the participants did not report that the pamphlets they received help them understand what to expect. One participant stated that they contained “resources that you can call to set up appointments” (Patient 10). Others indicated that they weren’t applicable to their situation, that the pamphlets they received contained “general information” or that they didn’t read them. More significantly, one participant with breast cancer shared the frustration that one of her friends, who had also been diagnosed with breast cancer expressed after reviewing one such pamphlet. She reported that her friend said:

... that was kind of frustrating that in all of the pamphlets they’re advertising women who are twenty years, thirty years, and they have no wrinkles, they have no age spots, they’ve got tight skin, they’re like beautiful young women. And they’ve got these bald heads and she thought it was a little bit depressing to see, you know, she’s thinking she’s going to look like the pamphlet, she’s going to have this tight young skin with the bald head. And when she did lose her hair she was kind of let down by that and said, ‘I went to [that] program because I wanted to look like these girls on the pamphlet’. (Secondary 18.1)

This example is important for two reasons. The first is that it highlights the importance of expectations to those experiencing cancer. Second, it demonstrates that participants are affected by the information they come in contact with in unintended ways.



The last piece of the instrumental identities that the participants used to maintain their cancer identity was their relationship with their healthcare providers. This relationship is closely related to information gathering. This is because, in addition to receiving information in the form of pamphlets from their healthcare providers, participants received information that affected their expectations directly from their healthcare providers. When participants described the type of information that they received from their physicians they described receiving statistics and information about why specific treatment options would be best for them. When one participant was asked if she had received enough information from her doctors she said “They have. Definitely, in trying to make surgical decisions. Information on statistics of the different options and which ones would be better or worse, or when ranges were similar. That made it a lot easier to decide.... Things like that. That was really good, statistical wise” (Patient 5). However, physicians also reportedly explained the limitations of statistics. When describing the discussion regarding statistics that one participant had with their physician, he pointed out that the surgeon had highlighted one challenge with relying on statistics “He sort of emphasized it’s a numbers game. I guess in reality, if I get sick in three weeks from now it’s a 100% failure for me personally, you know. He’s just giving me population statistics.... Who knows how it will pan out” (Patient 11).

Statistics were important because, like the other information that the primary participants gathered, they were the basis of expectations and goals. One primary participant who had undergone radical prostatectomy for prostate cancer and was now waiting to make treatment decisions regarding a potential relapse shared that his hope for the future was based on statistics. “Well, they say, from what I’ve been told and what I’ve read, that after prostate surgery there is an 80% five-year survival rate. So I would like to be in that 80% to start with. I would like to live a long time - five years is the first goal” (Patient 16). However, it was also made clear by another

participant who was an engineer that not everybody had the same comfort level with statistical information:

And I've read the statistics on how much [radiation prevents local recurrence], because I like that kind of stuff. And probably not everybody likes that much technical detail. But I actually feel more comfortable the more that I get. But everybody is different. (Patient 5)

Despite varying levels of comfort with statistical information, the data suggested that receiving statistics or information from health care providers was generally appreciated.

However, as data analysis progressed, it emerged that receiving information was not universally helpful. Some participants reported that the more information that could be gathered or shared the better - reporting that information helped participants to "ease fear" and "know what to expect." This was not the case for everyone. One participant described the challenge of receiving information that lowered expectations "If I were to read a bunch of stuff about how bad chemo was, and I'm sitting here waiting [to find out] if I have to have it? You overthink things and get yourself worked up" (Patient 6). While avoiding information that might be upsetting may be useful in the short-term, the consequences of unmet expectations were evident from the data collected. When one participant was contacted for her follow-up interview, she reported to of started chemotherapy for her breast cancer. Although bone pain had been explored as a potential side-effect of her chemotherapy, it was substantially worse then she had been led to expect

Joint pain, the ribs feel like they're cracked. The hips feel like they're going to break....  
They said you may experience some muscle or joint pain. And to take Tylenol for it, but,

so I understood that. But, the degree of the pain was far beyond what I expected. (Patient 1)

She also was in the midst of a neutropenic episode induced by the chemotherapy and had been told to stay home until it resolved, resulting in her unexpectedly missing life events which were important to her. From the data it is clear that providing the participant with information was very complicated. Given the numerous sources that participants acquired information from, the fight to be positive, the tendency to avoid information that could be perceived as upsetting and the consequences of unmet expectations, how gathering information affected the cancer experience of the primary participants was perhaps the most intricate area explored in this study.

In addition to providing participants with information, physicians aided the participants in making treatment decisions and were the gateway to the treatments that provided the motivation for maintenance of the cancer identity and engaging with the healthcare system. How the treatment decision processes played out in the data was important because it identified that complying with physician's recommendations was an important part of many of the participant's instrumental identities as part of the cancer experience. Characterization of the decision making processes was possible because many primary participants were interviewed after they had surgical treatment and before and after they had met with the oncologists to make decisions about chemotherapy or radiotherapy. At the time of the first interview participants spoke of how they experienced the decision making processes regarding the surgeries they had undergone and how they were expecting to make treatment decisions regarding chemotherapy and radiotherapy. Participants described, when they were presented with different options, making their decisions based on their expectations of the outcome and what the procedure would involve. One participant shared making

her decision regarding which surgical procedure to have based on what she thought would result in the least amount of pain:

The doctor told me why I needed surgery. One to remove the lump and after they research the lump and after, if the lump has cancer, there will be a second surgery to remove the lymph nodes. So the doctor asked me ‘first time to remove the lump and second surgery for lymph nodes or same time to remove lump and lymph nodes?’ And I think why do I need to hurt two times, so I pick [the] second way.... because I don’t want to hurt [a] second time. (Patient 3)

Other participants experienced that they based their surgical decisions on what information they found on the internet. One participant reported struggling with her decision to proceed with a double mastectomy and reconstruction or a lumpectomy. When asked what was most helpful in her helping her make up her mind regarding the double mastectomy she said

I would say forums from people that have already gone through it, I found them really valuable.... online – visuals, looking up photos of women that have gone through it before and after. I found that beneficial. Testimonies from, well, the website from [the plastic surgeon], reading through that extensively, thoroughly, inside and out.... It was just, I guess, it was testimonies more than anything. (Patient 18)

Other participants described a more directive approach, with little opportunity for decision making on their part. One participant treated for colon cancer described a much different decision making processes:

Like the doctors I have had up until now, it's just like okay, you have cancer, you need to do this. And you just blindly, yup, I'll go and get the CT and I'll go see the surgeon, and the surgeon says you have to, you need to have surgery, and this is what we are going to do. Like you just blindly follow. (Patient 12)

When it came to exploring how they expected the decision making processes would go with the medical or radiation oncologists and then reviewing how the process went in the follow-up interview further insights were obtained. When asked about how they were expecting to make treatment decisions about radiation or chemotherapy participants generally discussed a review process of treatment recommendations, and ultimately accepting the recommendations of the treating physicians. In describing her processes in preparing to making decisions about treatment with her physician one participant described her processes of determining whether to go along with her doctor's recommendations:

Oh, I'll do what the doctor suggests. I'll put it to him, what would he do in the situation? I mean he'd be honest and say, what would you do in this situation? (Patient 8)

Other participants viewed being involved in decision making as a preference, but one that was not entirely practical at all times. For instance, one participant articulated this when she said:

I think a lot of it depends on the type of the cancer and what the options are, and this is it, you have to do this, and I get that. So where I can participate and make a decision that is important to me. (Patient 10)

What was particularly fascinating about the data collected was that in cases where participants expressed that while participants anticipated being a part of the decision making processes prior to meeting with the oncologists to make decision about chemotherapy and radiation therapy, after they met with the medical or radiation oncologist they indicated that they were going to do whatever the oncologists suggested all along.

In general, the sentiment expressed about the decision making processes for chemotherapy or radiotherapy by the participants in their follow up interviews was “I was pretty much set to do whatever [the doctor] decided was instore for me” (Patient 1). This was helpful in understanding how the participant’s decision making processes progressed. It became clear that the major decision for many participants was not between which treatments to take, but about whether or not to trust the physician’s recommendations. It emerged from the data that there two aspects to this processes, the first was that the information and recommendations had to fit with what they already knew and make sense logically. Many participants referred to the previous information gathering that they had undertaken prior to meeting with physician’s as the metric by which to judge the physician’s recommendations. One secondary participant described this process:

We have been doing, and we’ll have done some research, and will possibly do further research, if it makes sense to me and we’ve answered all those questions, I would strongly

suggest to her that we go with [that] as long as it makes sense.... As long as we feel comfortable that it makes sense.... As long as it's kind of a decision tree, and they're following through on that decision tree, then I'm good. (Secondary 8.1)

Trust was established based on how the physician's interacted with the participants. This included taking time to explain treatments and respond to questions. When asked how he was able to trust his physician's, one participant emphasized patience and communication. He shared that his doctor earned his trust when "he had taken his time to explain completely, I've been to see many other doctors and I felt the pressure a lot time being in the room with a doctor that is on a busy schedule... he was so patient, took time to answer all my questions, repeated at the end did I have anymore questions" (Patient 11). Other participants expressed that they felt they could trust the physicians when they showed interest in the participant's outside of their pathology. This included addressing the emotional stress of the cancer experience in their consultation. It also included connecting with the participant in ways that recognized that the participant was more than their cancer diagnosis. One participant described the team of healthcare providers in the following way:

Every doctor we went to was perfect. They are the nicest. We ended up with a dream team. When the doctor can sit down and talk to you about going to Jamaica and tell you where to go? I have nothing to say but the nicest things about the doctors? (Secondary 6.1)

Trust in physicians was also tied to trust in the healthcare system. In addition to putting faith and hope in the healthcare system as a whole, participants put their faith in the credentialing system that physicians had to go through before practicing. One participant said of his faith in physicians

“I guess it extends to the confidence in meeting a person [that has gone through] been certified by U of M or whatever our system is. [I] have confidence in that system, so that is for most in my mind” (Patient 11). Regardless of how trust was established, in general the relationships that the participants had formed with their physicians during their cancer experience were based on a tremendous amount of trust that was formed over a very short time.

The contrast between the physician relationships and the other “close” relationships that the participants had was initially puzzling. From a purely theoretical perspective, it was puzzling that the participants could place such an immense amount of trust in a relative stranger. This was because, unlike the relationships with physicians where trust was established in minutes, many of the other “close” relationships that involved trust took years or decades to establish. However, because of the importance of the relationship of the primary participants with their physicians, the model needed to fit both physician-patient relationships and the other relationships that were represented in the participants lives. That is why, in this theoretical model, relationships are seen as aspects of instrumental identity as appose to terminal identities. In the same way that it is through their relationships with their children and their partners that the participants had families, it was through their relationships with their physicians that the participants were treated for their cancer and maintained their cancer identities.

To summarize this section, one of the important findings of this study is that while the pre-existing terminal identities of the participants did not change after the cancer diagnosis, the cancer identity emerged as a new terminal identity. This identity was important for the participants to maintain because through it the body could be cared for and possibly returned to health. Instrumental identities that were used to maintain this identity included hope and faith in the health care system, responding to the expectations of others, keeping positive, avoiding the “dark place”,



gathering information, and establishing relationships with physicians in order to obtain healthcare. The term's "fight" and "battle" were also explored, and while not all participants related to them, most referred to keeping positive, gathering information and taking treatment as part of the instrumental identities.

**Routine.** The final aspect of identity that was affected by the cancer experience was the participant's routine. Disruptions fell into two main categories. First, the routines that had been established by participants to help them reach their pre-cancer goals and maintain their pre-cancer identities was largely disrupted. Second, many participants demonstrated challenges with establishing new routines after diagnosis. How the participants described the effects of these disruptions on their lives supported the importance of routine in maintaining the participant's identities.

Even before the diagnosis was made, participants experienced disruptions to their identity by the cancer. One participant described the challenges of needing to take time away from a new job in order to get a breast lump investigated:

... [after detecting a lump, the family doctor] sets up the mammogram. They call me the day before. And I am new into my job, you gotta understand that.... So I missed that mammogram, and I can feel it growing inside of me and I am like, oh no, I gotta go. So I am like, okay, give the number, so I can talk to them and I can set up the appointment for the later part of the day so I can tell my boss I need to be at this appointment. (Patient 13)

While her experience may be overlooked as minor inconvenience, when put in the larger context of what she was trying to accomplish in her job, the gravity of the impact in disruption to her

routine becomes more evident. When asked to reflect on her experience of going on medical leave from her new job where she was trying to establish herself as a good employee she said:

Very hard.... I thought he was understanding and I thought I'd only be off a couple of weeks and here we are six weeks later and I know he's not happy with me. I know he's disappointed in me and that stresses me out because I am trying so hard to fit in and belong there, and like I said, I am the only woman there... So for me to be diagnosed with cancer and have this time off is very disappointing. (Patient 13)

Participants also expressed that being away from work resulted in a loss of major social connections. One participant described a major source of fun in her life as socializing with and going "out with the girls from work" (Patient 4). She said that majority of her friends came from work, but since going on medical leave she was only seeing people from work about once a month. Participants also described interruptions to their routines as disrupting their goals for the future. Several participants described postponing plans to travel with their families, either because of inability to work to generate funds, or because treatment itself was required. One set of primary and secondary participants even identified that pursuing medical treatment for a chronic condition of one individual in the family was being delayed because of a perceived need for the primary participants more urgent cancer treatment.

For rural participants, the need to travel for medical appointments also served to disrupt routine. A significant proportion of participants interviewed lived over 100 km away from the center where their medical appointments and expected treatments would take place. Participants who had to travel long distances to appointments described an incredible amount of frustration

with the amount of travel required to acquire medical care. One participant who lived over two hours from the cancer center was literally shouting and banging his fist on the table when he described his experience with coordinating appointments:

I was into Winnipeg this week. And I am home. And I am into a doctor tomorrow. And I am seeing an oncologist on Tuesday in Winnipeg. My family doctor is tomorrow. I don't know what is happening after that. It's day by day for me. (Patient 7)

Other participants expressed frustration with needing to travel for brief appointments. One participant described travelling to see the medical oncologist to discuss something that could have been discussed over the phone:

Instead of making me drive five hours, waste my day, only to say, 'yes please, test my tumor, you could've phoned me and said we have this program running, would you like us to test this tumor and then we will have the results in two weeks, no need to come right now, you can wait'. It's like you could've phoned. You know what I mean? (Patient 6)

Other participants discussed concerns regarding needing treatment in the major center. One participant reflected the experience of a friend that lived in her area that needed radiation in Winnipeg saying 'he actually had to hire a driver to take him in every day. Apparently you can't drive yourself' (Secondary 17.1)

That the cancer diagnosis certainly disrupted existing routines is undeniable. However, what emerged as the most consistently challenging aspect of the cancer experience was that it had

prevented the participants from establishing new routines and prevented them from planning for the future. Many participants were asked in the interviews what the hardest part of the cancer experience had been. When one secondary participant was asked what the hardest part of his wife being diagnosed with cancer was for her he replied:

Just the waiting. Waiting and appointments. Waiting for appointments. Or even if you have the appointment but it's two or three weeks away, what's going to happen? Am I dying or not? (Secondary 17.1)

When asked what had been the hardest part for him he replied "Waiting. You can't schedule anything. I can't commit to anything" (Secondary 17.1) This was likely compounded by the fact that the couple lived in a rural community, hours away from the oncology specialists. Interestingly, when his wife, who was the primary participant, answered this question she said "the fatigue of driving, the fatigue of waiting" (Patient 17) When she was asked to clarify what aspect of waiting was hard she indicated that the hard part of waiting was finding out when the appointments were going to be. This is an important response, because it reflects what her husband described as the hardest part of the experience for him.

