

THE ROLE OF CARE ENVIRONMENTS IN THE EXPERIENCE OF BREAST
CANCER CARE

“IT’S A LIFE ALTERING EXPERIENCE”: EXAMINING THE ROLE OF CARE
ENVIRONMENTS IN THE EXPERIENCE OF BREAST CANCER CARE

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ABSTRACT

Ontario's Regional Cancer Programs provide an organized system of adjuvant treatment and follow-up care in its 13 Regional Cancer Centres. For breast cancer patients in particular, these centres become a part of daily activities, as appointments over five years of cancer care result in patients repeatedly accessing these centres at varying frequencies over their treatment periods. The experience of seeking out and receiving care has grown to incorporate cancer care services that exist on a variety of spatial scales, in both formal and informal environments (e.g. support groups, workshops). This study focuses on the role of geography in health behaviors and care experiences of breast cancer patients. Individual interviews were conducted with patients ($n=23$) attending the Juravinski Cancer Centre in Hamilton, Ontario about their care experiences in their community, and the location and organization of the centre. Rosenstock's (1966) health belief model and Bandura's (1986) social cognitive theory informed the analysis of patient satisfaction and produced attitudes that impact the likelihood of health action. Results demonstrated that patients were generally satisfied with their interactions with health care providers and the design and location of the centre. Parking and perceived disconnect between the centre and community health care providers (e.g. family doctors) were identified as being sources of patient dissatisfaction. Patients made sense of their care experience through 'routinization' – fixed times and predictable intervals – of travel and appointment schedules. Satisfaction with accessibility to health care providers when at home (e.g. call-in services) appeared to impact at-home adherence to medication and suggested lifestyle changes. Uptake of community support services depended on patient perceptions of need, suitability and proximity, but went largely unused. Patients' understanding of their care experiences highlight the need to give greater consideration to geography and the physical care environment in the future planning of breast cancer care services.

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LIST OF ABBREVIATIONS

CCO: Cancer Care Ontario
HNHB LHIN: Hamilton Niagara Haldimand Brant Local Health Integration Network
JCC: Juravinski Cancer Centre
LHIN: Local Health Integration Network
RCC: Regional Cancer Centre

CHAPTER ONE

Introduction to Study

1.1 Research Problem

Creating a patient-centric system of cancer care is contingent upon the ability to understand the experience of cancer patients and their navigation of the organization and placement of care. Such a patient-centred system is evermore important in the province of Ontario where, although people are increasingly surviving cancer, the number of new cases is projected to increase as the population continues to age and grow (Cancer Care Ontario, 2011). Patient satisfaction and unmet needs within cancer care and how these translate into adherence to recommended health actions, is an area that can be further understood to improve the journey through care of current and future patients.

Breast cancer is the most frequently diagnosed cancer among women in Ontario and is the second most common cause of cancer death in the province (CCO, 2011). Adherence to breast cancer treatment, in particular, is becoming increasingly complex as the use of long-term hormonal treatment is changing the perception of breast cancer towards that of a ‘chronic disease’, causing already sub-par compliance to further decrease over time (Kirk and Hudis, 2008; Sullivan et al., 2004). Outside of clinic appointments, health care providers lose control over patients’ at-home adherence behaviors (e.g. taking prescription medication, following recommended lifestyle changes). Strategies to increase adherence can be informed by identifying the variations that exist amongst patients’ attitudes towards treatment and how care environments shape them.

With the creation of Regional Cancer Centres in Ontario, the experience of seeking out and receiving care has grown to incorporate health services that exist on a variety of geographic scales – regional, community, patient homes - in both formal and informal environments. Medical treatment and supportive counseling are provided through the centres, while support groups and resources (e.g. prostheses, garments) are found in the community settings. For breast cancer patients in particular, these centres become a part of daily activities, as appointments over five years of cancer care cause patients to repeatedly access these centres at varying frequencies over the course of their treatment. With the centralization and specialization of cancer services, patients may have to travel considerable distances and stay away from their homes during treatment (Payne et al., 2001). Patients' homes also become care environments as treatment extends beyond the cancer centre to include daily medication and prescribed lifestyle changes.

Cancer care services on a variety of environmental scales also pose a number of 'barriers' patients perceive to exist in the physical and social environment. As recognized by health behavior theories (Redding et al., 2000), the perception of barriers can significantly compromise a patient's likelihood to initially and continually take-up recommended health actions. Specifically, Rosenstock's (1966) Health Belief Model conceptualizes the relationship between patient perceptions of barriers in health care (e.g. dissatisfaction with interaction, challenged accessibility) and their decision to continually uptake and adhere to care. Understanding the role of environments of cancer care in producing these perceptions of existing barriers can help to understand the role of the physical and social environments in producing patient satisfaction and attitudes towards

breast cancer care.

In understanding the attitude formations of patients who encounter health care environments and providers, Stacey et al. (2009) suggest an analytical shift towards the “demanding encounter” to recognize the role of care environments in the care experience. This shift places patient experience within its broader *environmental context*, emphasizing the constraints faced by patients and their providers within settings of care. Expressed satisfaction with current environments of care can highlight areas of success to support current policies, as well as inform the design of future policies and Regional Cancer Centres. Areas of expressed dissatisfaction and perceived barriers can help to identify areas in need of improvement to ensure a more positive experience for current and future patients.

1.2 Research Context

This study takes place at the Juravinski Cancer Centre in Hamilton, Ontario. This Regional Cancer Centre is one of 13 that exist in Ontario and is located within the Hamilton Niagara Haldimand Brant Local Health Integration Network. As will be further detailed in Chapter 3, this centre treats patients that travel from all over the network as well as from neighbouring areas (e.g. Waterloo-Wellington). Patients who attend the centre travel varying distances for treatment and supportive care. Participants in the study are patients at the centre, who have a breast cancer diagnosis and range from early treatment stages to follow-up care.

1.3 Research Question and Objectives

To understand the role of care environments in the patient experience of breast cancer care, the following research question guides this thesis: how do different care environments influence patient satisfaction with breast cancer care and resultant attitudes towards treatment?

The corresponding study objectives are:

1. To gain an understanding of the role of *geography* in the experience of receiving cancer care.
2. To evaluate aspects of the environment that are associated with patient satisfaction and/or dissatisfaction and how they may impact health beliefs related to adherence to care.
3. To identify areas of success and possible improvement in current environments of cancer care.

1.4 Outline of Chapters

The following set of chapters will begin with a review of current literature that places this thesis project within the research agenda of the health geography discipline, which highlights the role of geography in the study of broader well being, as well as models of health and health care. Drawing from a multi-disciplinary body of journals, studies and theories on patient satisfaction and adherence to care will also be reviewed. An understanding of patient behaviors will be established with a review of literature highlighting patient roles in cancer care and the environments in which they occur. An outline of the study design and methodology will then be made that will detail the

research setting, methods and collected data. Through coding the qualitative data, the results of the analysis will then be presented and organized by identified themes. A discussion relating the emergent themes to existing literature will then be made to highlight the contributions of this research and its policy implications.

CHAPTER TWO

Literature Review

2.1 Introduction

Factors associated with patient satisfaction and overall attitudes towards care can be drawn from a variety of areas throughout the course of cancer care. Here, ‘care’ refers to both the medical treatments that are delivered in clinical environments as well as support services that are also available to patients. Cancer care research branches from a multitude of approaches and disciplines specifically in the area of delivery and human experience. Looking at how people perceive the challenges and benefits of breast cancer care and the health services involved after diagnosis can be organized into Rosenstock’s Health Belief Model (HBM). Established in the 1960s, the HBM recognizes various factors that affect the initial and continual uptake of health services during the presence of an illness. Perceived benefits and consequences of the experience of an illness and its required care, factor into the choices individuals make when seeking and receiving health services (Sherbourne et al., 1992). In this model, individual perceptions are modified by sociopsychological factors such as the perceived threat the disease poses as well as a variety of cues for action like the advice of a diagnosing physician. These all lead into a ‘likelihood of action’ stage where individuals weigh benefits and barriers of action (e.g. health care) and decide on continuing to take-up health services (Becker and Maiman, 1975).

In literature concerning cancer care, stages and aspects of the health belief model are often present in research objectives in order to understand the act, pursuit and

experience of treatment for people with a diagnosis. The most common dimensions evaluated in more recent cancer literature include overall satisfaction, level of information received as well as patient-provider interactions (Sandoval et al., 2006). Using the umbrella term of ‘patient-centre care’, studies seek to understand and improve the design, delivery and experience of cancer care for the most optimal of health outcomes for patients pursuing treatment for a cancer diagnosis. Research has demonstrated that satisfaction with cancer treatment is associated with a patient’s compliance to treatment and continuity of care (Walker et al., 2003). Adherence to breast cancer treatment, in particular, is becoming increasingly complex as the use of long-term hormonal treatment is changing its perception towards that of a ‘chronic disease’, causing already sub-par compliance to further decrease over time (Kirk and Hudis, 2008).

The following will review the changes and present focus of current health geography literature to position this thesis within the larger arena of geography research. An examination of the theories, measurements and application of patient satisfaction and adherence, taken from a variety of disciplines, will follow. The changing preferences for involvement and interaction between patients and their health care providers will also be discussed, and followed up with a discussion of how the environment impacts the experience of care.