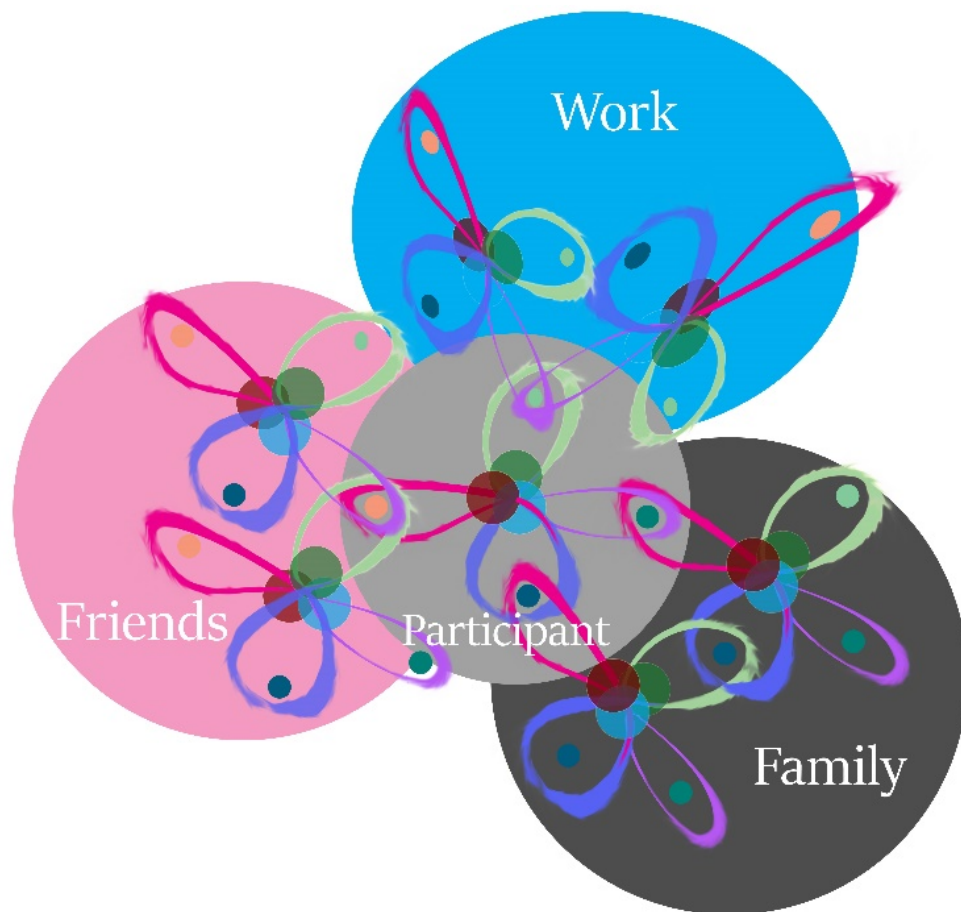
While the data suggests that the primary participants were concerned about the details of their treatments or prognosis, what emerged from the data was a strong indication that at the time of the interviews the majority of the participants were the most frustrated by the inability to plan their lives in the next weeks and months. This was not a uniform experience however, and reflects important differences in the cancer experience of the participants that were included in this study. The majority of participants in this study, i.e. those with breast, colon or lung malignancies, had

undergone their initial surgery. These participants had their initial interview while in the weeks and months between that initial surgery and waiting to see the medical and radiation oncologist for adjuvant treatment consideration. This was initially the plan for all disease sites included in the study, however it became apparent that this strategy would not work for the participants with gynecological malignancies as there was not window to interview these participants after the pathology was known and before the decision to start chemotherapy was made. Therefore, participants with gynecologic malignancies were recruited based on a high clinical suspicion of the gynecology oncologist that the participant would need adjuvant chemotherapy post-operatively. From the participant perspective this meant that there was no waiting after surgery for a referral appointment with the medical or radiation oncologist.

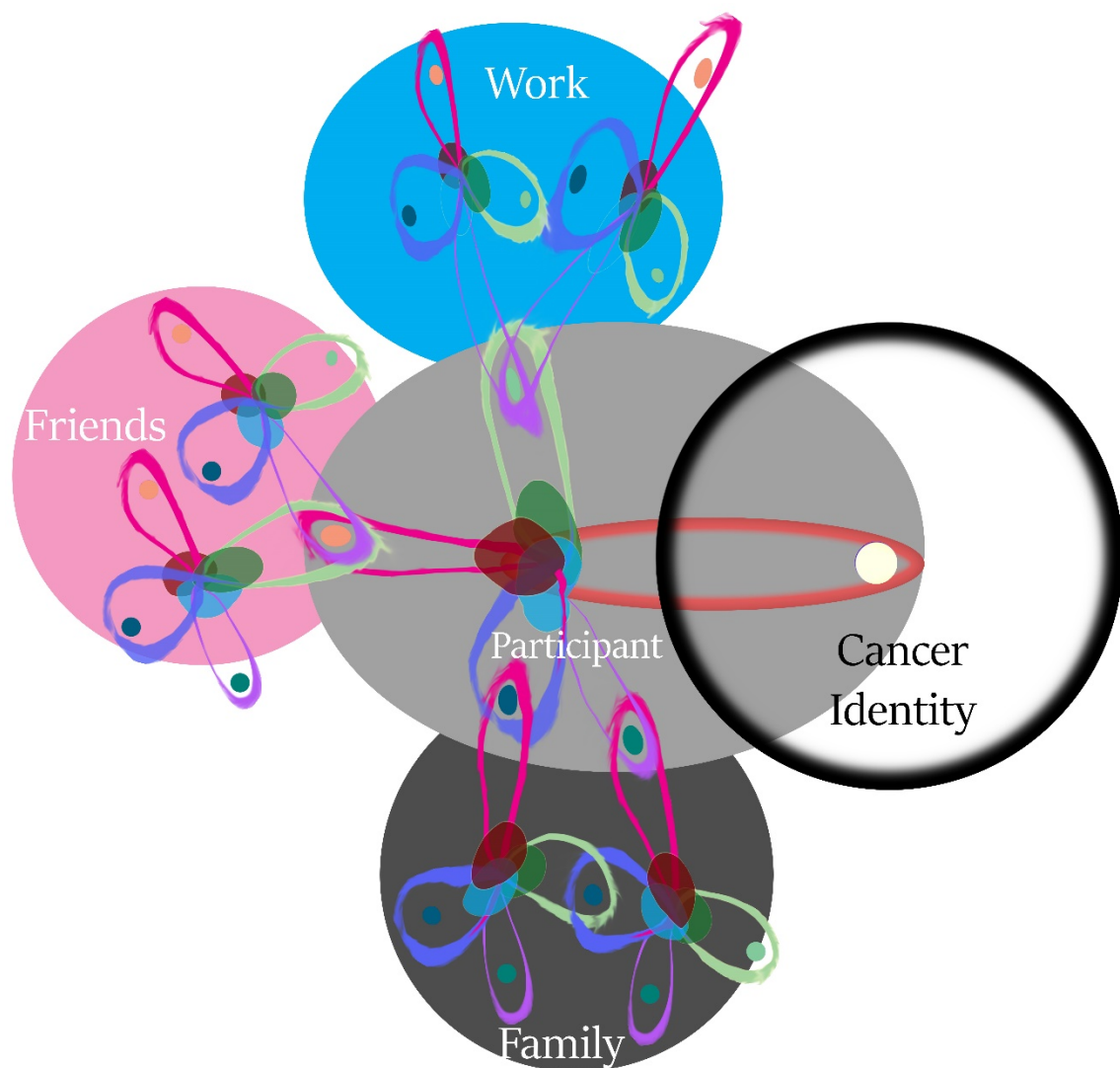
Two participants with gynecological malignancies were interviewed; these interviews were conducted prior to their initial surgery. The data collected from them contrasted in important ways with those from the other participants that were post-surgery and had been waiting to make adjuvant treatment decisions. When one participant was asked what had been the hardest part of her cancer experiences, no reference to waiting emerged. She said “The hardest part, if maybe I don’t see my grandkids growing up, you know? And I think I am pretty far gone with the cancer” (Patient 9). The other participant shared that for her the hardest part was tied to the fact that her husband had recently passed away from cancer and she felt she was reliving that experience. In contrast to the other participants, both of these participants were still working and had not yet experienced the same interruptions to their routines that many of the other primary participants did.

In summary, the cancer experience affected the routines of the participants in a number of ways. Participants described the interruptions to their regular activities as inhibiting their ability

accomplish the goals they had at work and in their families. Rural participants experienced an added disruption due to the need to travel for appointments and for treatment. Lastly, participants indicated that inability to plan for the upcoming days and weeks was one of the most challenging aspects of the cancer experience. This bore a stark contrast to participants who had not experienced the same disruptions to routine, who expressed that what made the cancer experience hard was related to more existential and emotional challenges. Figures 4 and 5 are provided as summary figures, graphically representing identity before and after the cancer experience.



*Figure 4.* Representation of simplified pre-cancer diagnosis identity. This image demonstrates the inter-connectedness of individual identities with the participant and the other individuals in the lives of the participants.



*Figure 5.* Representation of simplified post-cancer diagnosis identity. This image demonstrates the effect that the cancer experience has on the participant's identity, including changes to routine and relationships with friends, family and work.



## **CHAPTER 4: REFLECTING ON THE FINDINGS**

### **The New Model and The Old Research Questions**

By using grounded theory, a model was able to be constructed that was useful for describing the experience of patients that had recently been diagnosed with cancer. Interestingly, the model evolved significantly over the course of data collection. The profound evolution of the model during data analysis reflects an area of contention in the grounded theory literature. The model that emerged at the end of the study can be used to address the research questions that guided the initial inquiry of this study. This section will begin by discussing the important methodological factors that lead to the theoretical model evolving from the literature review. Then, the research questions that guided this study will be directly addressed.

### **Grounded Theory Methodology and Evolution of the Model**

In keeping with what Strauss and Corbin (1998) described, the initial literature review was useful in that it was used to “formulate questions to act as a stepping off point during initial observations and interviews”. As data collection continued, particularly with respect to understanding the concepts of values, and personal and social identity, it became clear that the structural concepts of the model that was synthesized from the literature needed revisions. This was somewhat consistent with what others have noted – that the researcher can expect that concepts previously known or uncovered in the literature search may be found to be of varying levels of importance as the study progresses (McCallin, 2003).

As data collection progressed, the model evolved for three main reasons. First, how primary participants described themselves was consistent with how they were described by the secondary participants, therefore the terms personal and social identity were abandoned. Second, participants described their relationships with their friends, families and physicians as necessary

for maintaining identities, not as identities in themselves as was presumed in the initial model. The third reason was that the participants description of their values fit strongly with a pre-existing framework of values described by Rokeach (1973, 1979) – a framework that the researcher came across after the initial literature review had been completed.

In Rokeach's framework, values are divided into two main categories – terminal values and instrumental values. The framework is the basis for the Rokeach Value Survey (RVS) which is a quantitative tool that has been used to study values and changes in values of individuals and groups of individuals. The survey itself consists of ranking two separate lists of 18 'terminal values' and 18 'instrumental values' and the instructions for the respondent to "arrange them in order of importance to YOU, as a guiding principle in YOUR life" (Rokeach, 1973, p. 27). The terminal values list consists of adjectives which describe relatively abstract concepts that could be acquired in life. Several terminal values listed in the survey include *freedom*, *happiness*, *national security*. The instrumental values reflect characteristics that are brought to the tasks of life. Instrumental values included *honest*, *responsible*, *helpful* and *polite*.

The terminal values in Rokeach's framework are worth mentioning because Rokeach's concept of terminal values was found to be startlingly similar to the theoretical concept that emerged in this study – rationalizing the labeling of the emerging concept in a way that linked it Rokeach's previous work. As in the RVS, the terminal values listed by the participants can be argued to be "end states of existence". For instance, according to Rokeach, that the terminal value of "wisdom is an end-state but education is not" (Rokeach, 1973, p. 29), because wisdom is achieved and education is a process (i.e. the processes of achieving wisdom or knowledge). From the data collected in this study, the end states of having family, friends and a job are seen as desirable similar to the terminal values of the RVS.

However, what is also worth noting is the differences between the terminal values listed in the RVS and those that emerged in this study. The difference is perhaps related to how the list of terminal values in the RVS was generated compared to the terminal values that were described in this study. In essence, both the lists of instrumental values and terminal values in the RVS were generated based on expert opinion. The choice of 18 words for each list was chosen as a balance between not omitting important values and wanting the list to not become burdensome (Rokeach, 1973, p. 29). In the case of instrumental values, the list was generated from a list of 555 previously derived personality trait words. In this list only non-synonymous words that “were likely to be useful” were chosen by Rokeach and his team (1973, p. 29). The list of terminal values was also selected based on what could be described as ‘expert opinion’. Rokeach describes generating this list based on “a review of the literature mentioning various values found in American society and in other societies, the writers own terminal values, those obtained from 30 graduate students in psychology, and those obtained by interviewing a sample of about 100 adults ... after the notion of terminal values had been explained to them (Rokeach, 1973, p. 29).” This processes resulted in several hundred potential terminal values which were reduced by Rokeach and his team to the maximum of 18 which were not considered to have synonymous meaning and represented “end states of existence” (Rokeach, 1973, p. 29).

Certainly, there is face validity to the suggestion that there is overlap between the values listed in the RVS and those indicated by the participants. For instance, the RVS terminal values of true friendship, family security, and sense of accomplishment fit well with the terminal values identified through the data collection process here of family, friends and job. However, it did not emerge from the data in this study that less value is placed on friendships that the participants may not define as “true”. Nor was it clear that jobs were valued because of the associated sense

of accomplishment, or what the relationship between family and family security was. Perhaps future work will determine how the items of the RVS relate to the lived experience of cancer patients and the model developed in this project. However, based on the findings of this study, theorizing about the connection between the concepts established here and the actual values listed in the RVS reaches beyond the data that was collected.

The temporal relationship in evolution of this study and the researcher's discovery of Rokeach's work is important because it highlights an important topic for grounded theory methodologists – i.e. the timing of the literature review in grounded theory studies. In preparing for data collection a formal literature review was undertaken prior to data collection. In keeping with what Strauss and Corbin (1998) suggested, this prepared “the mind to gain insight”, it also anchored the data collection and researchers perspective in pre-existing work. In addition, formal literature review preceding data collection is certainly expected as part of a graduate studies project and likely helped to satisfy both institutional and ethical review boards so that the study could proceed.

However, not all grounded theory theorists are proponents of an in-depth literature review occurring before data collection. Glaser, who co-pioneered grounded theory methodology with Straus, indicated concerns to the literature review pre-empting data collection. His recommended approach was to perform the majority of the literature search towards the end of data collection and analysis and weave the literature into the emerging data. This approach is intended to help the researcher avoid being “sidetracked by received knowledge and interpretations that support taken-for-granted assumptions, which are not relevant to the new area of study” (McCallin, 2003, p. 63). In other words, Glaser was concerned that performing an in-depth literature search prior to data collection may shape the perception by which the researcher views the participants

experience, as oppose to the participant's experience creating the lens by which to view and explore the existing literature. In addition, Glaser was concerned that new researchers in a field may "feel daunted by writers or specialists in the field ... [questioning] their ability to add new research of value" or be influenced by "rhetorical jargon" (as cited in McCallin, 2003, p. 63).

These concerns are certainly valid, as evidenced by the abandonment of the concepts of personal and social identity. Furthermore, it is perhaps fortunate that Rokeach's work was not discovered until after the proposal, research questions and initial interview guide had been formulated and approved by the supervisory committee. Being familiar with Rokeach's work before these steps were completed may have resulted in values being explored in a way that was closely guided by Rokeach's framework of values and the terminal and instrumental values in the RVS - perhaps completely missing the importance of family, friends and work for the participants and their connection to routine.

### **Addressing the Research Questions**

As suggested by Strauss and Corbin (1998), the literature review that took place before the study initiated served as an initial orientation to the to the topic of identity in cancer experience. In the same way, the initial research questions that emerged from the literature review formed the basis for investigation. While the relevance of some of the questions is questionable given how the theory emerged from the data, it is still important to formally address these questions as they served as the initial starting point for exploration of the participant's experience. The research questions consisted of two main questions, each with two sub-questions. The first question and its sub-questions were descriptive requiring an exploration of the participant's experience. While these questions have been addressed in detail in the results section, they will be formally summarized next. This will be followed by an exploration of the

second set of questions which call for recommendations based on the interpretation of the participant's experience using the completed model.

**Question 1: How do the patients perceive their own personal, social identities and values?** The theory that emerged from this study indicated that there was not a useful distinction between how the primary participants perceived themselves (i.e. their personal identity) in their various roles and how others perceived them in those roles (i.e. their social identity). The primary participants were also able to identify what they valued, and these were subsequently able to be classified as terminal and instrumental values. Importantly, terminal values existed as the major motivating factor for participants. The participants consistently identified their terminal values as their friends, family, work and employment. The first sub-question asked how personal and social identities changed while undergoing initial treatment? The data collected from both the primary and secondary participants indicated that there was a preservation of the terminal identities of the primary participants. However, what was observed was a change in how the primary participants maintained their identities. For instance, primary participants recognized that they still had employment, even if they were on medical leave. In contrast, the instrumental identities that the primary participants used to maintain their terminal identities changed dramatically. The data suggested that the primary participants were unable to consistently maintain aspects such as reliability and friendliness. In addition, many interpersonal relationships and friendships were transformed at least temporarily. In relationships where support was generally considered mutual or was given from the primary participant to a friend, spouse or a child, the direction of support was predominantly towards the primary participant. However, the data also suggested that the primary participants were motivated to regain their previous instrumental identities, after surgery. The second sub-question was with regards to the decision

making process and asked how the primary participant considered their values, personal and social identity while making treatment decisions. What was discovered was that participants generally were accepting of the recommendations of their healthcare team. Furthermore, gathering information by the primary participant and their friends and family to make treatment decisions based values and identities was not a significant part of the decision making processes. Alternatively, information was gathered by the primary participant and their friends and family predominantly to re-assure the participants that their treatment was moving in an expected direction and to establish and clarify expectations.

**Question 2: How can treatment be provided that is congruent with a patient's values?** This is a complicated question, because treatment as relevant to the cancer experience may refer both to a specific intervention that occurs in a defined period of time or processes that involve seeking treatment, receiving the intervention, and adapting to the mental and physical consequences of the treatment. A response to this research question regarding treatment as a specific, isolated intervention will be explored first followed by treatment as a collection of processes.

Regarding treatment as a specific intervention, the participants described their terminal values as some combination of friends, family and work. These terminal values were also reflected directly in their terminal identities, with the participants using their instrumental identities to maintain their identities and establishing a routine to maintain these terminal identities over time. Of the instrumental identities the participant uses to maintain their terminal identities, the body or physical form is presumed to critical to all terminal identities. The vary basis of the cancer identity in this model is suggested to be to restore the body to a healthy state so that the participants can re-establish their routines and therefore maintain their various

terminal identities. Therefore, in the broadest sense, any treatment option that is meant to restore health fits with a patient's values. Participants routinely indicated that they expected the doctors to tell them the plan and that they would go along with it. While some indicated that they appreciated being involved in treatment decision making, this was certainly not a requirement of the patient-physician relationship. The participants were willing to take any recommendation from the physicians, as long as it made sense. This was part of the experience of battling cancer – as one participant put it, that fight was “doing whatever I need to ... to get better, and get back to work so I can have a life” (Patient 4). As she indicated in the interview, this meant doing what the doctors recommended.

The importance of doctor's recommendations to the participants is supported by the existing literature. For instance, one prospective Canadian study examining the choice for breast conserving therapy in women with stage I and IIa breast cancer found that in a sample of 157 participants, choice of breast conserving therapy compared to modified radical mastectomy was best predicted by the identity of the surgeon and recommendations of the physician (Temple et al., 2006). Interestingly, in this study women reported being central to the decision making processes, even though a significant discrepancy between the amount of information received about the various surgical options was less than the information the patients felt that they required to satisfy their information needs. It is possible that the feeling of being central to the decision making processes despite not receiving enough information reflects the observation in this study – that the decision making processes for the participants is not about choosing between the treatment options of breast conserving therapy and mastectomy, but choosing to proceed with the physician's recommendations.



In order to understand how to better provide treatment options that fit with the participant's values, specific research is needed that focuses on exploring the factors influencing how physicians make their treatment recommendations. Retrospective population data exists outlining patterns in choices between different surgical, chemotherapy and radiotherapy options (Ananda et al., 2009; Francescutti et al., 2009; Yi et al., 2009). However, this data does not add the kind of insight that would be necessary to begin to develop strategies to provide care consistent with patients values in a way that is acceptable to physicians and other healthcare providers (D. Feldman-Stewart, Brundage, Tishelman, & Team, 2005).

What can be said is that the model suggests that when choices between treatment options are relatively equivalent, care should be considered to anticipate how the treatment plan will affect the patient's routine and their ability to utilize their instrumental identities to maintain their terminal identities. For instance, the choice between breast conserving therapy including radiotherapy and mastectomy may represent a significant disruption to the routine of a participant who lives in a remote rural area due to the need for several weeks of radiation which, in Manitoba at least, is only available in two cities located in the southern portion of the province. These types of considerations may represent an important opportunity for progression of existing guidelines. In fact, an informal scanning search of existing literature and recommendations suggest that recommendations may be based primarily on epidemiological outcomes with little consideration for interruptions to the participants pre-established routines or ability to maintain terminal identities outside of the cancer identity (Gradishar et al., 2015; Johns & Dixon, 2016).

Without further exploring what factors affect how physicians make recommendations, it is challenging to make useful suggestions about how treatment can be provided that is congruent

with patient's values. However, what can safely be said is that many participants experienced considerable disruption to their routines and a relative inability to plan for the future while waiting for consultations with physicians. These disruptions continued, in some cases beyond the consultations with their medical and radiation oncologists, as participants reported experiences unexpected side-effects of treatment and uncertainty about further treatments following chemotherapy. Both the secondary and the primary participants described adjusting their routines in order to ensure they wouldn't miss phone calls regarding the timing of their appointments with their oncologists. Participants who had not met with their oncologists also expressed a high degree of uncertainty about when they might be able to return to their jobs and plan for the future. Additionally, this was also true for some that had met with their oncologists. The participant's inability to maintain their routines and plan for the future emerged as a major theme in the data collected that was not desirable for the participants.

Suggestions for how these disruptions could be mitigated come directly from the data collected in this study as well as from interpretation of the model which emerged from this study. Participants indicated that simply knowing when their appointments with their medical and radiation oncologists were quicker after initial surgery had been completed would be helpful, even if the actual appointments did not occur any sooner. This is supported by the model which evolved in this study because knowing when consultations are scheduled far in advance allows the participant to plan their routine and maintenance around their scheduled appointments.

Additionally, participants indicated not being fully aware of how the morbidity associated with specific treatments would affect their ability to carry out their routine. Information that speaks directly to how instrumental identities may be affected through treatment and recovery would likely enhance the participant's ability to plan and manage their lives. Interestingly, the

importance of this type of information is not evident in the literature that explores information needs (Lim, Butow, Mills, Miller, & Goldstein, 2016; Rutten, Arora, Bakos, Aziz, & Rowland, 2005; Wong et al., 2011). In a systematic review of 112 articles exploring the information needs of cancer patients, Rutten et al. (2005) identified that only 6% of articles addressed interpersonal issues and it was not clear from the review whether any of the articles addressed maintaining aspects of life outside of cancer treatment.

Lastly, in contrast to disruptions in routine and challenges with accurately planning for the future, participants indicated that positive changes did occur in their identities. Participants frequently identified the support they received from their friends, family and employees as positive effects of the cancer experience. In addition, participants also recognized that their families had become ‘closer’ which was seen as a positive result of the cancer diagnosis and the cancer experience. These findings, as well those that indicated that participants become more aware of their terminal value hierarchy and relied increasingly on their faith are consistent with those of other studies. For instance, in a study of primary participants with colon cancer that also included family members, Mosher et al. (2017) identified that participants described closer relationships, greater appreciation of life, clarifying of life priorities, increased faith and more empathy following discharge.

### **Putting the Findings in Perspective and Motivating Future Research**

Several considerations should be made when interpreting the findings of this study and the theoretical model that evolved from it. The first was that a sampling bias may be present in the participants. This concern is related in part to the method in which the sample was obtained. Participants were contacted through several different means and at varying times in the progression through the cancer experience. The majority of the participants were contacted

directly at the time of setting up their appointment to meet the medical and radiation oncologist. However, participants with gynecological malignancies were recruited in clinic by the gynecology surgeons at the time of consent for initial surgical intervention, and prostate participants were recruited through letters of invitation which were disseminated in tandem with radiation-oncology referrals. In all cases, it was made clear that this study offered no remuneration for time involved in the study or other secondary benefit to the participants. When the study was designed, this was not considered to be a significant issue in obtaining a representative sample. However, given the consistency with which participants described their general instrumental identities as friendly, helpful or indicated that helping others was a major motivator for being involved in the study, it is important to consider that the interpretations of this study are built on a sample which is more altruistic or has a particularly pro-social skew. This could also be the effect of the phenomena of increased empathy described by Mosher et al. (2017). Regardless, in the future, if further studies are undertaken to explore the concept of identity established in this study, motivation for study involvement should be considered when designing the recruitment strategy.

Additionally, 12 of the 18 primary participants were female breast cancer patients with the average age of the primary participants being relatively tightly distributed ( $M = 55.44$ ,  $SD = 11.99$ ). It is hard to know how the ages, genders and diagnosed malignancies of the participants influenced the evolution of the model. One plausible theory is that prominence of the terminal identities of being spouses, parents, friends and employees was related to the majority of the participants being within the psychosocial life stage defined by Erikson as Generativity versus Stagnation (Kaplan, Ruiz, Sadock, & Sadock, 2009). This psychosocial stage generally occurs between the ages of about 40 years and about 60 years and is primarily concerned with

“establishing and guiding the next generation” (Kaplan et al., 2009). This certainly fits with terminal value of family stated by many of the participants and the terminal identities of being parents and spouses that many identified.

Exploring the cancer experience with a predominantly age based sampling strategy would be informative. In the data the functional connection between the participant’s individual goals, terminal identities, terminal values and routine was consistent even in cases where the participants differed in their stated terminal values or terminal identities. Therefore, two predictions can be made, first that exploration of what participants would describe as their terminal values would be closely linked to the stages described by Erikson. Second, that what would be described as challenging by the participants may differ dramatically by Eriksonian life stage. This is because what was seen as distressing to the participants in this study was the inability to plan and maintain the routines that the participants had established in relation to what they valued - i.e. in the case of the majority of the participants in this study: friends, family and employment. For instance, a cohort of participants between the ages of 21 and 40, presumed to be in the Intimacy versus Isolation stage (Kaplan et al., 2009), may express the terminal identity of family only intermittently, but would consistently express terminal values and terminal identities reflecting efforts to establish intimate relationships and initiate productive careers. This is certainly an area in which future exploration would be valuable.

Lastly, the researcher had hoped to recruit participants from a wide range of cultures including northern and remote communities of Manitoba, as well as participants that self-identified as Indigenous in an effort to generate the theory presented here from a representative sample of Manitobans. However, while this was the hope, the priority was to do this in a way that acknowledged criticisms regarding how some research with Indigenous participants has

been carried out in the past (L. T. Smith, 2012). Therefore, every attempt was made to engage participants, including Indigenous participants, in a way that was mindful of transformative philosophy (John W. Creswell, 2013). In other words, the researcher viewed the participants, including Indigenous patients, as potentially vulnerable. Vulnerable in that substantial power imbalances exist both in the clinical experience between healthcare professionals and patients, as well as in the research experience between researchers and study participants. In keeping with Creswell's description of transformative frameworks, the hope was to have the research "inquiry completed 'with' [the participants] rather than 'on' or 'to' [the participants]"(2013, p. 22).

As a result, aside from engaging with the administrative bodies which represented the various Indigenous groups in Manitoba and obtaining their support, no specific efforts were made to recruit Indigenous participants. Perhaps as a result of this recruiting strategy, and not actively searching out participants of diverse cultural backgrounds, this study contained only one participant that self-identified as Indigenous and only four participants identified as recent immigrants. As an aside, these identifying features were not explicitly reported in this study in order to protect the identity of the participants both in their communities and to their healthcare providers.

This does raise the question of the applicability of the model of identity forwarded in this study to Indigenous peoples and those that do not identify with the predominantly European based culture. Interestingly, Erikson's work, including work that was the basis for his developmental stages, did include research involving the Oglala, a subtribe of the Lakota (referred to by some as Sioux), located in North Dakota, and the Yurok Tribe located in California (Erikson, 1939, 1963/1993). He described his position with Indian Services during his

research with the Oglala as a “mental hygienist” (Erikson, 1939, p. 101) and the motivation for his research with the Oglala, beginning in the late 1930s as an:

... urgent purpose of trying to find out when came the tragic apathy with which Sioux Indian children quietly accepted and then quietly discarded many of the values taught them in the immensely thoughtful and costly experiment of federal Indian education (Erikson, 1963/1993, p. 114).

Erikson noted significant differences in the development of the Oglala children in responses to authority and to education provided in what can only be described as the European tradition. He observed “the ancient principles of child training still operating in the remnants of the tribe undermining the establishment of a white conscience” (Erikson, 1963/1993, p. 154). He described that what he believed was “wrong” with the children as “obvious enough: there were two rights for them, one white and one Indian” (Erikson, 1939; 1963/1993, p. 114). These observations are important for two reasons. The first reason is simply a practical one. His observations identify developmental differences in identity and developmental stages between Indigenous populations and those of European descent that have come to North America in the last several hundred years. This confirms important concerns that the model that evolved from this project *may* not be widely applicable, even across cultural groups in Manitoba.

Erikson’s observations are also important for another reason. This is because they highlight the ethical, moral and philosophical tragedy that can occur when researchers perform research *on* participants. The motivation for Erikson’s observations, as clearly identified in the previous quote, represented a contribution to the effort of the American government to assimilate

Indigenous peoples into its predominantly European culture. His task was to determine why the Native American boarding school system was ineffective at ‘sanitizing’ the Indigenous children of their culture, and to presumably contribute to the conversation about how this process could become more efficient. The report in which he summarized the findings of his research with the Oglala is both fascinating and horrific (Erikson, 1939). On the one hand, he articulates prejudices by both European educators as well as the Oglala children and their parents, and the tragic effects of the loss of tradition and cultural identity on the psychological development of the Indigenous children he observed. On the other hand, he concludes his report with two equally heinous solutions to the original question that guided his research. The first is literally causing the Oglala “to starve, thus hoping to bring [their] attention to new economic values and consequently for new educational values” (Erikson, 1939, p. 151). The second solution he posited was “the proper influence on and the wise utilization of the [Oglala] child’s early education” (Erikson, 1939, p. 152), advocating for the processes of cultural assimilation to begin earlier in a child’s life than was already undertaken by the American government’s Department of Indian Services.

An important consideration to be drawn from Erikson’s research is that the nature and origin of the research question matters. In his research, Erikson was essentially determining how to help the government with their agenda to culturally assimilate the Indigenous peoples. But what if Erikson’s research question was informed by the needs of the population he was engaging with? What if instead of determining how to better, in the infamous words of Captain Richard H. Pratt, “kill the Indian, and save the man” (as cited in Dawson, 2012), Erikson was tasked with helping to provide the Oglala children with the tools they needed to maintain their identity and values and live in way that they found satisfying within the American culture they



found themselves in? Perhaps what he observed and the conclusions he provided would have reshaped approaches to education for Indigenous peoples both in the United States and in Canada. Perhaps this would have transformed the boarding school systems in these nations, that are now condemned as human rights tragedies that continue to haunt many of the individuals, families and communities that they affected.

Erikson's research with the Oglala provides an extreme example of how research, once considered ethical and important, can in retrospect, be later criticized. This is an important lesson to those undertaking research work where a significant power imbalance exists, including in the healthcare setting. In this study it was identified that obtaining medical care comes at a considerable cost to patients' ability to maintain their routine and aspects of their identity. In this study the participants allowed their identities to be affected, and largely based their treatment choices, on their health care providers' recommendations – clearly identifying an important power differential. Yet, from the data collected we can surmise that the concepts of routine and identity may not have been strongly considered in existing adjuvant treatments and patient flow processes. While the goal of adjuvant therapy is to prevent recurrence and prolong life, it is challenging to know how the current processes involving providing adjuvant treatment will be viewed decades from now. Perhaps supporting identity through the cancer experience will someday be considered as important as promoting survival of the physical body – adding important considerations to the processes involved in delivering healthcare.

### **Conclusion**

This study used grounded theory to explore identity in the context of cancer patients that have recently been diagnosed and are expected to be making decisions regarding additional radiation therapy and chemotherapy. While the literature review which preceded data collection provided a strong basis to begin exploration, the interviews conducted with the primary and secondary participants allowed for an understanding of identity that was grounded in the participant's lived experience. The theory which evolved from this study consisted of the core concepts of terminal and instrumental values, terminal and instrumental identity and routine. This study also identified the emergence of a new terminal identity, the cancer identity which resulted from the cancer diagnosis.

The model which evolved from this study provides insight into the challenge of maintaining pre-existing routines through the cancer experience. It also suggests that participants may benefit from information that helps them maintain their terminal identities through the cancer experience. Such information includes that which informs realistic expectations of how treatment will affect their instrumental identities and being provided with as much notice as possible regarding when medical appointments and procedures are scheduled in order to support the maintenance of the patients' routine. In addition, there is a need to explore whether the model which emerged from this study, and the terminal values identified in this study, are representative across the wide cultural, age and geographic differences present in Manitoba. As an exploratory study, this work raises a number of new research questions. However, it also has provided insights that are relevant to the experience of cancer in Manitoba and offered an opportunity for solutions to some of the challenges of the cancer experience raised by its participants.