2.2 Health Geography

Health geography has shifted from the earlier subdiscipline of medical geography in its research agenda. While medical geography is primarily concerned with the interests of the medical world and disease, health geography highlights the role of geography in

the study of broader well-being as well as models of health and health care (Kearns and Moon, 2002). Research within this evolving domain of geography produces implications for health care policy as it inquires into the efficiency of health service provision (Kearns, 1995; Luginaah, 2009). Space and place in this area of geographical research has garnered much attention and recognition that both macro- and micro-scale factors influence the relationship between people and their settings (Luginaah, 2009). This in turn can be applied to the delivery of holistic cancer care as social supports and medical treatments span multiple settings that are both built and designed based on a variety of geographic scales.

Health geographers seek to understand the experiences of health by asking how place is *articulated* and *used* (Kearns and Moon, 2002; Luginaah, 2009). This subdiscipline looks for an understanding of experience of place and how it relates to health behaviors. Kearns and Moon (2002) argue that place be seen as an operational construct with meaning, and not just an inactive ‘container’ where events occur. Research looks at the role of both literal place and perceived place in relation to the world, increasing the need for qualitative research as it calls upon attention to the voices of the researched people (Kearns and Moon, 2002).

Research into the experience of cancer care delivered through regional cancer programs and centres, reflects this change that medical/health geography has undergone. Patients ‘consume’ care in very different ways and geographers are beginning to understand the multiple geographical features of this process of consumption (Parr, 2003). While traditional medical geography has and continues to concern itself with the

ecological aspects of cancer, the perceptions and lived experiences of seeking and receiving cancer care and other health services is reflective of the current arena of health geography. As this literature review will continue to explore, the role of patient satisfaction, patient needs, interactions with environments of care, as well as its subsequent effects on patient compliance, are all ways to explore this area of health geography. Overall, this study speaks to both of the aforementioned streams as it seeks to investigate a variety of scales, spaces and places (Meade and Emch, 2010).

2.3 Patient Satisfaction

2.3.1 Defining and Measuring

Satisfaction with care stands as both a relevant concern to institutions as well as patient-level outcomes in the treatment of such life-threatening illnesses as cancer (Walker et al., 2003). As an area of increasing research interest, patient satisfaction can be interpreted as both a dependent and independent variable. It reflects a patient's evaluation of the structure, process and outcome of their care, but is also a predictor of behaviors such as continuity with provider and compliance (MacKeigan and Larson, 1989). Ware and Davies (1983) rationalize the need for studying satisfaction amongst consumers of health care because of the ways in which it can impact behaviors. Care seeking, reactive and adherence behaviours are areas of consumer behaviour that are argued to respond differently to satisfaction with experience (Ware and Davies, 1983). Specifically, the effect of satisfaction on adherence behaviour, whether patients follow advice and instructions while under care, is particularly important in this study. 'Patient satisfaction' is inherently a multifactoral measurement that reflects a range of experiences that

individuals may have during an illness (Sherlaw-Johnson et al., 2008; Landercasper et al., 2010). It has been used to *complement* measures of institutional performance and clinical outcome (Sherlaw-Johnson et al., 2008) and increasingly on its own to evaluate medical treatments, interventions and services (Speight, 2005). While the rationale for studying patient satisfaction can easily be made in the area of cancer care research, an exact definition and ‘gold standard’ for measurement remains a challenge due to its comprehensive nature.

‘Patient satisfaction’ remains ill defined but can be generally described as an individual’s experience compared with their expectations. It assumes that patients attach values to different attributes of treatment or service that are unique to their individual experience (Speight, 2005). The term has further been conceptualized into a three-level hierarchical model, which looks at satisfaction with health care delivery, treatment and medication (Speight, 2005). Often patient satisfaction is measured with the end goal of further informing what has been termed as ‘patient-centred care’, an area that will later be explored in this literature review. However, the lack of consensus in the research community over defining patient satisfaction, translates into the design patient-centred care, as there is little consensus on what it is and how it is achieved (Speight, 2005; McCormack et al., 2011). The wide variety of approaches to measuring and defining patient satisfaction is both an advantage because it produces myriad insights, but also an obstacle in promoting the inclusion of the patient perspective (Speight, 2005). Findings, as will be shown, that have come out of patient satisfaction studies demonstrate the different areas patients view as critical to their illness and treatment experience.

2.3.2 *Patient Satisfaction with Services and Care: Variables Under Study*

MacKeigan and Larson's (1989) early literature review of patient satisfaction with pharmacy services found that convenience, quality of services, physical environment, interpersonal skills and perceived competency of pharmacists, are all areas in which patients reflect on their satisfaction with pharmacy experiences during their illnesses. A study of patient satisfaction and staff attention to emotional needs found that perceived attention to psychosocial aspects of illness made patients more satisfied with their clinic visits (Walker et al., 2003). 'Staff behavior' has also emerged as a strong theme in Rowlands and Noble's (2008) qualitative study of inpatients at a regional cancer center in the UK. Despite being told that the study was concerned with satisfaction with physical environments, 'staff behaviours' emerged as the strongest theme and similar to the pharmacy study, competence and knowledge were identified as most important (Rowlands and Noble, 2008).

It has also been shown that the frequency of visits has an impact on patient satisfaction. In a study of routine follow-up care of patient with a breast cancer diagnosis, 67% of patients expressed satisfaction in the routine nature and scheduled frequency of clinic visits and knowing that there was a scheduled appointment every designated number of months (Pennery and Mallett, 2000). What varies, however, is satisfaction with how *often* the scheduled visits are. Pennery and Mallet (2000) found that patients who had scheduled routine appointments more often than others, viewed it as an indicator that their health was not reverting back to normal.

How an appointment time is used is also linked to patient satisfaction while total

time length of a visit is not (Walker et al., 2003). Opportunities given for patients to talk about their feelings about their diagnosis as well as a dedicated segment of the appointment to counseling, are both positively related to patient satisfaction (Eide et al., 2002; Walker et al., 2003). Additionally, the duration of physical examinations and history taking during an appointment has been shown to have no significant correlation with patient satisfaction (Eide et al., 2002).

Overall, patient satisfaction with care can have positive outcomes during illness. Satisfaction with care has been shown to serve as an indicator of treatment effectiveness (Bakken et al., 2000). It has also, as will be detailed later on, been shown to have an impact on compliance and how patients self-assess and report their health status (Cameron, 1996; Peabody et al., 2003). Focus on how care, and all the services it includes, responds to patient needs is an increasingly large area of patient satisfaction literature. This thesis seeks to add to this area of research by taking what has been identified as factors in patient satisfaction (e.g. perceived quality of services, convenience, communication, etc) and understanding how the built environment impacts the experience of them.

2.3.3 Patient Satisfaction and the Needs of the Patient

Presentation styles, frequency of imparted information and open negotiations are all different factors that have been identified as being conducive to meeting patient ‘needs’ for understanding diagnosis and treatment (Hack et al., 2005). What continues to drive studies on patient satisfaction and patient-centred care is an increased recognition that needs vary among patients. Those with a breast cancer diagnosis have been shown to have needs that change over time and that are specific to them, calling for individualized

care design for each patient (Pennery and Mallet, 2000). In their systematic literature review of empirical studies on the content and process of communication with cancer patients, Hack and colleagues (2005) conclude that physicians need to move towards tailored approaches for care, and away from one-size fits all methods. The unique nature and variety of skills, needs, values, beliefs and emotions of patients, as well as all the external factors that modify these relationships, have made it important that research and design move towards creating these individualized approaches (Hack et al., 2005). The recognition of this can be seen in the vast amount of patient-provider communication literature.

2.3.4 Patient-Provider Communication

Critical to the ultimate goal of patient-centred care is the quality of communication in the patient-provider relationship. Care of cancer patients involves a high-level of interpersonal contact and communication (Sapir et al., 2000). Hack and colleagues (2005) argue that patient-centred communication occurs for the purpose of addressing individual goals and the receipt of optimal care. Complex communication processes are critical for patients to make informed decisions throughout the different dimensions of their care (Breitsameter, 2010). The patient perception of patient-centred communication is associated with increased satisfaction with information as the verbal delivery of diagnosis and treatment information leads to greater understanding (Mallinger et al., 2005). Patient engagement with health care providers typically includes having actual access to health care providers, the sharing of information, involvement in decision-making and self-care activities, the provider's respect and support for the

decisions of the patients, as well as management of patient concerns (Bakken et al., 2000). What remains an actively researched area is how to foster support and active communication that is aligned with patient satisfaction. The quality of the communication, such as opportunity for patient discussion, can affect patient outcomes (Wengström, 2007). However, similar to measures of patient satisfaction, communication is difficult to assess in cancer care because many different health care providers are involved in cancer care (McCormack et al., 2011).

In a literature review focused on the impact of ineffective communication between cancer patients and clinicians, Thorne and colleagues (2005b) identified a growing body of evidence that poor communication in cancer care is prevalent and that it can exert quite a burden to patients. The results of ineffective communication skills can lead to misunderstandings among patients about the nature and seriousness of their disease. Poor communication and reduced patient satisfaction is one of the most commonly documented associations in communication literature (Thorne et al., 2005b). In studies of chronic illness, patient satisfaction with doctor-patient interactions has been shown to be the strongest and most consistent predictor of adherence (Spernak et al., 2007). What makes communication in cancer care so appealing to study is that it is amongst those aspects of the care experience that can be modified at any point throughout the trajectory (Thorne et al., 2005b).

Camaraderie and perceived human connection in communication with physicians and other patients have also been linked to effective communication (Payne et al., 2001; Thorne et al., 2005a). The effectiveness of communication in cancer care also varies with

a patient's stage in their illness (Thorne et al., 2005a; Thorne et al., 2005b) and requires an assessment of individual patient needs (Sapir et al., 2000). In a study of 'helpful' and 'unhelpful' communication with cancer patients, the language of 'being known' emerged as a prominent theme. This linguistic form includes acknowledgements of the patient's personhood within the context of the inherently difficult nature of the disease (Thorne et al., 2008). Additionally, acknowledging a patient's fears validates patient experience and allows them to talk about concerns they have (Hack et al., 2005; Stajduhar et al., 2009). Alternatively, technical, standardized and a perceived disinterest in a provider's communication with patient, has been shown to be ineffective (Thorne et al., 2005a).

Physical interaction, on the provider's part, has also been shown to be effective in communication interactions with a patient. The accessibility of providers and other hospital staff during and in between routine appointments has been identified as a source of patient satisfaction as questions and concerns can be answered (Pennery and Mallett, 2000). Eye contact, sitting down at patient level, remembering a patient's name and their case details, touch of hand, as well as unrushed consultations with informal talk, are all elements of interaction that are conducive to making communication effective (Eide et al., 2002; Thorne et al., 2005a; Stajduhar et al., 2009). Rushed conversations during appointments can be perceived as being dismissed and 'written off' by patients (Stajduhar et al., 2009). Patients' perceptions that physicians are attentive and sympathetic when communicating with them are also considered conducive to effective communication (Hack et al., 2005). Patients have also reported that communication in care is best when providers explain and engage with them a discussion about their planned course of action.

In turn, the reciprocal conversation about a patient's report of adherence can be useful for the providers, as they can determine whether the agreed upon action has occurred (Fung and Hays, 2008).

Communication with a health care provider can have a profound impact on the human experience of cancer care (Thorne et al., 2008). In a study of inpatients at a regional cancer centre, it was found that the quality of patient-provider communication helps to reduce the anxiety that accompanies a life-altering diagnosis such as cancer being in its advanced stages (Rowlands and Noble, 2008). As evidenced in Thorne and colleagues' (2008) work, and as will be further discussed later, a widespread belief amongst cancer patients is that communication can have an impact on disease outcome because of its influence on comfort, inclusion, clarity and hope. Effective communication with providers throughout care has the potential to make patients feel like active agents in their own care, with feelings of optimism and psychological comfort (Thorne et al., 2008). The perspective that communication has a positive influence in treatment has led to the increasing belief that effective communication is a basic right of patients (Thorne et al., 2008). Providers also believe it to have an important role in client adherence to the care they provide (Bakken et al., 2000). Research into the relationship between cancer patients and their interaction with nurses, is the primary focus of Radwin and colleagues' (2004) study of more than 450 patients waiting for their appointment at a cancer clinic. Here patients appeared to be satisfied with their nurses and hold them in a relatively high esteem when they were perceived by the patients to have a caring attitude and to be quite knowledgeable during interaction (Radwin et al., 2004). As shown, the relationship

between patients and their providers can be critical to the perceived quality of care, clinical outcomes and overall satisfaction with the treatment experience. The physical spaces involved in health care – chemotherapy suites, examination rooms, counselor's offices – provide environmental context for interaction and can vary in how conducive they are to building effective relationships, interaction and opportunities for knowledge translation.

Additionally, patient satisfaction based on the level of engagement with providers has also been an area of focus in HIV/AIDS care (Bakken et al., 2000; Chow et al., 2010). Bakken and colleagues (2000) find no variations in level of engagement based on age, gender and ethnicity as well as amongst the different types of health care providers that engage with HIV/AIDS patients. Consistent with existing literature, their study also found that patients more engaged with health care providers were more likely to follow the advice of their providers, comply with medication regimens, and were less likely to miss appointments (Bakken et al., 2000). Chow and colleagues (2010) similarly found that the accessibility and availability of health care providers during visits is related to patient satisfaction with care. This becomes relevant in the area of cancer care as HIV/AIDS also involves a demanding schedule of routine treatment and care. Research into the role of patient-provider interaction in disease treatment highlights the communication, exchange and receipt of information between those seeking care and those providing the sought care.

2.3.5 Patient Information Needs

Patient knowledge and access to information is regarded as both a resource and an

entitlement; it becomes a means of empowering patients to behave as consumers of health care (Pollock et al., 2011). Satisfaction with the provision of information about illness has come to be seen as an important service outcome and quality marker (Pollock et al., 2011). Consistent amongst cancer care research into the provision of information is the finding that the ‘right’ amount of information varies amongst patients (Whelan et al., 1997; Leydon et al., 2000; Hack et al., 2005; Wenger, 2007). A cancer diagnosis can potentially invoke fear and feelings of uncertainty and the attitudes to cancer that patients adopt as well as their strategies for coping with a diagnosis can constrain or encourage information seeking behaviors (Leydon et al., 2000).

Variability is shown to exist in patients’ attitudes towards wanting information that is beyond the ‘basics’ of diagnosis, treatment options and side effects (Leydon et al., 2000; Hack et al., 2005), with earlier studies demonstrating that newly diagnosed patients have greater informational needs and appear to want the most amount of information (Whelan et al., 1997). Using in-depth qualitative interviews with outpatients at oncology clinics, Leydon and colleagues (2000) identify three overarching attitudes that impact a patient’s desire for and efforts to obtain information that is additional to the ‘basics’ given to them. *Faith* in the health care provider’s expertise, *hope* to carry on with life as normal (gained through knowing and not knowing further information) as well as *charity* towards other patients is expressed in the recognition that scarce information resources and explanations have to be shared amongst many patients (Leydon et al., 2000). Additionally, knowing who to go to with questions and opportunities to learn about the ‘next steps’ in patient care, have been identified as predictors of how patients perceive

their quality of care (Sandoval et al., 2006).

As previously stated, the rationale and need for information is mainly that a patient's knowledge and understanding of the dimensions of their treatment affect adherence to medication and treatment regimens (Cameron, 1996). Provision and access to information is also critical in dispelling misperceptions of breast cancer diagnoses and negative attitudes towards treatment (Hall et al., 2008). In a survey on the topic of 'breast health', over 1000 women responded about their knowledge and attitudes towards screening, early detection and treatment for a breast cancer diagnosis. Inaccurate knowledge on survivorship, rationale for early detection and the experience of treatment is shown to lead to a 'fatalistic attitude' towards breast cancer (Hall et al., 2008). Women with this attitude believe not much can be done to prevent breast cancer and to cure it if found early. They also believed that treatment could be worse than the disease itself (Hall et al., 2008). Due to these potential consequences of inadequate and inaccurate information for patients, it has become increasingly important to study the current availability and level of knowledge amongst patients.

It has also been shown that more informed patients become more actively engaged with their care providers in constructive dialogues and discussion of treatment, however despite this critical outcome, full disclosure and satisfaction with information does not always exist (Harbeck and Haidinger, 2007; Pollock et al., 2011). In an evaluation of patient knowledge of endocrine adjuvant therapy for breast cancer, Harbeck and Haidinger (2007) find patient knowledge of treatment options can be 'suboptimal' – inaccurate and incomplete – when making care decisions.

Overall, patients are appearing to not get enough information during their visit to clinics (Whelan et al., 1997; Sapir et al., 2000; Stacey et al., 2009; Chow et al., 2010). In a qualitative study of patients attending oncology day services, Sapir and colleagues (2000) concluded that despite a statement of high satisfaction, many patients did not fully understand their disease status. Educated and middle class patients appear to increasingly be seeking information on the internet. While this is often beneficial for the patient's own knowledge needs, it does however become a contextual factor in the interactions patients have with providers as patients bring information they found online to their appointments with the intent of discussing it (Stacey et al., 2009).

High patient satisfaction with information has been shown to exist within different areas of cancer care. In a study of breast cancer survivors, satisfaction with information occurred when patients understood surgical treatments and their initial diagnosis (Mallinger et al., 2005). Additionally, the clarity and sensitivity health care providers use when talking about diagnosis is also associated with high satisfaction with information (Sapir et al., 2000). Self-efficacy and perceived emotional support from a physician have been identified as significant modifiable determinants of patients' breast cancer knowledge (Chen et al., 2008). With satisfaction with information, patients can be empowered with hope and knowledge that their breast cancer can be managed (Harbeck and Haidinger, 2007).

Amidst these areas of expressed information satisfaction, there are also areas of care with which patients have articulated low satisfaction. Psychological needs such as being able to communicate with family members, as well as the long-term physical

sequelae of having breast cancer, such as lymphedema, were identified as areas of low satisfaction with information amongst breast cancer survivors (Mallinger et al., 2005). As previously mentioned, low satisfaction with information can cause many to adopt a fatalistic attitude towards the disease, as misperceptions, inaccurate information on treatment and overall unawareness of different aspects of care, can prove detrimental to the prevention and active treatment of breast cancer (Hall et al., 2008).