### References

- Ananda, S., Kosmider, S., Lim, L., Barnett, F., Desai, J., & Gibbs, P. (2009). Adjuvant chemotherapy for stage II and stage III colon cancer-What is happening in routine practice? *Journal of Clinical Oncology*, 27(15 suppl.). Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/27964464>  
doi:10.1200/jco.2009.27.15\_suppl.e15046
- Arterburn, D. E., Westbrook, E. O., Bogart, T. A., Sepucha, K. R., Bock, S. N., & Weppner, W. G. (2011). Randomized trial of a video-based patient decision aid for bariatric surgery. *Obesity*, 19(8), 1669-1675. doi:10.1038/oby.2011.65
- Australian Diabetes Educators Association. (2008). Client centered care. Retrieved from [https://www.adea.com.au/wp-content/uploads/2013/08/150415\\_Person-Centred-Care-Information-Sheet-FINAL-APPROVED.pdf](https://www.adea.com.au/wp-content/uploads/2013/08/150415_Person-Centred-Care-Information-Sheet-FINAL-APPROVED.pdf)
- Baile, W. F., Lenzi, R., Parker, P. A., Buckman, R., & Cohen, L. (2002). Oncologists' attitudes toward and practices in giving bad news: An exploratory study. *Journal of Clinical Oncology*, 20(8), 2189-2196.
- Bastiaens, H., Van Royen, P., Pavlic, D. R., Raposo, V., & Baker, R. (2007). Older people's preferences for involvement in their own care: A qualitative study in primary health care in 11 European countries. *Patient Education and Counseling*, 68(1), 33-42.  
doi:10.1016/j.pec.2007.03.025
- Bauman, A. E., Fardy, H. J., & Harris, P. G. (2003). Getting it right: Why bother with patient centred care? *The Medical Journal of Australia*, 179(5), 253-256.
- Beauchamp, T., & Childress, J. (2001). *Principles of biomedical ethics* (5th ed.). New York: Oxford University Press. (Original work published 1978)

- Beaulieu, M.-D. (2013). Toward a patient-centred health care system. *Canadian Family Physician*, 59(1), 109.
- Binnie, A., Titchen, A. (1999). *Freedom to practice: The development of patient-centered nursing*. London: Butterworth Heinemann.
- Brehaut, J. C., O'Connor, A. M., Wood, T. J., Hack, T. F., Siminoff, L., Gordon, E., & Feldman-Stewart, D. (2003). Validation of a decision regret scale. *Medical Decision Making*, 23(4), 281-292.
- Brown, D., McWilliam, C., & Ward-Griffin, C. (2006). Client-centered empowering partnering in nursing. *Journal of Advanced Nursing*, 53(2), 160-168.
- Buerhaus, P., Donelan, K., Ulrich, B., Norman, L., Willimas, M., & Dittus, R. (2005). Hospital RNs' and CNOs' perceptions of the impact of the nursing shortage on the quality of care. *Nursing Economics*, 23(5), 214-221.
- Canadian Partnership Against Cancer. (2014). Improving the Cancer Journey. Retrieved from <http://www.partnershipagainstcancer.ca/priorities/cancer-journey/>
- Charmaz, K. (2006). *Constructing grounded theory* (Kindle, 2nd ed.). Thousand Oaks, CA: SAGE.
- Chrystal, K., Allan, S., Forgeson, G., & Isaacs, R. (2003). The use of complementary/alternative medicine by cancer patients in a New Zealand regional cancer treatment centre. *New Zealand Medical Journal*, 116(1168), U296.
- Clare, L., Rowlands, J., Bruce, E., Surr, C., & Downs, M. (2008). The experience of living with dementia in residential care: An interpretative phenomenological analysis. *Gerontologist*, 48(6), 711-720.

- Clobert, M., Saroglou, V., & Van Pachterbeke, M. (2015). Who turns to acupuncture? The role of mistrust of rationality and individualist success. *Journal of Alternative and Complementary Medicine*. doi:10.1089/acm.2014.0229
- Cowen, V. S., & Cyr, V. (2015). Complementary and alternative medicine in US medical schools. *Journal of Advances in Medical Education and Practice*, 6, 113-117.  
doi:10.2147/AMEP.S69761
- Creswell, J. W. (2013). *Qualitative inquiry and research design : Choosing among five approaches* (Kindle, 3rd ed.). Thousand Oaks, CA: SAGE.
- Creswell, J. W. (2014). *Research design: Qualitative, quantitative, and mixed methods approaches* (4th ed.). Thousand Oaks, CA: SAGE.
- Creswell, J. W., & Plano Clark, V. L. (2010). *Designing and conducting mixed methods research* (2nd ed.). Los Angeles, CA: SAGE.
- Crossing the quality chasm: a new health system for the 21st century*. (2001). Washington DC: National Academy Press.
- Dawson, A. S. (2012). Histories and memories of the Indian boarding schools in Mexico, Canada, and the United States. *Latin American Perspectives*, 39(5), 80-99.
- DeVita, V. T., Lawrence, T. S., & Rosenberg, S. A. (2011). *DeVita, Hellman, and Rosenberg's cancer : principles & practice of oncology* (9th ed.). Philadelphia: Wolters Kluwer Health/Lippincott Williams & Wilkins.
- Duggan, P. S., Geller, G., Cooper, L. A., & Beach, M. C. (2006). The moral nature of patient-centeredness: Is it "just the right thing to do"? *Patient Education and Counseling*, 62(2), 271-276.

Dwamena, F., Holmes-Rovner, M., Gaulden, C. M., Jorgenson, S., Sadigh, G., Sikorskii, A., . . .

Olomu, A. (2012). Interventions for providers to promote a patient-centred approach in clinical consultations. *Cochrane Database of Systematic Reviews*, 12, CD003267.

doi:10.1002/14651858.CD003267.pub2

Edwards, A., Elwyn, G., Hood, K., Atwell, C., Robling, M., Houston, H., . . . Study Steering, G.

(2004). Patient-based outcome results from a cluster randomized trial of shared decision making skill development and use of risk communication aids in general practice. *Family Practice*, 21(4), 347-354. doi:10.1093/fampra/cmh402

Elwyn, G., Dehlendorf, C., Epstein, R. M., Marrin, K., White, J., & Frosch, D. L. (2014). Shared decision making and motivational interviewing: achieving patient-centered care across the spectrum of health care problems. *Annals of Family Medicine*, 12(3), 270-275.

doi:10.1370/afm.1615

Erikson, E. H. (1939). Observations on Sioux education. *Journal of Psychology*, 7, 101.

Erikson, E. H. (1993). *Childhood and society* (Kindle ed.): W. W. Norton & Company. (Original work published 1963)

Ezzo, J., Wright, K., Hadhazy, V., Bahr-Robertson, M., Mac Beckner, W., Covington, M., &

Berman, B. (2002). Use of the Cochrane electronic library in complementary and alternative medicine courses in medical schools: is the giant lost in cyberspace? *Journal of Alternative and Complementary Medicine*, 8(5), 681-686.

doi:10.1089/107555302320825200

Feldman-Stewart, D., Brundage, M. D., Tishelman, C., & Team, S. C. (2005). A conceptual framework for patient-professional communication: An application to the cancer context.

*Psycho-oncology*, 14(10), 801-809; discussion 810-801. doi:10.1002/pon.950

- Feldman-Stewart, D., Madarnas, Y., Mates, M., Tong, C., Grunfeld, E., Verma, S., . . . Brundage, M. (2013). Information needs of post-menopausal women with hormone receptor positive early-stage breast cancer considering adjuvant endocrine therapy. *Patient Education And Counselling*, 93, 114-121.
- Feldman-Stewart, D., Tong, C., Siemens, R., Alibhai, S., Pickles, T., Robinson, J., & Brundage, M. D. (2012). The impact of explicit values clarification exercises in a patient decision aid emerges after the decision is actually made: evidence from a randomized controlled trial. *Medical Decision Making*, 32(4), 616-626. doi:10.1177/0272989X11434601
- Flagg, A. J. (2015). The role of patient-centered care in nursing. *Nursing Clinics of North America*, 50(1), 75-86. doi:10.1016/j.cnur.2014.10.006
- Francescutti, V., Farrokhyar, F., Tozer, R., Heller, B., Lovrics, P., Jansz, G., & Kahnamoui, K. (2009). Primary tumor and patient characteristics in breast cancer as predictors of adjuvant chemotherapy regimen: A regression model. *Journal of Clinical Oncology*, 27(15 supp.).
- Freire, P. (2013). *Education for critical consciousness*. Chennai, India: Bloomsbury. (Original work published 1974)
- Freire, P. (2014). *Pedagogy of the oppressed: 30th anniversary edition*. New York, NY: Bloomsbury. (Original work published 1970)
- Fulford, K. W., Ersser, S., & Hope, T. (1996). *Essential practice in patient-centered care*. UK: Blackwell Science Ltd.
- Gerteis, M., Edgman-Levitan, S., Daley, D., & Delbanco, T. L. (1993). *Through the patient's eyes: understanding and promoting patient-centered care*. San-Francisco, CA: Jossey-Bass.

- Giordano, J., Boatwright, D., Stapleton, S., & Huff, L. (2002). Blending the boundaries: Steps toward an integration of complementary and alternative medicine into mainstream practice. *Journal of Alternative and Complementary Medicine*, 8(6), 897-906.  
doi:10.1089/10755530260511892
- Glaser, B. G., & Strauss, A. L. (1999). *The discovery of grounded theory: Strategies for qualitative research* (Kindle ed.). Piscataway, NJ: AldineTransaction. (Original work published 1967)
- Goel, V., Sawka, C. A., Thiel, E. C., Gort, E. H., & O'Connor, A. M. (2001). Randomized trial of a patient decision aid for choice of surgical treatment for breast cancer. *Medical Decision Making*, 21(1), 1-6.
- Government of Manitoba. (2001). Manitoba's aboriginal community: A 2001 to 2026 population and demographic profile.
- Government of Manitoba. (2013). *Manitoba immigration facts - 2012 statistical report*. Retrieved from [https://www.gov.mb.ca/labour/immigration/pdf/manitoba\\_immigration\\_facts\\_report\\_2012.pdf](https://www.gov.mb.ca/labour/immigration/pdf/manitoba_immigration_facts_report_2012.pdf).
- Gradishar, W. J., Anderson, B. O., Balassanian, R., Blair, S. L., Burstein, H. J., Cyr, A., . . . Kumar, R. (2015). NCCN Guidelines Insights Breast Cancer, Version 1.2016. *Journal of the National Comprehensive Cancer Network*, 13(12), 1475-1485.
- Hedayati, E., Johnsson, A., Alinaghizadeh, H., Schedin, A., Nyman, H., & Albertsson, M. (2013). Cognitive, psychosocial, somatic and treatment factors predicting return to work after breast cancer treatment. *Scandinavian Journal of Caring Sciences*, 27(2), 380-387.  
doi:10.1111/j.1471-6712.2012.01046.x



- Hedderson, M. M., Patterson, R. E., Neuhouser, M. L., Schwartz, S. M., Bowen, D. J., Standish, L. J., & Marshall, L. M. (2004). Sex differences in motives for use of complementary and alternative medicine among cancer patients. *Alternative Therapies in Health and Medicine*, 10(5), 58-64.
- Heiney, S. P. (2014). Social disconnection in African American women with breast cancer. *Oncology Nursing Forum*, 41(1), E28-34. doi:10.1188/14.ONF.E28-E34
- Herman, C. (2006). What makes a screening exam "good"? *Virtual Mentor*, 8(1), 34-37. doi:10.1001/virtualmentor.2006.8.1.cpr11-0601
- Herrmann, N., & Gauthier, S. (2008). Diagnosis and treatment of dementia: 6. Management of severe Alzheimer disease. *Canadian Medical Association Journal*, 179(12), 1279-1287. doi:10.1503/cmaj.070804
- Herrmann, N., Gauthier, S., & Lysy, P. G. (2007). Clinical practice guidelines for severe Alzheimer's disease. *Alzheimers & Dementia: Journal of the Alzheimer's Association*, 3(4), 385-397. doi:10.1016/j.jalz.2007.07.007
- Hitlin, S. (2003). Values as the core of personal identity: Drawing links between two theories of self. *Social Psychology Quarterly*, 66(2), 118-137. doi:10.2307/1519843
- Hogg, M. A., Terry, D. J., & White, K. M. (1995). A tale of two theories: A critical comparison of identity theory with social identity theory. *Social Psychology Today*, 58(4), 14.
- Johns, N., & Dixon, J. M. (2016). Should patients with early breast cancer still be offered the choice of breast conserving surgery or mastectomy? *European Journal of Surgical Oncology*, 42(11), 1636-1641. doi:10.1016/j.ejso.2016.08.016
- Johnson, M. O. (2011). The shifting landscape of health care: Toward a model of health care empowerment. *American Journal of Public Health*, 101(2), 265-270.

- Kaplan, H. I., Ruiz, P., Sadock, B. J., & Sadock, V. A. (2009). *Kaplan & Sadock's comprehensive textbook of psychiatry* Retrieved from [http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=booktext&NEWS=N&DF=bookdb&AN=01412563/9th\\_Edition&XPATH=/PG\(0\)](http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=booktext&NEWS=N&DF=bookdb&AN=01412563/9th_Edition&XPATH=/PG(0))
- Kinmonth, A. L., Woodcock, A., Griffin, S., Spiegel, N., & Campbell, M. J. (1998). Randomised controlled trial of patient centred care of diabetes in general practice: impact on current wellbeing and future disease risk. *British Medical Journal*, 317(7167), 1202-1208.
- Kitson, A., Marshall, A., Bassett, K., & Zeitz, K. (2013). What are the core elements of patient-centred care? A narrative review and synthesis of the literature from health policy, medicine and nursing. *Journal of Advanced Nursing*, 69(1), 4-15. doi:10.1111/j.1365-2648.2012.06064.x
- Kuntz, J. L., Safford, M. M., Singh, J. A., Phansalkar, S., Slight, S. P., Her, Q. L., . . . Hornbrook, M. C. (2014). Patient-centered interventions to improve medication management and adherence: a qualitative review of research findings. *Patient Education and Counseling*, 97(3), 310-326. doi:10.1016/j.pec.2014.08.021
- Lamiani, G., Meyer, E. C., Rider, E. A., Browning, D. M., Vegni, E., Mauri, E., . . . Truog, R. D. (2008). Assumptions and blind spots in patient-centredness: action research between American and Italian health care professionals. *Medical Education*, 42(7), 712-720. doi:10.1111/j.1365-2923.2008.03038.x
- Lawrence, M., & Kinn, S. (2012). Defining and measuring patient-centred care: an example from a mixed-methods systematic review of the stroke literature. *Health Expectations*, 15(3), 295-326. doi:10.1111/j.1369-7625.2011.00683.x

- Lee, E. H., Klassen, A. F., Lawson, J. L., Cano, S. J., Scott, A. M., & Pusic, A. L. (2015). Patient experiences and outcomes following facial skin cancer surgery: A qualitative study. *Australasian Journal of Dermatology*. doi:10.1111/ajd.12323
- Lehto, U. S., Helander, S., Taari, K., & Aromaa, A. (2014). Patient experiences at diagnosis and psychological well-being in prostate cancer: A Finnish national survey. *European Journal of Oncology Nursing*. doi:10.1016/j.ejon.2014.10.018
- Lim, B. T., Butow, P., Mills, J., Miller, A., & Goldstein, D. (2016). Information Needs of the Chinese Community Affected by Cancer: A Systematic Review. *Psycho-oncology*. doi:10.1002/pon.4347
- Lincoln, N. D., Travers, C., Ackers, P., & Wilkinson, A. (2002). The meaning of empowerment: The interdisciplinary etymology of a new management concept. *International Journal of Managment Reviews*, 4(3), 19.
- Little, M., Paul, K., Jordens, C. F., & Sayers, E. J. (2002). Survivorship and discourses of identity. *Psycho-oncology*, 11(2), 170-178.
- Locke, J., & Winkler, K. (1996). *An essay concerning human understanding : Abridged and edited, with an introduction and notes*. Indianapolis, ID: Hackett Publishing Co. (Original work published 1689)
- Lusk, J. M., & Fater, K. (2013). A concept analysis of patient-centered care. *Nursing Forum*, 48(2), 89-98. doi:10.1111/nuf.12019
- Markowitsch, H. J., & Staniloiu, A. (2012). Amnesic disorders. *Lancet*, 380(9851), 1429-1440. doi:10.1016/S0140-6736(11)61304-4
- Mathieu, E., Barratt, A., Davey, H. M., McGeechan, K., Howard, K., & Houssami, N. (2007). Informed choice in mammography screening: a randomized trial of a decision aid for 70-

- year-old women. *Archives of Internal Medicine*, 167(19), 2039-2046.  
doi:10.1001/archinte.167.19.2039
- McCallin, A. (2003). Grappling with the literature in a grounded theory study. *Contemporary Nursing*, 15(1-2), 61-69.
- McCarthy, B. (2006). Translating person-centred care: A case study of preceptor nurses and their teaching practices in acute care areas. *Journal of Clinical Nursing*, 15(5), 629-638.  
doi:10.1111/j.1365-2702.2006.01366.x
- McCormack, B., & McCane, T. V. (2006). Development of a framework for person-centered nursing. *Journal of Advanced Nursing*, 56(5), 472-479.
- McDaniel, S. H., Morse, D. S., Reis, S., Edwardsen, E. A., Gurnsey, M. G., Taupin, A., . . . Shields, C. G. (2013). Physicians criticizing physicians to patients. *Journal of General Internal Medicine*, 28(11), 1405-1409. doi:10.1007/s11606-013-2499-9
- McDonald, R., Tomlins, A., Smith, S., & Harmston, C. (2013). Outcomes of faecal occult blood tests requested outside the UK National Bowel Cancer Screening Programme. *Journal of Clinical Pathology*, 66(4), 330-334. doi:10.1136/jclinpath-2011-200406
- McEwen, M., & Wills, E. M. (2014). *Theoretical basis for nursing* (4th ed.). Philadelphia: Wolters Kluwer Health/Lippincott Williams & Wilkins.
- McMillan, S. S., Kendall, E., Sav, A., King, M. A., Whitty, J. A., Kelly, F., & Wheeler, A. J. (2013). Patient-centered approaches to health care: A systematic review of randomized controlled trials. *Medical Care Research And Review*, 70(6), 567-596.
- Mead, N., & Bower, P. (2000). Patient-centredness: A conceptual framework and review of the empirical literature. *Social Science Medicine*, 51(7), 1087-1110.