Patients can get information from a variety of formal and informal sources. The staff at cancer care clinics appear to be the most cited source of information identified by patients (Wengström, 2007; Chen et al., 2008; Rowlands and Noble, 2008; McCormack et al., 2011). Competent and knowledgeable staff members at cancer care centres with effective communication skills, appear to be a vital information resource for patients (Rowlands and Noble, 2008). Clinicians can and have had a critical role in providing patients with information and also helping them to identify and evaluate resources that are accurate, easy to use and meet their needs (Wengström, 2007; McCormack et al., 2011). Interpersonal communication skills of health care providers help to make them trusted sources of information for patients (McCormack et al., 2011). Beyond face-to-face interaction with health care providers and other staff members in cancer centres, patients also seek information through printed sources. In a study to identify modifiable determinants associated with low breast cancer knowledge, Chen and colleagues (2008) identify that 85% of participants use written information in the form of books and pamphlets. These sources of information have and can play a potentially critical role in knowledge development as educational materials such as these can be requested by

patients or their providers to deal with uncertainty (McCormack et al., 2011).

Time spent in the waiting room can also play a role in the information received and used by patients attending a clinic. The use of information and need for more written material emerged in Chow and colleagues' (2010) HIV/AIDS care work. Conversation with other patients while waiting, has also been identified as a modifiable factor to increase the knowledge of patients (Chen et al., 2008). Through interaction with providers during appointments and time spent waiting in cancer clinics, patients come across a variety of opportunities to interact and gain information. Their own attitudes and practices of obtaining this information as well as the outward expression of assistance and communication on the provider's part can facilitate addressing patient information needs.

Lastly, an important dimension that must also be mentioned when discussing communication, information needs and overall patient satisfaction, is the challenge that health care providers must overcome to provide their patients with the care that they need. Physicians are challenged to communicate bad news, discuss prognosis and even switch from curative treatment to supportive care, all the while trying to give realistic and appropriate information to their patients over the course of treatment and follow-up care (Eide et al., 2002). Patients that come with information they have independently obtained from in the internet can also create demanding encounters as they may use it to challenge the physician's expertise (Stacey et al., 2009). Communicating medical risk appears to be one of the most challenging aspects of information provision that doctors face (Breitsameter, 2010). Inherent to risk is the acceptance that uncertainty exists in the situation and when attempting to inform patients so they may make a decision, it is

difficult to explain risks and uncertainties of their care (Breitsameter, 2010). Additionally, health care providers must respond to the changing needs of patients, a task that is difficult to do as individual patients vary in the amount of information they desire at different points in their treatment trajectory and also in the styles of communication that they prefer (Leydon et al., 2000). It remains a challenge to providers to be able to identify what ways work best for their patients.

The challenge posed to so many oncologists is “how can you determine the appropriate type and amount of information to impart on patients?” (Hack et al., 2005, p. 833). The challenge for those involved in breast cancer care is how to best foster active support and communication that is appropriate for each patient’s situation (Wengström, 2007). Often at times, the patients themselves offer very little assistance in helping providers answer this question as they themselves may be unaware of what it is they need. In McCormack and colleagues’ (2011) qualitative study, they identified that patients are, at times, unsure and unable to articulate their information needs, giving clinicians the task of assisting their patients to identify and vocalize their needs. In a study of information delivery in British cancer centres, respondents expressed that they tended to feel so stunned and overwhelmed throughout their treatment that they often could not think of questions to ask and that information was not an immediate priority (Pollock et al., 2011). Health care providers remain challenged in their attempts to respond to the needs of their patients as areas of ‘need’ are variable and not often directly expressed by the patients.

The literature demonstrates that patients *do* have a desire to be informed about their diagnosis and treatment options. The challenge, however, is that not all patients

desire the same amount, learn the same way and seek out information in the same manner. Communication styles differ and can be impacted by myriad aspects in the social and physical environments involved in cancer care. While information for patients may not always be given or requested, it has grown to be accepted as a basic right of patients. The ‘informed patient’ can be beneficial to both the health care provider and patient themselves, as it can lead to more effective communication and positive attitudes towards care.

2.3.6 Gaps in Patient Satisfaction Literature

What can still be furthered in this area of literature is to develop an understanding of how the physical environments that are involved in a patient’s journey through breast cancer care, can effect patient satisfaction. While studies have explored patient needs and communication with providers, a third dimension that factors into patient satisfaction is the physical areas where care is obtained. How conducive are the clinical layouts of cancer centres to making fellow patients and health care providers accessible for questions and the realization of patient information needs? How does the experience of routine travel to regional cancer centres impact patient satisfaction with the care they receive? The role of physical space and experience in environments across multiple scales during the course of breast cancer care plays a potential role in how satisfied patients are with their opportunities for communication with providers, their familiarity with the care environment as well as the ability to act independently on behalf of themselves to gain the knowledge they wish to have about their disease. Studies on patient satisfaction with

information need to consider the broader context in which the process of care occurs (Wengström, 2007).

2.4 Adherence in Cancer Care

As previously mentioned, the HBM connects experience and perceptions with decisions to potentially uptake a certain health behavior. Adherence is one of these behaviors. Two different types – general and specific – are distinguished between in the realm of medical care research. *General* adherence looks at patients' overall compliance with physician instructions while *specific* adherence refers to patients' performance of specific treatment behaviours (Spernak et al., 2007). In addition to behaviour, compliance is also an attitude; a willingness or intention to follow prescribed regimens (Cameron, 1996). Overall, studies looking at adherence are concerned with the extent to which a person's behavior coincides with the medical advice they have been given (Cameron, 1996).

2.4.1 Measuring Adherence

One way to measure adherence in breast cancer treatment is to use medical records of chemotherapy and radiotherapy appointments (Balasubramaniam et al., 2003). In cancer care studies that look at adherence both in front and away from a provider (e.g. taking medication at home) a popular method for measuring adherence is patient self-report where patients responds to questionnaires or qualitative interviews regarding how they have or have not followed health advice given to them (Sherbourne et al., 1992; Kirk and Hudis, 2008; Ruddy and Patridge, 2009). The limitation, however, to this type of measurement is that patients tend to overestimate their adherence when asked. Some

patients may feel the need to reply in a socially desirable way and this manner may not be actually reflective of their current and past habits (Sherbourne et al., 1992). In an editorial for the *Annals of Oncology* Ruddy and Partridge (2009) discuss methods of measuring adherence and their levels of accuracy. Citing an earlier study, they discuss a comparison of prescription refills and patient self-reports – two measurements of adherence – in hormonal therapy for breast cancer care and find that adherence based on the refills was significantly lower than what was reported by the patients (Ruddy and Partridge, 2009). Self-reports of adherence fall under the umbrella term of ‘patient reported outcomes’, specifically in the health behaviors domain. As shown in Figure 2.1, adherence and other health behaviors are influenced by patient satisfaction and quality of care that is received (Fung and Hays 2008). Patient satisfaction with medical care is one of the most reliable predictors of adherence and can even be used as a proxy measure/indicator for a patient’s future adherence (Sherbourne et al., 1992; Speight, 2005).

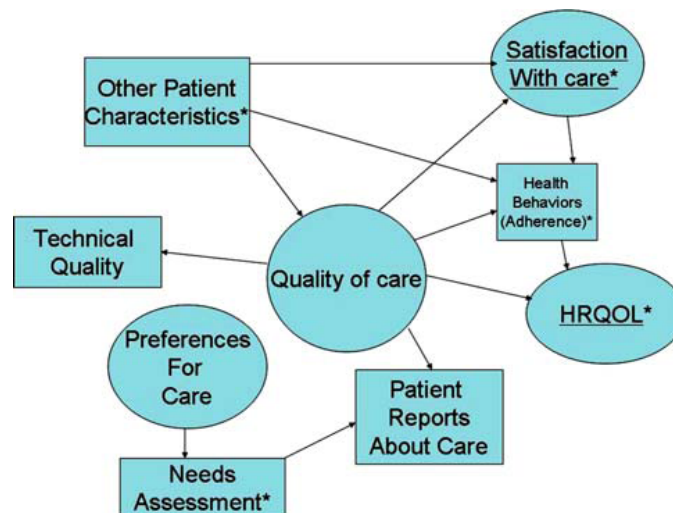


Figure 2.1: Hypothesized relationship amongst different patient-reported outcomes of care (indicated with *; HRQOL = Health Related Quality of Life). (Fung and Hays, 2008).

2.4.2 Factors decreasing adherence

Studies seeking to understand reasons for nonadherence to treatment and medical advice identify a number of areas for consideration. In their survey of women with breast cancer, Kirk and Hudis (2008) state that ‘side effects’ of medication were the primary reason for nonadherence amongst respondents, a result also confirmed in a study done by the American Society of Clinical Oncology (2009). Additionally, the complexities of oral medication can decrease compliance to prescriptions as it can lead to a misunderstanding of package instructions or patients being confused over the instructions once they take the medication home (American Society of Clinical Oncology, 2009). Demanding ‘dosing schedules’ where oral medication needs to be taken at multiple points of the day has also led to poor adherence (Findlay et al., 2007; American Society of Clinical Oncology, 2009). A perceived lack of symptoms can also decrease compliance as when patients no longer feel sick they may forget to take a dose or discontinue their treatment (Harbeck and Haidinger, 2007). Lastly, not grasping the clinical importance that commitment to daily treatment regimens would have on therapeutic outcomes has been identified as leading to a decrease in compliance to medication (American Society of Clinical Oncology, 2009; Kirk and Hudis, 2008).

2.4.3. Factors Increasing Adherence

Critical to designing patient-centred care for cancer patients is an understanding of what factors in the physical and social environments are conducive to encouraging compliance throughout treatment and follow-up care. Ensuring patients understand the clinical rationale and positive effects on outcome that result from medication adherence,

has been identified as a factor in increasing prescription compliance (American Society of Clinical Oncology, 2009; Kirk and Hudis, 2008). Convenience of appointments and simple dosage schedules can also have positive effects on adherence amongst breast cancer patients (Findlay et al., 2007). Engagement with healthcare providers during treatment for a chronic illness as well as behavioral thinking have demonstrated increased compliance in treatment (Bakken et al., 2000; Spernak et al., 2007).

2.4.4 General Factors Affecting Adherence

Patient satisfaction and patient-provider relationships are the most cited and studied factors that affect patient adherence to treatment for chronic illnesses such as breast cancer (Ware and Davies, 1983; Sherbourne et al., 1992; Hall et al., 1993; Cameron, 1996; Bakken et al., 2000; Spernak, 2007). Studies have also shown that satisfaction with financial and interpersonal aspects of care are positively associated with adherence (Sherbourne et al., 1992; Hall et al., 1993). Patient's expressed satisfaction with their doctors has been found to mediate the effect of patients' behavioural thinking on general and specific adherence (Spernak et al., 2007). In a review of therapeutic regimens studies, Cameron (1996) concludes that compliance is the result of individual interactions with providers and others in the clinic environment. The duration and complexity of treatment can also influence how compliant patients are throughout the course of care (Cameron, 1996). Social isolation and social support are not only psychological determinants of adherence but also have practical implications on a patient's ability to meet the demands of cancer treatment (Cameron, 1996).

2.4.5 General Reasons for Adherence

Adherence is the main determinant of the effectiveness of therapeutic regimens that are involved in breast cancer care and other chronic illnesses (Cameron, 1996). Beyond the initial diagnosis, strong adherence throughout breast cancer treatment has been associated with prolonged recurrence free status of the disease as well as overall long-term survival (Wöckel et al., 2009). Poor patient outcomes that result from nonadherence can result in therapeutic outcome goals being unreached and overall poor patient outcomes for survival (Cameron, 1996). While this stands as a major concern for patients, it is also a large concern for their oncologists. Oral aromatase inhibitors prescribed as follow-up treatment post-surgery is critical for positive patient outcomes. Ensuring that patients take this oral medication is an ongoing concern for oncologists who lose control of medication administration when it is no longer in the hospital setting but rather the patient's home (American Society of Clinical Oncology, 2009).

In sum, the literature suggests that despite therapeutic regimens being most critical to breast cancer care, optimal adherence varies greatly amongst patients. Complexities, side effects and patient knowledge have all been demonstrated to have an effect in encouraging and compromising patient adherence to their health care providers' instructions. Patient empowerment – knowledge of treatment options and involvement in treatment decisions – can have a great deal of power in establishing and maintaining adherence. While the different methods for measuring patient adherence are flawed, the most popularly used is 'patient self-report'. With this method, one of the main concerns is that patients respond to questions about their compliance in ways they perceive to be

‘socially desirable’ and thus tend to overestimate. It remains that despite these flawed methods, health care providers need to be aware of how adherence their patients are to the areas of care that they prescribe. What can be done to improve patient reports of adherence, is to ensure that clinical and supportive care environments are set up in such a way that patients feel comfortable to be honest (e.g. private).

2.4.6 Gaps in Adherence Literature

Research in the adherence behaviors of breast cancer patients and others with chronic illnesses, has produced a number of insights into factors that encourage and compromise attitudes of adherence to treatment. What can still be done, however, is to look into the role of the physical environment across multiple scales. While interaction with health care providers appears to be a good indicator of adherence, the contextual factors that the built environment creates in these interactions can also be considered to play a role. The creation of regional cancer centres in the province of Ontario has allowed for a unique organization of cancer services to be grouped together in the different centre locations. While it may be convenient for patients who need to see multiple providers for different health services to get more than one appointments done in one day at one place, it also means that if patients consider the centre inconvenient to access they have very few options and must then consistently travel to the Regional Cancer Centre. The role of the physical environment in being conducive to patient interaction with health care providers, obtaining scheduled prescription refills, keeping up with frequent radiation and chemotherapy appointments, as well as the location of support groups relative to a patient’s home, can all be potentially associated with the adherence behaviors of patients.

2.5 Patient Roles in Cancer Care

2.5.1 Shared Decision-Making and Collaboration

The role a patient takes on when diagnosed can determine how involved they are in their care, as well as their overall experience. Patients are increasingly being given access to comprehensive information about their disease and treatment, as well as an overall greater involvement in the treatment decision-making process (Wengström, 2007). In the past, physicians made most decisions for patients but beginning in the 1990s physicians began to increasingly view clinical decisions in breast cancer care as a joint venture involving components of patient knowledge and preference (Levine et al., 1992). A review of more recent literature shows collaborative roles for patients and shared decision-making is the most preferred by patients (Hack et al., 2005). Involvement in decisions is most preferred by patients and when opportunities are not given it can lead to dissatisfaction with the care experience and the degree to which they felt involved (Harbeck and Haidinger, 2007).

A patient's satisfaction with their involvement in decision-making has been seen to vary with patient characteristics such as level of education and access to the internet (Wengström, 2007). Preferences for involvement may vary as abilities to participate change throughout the course of breast cancer care. Patient preferences are also unstable as new information and patients gaining experience with their illness can change views on participation (McCormack et al., 2011). Despite professed desires to be a part of decision-making, qualitative studies of cancer patients have shown that it is not always fulfilled and patients who look back on their care are not satisfied with the degree to which they

were involved (Harbeck and Haidinger, 2007; McCormack et al., 2011; Pollock et al., 2011).

2.5.2 Changing Patient Role

In a document analysis of public accounts by people with personal experiences of cancer dating back to 1945, Winslow and colleagues (2005) track the transformation of the ‘patient voice’ being heard. Cancer patients have grown from the role of being objects of medical care with treatment *done* to them, into a more challenging role calling for patient autonomy in the early 1970s (Winslow et al., 2005). Patients have taken on a more informed role in their care so they can be more engaged, understanding and contributive towards treatment decisions (Harbeck and Haidinger, 2007). The emergence of patient satisfaction studies has more or less paralleled the rise of the patient as an active consumer of health care services rather than just a passive recipient (Speight, 2005; Pollock et al., 2011). While this increased active role can often be beneficial to aspects such as adherence and attitudes towards treatment, there is, however, a downside. ‘Provider shopping’ and demanding certain treatments can result from this increased involved role, making appointments and other opportunities for provider interaction to become a ‘demanding encounter’ which is not always conducive to the best care (Stacey et al., 2009).

2.5.3 The ‘Internet-Informed’ Patient

Amongst these changing roles, the most recent to emerge is that of the ‘internet-informed’ patient. Information and resources available on the internet provides patients with the opportunity to increase their knowledge of their disease when outside of the

hospital environment. The internet has been described as an equalizing and empowering force for patients to engage with doctors, since they get information they may not normally have access to (Stacey et al., 2009). However, it has been found that seeking and gathering information online does not necessarily mean patients will use it or discuss it with clinicians. In Stacey and colleagues' (2009) ethnographic study of the socio-cultural context of the doctor-patient relationship, not all participants who had come to the clinic after researching their cancer online brought up what they found when face-to-face with their oncologist. In addition to the socio-cultural context, other more predictable factors such as power differentials were shown to affect the patients' willingness and ability to share internet information with their providers (Stacey et al., 2009). While the internet can give patients the power they need for greater decision-making involvement, it does come down to the patient's own characteristics for whether they chose to get involved or not.

2.5.4 Gaps in 'Patient-Role' Literature

Existing literature demonstrates the variability and changing role of the patient in the different dimensions of their care. The increasing evidence showing patient preference for shared decision-making and a collaborative role in the treatment process also opens up areas for further consideration. The environment – be it clinical layout, access to support groups to connect with other patients, availability of staff – that this collaboration takes place in can play a role in patient involvement. Whether it is having access to people and resources to increase patient knowledge to take this involved role or if it is just simply being able to interact with doctors in the clinical setting, the different environments

involved in cancer care can have an influence on the patients within them. As Stacey and collaborators (2009) highlight, various contextual factors impact the patient-provider relationship and interaction during hospital visits. Whether patients feel the clinical environments are encouraging of questions (i.e. make health care providers available to ask questions) or whether they feel comfortable enough to take on a more involved role, can be potentially reliant on the layout and design of their environments of care.

2.6 Environments of Care

2.6.1 Ecological Comparisons

In their study of landscapes of care, Milligan and Wiles (2010) posit that care and care relationships are shaped and located in the places and spaces that span from the local to the global. Geographical work is increasingly looking at the role of spaces that enable interactions. Socio-economic, structural and temporal processes shape the practice and experience of care at different spatial sites and scales, at personal, private and public settings, on local, regional and national levels (Milligan and Wiles, 2010). In a comparative study of cancer patients from urban and rural environments in Canada, rural-urban differences were apparent in the care giving experiences amongst family members. In rural areas, transportation, proximity to health services and amenities emerged as challenging obstacles to overcome in receiving cancer care (Maddalena et al., 2010).