- Melnyk, B. M., & Fineout-Overholt, E. (2011). *Evidence-based practice in nursing & healthcare : A guide to best practice* (2nd ed.). Philadelphia, PN: Wolters Kluwer/Lippincott Williams & Wilkins.
- Millenson, M. L., DiGioia, A. M., Greenhouse, P. K., & Swieskowski, D. (2013). Turning patient-centeredness from ideal to real: Lessons from 2 success stories. *Journal of Ambulatory Care Management*, 36(4), 319-334.
- Montazeri, A., Sajadian, A., Ebrahimi, M., Haghighat, S., & Harirchi, I. (2007). Factors predicting the use of complementary and alternative therapies among cancer patients in Iran. *European Journal of Cancer Care (Engl)*, 16(2), 144-149. doi:10.1111/j.1365-2354.2006.00722.x
- Mosher, C. E., Adams, R. N., Helft, P. R., O'Neil, B. H., Shahda, S., Rattray, N. A., & Champion, V. L. (2017). Positive changes among patients with advanced colorectal cancer and their family caregivers: A qualitative analysis. *Psychological Health*, 32(1), 94-109. doi:10.1080/08870446.2016.1247839
- Muller-Engelmann, M., Keller, H., Donner-Banzhoff, N., & Krones, T. (2011). Shared decision making in medicine: the influence of situational treatment factors. *Patient Education and Counseling*, 82(2), 240-246. doi:10.1016/j.pec.2010.04.028
- Nelson, S., & Gordon, S. (2006). *The complexities of care: Nursing reconsidered*. Ithaca, NY: ILR press.
- Page, K. (2012). The four principles: Can they be measured and do they predict ethical decision making? *BioMed Central Medical Ethics*, 13(10), 8.
- Pelzang, R. (2010). Time to learn: Understanding patient-centered care. *British Journal of Nursing*, 912-917.

- Perry, J. (1975). *Personal identity*. Berkeley, CA: University of California Press.
- Pulvirenti, M., McMillan, J., & Lawn, S. (2011). Empowerment, patient centred care and self-management. *Health Expectations*, 17, 303-310.
- Quill, T. E., & Brody, H. (1996). Physician recommendations and patient autonomy: Finding a balance between physician power and patient choice. *Annals of Internal Medicine*, 125(9), 763-769.
- Raabe-Meyer, G., Kaiser, C., & Bauersfeld, W. (2010). [Medicine and natural science--time for a change in paradigm]. *Clinical Laboratory*, 56(9-10), 501-504.
- Redman, R. W. (2004). Patient-centered care. *Research and Theory for Nursing Practice*, 1, 11-14.
- Registered Nurses' Association of Ontario. (2006). Registered Nurses' Association of Ontario Guideline Development Methodology. Ottawa, ON: University of Ottawa.
- Richardson, M. A., Sanders, T., Palmer, J. L., Greisinger, A., & Singletary, S. E. (2000). Complementary/alternative medicine use in a comprehensive cancer center and the implications for oncology. *Journal of Clinical Oncology*, 18(13), 2505-2514.
- Robinson, J., Callister, L., Berry, J., & Dearing, K. (2008). Patient-centered care and adherence: Definitions and applications to improve outcomes. *Journal of the American Academy of Nurse Practitioners*, 20(12), 600-607.
- Robinson, N. C. (1991). A patient-centered framework for restructuring care. *Journal of Nursing Administration*, 21(9), 29-34.
- Rogers, A., Kennedy, A., Nelson, E., & Robinson, A. (2005). Uncovering the limits of patient-centeredness: implementing a self-management trail for chronic disease. *Qualitative Health Research*, 125(2), 224-239.

- Rokeach, M. (1973). *The nature of human values*. New York, NY: Free Press.
- Rokeach, M. (1979). *Understanding human values: Individual and societal*. New York, NY: Free Press.
- Rutten, L. J., Arora, N. K., Bakos, A. D., Aziz, N., & Rowland, J. (2005). Information needs and sources of information among cancer patients: A systematic review of research. *Patient Education and Counseling*, 57(3), 250-261. doi:10.1016/j.pec.2004.06.006
- Scholl, I., Zill, J. M., Harter, M., & Dirmaier, J. (2014). An integrative model of patient-centeredness - a systematic review and concept analysis. *PLoS One*, 9(9), e107828. doi:10.1371/journal.pone.0107828
- Shaller, D. (Producer). (2010, July 9). Patient-centered care: What does it take? . *Picker Institute, Oxford and The Commonwealth Fund*. Retrieved from <http://tinyurl.com/shaller>
- Shell, L. (2015). The picture of happiness in Alzheimer's disease: Living a life congruent with personal values. *Geriatric Nursing*, 36(2 Suppl), S26-32. doi:10.1016/j.gerinurse.2015.02.021
- Smith, L. T. (2012). *Decolonizing methodologies: Research and indigenous peoples* (Second edition. ed.). New York, NY: Zed Books.
- Smith, S. K., Trevena, L., Simpson, J. M., Barratt, A., Nutbeam, D., & McCaffery, K. J. (2010a). Appendix 2: Values clarification exercise. *British Medical Journal*, 341, c5370. doi:10.1136/bmj.c5370
- Smith, S. K., Trevena, L., Simpson, J. M., Barratt, A., Nutbeam, D., & McCaffery, K. J. (2010b). A decision aid to support informed choices about bowel cancer screening among adults with low education: randomised controlled trial. *British Medical Journal*, 341, c5370. doi:10.1136/bmj.c5370

Stacey, D., Legare, F., Col, N. F., Bennett, C. L., Barry, M. J., Eden, K. B., . . . Wu, J. H. (2014).

Decision aids for people facing health treatment or screening decisions. *Cochrane*

*Database of Systematic Reviews*, 1. doi:10.1002/14651858.CD001431.pub4

Starr, S. S. (2008). Authenticity: A concept analysis. *Nursing Forum*, 43(2), 55-62.

doi:10.1111/j.1744-6198.2008.00096.x

Stewart, M. (2001). Towards a global definition of patient centred care. *British Medical Journal*, 322(7284), 444-445.

Strauss, A. L., & Corbin, J. M. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2nd ed.). Thousand Oaks, CA: SAGE.

Temple, W. J., Russell, M. L., Parsons, L. L., Huber, S. M., Jones, C. A., Bankes, J., & Eliasziw,

M. (2006). Conservation surgery for breast cancer as the preferred choice: a prospective analysis. *Journal of Clinical Oncology*, 24(21), 3367-3373.

doi:10.1200/JCO.2005.02.7771

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349-357. doi:10.1093/intqhc/mzm042

Trenton, M. (1999). Endurance, Psychological Continuity, and the Importance of Personal

Identity. *Philosophy and Phenomenological Research*, 59(4), 983-997.

doi:10.2307/2653565

Trevena, L. J., Irwig, L., & Barratt, A. (2008). Randomized trial of a self-administered decision aid for colorectal cancer screening. *Journal of Medical Screening*, 15(2), 76-82.

doi:10.1258/jms.2008.007110



Tuncel, T., Sen, V., Kelekci, S., Karabel, M., Sahin, C., Uluca, U., . . . Haspolat, Y. K. (2014).

Use of complementary and alternative medicine in children who have no chronic disease.

*Turkish Archives of Pediatrics*, 49(2), 148-153. doi:10.5152/tpa.2014.1498

Turner, J. H. (2013). *Contemporary sociological theory*. Los Angeles, CA: SAGE.

University of Manitoba. (2015). Framework for research engagement with First Nation, Metis, and Inuit peoples. Winnipeg, MB.

Violette, P. D., Agoritsas, T., Alexander, P., Riikonen, J., Santti, H., Agarwal, A., . . . Tikkinen, K.

A. (2015). Decision aids for localized prostate cancer treatment choice: Systematic review and meta-analysis. *CA: A cancer journal for clinicians*. doi:10.3322/caac.21272

Vogel, B. A., Bengel, J., & Helmes, A. W. (2007). Information and decision making: Patients' needs and experiences in the course of breast cancer treatment. *Patient Education and Counselling*, 71, 79-85.

Vrdoljak, D. (2012). Teaching evidence based medicine in family medicine. *Acta Medica Academica*, 41(1), 88-92. doi:10.5644/ama2006-124.42

Wakefield, C. E., Meiser, B., Homewood, J., Peate, M., Taylor, A., Lobb, E., . . . Group, A. G. C. (2008). A randomized controlled trial of a decision aid for women considering genetic testing for breast and ovarian cancer risk. *Breast Cancer Research and Treatment*, 107(2), 289-301. doi:10.1007/s10549-007-9539-2

Wengstrom, Y., Aapro, M., Leto di Priolo, S., Cannon, H., & Georgiou, V. (2007). Patients' knowledge and experience of adjuvant endocrine therapy for early breast cancer: A European study. *The Breast*, 16, 462-468.

- West, E., Barron, D. N., & Reeves, R. (2005). Overcoming the barriers to patient-centred care: Time, tools and training. *Journal of Clinical Nursing*, 14(4), 435-443. doi:10.1111/j.1365-2702.2004.01091.x
- Wilson, F., Ingelton, C., Gott, M., & Gardiner, C. (2014). Autonomy and choice In Palliative Care: Time for a new model? *Journal of Advanced Nursing*, 1020-1029.
- Wong, J. J., D'Alimonte, L., Angus, J., Paszat, L., Soren, B., & Szumacher, E. (2011). What do older patients with early breast cancer want to know while undergoing adjuvant radiotherapy? *Journal of Cancer Education*, 26(2), 254-261. doi:10.1007/s13187-010-0188-5
- Yi, M., Hunt, K. K., Arun, B. K., Bedrosian, I., Gutierrez Barrera, A. M., Kuerer, H. M., . . . Meric-Bernstam, F. (2009). Factors leading to the decision for contralateral prophylactic mastectomy in patients with breast cancer. *Journal of Clinical Oncology*, 27(15 supp.), 1528.
- Zollman, C., & Vickers, A. (1999). What is complementary medicine? *British Medical Journal*, 319(7211), 693-696.

## **Appendix A: The Fictional Case of Jan**

### **Appendix A.0: Introducing Jan**

The following fictional case of Jan is used to illustrate how the model of individual identity relates to an individual. It is divided into subsections to correspond with the appropriate sections of the literature review. The idea of providing exemplary illustrative cases is drawn from concept analysis, and is a powerful tool for understanding how abstract concepts relate to real life (McEwen & Wills, 2014). This initial section introduces Jan as well as pertinent aspects of her identity. For further clarification of the model of individual identity presented in this paper, Jan and the various scenarios she is presented in the main text of this paper are graphically conceptualized in corresponding figures.

Jan is a 46 year old new divorcee who is the mother of two children, Kyle and Sophie. Jan has sole custody of her 16 year old daughter, Sophie. Together they live in Thompson, MB. Kyle is 19 and attending university in Winnipeg, MB. Prior to the divorce, Jan was a stay at home mother, but shortly after Kyle started University she divorced her husband who had recently developed a substance abuse problem and was becoming increasingly verbally and physical abusive. Jan recently managed to get a job working as an assistant to a lawyer in a small law firm in town in order to help Kyle pay for school and to support Sophie and herself. Jan sees herself as a fit person, and runs and works out regularly.

Jan has several personal identities. She sees herself as a supportive parent, an identity that has evolved from her values of individuality and legacy. She also sees herself as a good employee, which is informed by her valuing hard work. Jan also sees herself as fit person, and values her own health and body. Prior to being divorced, Jan had the personal identity of soul mate, she truly felt that her husband was hers. Although she no longer has this identity, she

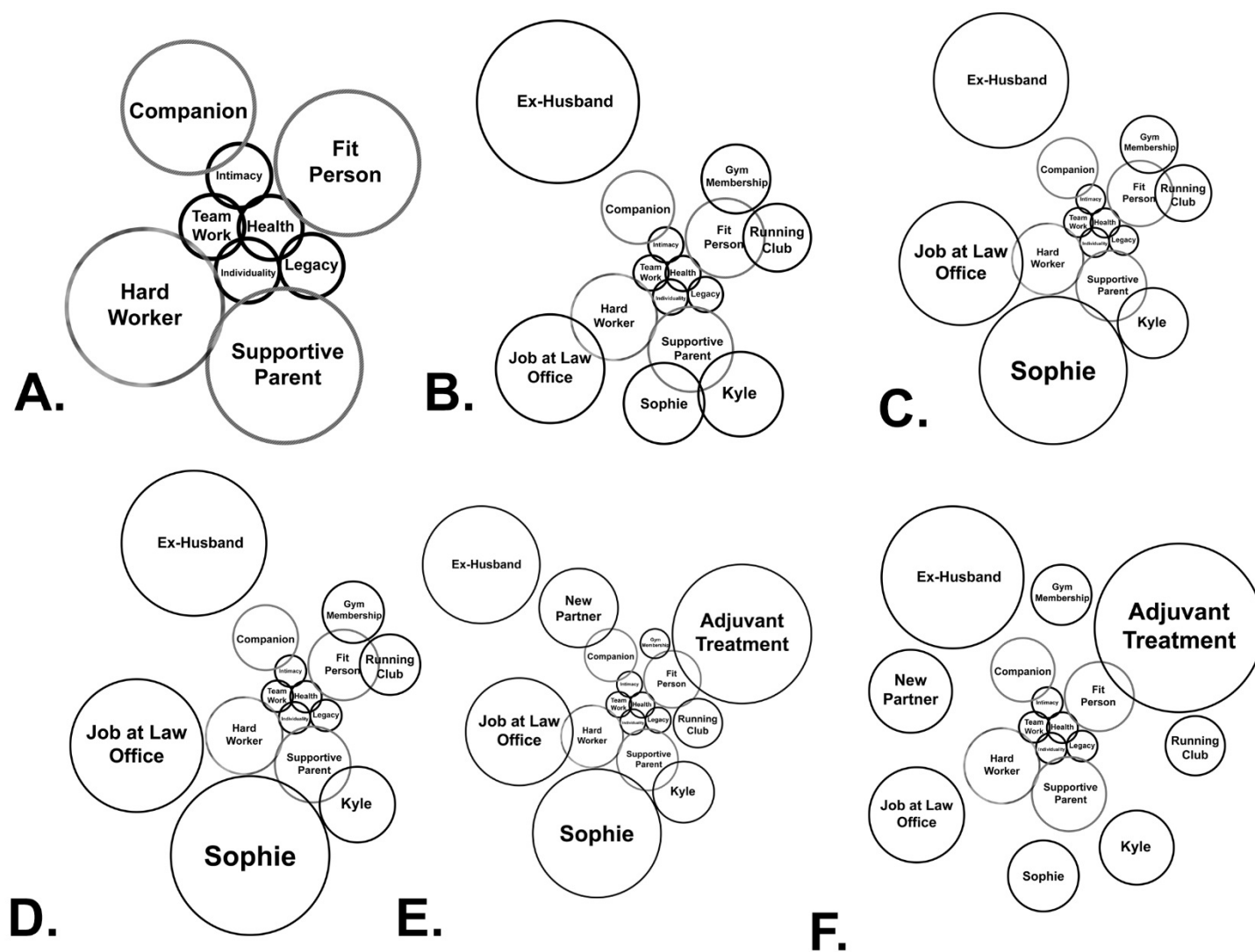
continues to value companionship, and describes herself as being somewhat unhappy with her relationship status of single. Jan's identity is graphically illustrated in Figure 5.a, how these identities are connected with the larger social world is illustrated in Figure 5.b.