Additionally, demonstrating that where cancer patients live matters, Gorey and colleagues (2010) compared cancer care in affluent and impoverished areas and found unequivocal support for the hypothesis that breast cancer patients in poor urban neighborhoods are disadvantaged compared to their affluent counterparts. Long waits for

surgery and radiation therapy, non-receipt of breast conserving surgery and hormonal therapy, as well as shorter survival were evident. Gorey and colleagues (2010) also furthered this study to compare Canada and the USA, using a health insurance theory that women living in poor urban Canadian neighbourhoods would be significantly advantaged compared to their American counterparts because of the relatively equitable health care system that exists in Canada. The results demonstrate that poor Ontario women are largely advantaged on most breast cancer indices and overall survival, than their counterparts in California (Gorey et al., 2010). The ecological comparisons show that where you live – urban/rural, affluent/impoverished, universal health care/ two-tiered system – impacts your experience and outcome of cancer care as it factors into how care is realized and provided to breast cancer patients.

2.6.2 Access to Care

Mobility, be it a person's individual ability or availability of transportation, affects your access to care. In a study on the effects of geography and spatial behavior on health care utilization, Arcury and colleagues (2005) find that many factors play a role in attending appointment for chronic care. Having a driver's license, use of provided rides and distance from regular care, were amongst the factors identified as determinants of access to care. Overall the study shows that more 'mobile' people have better access to care for chronic disease (Arcury et al., 2005). When considering the geography within areas of care and caring, it becomes evident that it can be viewed as a process, an achievement and a construction (Parr, 2003).

Decreased access to cancer care in Canada has been shown to be reflective of

perceptions and knowledge of health care. In the palliative care phase of cancer, lack of trust in the health care system as well as a lack of diversity amongst health care staff can serve as institutional barriers (Maddalena et al., 2010). Health and social services throughout the treatment trajectory can go unaccessed when patients and their personal support network lack adequate knowledge of the health system and the disease itself (Maddalena et al., 2010). Single-parenthood, rural isolation, low income, transportation issues and lack of comfort navigating the health system, have demonstrated effects on decreasing access to cancer care (Maddalena et al., 2010).

A more specific area of access to care studies are those that look at the journey-to-care experience of patients. With the centralization and specialization of cancer services, some patients are faced with the decision to either travel considerable distances to care or stay away from home during treatment (Payne et al., 2001). Patients who drive themselves to appointments have been shown to value the feeling of independence that is produced amidst the lifestyle changes brought on by diagnosis and treatment (Payne et al., 2001). In their exploration of the difference between ‘proximity’ and ‘distance’ involved in care, Milligan and Wiles (2010) argue that the two terms are not solely spatial but also reflect emotional closeness. A caregiver or provider may be a physical distance away from a patient’s home, but their involvement in organizing and providing care can make them emotionally proximate (Milligan and Wiles, 2010). Navigation assistance – strategies that ensure patients are informed of where supports are and how to access them – is also seen by cancer patients to be fundamental to obtaining care and enabling self-management. In studies of cancer care, patient navigation includes reducing barriers,

access to timely and continuous care, as well as targeted sets of services (McCormack et al., 2011).

The travel experience to care can be affected by many factors experienced by the patient. In a study of travel times to care involving cancer patients undergoing routine visits to a clinic, Haynes and colleagues (2006) found that the same journeys over the same roads produce very different travel experiences. These varying experiences can be attributed to the individual characteristics of the drivers, their vehicles, traffic, roadwork and weather (Haynes et al., 2006). Self-report estimates compared to those obtained with geographical information systems indicate that patients overestimate the time it takes to get to their appointments (Haynes et al., 2006). Additionally, although literature on the topic is contradictory, there is evidence that long distance travel to cancer care is inconvenient for patients and may impact on compliance with treatment (Payne et al., 2001).

2.6.3 Micro-Environments in Cancer Care

Micro-landscapes of care include the home and the hospital room (Milligan and Wiles, 2010). Similar to journey-to-care studies, research on the micro-environments involved in health care have shown that different individuals can experience the same setting in different ways (Curtis and Riva, 2010). In a qualitative study of patients at a regional cancer centre, results showed that the cleanliness, a view of the outside, light and airy environment, affected their mood while in the centre and how conducive to interaction and mutual support the environment felt (Rowlands and Noble, 2008). Patients' perceptions and feeling of comfort in the micro-environment is associated with

patient outcomes (Aiken et al., 2008; Rowlands and Noble, 2008). The layout of clinics has also demonstrated impacts on the productivity and effective collaboration between staff and professionals (Oandasan et al., 2009).

In a comparison of multiple hospitals and the cancer patients that use them, Sherlaw-Johnson and colleagues (2008) displayed evidence of systemic hospital-level factors that influence satisfaction, which included wait times, privacy, coordination after discharge and hospital management. Similar results for wait times affecting satisfaction in cancer care have also been found elsewhere (Pennery and Mallett, 2000). Delays in appointments and administrative aspects in the hospital environment have demonstrated impacts on patient dissatisfaction as well (Pollock et al., 2011).

Experiences within hospitals are particularly important to cancer patients and have a lasting ‘safety net’ effect on them as they associate the built environment with the specialist care they received for their diagnosis once treatment is over (Pennery and Mallett, 2000). The hospital environment is also important because of the routine nature of appointments in breast cancer care, especially during the follow-up phase. The feelings and experiences patients associate with the hospital environment can lead to episodes of anxiety or increased comfort when patients get closer to their upcoming appointments (Pennery and Mallett, 2000). It has, however, been found that patients’ expectations of the clinic environment end up being met by their actual experience, leading to positive acceptance of the existing environment and with the occasional criticism being stated apologetically (Rowlands and Noble, 2008).

Additionally, clinical encounters between patients and health care providers

greatly contribute to the influence of the micro-environment in the patient experience of care. Patient-provider communication literature is beginning to undergo an analytical shift away from the study of ‘demanding patients’ towards that of ‘demanding encounters’, where provider-patient conflict is placed within a broader environmental context. This ‘shift’ emphasizes constraints that face *both* the doctor and the patient when they interact in the clinical – micro-environment – setting (Stacey et al., 2009). This change emphasizes aspects of the contextual environment that may challenge and compromise the quality of patient-provider interaction. In *nurse*-patient encounters, the physical environment has a proven effect on patient outcomes where improved nurse staffing, education and the care environment lead to improved patient outcomes (Aiken et al., 2008).

Lastly, studies of micro-level environments and cancer care look towards creating the most optimal healing environments. Creating these environments demands an understanding of how health care providers and their patients share and experience space together in the consultation (Frankel et al., 2005). Using videotaped encounters and independent commentary from patients, Frankel and colleagues (2005) conducted a study to build knowledge on the elements required for optimal healing environments and intervening on ‘both sides of the stethoscope’ (p.38). They found that decreased ‘social distance’ between doctor and patient was critical to creating these environments. Other studies have also identified wards that are friendly and conducive to interaction, as well as have accessible staff, are also most ideal for the micro-environment (Pennery and Mallett, 2000; Rowlands and Noble, 2008).

2.6.4 Regionalized Cancer Care

Cancer care involves a complex organization of actors and actions that involve multidirectional flows and connections, involving ongoing responsibility and commitment (Milligan and Wiles, 2010). This is especially evident in the design and use of regional cancer centres in Ontario that puts together networks of individuals and services for cancer care. Studies of such centres in the UK have given valuable insights into the experience of the clinic environment, patient roles, staff behavior and overall cancer care experience (Payne et al., 2001; Rowlands and Noble, 2008).

Over the past two decades, patient experience at regional cancer centres has appeared in a variety of studies (Levine et al., 1992; Whelan et al., 1997; Sandoval et al., 2006). While the organization of care in a regionalized cancer centre was not the main objective of this research, the patients who used them were sampled for insights into the experience of care they received there. Newly diagnosed patients attending the Hamilton, Ontario centre were interviewed by Whelan and colleagues (1997) about their needs as patients where the majority (75%) reported hearing about the Canadian Cancer Society's driver service to get them to the centre and a smaller portion (29%) reported using community resources closer to their homes. Lastly, sampling from all the regional cancer programs across Ontario, Sandoval and colleagues (2006) found that cancer patients perceived physician knowledge of follow-up care, 'next steps', awareness of test results and knowing who to go to with questions, as common factors influencing the perception of quality of care.

2.6.5 Resources in the Community Environment

While travel to regional cancer centres is necessary for breast cancer treatment, support services are often located closer to home. Access to social support has been linked to stress reduction and overall improvement in care (Rowlands and Noble, 2008). Self-care outside of clinical interactions and assistance with day-to-day activities highlights the importance of the support systems that facilitate its provision (McCormack et al., 2011). Different options and avenues for support within one's community exist. Organized support groups and special aids exist at the community scale, but are used infrequently (Whelan et al., 1997). Online communities and chat rooms as support groups are increasingly popular among patients, especially to discuss information about diagnosis and cure (Stacey et al., 2009). Also, informal support can be found through published experiences of living with cancer that allow patients to support and advise others through their own personal knowledge. These can be found in books, lay periodicals, academic journals and websites (Winslow et al., 2005).

2.6.6 Gaps in Environments of Care Research

In a literature review of medical geographical studies of care and caring, Parr (2003) identifies the need for more work to be done concerning the 'micro-geographies' of care in hospitals, in order to understand 'place' in multiple ways. While the above studies have begun to explore this area, more work is needed when the target is to design patient-centred care. How patients navigate and make sense of the environment when they are repeatedly frequenting it over the typical five-year treatment period of breast cancer is an area for further investigation. What is interesting about regional cancer

centres is that they include all types of adjuvant therapy, follow-up care as well as social support services with dieticians, social workers and genetic counselors. Patients who have completed their adjuvant therapy will still travel to and enter the same space they experienced chemotherapy, radiation and any moments along their treatment where they were told about their prognosis, during the follow-up care phase. The mental associations people place with this physical environment as well as experiences of navigating its complex layouts, can determine patient satisfaction with care and will be looked at in this study.