### **Appendix A.1: Social identity, social group identity and symbolic interactionism**

This first scenario is used to demonstrate the concept of symbolic interactionism as well as to further clarify the concepts of values, and personal and social identity as they pertain to the model of individual identity. Jan finds herself in a situation where she must decide if she is going to leave work early to see her daughter in a school play. If Jan chooses to leave work to support her child it might suggest that she holds her personal and social identity as a parent higher in her identity hierarchy, then her personal identity as a good employee and her value of hard work. The choice to stay at work would suggest that her identity as an employee is more important to her.

However, in some workplaces the social group identity may hold parenting as a highly important value. For instance, in a workplace that is dominated by parents, attending the play may put her closer to the group norm behavior than an employee who does not have children. In that case, depending on the values of the group identity of her place of employment, her personal identity as a team player may be in hierarchy over her role as a supportive parent. For instance, if Sophie was trying to create an identity of her own, independent of her mother, attending the play may be unsupportive of Sophie's efforts. Then, Jan choosing to attend the play would place her personal identity as a supportive parent below her personal identity as a providing parent and a member of the team at work. The dynamic and complex hierarchy between values and identities illustrates the term symbolic interactionism.

In Jan's case, if her workplace was supportive and her daughter wanted her at the play, leaving work early to attend wouldn't be a difficult choice. However, when a choice must be



*Figure 6.* Model of identity built on illustrative case used in Appendix A. A. Illustrates Jan's personal self, values are represented by the smaller circles at the center of the image, with the larger circles representing her personal identities. B. Jan's social identities are added. Note that Jan's ex-husband is not connected to Jan's individual identity, and that her personal identity as a companion is not realized through a social identity. C. Integration is achieved when Jan is able to maintain her commitment to Sophie and her commitment to her work. D. Adaptation occurs when Jan's social identity is altered due to conflicting pressures from Sophie and her Job. E. Integration occurs when Jan is able to maintain her identity with the addition of adjuvant therapy to her identity. F. When adjuvant therapy requires giving up aspects of her personal identity, Jan must adapt to a new identity, with many aspects of her personal identity not being realized.

made that puts an individual's personal identities in conflict the individual makes the choice they believe that is best in keeping with their values. This may result in compromising one or several personal identities. The process by which a person is forced to maintain a social identity that is not in keeping with their personal identity, because it is seen as the only way in which important values can be honored, is *adaptation*. When Jan left her husband she had to adapt to what was becoming a bad situation. Although she valued companionship and had established a personal identity through her marriage that allowed expression of this value, commitment to the personal identity was in conflict with her other identities. Because she valued her legacy and her body she chose to adapt her identity to honor her other values by abandoning her personal identity as a soul mate. This is in contrast with *integration*, which occurs when an individual is able to take on a new social identity while maintaining their personal identity and in doing so is able to continue to honor their values.

In Jan's case, if her work place is not supportive of her going to see her child's play but she feels that to fulfill her personal identity as a supportive parent she should leave work early to attend it, then her social identity as a team player at her job may be compromised. It is up to Jan to determine if she wished to try to integrate her personal identity as a supportive parent into her role as an employee and a team player, or if she adapts, pushing her personal identity as a supportive parent aside for the time being. This scenario is illustrated in Figure 5.c.

### **Appendix A.2: Exploring the Concept of Memory and Identity**

Jan's mother Margaret has late stage Alzheimer's dementia. This is defined as requiring full time personal assistance, loss of awareness of recent experiences, and increasing difficulty with communication (Herrmann & Gauthier, 2008). Jan recognizes Margaret, in part, because

she remembers her. Jan is able to recall memories of time spent with Margaret, and feels connected to Margaret even when Margaret does not remember Jan. Although how Jan sees Margaret has changed, Jan continues to have a sense of who Margaret is that is rooted in past memory.

Margaret on the other hand does not always recognize Jan. She cannot recall who Jan is, and therefore the previous social identity that she had of Jan does not exist. However, despite not being able to recall who Jan is, Margaret is able to reflect on her own personal values, and express treatment decisions (Clare et al., 2008). This is not uncommon for individuals with dementia, including those in the mid to late stages, suggesting that personal identity is rooted in values, not memory.

### **Appendix A.3: Exploring treatment making decisions with values and identity**

Jan is diagnosed with an early stage breast cancer, after the discovery of a small lump in her right breast by a man she has recently begun dating. Jan receives a lumpectomy, and she is told that she will need radiation therapy that will require prolonged trips to either Brandon or Winnipeg. In addition, she is told that she will require hormone therapy for at least five years and that the size of the lump was just big enough that it would not be unreasonable to give chemotherapy. This would mean a total of close to six months of intense treatment and the possibility of not being able to work during this time.

The choice as presented to Jan is whether or not she wants chemotherapy. The real question according to the model of individual identity is: will she be able to integrate to this new situation or will she have to adapt? If she is forced to adapt, what aspects of her identity will she be forced to compromise in order to increase her chance of cure? Jan is nervous about how the strain of being sick and losing her hair will affect the social identity she has established with her

new boyfriend, her personal identity as a companion and her value of intimacy. She is also worried that as a single parent, taking extra sick days or time off work will compromise her group identity at the office where she works, her social identity as an employee and her personal identity as a hard worker. This would potentially result in a decreased ability to care for her children, compromising an aspect of Jan's personal identity that is very important to her: being a supportive parent. These concerns are all juxtaposed with Jan's core value of health, and her personal identity as a healthy person.

In an ideal world Jan would not have to make a choice between what aspects of her identity she wishes to honor. She would be able to maintain her current personal identities in addition to receiving treatment, this is the principle discussed above of integration. But it certainly seems that in choosing between adjuvant chemotherapy, many aspects of Jan's identity will be in jeopardy and she will be forced to make a choice about which aspects of herself to abandon and which to maintain, reflecting the concept of adaptation. This scenario is illustrated in Figure 5.d.



## Appendix B: Demographic Record for Primary and Secondary Participants

### *A: Primary Participant Demographics and Information Record*

*Researcher to complete:*

1. Study ID #:

2. Age

3. Gender

Male

Female

4. Primary Postal Code

5. Indigenous participant

Yes

No

If yes, which group:

6. Self-identified cultural group

7. Occupation and occupational status

8. Malignancy Diagnosis

9. Stage

10. Initial Curative Procedure

11. Present for Secondary Interview

Yes

No

12. Date and time for follow up phone call

13. Number of secondary participants

14. First Interview completed on:

Date:

Time:

15. Follow up interview completed on:

Date:

Time:

### *B: Primary Interviewee Demographic Response Questionnaire*

*Interviewee to complete*

**DATE OF BIRTH:** Month\_\_\_\_\_Day\_\_\_\_\_Year\_\_\_\_\_

**EDUCATION:**

Highest Level of School Completed

Did not Finish High School\_\_\_\_\_1

Finished High School \_\_\_\_\_2

Some Post-High School Community College or University\_\_\_\_\_3

Completed Post-High School Community College or University\_\_\_\_\_4

**USUAL RESIDENCE:**

Urban\_\_\_\_\_ 1

Rural\_\_\_\_\_ 2

**MARITAL STATUS:**

Married or Common law/cohabitating\_\_\_\_\_1

Widowed\_\_\_\_\_2

Divorced\_\_\_\_\_3

Separated\_\_\_\_\_4

Never married\_\_\_\_\_5

**WHICH OF THE FOLLOWING BEST DESCRIBES YOUR SITUATION?**

Working full-time\_\_\_\_\_1

Working part-time\_\_\_\_\_2

Retired\_\_\_\_\_3

Unemployed\_\_\_\_\_4

Student\_\_\_\_\_5

On leave from work\_\_\_\_\_6

**WHO IS WITH YOU TODAY FOR THIS INTERVIEW?**

Spouse/partner\_\_\_\_\_1

Friend\_\_\_\_\_2

Daughter/ Son\_\_\_\_\_3

Sibling\_\_\_\_\_4

No one; I'm alone\_\_\_\_\_5

Other (please specify) \_\_\_\_\_6

**WHEN WERE YOU TOLD YOU HAD CANCER?**

Month\_\_\_\_\_ Year \_\_\_\_\_

**WHAT KIND OF CANCER WERE YOU DIAGNOSED WITH?****WHEN ARE YOU EXPECTING TO SEE AN ONCOLOGIST?**

Date:

**DO YOU KNOW IF YOU NEED FURTHER TREATMENT?**

YES

NO

*C. Secondary Participant Information and Demographics Record**Researcher to complete*

1. Secondary Participant ID (i.e. Primary participant ID + secondary ID #)

2. Age

3. Gender

Male

Female

4. Relationship to primary participant

5. Occupation and occupational status

6. Present for Principal Interview

Yes

No

7. Principal Participant present for secondary interview

Yes

No

8. Indigenous participant:

Yes

No

Which group:

9. Self-identified cultural group:

*D: Secondary Interviewee Demographic Response Questionnaire**Secondary Interviewee to complete***DATE OF BIRTH:** Month\_\_\_\_\_Day\_\_\_\_\_Year\_\_\_\_\_**EDUCATION:**Highest Level of School Completed

Did not Finish High School\_\_\_\_\_1

Finished High School \_\_\_\_\_2

Some Post-High School Community College or University\_\_\_\_\_3

Completed Post-High School Community College or University\_\_\_\_\_4

**USUAL RESIDENCE:**

Urban\_\_\_\_\_ 1

Rural\_\_\_\_\_ 2

**WHAT IS YOUR RELATIONSHIP TO THE PRIMARY PARTICIPANT?**

Spouse/partner\_\_\_\_\_1

Friend\_\_\_\_\_2

Daughter/ Son\_\_\_\_\_3

Sibling\_\_\_\_\_4

Other (please specify) \_\_\_\_\_5

**HOW LONG HAVE YOU KNOWN THE PARTICIPANT?**

**DO YOU KNOW WHAT KIND OF CANCER THE PRIMARY PARTICIPANT HAS  
(circle one)?**

**Yes**

**No**

**If yes, what kind?**

**DO YOU KNOW IF THE PRIMARY PARTICIPANTS CANCER CAN BE CURED?**

**Appendix C: Initial Preliminary Interview Guide**

Note: Text in italics represents dialogue to be spoken to the participant.

Introduction:

*Thank you for agreeing to meet with me. My name is Mac Thiessen. I am a physician with special training in oncology. I am currently interested in understanding the different identities and values that patients who are being treated with cancer have and am studying this through a Masters program. Specifically, I am interested in understanding how being diagnosed and receiving treatment for cancer has affected you, and what challenges to your identity further cancer treatment, if necessary, may bring. The interview should take approximately 60 minutes. If you have friends or family that would like to participate they will be included in an additional part of the interview. I will begin by asking about why you agreed to be a part of this study. Then we will explore who you are to yourself and other people, as well as changes to these identities since you have been diagnosed with cancer. We will also explore how these aspects of you might be affected if you decide to take chemotherapy. Next, we will explore what your values are, and how these have affected your journey so far, and the role they play in your thinking about chemotherapy.*

*We can pause at any time, I appreciate that we might talk about some sensitive topics so if you want to take a break please let me know. If you feel that you want to stop the interview all together please say so.*

**See Next Page for Questions**

**Note:** Numbered questions indicate main questions, with alphabetized questions indicating possible prompts.

**Initial Open-Ended Question:**

1. Tell me about why you agreed to be a part of this study? (Rapport building)

**Exploring Social Identity:**

2. Tell me about who you are to other people:
  - a. How do you spend your days?
  - b. What does an average week look like for you?
  - c. Tell me about your family.
  - d. What do you do for fun?
  - e. Do you have different groups of friends or just one group?

**Exploring Personal Identity**

3. Describe yourself as a person:
  - a. What kind of person are you at work?
  - b. What role do you play in your family?
  - c. What role do you have in your group of friends?



**Exploring Values**

We are now going to talk about values. Values are ideas that we believe to be important that generally change very little over time. They guide us in making plans for the future and inform how we develop our identities. Examples of values are loyalty, strength, compassion, creativity, and personal health.

4. What would you describe as your important values?

Possible prompts would include exploring the personal identity roles i.e.: courage, honesty, creativity, obedience

- a. In your family, why did you describe your role as x? Why do you take on this role?

5. What are your goals for the next year? Ten years?

- a. How do you think further cancer treatment will affect these goals?
- b. Have you changed your goals (or do you think you will need to change your goals) because of your cancer diagnosis?

6. How do these goals relate to your values?

**Exploring the interaction of cancer diagnosis on personal identity, social identity and values:**

7. How did being diagnosed with cancer affect your job? (If applicable)

- a. You described the type of person you are at work as x, did this change at all?
- b. Were you able to meet the expectations of your job?

8. How did being diagnosed with cancer affect your family?

- a. You described the role you have in your family as x, did this change at all with the cancer diagnosis?

9. How did being diagnosed with cancer affect your friendships?
  - a. Did it affect how you are treated by your friends?
  - b. You described your role with your friends as x, did this change?
10. We discussed your values earlier. You felt that x,y,z etc. were important values. During the time of your diagnosis, did you feel that your values, or the relative importance of these values, changed?

**Considering adjuvant therapy in the context of values and personal and social identity:**

11. Have you been told that you will need or could have additional treatments for your cancer?

**If the participant is not aware of further treatment a statement similar to the following**

**would be made:** *I do not have adequate information to determine whether or not additional treatment is necessary, but many patients who have had surgery for cancer may receive additional treatments such as chemotherapy, radiotherapy or both. Imagine that you were told that you needed one of these treatments.*

12. What do you know about chemotherapy? What do you know about radiation therapy?
13. How do you think chemotherapy/radiation would affect your role in your family?
14. How do you think chemotherapy/radiation would affect your role at your job?
15. How do you think chemotherapy/radiation would affect your relationship with your friends?

**If appropriate:** *You have indicated that you have a friend/family member interested in participating in this study. You are welcome to observe their interview. We will be discussing changes they have observed in you over the last few months surrounding your diagnosis and surgery.*

**Supplemental Questions for Family and Friends:**

**If the additional participant(s) were not present for the initial portion of the interview repeat introductory statement.**

1. What kind of person would you describe (the participant) as?
2. What role does (the participant) play in your life?
3. How would you say the last few months have affected (the participant)? How?
4. Did the role (the participant) play in your life change during the last few months? How?
5. From what you know about cancer treatments, if (the participant) was to undergo chemotherapy or radiation, how do you think it would affect them?
  - a. How do you think it would affect the role they play in your life?

**Concluding statement for both the interview with the patient participant and the additional participants:**

*Thank you very much for your time. If you have any questions regarding our discussion or feel upset by any of the things we have talked about I have time to discuss these things with you. Or, if things comes up at a later time that you wish to discuss feel free to contact me through my email at [umthiesm@cc.umanitoba.ca](mailto:umthiesm@cc.umanitoba.ca) or my program supervisor, Dr. Tom Hack, at (204) 235-3791.*

*Alternatively, your family doctor is a great resource for discussing concerns about treatment.*

*Counselling support is also available through the psychosocial oncology department at Cancer Care Manitoba specifically for patients and their families.*

**Information with contact information for psychosocial supports will be left for both the participants and the main participants.**

**Follow-up Phone Interview Question Guide:**

*Thank you for being willing to talk with me again. The purpose of this interview is to follow up on our initial interview. Specifically I am interested in finding out how our initial conversation affected you or if you think it had any impact on your decisions about cancer treatment. I don't intend this to be a long conversation, but as before, if you wish to stop the conversation for any reason feel free to say.*

1. How did you feel after our first interview?
  - a. Did you find that our discussion helped you in anyway?
  - b. Were there parts of it that weren't helpful?
  - c. Had you thought about your values or the various roles you play in your own life before?
  - d. Did you think differently about yourself or your treatment decisions after we talked?
2. Do you think our conversation affected your treatment decision in anyway?
3. Do you think our conversation affected any of your relationships or the things you spend your time doing?
4. Is there anything you would like to say about our initial conversation, this study or in general about your experience that you have not had a chance to discuss?

*Thank you again for your time and participation in this study. If you have any further questions about this study or concerns, please don't hesitate to contact me through my email at [umthiesm@cc.umanitoba.ca](mailto:umthiesm@cc.umanitoba.ca) or my program supervisor, Dr. Tom Hack, at (204) 235-3791.*

**Appendix D: Primary Participant Interview Guide – Revised April 7th**

*Note: Additional dialogue prompts have been excluded from these appendixes for the sake of brevity. The sections in italics in the initial interview guides were unaltered throughout the study.*

**Initial Open-Ended Question:**

1. Tell me about why you agreed to be a part of this study? (Rapport building)

**Exploring Social Identity:**

2. Tell me about who you are to other people:
  - a. How do you spend your days?
  - b. What does an average week look like for you?
  - c. Tell me about your family.
  - d. What do you do for fun?
  - e. Do you have different groups of friends or just one group?

**Exploring Personal Identity**

3. Describe yourself as a person:
  - a. What kind of person are you at work?
  - b. What role do you play in your family?
  - c. What role do you have in your group of friends?

**Exploring Values**

4. What would you describe as your important values?

Possible prompts would include exploring the personal identity roles i.e.: courage, honesty, creativity, obedience

- a. In your family, why did you describe your role as x? Why do you take on this role?
5. What are your goals for the next year? Ten years?
- a. How do you think further cancer treatment will affect these goals?
  - b. Have you changed your goals (or do you think you will need to change your goals) because of your cancer diagnosis?
6. How do these goals relate to your values?

**Exploring the interaction of cancer diagnosis on personal identity, social identity and values:**

7. Tell me about what cancer means to you?
- a. Have you known anyone that was diagnosed with cancer? Was the role you play in their life changed by their diagnosis? Was the role they play in your changed?
  - b. As someone who is being treated for cancer, do you feel there are any expectations to “fight cancer”? What does that mean to you?
8. How did being diagnosed with cancer affect your job? (If applicable)
- a. You described the type of person you are at work as x, did this change at all?
  - b. Were you able to meet the expectations of your job?
9. How did being diagnosed with cancer affect your family?
- a. You described the role you have in your family as x, did this change at all with the cancer diagnosis?
10. How did being diagnosed with cancer affect your friendships?
- a. Did it affect how you are treated by your friends?

- b. You described your role with your friends as x, did this change?
11. We discussed your values earlier. You felt that x,y,z etc. were important values. During the time of your diagnosis, did you feel that your values, or the relative importance of these values, changed?
12. Different people see doctors, and the role of doctors differently. What do you think the relationship you have with the doctors treating you should be? Do you feel that the doctors you have come in contact with, during your journey with cancer, have met these expectations?

**Considering adjuvant therapy in the context of values and personal and social identity:**

13. Have you been told that you will need or could have additional treatments for your cancer?
14. What do you know about chemotherapy? What do you know about radiation therapy?
15. How do you think chemotherapy/radiation would affect your role in your family?
16. How do you think chemotherapy/radiation would affect your role at your job?
17. How do you think chemotherapy/radiation would affect your relationship with your friends?

**Appendix E: Secondary Participant Interview Guide – Revised April 7<sup>th</sup>**

*Note: Additional dialogue prompts have been excluded from these appendixes for the sake of brevity. The sections in italics in the initial interview guides were unaltered throughout the study.*

1. What kind of person would you describe (the participant) as?
2. What role does (the participant) play in your life?
3. How would you say the last few months have affected (the participant)? How?
  - a. How did being diagnosed with cancer affect them?
  - b. How did the diagnosis affect your relationship with them?
4. Did the role (the participant) play in your life change during the last few months? How?
5. What do you think a person being diagnosed with cancer should do?
6. What do you think the role of the doctor should be in helping your friend/family member?
  - a. What kind of relationship should exist between the patient, doctor and the patient's friends/family?
7. From what you know about cancer treatments, if (the participant) was to undergo chemotherapy or radiation, how do you think it would affect them?
  - a. How do you think it would affect the role they play in your life?



**Appendix F: Primary Interview Guide – Revised April 8<sup>th</sup>**

*Note: Additional dialogue prompts have been excluded from these appendixes for the sake of brevity. The sections in italics in the initial interview guides were unaltered throughout the study.*

**Initial Open-Ended Question:**

1. Tell me about why you agreed to be a part of this study? (Rapport building)

**Exploring Social Identity:**

2. Tell me about who you are to other people:
  - a. How do you spend your days?
  - b. What does an average week look like for you?
  - c. Tell me about your family.
  - d. What do you do for fun?
  - e. Do you have different groups of friends or just one group?

**Exploring Personal Identity:**

3. Describe yourself as a person:
  - a. What kind of person are you at work?
  - b. What role do you play in your family?
  - c. What role do you have in your group of friends?

**Exploring Values:**

4. What would you describe as your important values?

Possible prompts would include exploring the personal identity roles i.e.: courage, honesty, creativity, obedience

- a. In your family, why did you describe your role as x? Why do you take on this role?
5. What are your goals for the next year? Ten years?
- a. How do you think further cancer treatment will affect these goals?
  - b. Have you changed your goals (or do you think you will need to change your goals) because of your cancer diagnosis?
6. How do these goals relate to your values?

**Exploring the interaction of cancer diagnosis on personal identity, social identity and values:**

7. Tell me about what cancer means to you?
- a. Have you known anyone that was diagnosed with cancer? Was the role you play in their life changed by their diagnosis? Was the role they play in your changed?
  - b. As someone who is being treated for cancer, do you feel there are any expectations to “fight cancer”? What does that mean to you?
8. How did being diagnosed with cancer affect your job? (If applicable)
- a. You described the type of person you are at work as x, did this change at all?
  - b. Were you able to meet the expectations of your job?
9. How did being diagnosed with cancer affect your family?
- a. You described the role you have in your family as x, did this change at all with the cancer diagnosis?
10. How did being diagnosed with cancer affect your friendships?
- a. Did it affect how you are treated by your friends?

- b. You described your role with your friends as x, did this change?
11. We discussed your values earlier. You felt that x,y,z etc. were important values. During the time of your diagnosis, did you feel that your values, or the relative importance of these values, changed?
12. Different people see doctors, and the role of doctors differently. What do you think the relationship you have with the doctors treating you should be? Do you feel that the doctors you have come in contact with, during your journey with cancer, have met these expectations?

**Considering adjuvant therapy in the context of values and personal and social identity:**

13. Have you been told that you will need or could have additional treatments for your cancer?
14. What do you know about chemotherapy? What do you know about radiation therapy?
15. How do you think chemotherapy/radiation would affect your role in your family?
16. How do you think chemotherapy/radiation would affect your role at your job?
17. How do you think chemotherapy/radiation would affect your relationship with your friends?
18. What has been the hardest part of this experience for you?
19. What has been the best part?

**Appendix G: Secondary Interview Guide – Revised April 8**

*Note: Additional dialogue prompts have been excluded from these appendixes for the sake of brevity. The sections in italics in the initial interview guides were unaltered throughout the study.*

1. What kind of person would you describe (the participant) as?
2. What role does (the participant) play in your life?
3. How would you say the last few months have affected (the participant)? How?
  - a. How did being diagnosed with cancer affect them?
  - b. How did the diagnosis affect your relationship with them?
4. Did the role (the participant) play in your life change during the last few months? How?
5. What do you think a person being diagnosed with cancer should do?
6. What do you think the role of the doctor should be in helping your friend/family member?
7. What kind of relationship should exist between the patient, doctor and the patient's friends/family?
8. From what you know about cancer treatments, if (the participant) was to undergo chemotherapy or radiation, how do you think it would affect them?
9. How do you think it would affect the role they play in your life?
10. What do you think has been the hardest part of this experience for the primary participant?  
And for you? What has been the best part?

**Appendix H: Primary Interview Guide – Revised April 12**

*Note: Additional dialogue prompts have been excluded from these appendixes for the sake of brevity. The sections in italics in the initial interview guides were unaltered throughout the study.*

**Initial Open-Ended Question:**

1. Tell me about why you agreed to be a part of this study? (Rapport building)

**Exploring Social Identity:**

2. Tell me about who you are to other people:
  - a. How do you spend your days?
  - b. What does an average week look like for you?
  - c. Tell me about your family.
  - d. What do you do for fun?
  - e. Do you have different groups of friends or just one group?

**Exploring Personal Identity**

3. Describe yourself as a person:
  - a. What kind of person are you at work?
  - b. What role do you play in your family?
  - c. What role do you have in your group of friends?

**Exploring Values**

4. What would you describe as your important values?

Possible prompts would include exploring the personal identity roles i.e.: courage, honesty, creativity, obedience

- a. In your family, why did you describe your role as x? Why do you take on this role?
5. What are your goals for the next year? Ten years?
  - a. How do you think further cancer treatment will affect these goals?
  - b. Have you changed your goals (or do you think you will need to change your goals) because of your cancer diagnosis?
6. How do these goals relate to your values?

**Exploring the interaction of cancer diagnosis on personal identity, social identity and values:**

7. Tell me about your experience with being diagnosed?
8. Tell me about what cancer means to you?
  - a. Have you known anyone that was diagnosed with cancer? Was the role you play in their life changed by their diagnosis? Was the role they play in your changed?
  - b. As someone who is being treated for cancer, do you feel there are any expectations to “fight cancer”? What does that mean to you?
9. How did being diagnosed with cancer affect your job? (If applicable)
  - a. You described the type of person you are at work as x, did this change at all?
  - b. Were you able to meet the expectations of your job?
10. How did being diagnosed with cancer affect your family?
  - a. You described the role you have in your family as x, did this change at all with the cancer diagnosis?
11. How did being diagnosed with cancer affect your friendships?

- a. Did it affect how you are treated by your friends?
  - b. You described your role with your friends as x, did this change?
12. We discussed your values earlier. You felt that x,y,z etc. were important values. During the time of your diagnosis, did you feel that your values, or the relative importance of these values, changed?
13. Different people see doctors, and the role of doctors differently. What do you think the relationship you have with the doctors treating you should be? Do you feel that the doctors you have come in contact with, during your journey with cancer, have met these expectations?

**Considering adjuvant therapy in the context of values and personal and social identity:**

14. Have you been told that you will need or could have additional treatments for your cancer?
15. What do you know about chemotherapy? What do you know about radiation therapy?
16. How do you think chemotherapy/radiation would affect your role in your family?
17. How do you think chemotherapy/radiation would affect your role at your job?
18. How do you think chemotherapy/radiation would affect your relationship with your friends?
19. What has been the hardest part of this experience for you?
20. Have there been any good parts?
21. Is there anything else you would like to share?

**Appendix I: Primary Interview Guide – Revised April 14**

*Note: Additional dialogue prompts have been excluded from these appendixes for the sake of brevity. The sections in italics in the initial interview guides were unaltered throughout the study.*

**Initial Open Ended Question:**

1. Tell me about why you agreed to be a part of this study? (Rapport building)

**Exploring Social Identity:**

2. Tell me about who you are to other people:
  - a. How do you spend your days?
  - b. What does an average week look like for you?
  - c. Tell me about your family.
  - d. What do you do for fun?
  - e. Do you have different groups of friends or just one group?

**Exploring Personal Identity**

3. Describe yourself as a person:
  - a. What kind of person are you at work?
  - b. What role do you play in your family?
  - c. What role do you have in your group of friends?



**Exploring Values**

4. What are the most important things to you?
5. What would you describe as your important values?

Possible prompts would include exploring the personal identity roles i.e.: courage, honesty, creativity, obedience

- a. In your family, why did you describe your role as x? Why do you take on this role?
6. What are your goals for the next year? Ten years?
  - a. How do you think further cancer treatment will affect these goals?
  - b. Have you changed your goals (or do you think you will need to change your goals) because of your cancer diagnosis?
7. How do these goals relate to your values?

**Exploring the interaction of cancer diagnosis on personal identity, social identity and values:**

8. Tell me about what cancer means to you?
  - a. Have you known anyone that was diagnosed with cancer? Was the role you play in their life changed by their diagnosis? Was the role they play in your changed?
  - b. As someone who is being treated for cancer, do you feel there are any expectations to “fight cancer”? What does that mean to you?
9. Tell me about your experience with being diagnosed?
10. How did being diagnosed with cancer affect your job? (If applicable)
  - a. You described the type of person you are at work as x, did this change at all?
  - b. Were you able to meet the expectations of your job?

11. How did being diagnosed with cancer affect your family?
  - a. You described the role you have in your family as x, did this change at all with the cancer diagnosis?
12. How did being diagnosed with cancer affect your friendships?
  - a. Did it affect how you are treated by your friends?
  - b. You described your role with your friends as x, did this change?
13. We discussed your values earlier. During the time of your diagnosis, did you feel that your values, or the relative importance of these values, changed?
  - a. Did the importance of your personal health change?
14. Different people see doctors, and the role of doctors differently. What do you think the relationship you have with the doctors treating you should be? Do you feel that the doctors you have come in contact with, during your journey with cancer, have met these expectations?

**Considering adjuvant therapy in the context of values and personal and social identity:**

15. Have you been told that you will need or could have additional treatments for your cancer?
16. What do you know about chemotherapy? What do you know about radiation therapy?
17. How do you think chemotherapy/radiation would affect your role in your family?
18. How do you think chemotherapy/radiation would affect your role at your job?
19. How do you think chemotherapy/radiation would affect your relationship with your friends?
20. What has been the hardest part of this experience for you?
21. Have there been any good parts?
22. Is there anything else you would like to share?

**Appendix J: Primary Interview Guide – Revised April 24**

*Note: Additional dialogue prompts have been excluded from these appendixes for the sake of brevity. The sections in italics in the initial interview guides were unaltered throughout the study.*

**Initial Open-Ended Question:**

1. Tell me about why you agreed to be a part of this study?

**Exploring Social Identity:**

2. Tell me about who you are to other people:
  - a. How do you spend your days?
  - b. What does an average week look like for you?
  - c. Tell me about your family.
  - d. What do you do for fun?
  - e. Do you have different groups of friends or just one group?

**Exploring Personal Identity**

3. Describe yourself as a person:
  - a. What kind of person are you at work?
  - b. What role do you play in your family?
  - c. What role do you have in your group of friends?

**Exploring Values**

4. What are the most important things to you?
5. What would you describe as your important values?
6. How many months in advance do you generally plan?
7. What are your goals for the next year? Ten years?
  - a. How do you think further cancer treatment will affect these goals?
  - b. Have you changed your goals (or do you think you will need to change your goals) because of your cancer diagnosis?
8. How do these goals relate to your values?

**Exploring the interaction of cancer diagnosis on personal identity, social identity and values:**

9. Have you known anyone that was diagnosed with cancer? Was the role you play in their life changed by their diagnosis? Was the role they play in your changed?
10. As someone who is being treated for cancer, what does it mean to “fight cancer”? What does that mean to you?
11. Tell me about your experience with being diagnosed?
12. How did being diagnosed with cancer affect your job? (If applicable)
  - a. You described the type of person you are at work as x, did this change at all?
  - b. Were you able to meet the expectations of your job?

13. How did being diagnosed with cancer affect your family?
- a. You described the role you have in your family as x, did this change at all with the cancer diagnosis?
14. How did being diagnosed with cancer affect your friendships?
- a. Did it affect how you are treated by your friends?
  - b. You described your role with your friends as x, did this change?
15. We discussed your values earlier. During the time of your diagnosis, did you feel that your values, or the relative importance of these values, changed?
- a. Did the importance of your personal health change?
16. Can you characterize the relationship you have had with your doctors? Specifically, with regards to deciding about treatments?

**Considering adjuvant therapy in the context of values and personal and social identity:**

17. Have you been told that you will need or could have additional treatments for your cancer?
18. What do you know about chemotherapy? What do you know about radiation therapy?
19. How do you think chemotherapy/radiation would affect your role in your family?
20. How do you think chemotherapy/radiation would affect your role at your job?
21. How do you think chemotherapy/radiation would affect your relationship with your friends?
22. What has been the hardest part of this experience for you?
23. Have there been any good parts?
24. Is there anything else you would like to share?

**Appendix J: Secondary Interview Guide – Revised April 24**

*Note: Additional dialogue prompts have been excluded from these appendixes for the sake of brevity. The sections in italics in the initial interview guides were unaltered throughout the study.*

1. What kind of person would you describe (the participant) as?
2. What role does (the participant) play in your life?
3. How would you say the last few months have affected (the participant)? How?
  - a. How did being diagnosed with cancer affect them?
  - b. How did the diagnosis affect your relationship with them?
4. Did the role (the participant) play in your life change during the last few months? How?
5. What does it mean to fight cancer?
6. What do you think the role of the doctor should be in helping your friend/family member decide about cancer treatments?
7. From what you know about cancer treatments, if (the participant) was to undergo chemotherapy or radiation, how do you think it would affect them?
8. How do you think it would affect the role they play in your life?
9. What do you think has been the hardest part of this experience for the primary participant?  
And for you? What has been the best part?

**Appendix K: Primary Interview Guide – Revised May 1st**

*Note: Additional dialogue prompts have been excluded from these appendixes for the sake of brevity. The sections in italics in the initial interview guides were unaltered throughout the study.*

**Initial Open-Ended Question:**

1. Tell me about why you agreed to be a part of this study?

**Exploring Social Identity:**

2. Tell me about who you are to other people:
  - a. How do you spend your days?
  - b. What does an average week look like for you?
  - c. Tell me about your family.
  - d. What do you do for fun?
  - e. Do you have different groups of friends or just one group?

**Exploring Personal Identity**

3. Describe yourself as a person:
  - a. What kind of person are you at work?
  - b. What role do you play in your family?
  - c. What role do you have in your group of friends?