2.7 Health Belief Model

Among the existing health behavior models, the Health Belief Model (HBM) is one of the oldest and most used theoretical frameworks in health education, medicine and behavioral science studies (Rosenstock et al., 1988; Harrison et al., 1992; Redding et al., 2000). The use of theoretical models, such as the HBM, is critical in understanding current and future health behaviors as well as providing guidance for research and intervention development (Redding et al., 2000). This model assumes a ‘value-expectancy’ approach for a patient’s behavior under the conditions of uncertainty associated with an illness (Becker et al., 1977). Variables in the HBM appear to be significant to understanding behavior in the area of health care and are drawn from social-psychological theory. The variables reflect the subjective world of the behaving individual and not the objective world of the physician. From a well-established body of psychological and behavioral theory, the model uses two classes of variables: 1. psychological state of readiness to take a specific action and 2. extent to which a

particular course of action is believed to be beneficial in reducing a threat. The beliefs that suggest ‘readiness’ have both cognitive and emotional elements (Rosenstock, 1966).

Where it’s original purpose was to understand how and why people undertake preventive health actions more contemporary applications of the HBM use it to predict how patients follows prescribed therapies (Becker and Janz, 1985). The HBM operates under the hypothesis that people will seek to avoid their illness if they *perceive* the preventive or curative action to be less negative than the illness itself (Sherbourne et al., 1992). As shown in Figure 2.2, the model uses four dimensions to understand and predict health behavior by combining individual perceptions with modifying factors to understand the likelihood of any health action. A combination of susceptibility and severity produces an individual’s energy *to act* while the perceived benefits minus the perceived barriers produce an individuals preferred *path of action* (Becker and Janz, 1985). As this thesis is concerned with understanding the role of the environment in satisfaction with health care and attitudes of adherence, the part of the model that weighs *perceived benefits* against *perceived barriers* to the health action (within the ‘likelihood of action’ dimension) is most applicable. This part of the model suggests that patients go through a certain cost-benefit analysis when deciding on taking up a health action (i.e. adhering to their chemotherapy schedule). The likelihood of the action being pursued is assumed to depend on *perceived benefits* (i.e. being ‘cancer free’) being weighed against *perceived barriers* (i.e. travel distance to cancer centre, location in city). If the benefits are perceived to outweigh the assumed barriers, than a person is likely to practice the health action.

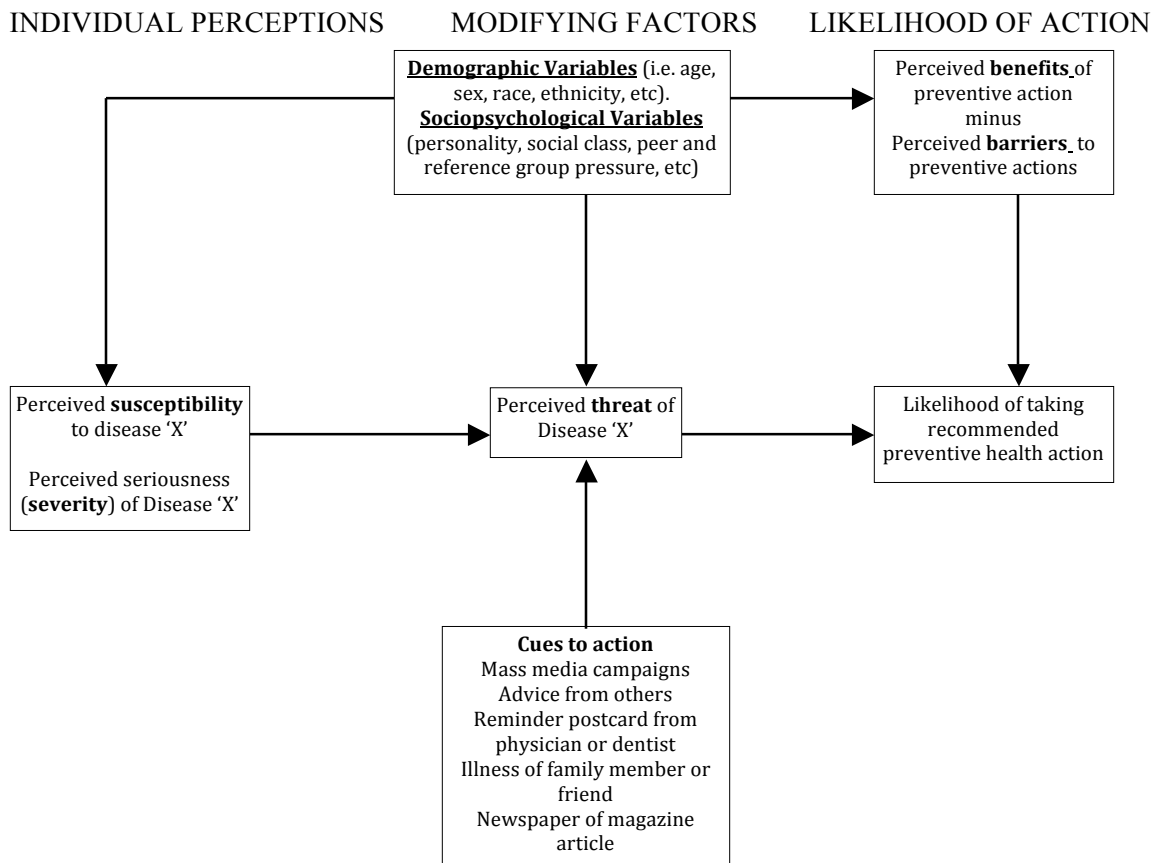


Figure 2.2: Health Belief Model (Rosenstock, 1966).

As Rosenstock (1966, p. 7) argued “an individual may believe that a given action will be effective in reducing the threat of disease, but at the same time see that action itself as being inconvenient, expensive, unpleasant, painful or upsetting. These negative aspects of health action arouse conflicting motives of avoidance.” How factors within care environments appear “inconvenient, expensive, unpleasant, painful or upsetting” can be highlighted in this thesis to better understand the health behaviors and experience of breast cancer patients.

Additionally, to improve the HBM and address the objectives of this thesis to include an emphasis on the environment, Bandura’s Social Cognitive Theory (SCT) will

be used to incorporate *expectancies* and *incentives* into understanding behavior. Revisiting the HBM design, Rosenstock and colleagues (1988) proposed that social learning theory be added to the HBM to better understand and direct studies to include environmental and social factors. SCT makes two contributions to explaining health behaviour that the HBM does not. First, it emphasizes the several source of information that go into acquiring expectations of the results of a health action. Secondly, and most importantly, it adds the concept of self-efficacy as distinct from outcome expectation. While the *perceived benefits* dimension of the HBM considers an individual's belief in a particular outcome, *self-efficacy* considers the conviction that one can successfully carry out the health behavior required for an outcome (Rosenstock et al., 1988). It is in adding the SCT dimension to the HBM that this thesis aims to understand the health behaviors of breast cancer patients that act within the defined environments of interest. The distinction and inclusion of both expectations of outcome (HBM) and self-efficacy (SCT) are important because both are critical to behavior.

2.8 Chapter Summary

This literature review began with a brief introduction of the Health Belief Model that links perception and experience to health behaviour outcomes. The look at the changes seen in health geography research agendas sets this study up quite well, as it speaks to the subdiscipline's focus on understanding broader human well-being and models of health care. The combination of macro- and micro-scale environmental influences that this study of breast cancer care will pursue is also inline with health geography's goal of understanding both the literal and perceived meanings of 'place' that

Kearns and Moon (2002) discuss.

Areas of patient satisfaction literature have been able to reflect both institutional measures of quality as well as patient outcomes in the delivery of care. Health care providers' different responses to patient needs for information on diagnosis and treatment appear to be the main concern for breast cancer patients. The profound effect that satisfaction with information has on compliance and patient outcomes emphasizes the importance of understanding factors that influence how patients perceive their care. The role of the environment in this important relationship is important to further explore, as it may effect how critical communication between patients and their health care providers is fostered. Additionally, the changing patient needs that varies amongst patients and point in treatment demonstrates the complexities that are involved in the experience of care.

Adherence literature has shown that compliance to treatment and health advice is both a behaviour and attitude that is influenced by multiple factors. Treatment options, changes to lifestyle, dosage schedules and overall knowledge, can and have been shown to impact a patient's adherence behaviours. The role of the environment as a contextual factor in engagement and treatment experience must be further explored to facilitate optimal compliance in breast cancer care. Attitudes present in this domain of cancer care also exist in a multidirectional relationship with the 'role' – passive, active, collaborative – a patient chooses to adopt in their care. How conducive environments of care are to make patients feel comfortable and confident enough to seek a shared decision-making role in cancer care, is an area to be further explored.

Furthermore, research around the different environment involved in care

demonstrates that the experience of cancer care draws influences from a variety of scales. What can still be done is to design a study that links the environmental influences from multiple scales *to* patient satisfaction and *in turn* resultant adherence, for a group of patients with a typically long-term and demanding treatment period (i.e. breast cancer patients). How the regional cancer centres that organize a network of holistic care for physical and psychosocial needs, poses an interesting implication in this relationship between environment and experience of care.