**Exploring Values**

4. What are the most important things to you?
5. What would you describe as your important values?
6. How many months in advance do you generally plan?
7. What are your goals for the next year? Ten years?
  - a. How do you think further cancer treatment will affect these goals?
  - b. Have you changed your goals (or do you think you will need to change your goals) because of your cancer diagnosis?
8. How do these goals relate to your values?

**Exploring the interaction of cancer diagnosis on personal identity, social identity and values:**

9. Have you known anyone that was diagnosed with cancer? Was the role you play in their life changed by their diagnosis? Was the role they play in your changed?
10. As someone who is being treated for cancer, what does it mean to “fight cancer”? What does that mean to you?
11. Tell me about your experience with being diagnosed?
12. How did being diagnosed with cancer affect your job? (If applicable)
  - a. You described the type of person you are at work as x, did this change at all?
  - b. Were you able to meet the expectations of your job?



13. How did being diagnosed with cancer affect your family?
- a. You described the role you have in your family as x, did this change at all with the cancer diagnosis?
14. How did being diagnosed with cancer affect your friendships?
- a. Did it affect how you are treated by your friends?
  - b. You described your role with your friends as x, did this change?
15. We discussed your values earlier. During the time of your diagnosis, did you feel that your values, or the relative importance of these values, changed?
- a. Did the importance of your personal health change?
16. Can you characterize the relationship you have had with your doctors? Specifically, with regards to deciding about treatments?

**Considering adjuvant therapy in the context of values and personal and social identity:**

17. Have you been told that you will need or could have additional treatments for your cancer?
18. What do you know about chemotherapy? What do you know about radiation therapy?
- a. How do you think chemotherapy/radiation would affect your role in your family?
  - b. How do you think chemotherapy/radiation would affect your role at your job?
  - c. How do you think chemotherapy/radiation would affect your relationship with your friends?
19. What has been the hardest part of this experience for you?
20. Have there been any good parts?
21. Is there anything else you would like to share?

**Appendix L: Secondary Interview Guide – Revised May 1st**

*Note: Additional dialogue prompts have been excluded from these appendixes for the sake of brevity. The sections in italics in the initial interview guides were unaltered throughout the study.*

1. What kind of person would you describe (the participant) as?
2. What role does (the participant) play in your life?
3. How would you say the last few months have affected (the participant)? How?
  - a. How did being diagnosed with cancer affect them?
  - b. How did the diagnosis affect your relationship with them?
4. Did the role (the participant) play in your life change during the last few months? How?
5. What does it mean to fight cancer?
6. What do you think the role of the doctor should be in helping your friend/family member decide about cancer treatments?
7. From what you know about cancer treatments, if (the participant) was to undergo chemotherapy or radiation, how do you think it would affect them?
8. How do you think it would affect the role they play in your life?
9. What do you think has been the hardest part of this experience for the primary participant?  
And for you? What has been the best part?

**Appendix L: Primary Interview Guide – Revised May 25th**

*Note: Additional dialogue prompts have been excluded from these appendixes for the sake of brevity. The sections in italics in the initial interview guides were unaltered throughout the study.*

**Initial Open-Ended Question**

1. Tell me about why you agreed to be a part of this study?

**Exploring Social Identity**

2. How do you spend your days?
3. What does an average week look like for you?
4. Tell me about your family.
5. What do you do for fun?
6. Do you have different groups of friends or just one group?

**Exploring Personal Identity**

7. Describe yourself as a person:
  - a. What kind of person are you at work?
  - b. What role do you play in your family?
  - c. What role do you have in your group of friends?

**Exploring Values**

8. What are the most important things to you?
9. What would you describe as your important values?
10. What are your goals for the three months? next year? Ten years?
  - a. How do you think further cancer treatment will affect these goals?
  - b. Have you changed your goals (or do you think you will need to change your goals) because of your cancer diagnosis?
11. How do these goals relate to your values?

**Exploring the interaction of cancer diagnosis on personal identity, social identity and values**

12. Have you known anyone that was diagnosed with cancer? Was the role you play in their life changed by their diagnosis? Was the role they play in your changed?
13. What do the terms “fight” or “battle” cancer mean to you?
14. Tell me about your experience with being diagnosed?
15. How did being diagnosed with cancer affect your job? (If applicable)
16. How did being diagnosed with cancer affect your family?
17. How did being diagnosed with cancer affect your friendships?
18. We discussed your values earlier. During the time of your diagnosis, did you feel that your values, or the relative importance of these values, changed?
  - a. Did the importance of personal health or family change?
19. Do you think a different type of cancer diagnosis would have affected your job, friends, family or how you see yourself differently? Say if you had been diagnosed with a potentially curable x or y cancer?

**Considering adjuvant therapy and the relationship with healthcare professionals in the context of values and personal and social identity**

20. What is it like to have so many different healthcare professionals making important decisions for you?
  - a. How does it feel to have to trust these people after only meeting them briefly?
  - b. Do you feel like you have been an active or passive participant in the decision making processes?
  - c. What kind of discussions have you had with people about your prognosis?
21. Have you been told that you will need or could have additional treatments for your cancer?
22. What do you know about chemotherapy? What do you know about radiation therapy?
  - a. How do you think chemotherapy/radiation would affect your role in your family?
  - b. How do you think chemotherapy/radiation would affect your role at your job?
  - c. How do you think chemotherapy/radiation would affect your relationship with your friends?
23. What has been the hardest part of this experience for you?
24. Have there been any good parts?
25. Is there anything else you would like to share?

**Appendix M: Primary Interview Guide – Revised June 13th**

*Note: Additional dialogue prompts have been excluded from these appendixes for the sake of brevity. The sections in italics in the initial interview guides were unaltered throughout the study.*

**Initial Open-Ended Question**

1. Tell me about why you agreed to be a part of this study?

**Exploring Social Identity**

2. How do you spend your days?
3. What does an average week look like for you?
4. Tell me about your family.
5. What do you do for fun?
6. Do you have different groups of friends or just one group?

**Exploring Personal Identity**

7. Describe yourself as a person:
  - a. What kind of person are you at work?
  - b. What role do you play in your family?
  - c. What role do you have in your group of friends?
  - d. What kind of patient are you?

**Exploring Values**

We are now going to talk about values. Values are ideas that we believe to be important that generally change very little over time. They guide us in making plans for the future and inform how we develop our identities. Examples of values are loyalty, strength, compassion, creativity, and personal health.

8. What are the most important things to you?
9. What would you describe as your important values?
10. What are your goals for the next three months? next year? Ten years?
  - a. How do you think further cancer treatment will affect these goals?
  - b. Have you changed your goals (or do you think you will need to change your goals) because of your cancer diagnosis?
11. How do these goals relate to your values?

**Exploring the interaction of cancer diagnosis on personal identity, social identity and values:**

12. Have you known anyone that was diagnosed with cancer? Was the role you play in their life changed by their diagnosis? Was the role they play in your changed?
13. What do the terms “fight” or “battle” cancer mean to you?
14. Tell me about your experience with being diagnosed?
15. How have you changed since being diagnosed with cancer?
  - a. How did being diagnosed with cancer affect your job? (If applicable)
  - b. How did being diagnosed with cancer affect your family?
  - c. How did being diagnosed with cancer affect your friendships?

16. We discussed your values earlier. During the time of your diagnosis, did you feel that your values, or the relative importance of these values, changed?

a. Did the importance of personal health or family change?

17. Do you think a different type of cancer diagnosis would have affected your job, friends, family or how you see yourself differently? Say if you had been diagnosed with a potentially curable x or y cancer?

**Considering adjuvant therapy and the relationship with healthcare professionals in the context of values and personal and social identity:**

18. What is it like to have so many different healthcare professionals making important decisions for you?

- a. How does it feel to have to trust these people after only meeting them briefly?
- b. Do you feel like you have been an active or passive participant in the decision making processes?
- c. What kind of discussions have you had with people about your prognosis?

19. Have you been told that you will need or could have additional treatments for your cancer?

20. What do you know about chemotherapy? What do you know about radiation therapy?

- a. How do you think chemotherapy/radiation would affect your role in your family?
- b. How do you think chemotherapy/radiation would affect your role at your job?
- c. How do you think chemotherapy/radiation would affect your relationship with your friends?

21. Are you concerned about how your appearance has changed or might change because of treatment?

22. What has been the hardest part of this experience for you?

23. Have there been any good parts?

24. Is there anything else you would like to share?



**Appendix N: Secondary Interview Guide – Revised June 13**

*Note: Additional dialogue prompts have been excluded from these appendixes for the sake of brevity. The sections in italics in the initial interview guides were unaltered throughout the study.*

1. What kind of person would you describe (the participant) as?
2. What role does (the participant) play in your life?
3. How would you say the last few months have affected (the participant)? How?
  - a. How did being diagnosed with cancer affect them?
  - b. How did the diagnosis affect your relationship with them?
4. Did the role (the participant) play in your life change during the last few months? How?
5. What does it mean to fight cancer?
6. What do you think the role of the doctor should be in helping your friend/family member decide about cancer treatments?
7. From what you know about cancer treatments, if (the participant) was to undergo chemotherapy or radiation, how do you think it would affect them?
8. How do you think it would affect the role they play in your life?
9. How about their appearance?
10. What do you think has been the hardest part of this experience for the primary participant?  
And for you? What has been the best part?

**Appendix K: Primary Interview Guide – Revised July 4**

*Note: Additional dialogue prompts have been excluded from these appendixes for the sake of brevity. The sections in italics in the initial interview guides were unaltered throughout the study.*

**Initial Open-Ended Question:**

1. Tell me about why you agreed to be a part of this study?

**Exploring Social Identity:**

2. Before you were diagnosed, what did the average week look like?
3. What was last week like?
4. Tell me about your family.
5. Do you have different groups of friends or just one group?

**Exploring Personal Identity**

6. Describe yourself as a person:
  - a. What kind of person are you at work?
  - b. What role do you play in your family?
  - c. What role do you have in your group of friends?

**Exploring Values**

7. What are the most important things to you?
8. What would you describe as your important values?
9. What are your goals for the three months? next year? Ten years?
  - a. How do you think further cancer treatment will affect these goals?
  - b. Have you changed your goals (or do you think you will need to change your goals) because of your cancer diagnosis?

**Exploring the interaction of cancer diagnosis on personal identity, social identity  
and values:**

10. Have you known anyone that was diagnosed with cancer? Was the role you play in their life changed by their diagnosis? Was the role they play in your changed?
11. What did you know about cancer before you were diagnosed?
12. What have you learned about cancer since the diagnosis?
13. What do the terms “fight” or “battle” cancer mean to you?
14. What does being a good cancer patient mean to you?
15. Tell me about your experience with being diagnosed?
16. How did being diagnosed with cancer affect your job? (If applicable)
17. How did being diagnosed with cancer affect your family?
18. How did being diagnosed with cancer affect your friendships?
19. We discussed your values earlier. During the time of your diagnosis, did you feel that your values, or the relative importance of these values, changed?

a. Did the importance of personal health or family change?

20. Do you think a different type of cancer diagnosis would have affected your job, friends, family or how you see yourself differently? Say if you had been diagnosed with a potentially curable x or y cancer?

**Considering adjuvant therapy and the relationship with healthcare professionals in the context of values and personal and social identity:**

21. Can you describe the characteristics of a good doctor?

22. Have you been told that you will need or could have additional treatments for your cancer?

23. What do you know about chemotherapy? What do you know about radiation therapy?

a. How do you think chemotherapy/radiation would affect your role in your family?

b. How do you think chemotherapy/radiation would affect your role at your job?

c. How do you think chemotherapy/radiation would affect your relationship with your friends?

24. What has been the hardest part of this experience for you?

25. Have there been any good parts?

26. Is there anything else you would like to share?

## Appendix L: University of Manitoba Ethics Approval



UNIVERSITY  
OF MANITOBA

Research Ethics - Bannatyne  
Office of the Vice-President (Research and International)

P126-770 Bannatyne Avenue  
Winnipeg, Manitoba  
Canada, R3E 0W3  
Telephone : 204-789-3255  
Fax: 204-789-3414

### HEALTH RESEARCH ETHICS BOARD (HREB) CERTIFICATE OF FINAL APPROVAL FOR NEW STUDIES Full Board Review

<b>PRINCIPAL INVESTIGATOR:</b> Dr. Maclean Thiessen	<b>INSTITUTION/DEPARTMENT:</b> U of M/Nursing	<b>ETHICS #:</b> HS19025 (H2015:394)
<b>HREB MEETING DATE:</b> October 26, 2015	<b>APPROVAL DATE:</b> November 23, 2015	<b>EXPIRY DATE:</b> October 26, 2016
<b>STUDENT PRINCIPAL INVESTIGATOR SUPERVISOR (If applicable):</b> Dr. T. Hack		
<b>PROTOCOL NUMBER:</b> NA	<b>PROJECT OR PROTOCOL TITLE:</b> Exploring the Identity of Adjuvant Cancer Patients Preparing to Make Treatment Decisions	
<b>SPONSORING AGENCIES AND/OR COORDINATING GROUPS:</b> NA		
<b>Submission Date(s) of Investigator Documents:</b> October 5 and November 17, 2015		<b>REB Receipt Date(s) of Documents:</b> October 5 and November 18, 2015

#### THE FOLLOWING ARE APPROVED FOR USE:

Document Name	Version(if applicable)	Date
<b>Protocol:</b> Protocol	V.1.0	October 4, 2015
<b>Consent and Assent Form(s):</b> Telephone Consent, to be Conducted via CCMB Referrals Office/Nursing Staff Regarding Records Review and Future Contact	V. 1.1	November 17, 2015
Consent for Primary Participant	V. 1.1	November 17, 2015
Consent for Participation of the Primary Participant's Friends or Family	V. 1.1	November 6, 2015
Consent to have Health Information Reviewed by Researcher and to be Contacted in the Future Regarding this Research Project	V. 1.1	October 17, 2015
<b>Other:</b> Questionnaires/Scales/Instruments Appendix as per letter submitted October 5, 2015	V. 1.0	October 5, 2015
Recruitment Poster	V. 1.0	October 4, 2015

#### CERTIFICATION

The University of Manitoba (UM) Health Research Board (HREB) has reviewed the research study/project named on this **Certificate of Final Approval** at the **full board meeting** date noted above and was found to be acceptable on ethical grounds for research involving human participants. The study/project and documents listed above was granted final approval by the Chair or Acting Chair, UM HREB.

#### HREB ATTESTATION

The University of Manitoba (UM) Health Research Board (HREB) is organized and operates according to Health Canada/ICH Good Clinical Practices, Tri-Council Policy Statement 2, and the applicable laws and regulations of Manitoba. In respect to clinical trials, the HREB complies with the membership requirements for Research Ethics Boards defined in

## Appendix M: Cancer Care Manitoba Approval



**CancerCare**  
MANITOBA  
*ActionCancerManitoba*

Dec. 10, 2015

Maclean Thiessen

○ 675 McDermot Avenue  
Winnipeg MB R3E 0V9  
Canada

○ 409 Taché Avenue  
Winnipeg MB R2H 2A6  
Canada

www.cancercare.mb.ca

**Re: RRIC #2015-057: Exploring the Identity of Adjuvant Cancer Patients  
Preparing to Make Treatment Decisions**

The above-named study has been approved by the CancerCare Manitoba (CCMB) Research Resource Impact Committee (RRIC).

The following departments at CCMB have signed off on this study: Nursing, Patient and Family Support Services, Patient Referrals Office

According to the CCMB RRIC submission form that you completed, NO CCMB paper charts will be required for this study and the study expected duration is 12 months.

A copy of the signed CCMB PHIA form for research is appended to this letter.

ANY SIGNIFICANT CHANGES TO THIS RESEARCH PROJECT MUST BE REPORTED TO THE RRIC BY SUBMITTING A "REQUEST FOR AMENDMENT FORM" FOR CONSIDERATION IN ADVANCE OF IMPLEMENTATION OF SUCH CHANGES. Significant changes include (but are not limited to): a change in the study design or in the data to be collected; a change in the study duration, the patient cohort to be studied, or the number of participants to be studied; the need to review CCMB paper charts (when not originally planned) or the need to review significantly more CCMB paper charts than originally planned; the addition of other trainees or co-investigators to the project; or the inclusion of additional individuals who will have access to the data or database.

Please cite the RRIC number for this study in all future correspondence with the RRIC about it. Please note that annual approval is not required if there are no changes to the project (as outlined above).

This approval is for RRIC use only. For ethics of human use and/or regulatory bodies, approval should be sought from the relevant parties as required.

Yours sincerely,

Rochelle Yanofsky, MD FRCPC  
Chair, CCMB Research Resource Impact Committee

Enclosure: Signed CCMB PHIA Form for Research

cc: Tracy Robinson – Nursing  
Jill Taylor-Brown – Patient and Family Support Services  
Sandi McFall – Patient Referrals Office  
File copy