Lastly, use of the HBM with SCT is appropriate for addressing the outcomes of this thesis as this model is increasingly being used to understand health behavior in curative settings. Here, the ‘curative setting’ includes the environments involved in breast cancer care with a main focus on a regional cancer centre used for treatment and supportive care health services. As Rosenstock (1966) as well as Becker and colleagues (1977) have argued, the HBM can and has been used to understand factors that play a role in compliance behaviors, which is an area of concern in breast cancer care as treatment can take up to five years and scheduled checkups follow in the years after. The practical implications of using the HBM are to assist in ensuring that present and future breast cancer patients have available to them, in their surrounding environments, the opportunities and resources to produce accurate health beliefs for optimal health behavior. The HBM provides a theoretical framework to understand behavioral change that can occur throughout the course of care. Rosenstock’s (1966) original argument that to change people is much more difficult to change their environment is still true in contemporary settings. Minimizing barriers to action and increasing the opportunities for

people to act on behalf of their own health can grow out of an understanding of how the environment affects satisfaction with breast cancer care and attitudes towards adherence. This thesis seeks to help fill these gaps in the literature by understanding the physical context within which care occurs and how it may play a role in producing patient satisfaction and shaping attitudes towards breast cancer care.

Chapter Three

Setting, Methods and Study Design

3.1 Introduction

This chapter outlines the methods and study design used to investigate the research question: how do different care environments influence patient satisfaction with breast cancer care and resultant attitudes towards treatment?

The corresponding study objectives are:

1. To gain an understanding of the role of *geography* in the experience of receiving cancer care.
2. To evaluate aspects of the environment that are associated with patient satisfaction and/or dissatisfaction and how they may impact health beliefs related to adherence to care.
3. To identify areas of success and possible improvement in current environments of cancer care.

3.2 Research Setting

3.2.1 *Breast Cancer in Ontario and Canada*

Breast cancer is the most commonly diagnosed form of cancer and second leading cause of cancer death amongst women in Ontario and throughout Canada. In the province, approximately one in 9 women are expected to develop breast cancer in their lifetime, while one in 29 will die of the disease. As seen in Table 3.1, in 2011 this rate amounted to 9 000 new diagnoses and 1 950 breast cancer deaths, among women in Ontario. Breast cancer is relatively rare amongst men and, as seen in Table 3.2, realized

to 190 diagnoses and 55 deaths at the national level in 2011 (CCS, 2011). Rates of diagnoses and mortality have undergone changes in the past few decades. In Canada, breast cancer diagnoses have rose steadily from 1980 to the early 1990s, with death rates declining in every age group since the mid 1980s. The establishment and use of provincial breast screening programs partly explains this rise in diagnoses (CCS, 2011).

Table 3.1: Estimated New Cases and Deaths for Breast Cancer, by sex, in Ontario and Canada, in 2011; * numbers not counted at the provincial level (CCS, 2011).

		Ontario	Canada
New Cases	Male	-*	190
	Female	9 000	23 400
Deaths	Male	-*	55
	Female	1 950	5 100

Table 3.2: Estimated Incidence and Death rates for Breast Cancer, by sex, in Canada, in 2011 (CCS, 2011).

	Male	Female
Incidence rate (per 100 000)	1	102
Death Rate (per 100 000)	<0.5	11

Post-surgery, treatment options include a combination of radiation therapy, chemotherapy, biological therapy, hormonal therapy and biological therapy, while some patients who are non-responsive to these traditional therapies, may participate in clinical trials. After completion of a therapeutic regimen, patients then enter a schedule of follow-up care that will continue for at least 5 years after treatment with the purpose of preventing and monitoring possible recurrence. In addition to medical treatments, some patients may also opt for supportive care, which is composed of a variety of programs and services for patients to address any emotional, physical and practical challenges associated with their breast cancer experience (CCE, 2012).

3.2.2 Organization of Cancer Care in Ontario

In Ontario, Local Health Integration Networks (LHINs) coordinate the delivery of health care services. The province is divided into 14 networks that coordinate and integrate care at the community level so they may be more responsive to the health service priorities that are identified at the local level (LHIN, 2006). In this study, the Regional Cancer Centre (RCC) serving the 1.4 million people in the Hamilton Niagara Haldimand Brant (HNHB) LHIN and all the cities and townships it contains, as seen in figure 3.1, is the main focus. The overall philosophy and organization of care in this centre is designed by the province but is responsive to the priorities set out at the local level by the LHIN.



Figure 3.1: The Juravinski Cancer Centre (approximate location denoted by red star) delivers cancer services to the HNHB LHIN under Cancer Care Ontario's directives (HNHB LHIN, 2005).

Cancer Care Ontario (CCO) is the provincial agency that oversees the delivery and design of cancer health services in the province. Primarily, CCO has organized care into Regional Cancer Programs that are networks of stakeholders, health care professionals and organizations. Currently, the province of Ontario is divided into 13 Regional Cancer Programs¹ that serve each of the 14 LHINs and can be seen in Figure 3.2. CCO oversees that these regional programs carry out province-wide quality standards of care while meeting the requirements and targets set out by the agency (CCO, 2011a). Each Regional Cancer Program is run out of a Regional Cancer Centre with a host hospital.

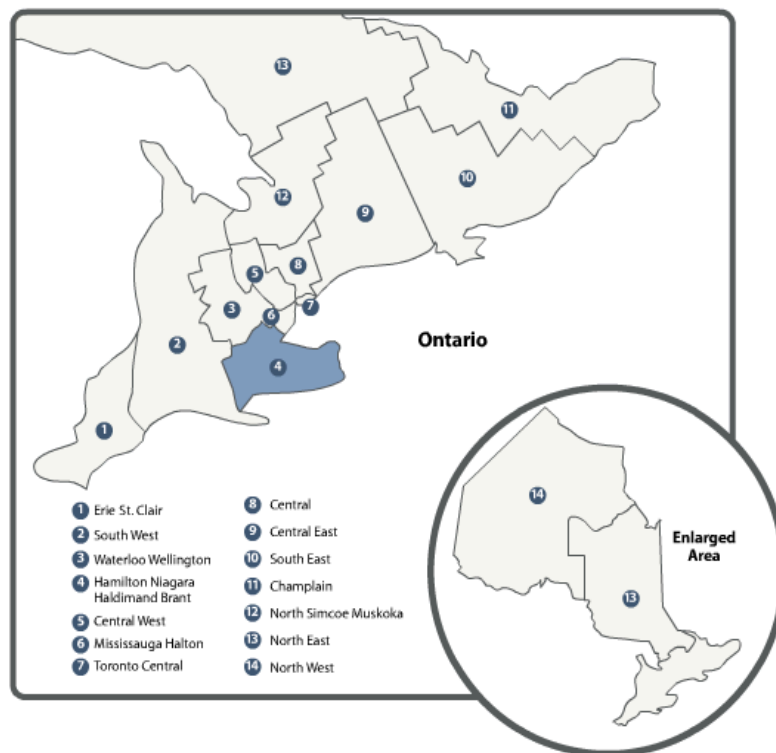


Figure 3.2: The JCC is located in LHIN #4 in a network of 13 Regional Cancer Programs (HNHB-RCP, 2010).

¹ The Mississauga Halton LHIN and the Central West LHIN are served by the Mississauga Halton Central West Regional Cancer Program.

CCO is also responsible for continual improvement of the current system of cancer care in the province. As the population in Ontario continues to age and grow, cancer diagnoses and the demand for care have and will keep increasing. Among the priority areas of CCO is the ‘improvement of the patient experience’ throughout the course of treatment and follow-up care (CCO, 2011b). As a result, regional programs are similarly interested in understanding and meeting this priority, which aided with the approval of this study by health care providers at the Juravinski Cancer Centre in Hamilton, Ontario.

3.2.3 Juravinski Cancer Centre

The main research setting for this study is the Juravinski Cancer Centre (JCC) in Hamilton, Ontario. Both recruitment of participants and data collection took place on site. The JCC is adjacent to the Juravinski Hospital and runs the Hamilton Niagara Haldimand Brant Regional Cancer Program. This program serves the counties of Brant, Burlington, Haldimand, Hamilton, Niagara and most of Norfolk. This cancer centre is comprised of a new patient referral service and 7 outpatient clinics. Patients come to the centre upon referral from a medical professional, and each year the JCC receives approximately 7 500 new referrals. Treatments and services available at the Juravinski include: diagnostic, radiation therapy, chemotherapy, clinical trials, an onsite pharmacy, a patient education library as well as a supportive care department. Canadian Cancer Society volunteers, an information desk at the main entrance and reception desks in each of the clinics, provide multiple ‘check-in’ points for patients visiting different areas of the centre (JCC, 2012).

The JCC is located on the Niagara Escarpment on Concession Street in Hamilton,

Ontario. The centre's parking garages, an area of interest in this study, are located adjacent to the centre as well as across the street from the hospital. Municipal lots, metered parking and street parking in the surrounding residential and business areas are also available. The centre cannot be accessed directly from the highway, however mountain access from downtown Hamilton, the Lincoln Alexander Parkway and the Red Hill Valley Parkway, connect the JCC to Highways 403 and the Queen Elizabeth Way for patients travelling within and outside the HNHB LHIN, as seen in Figure 3.3.

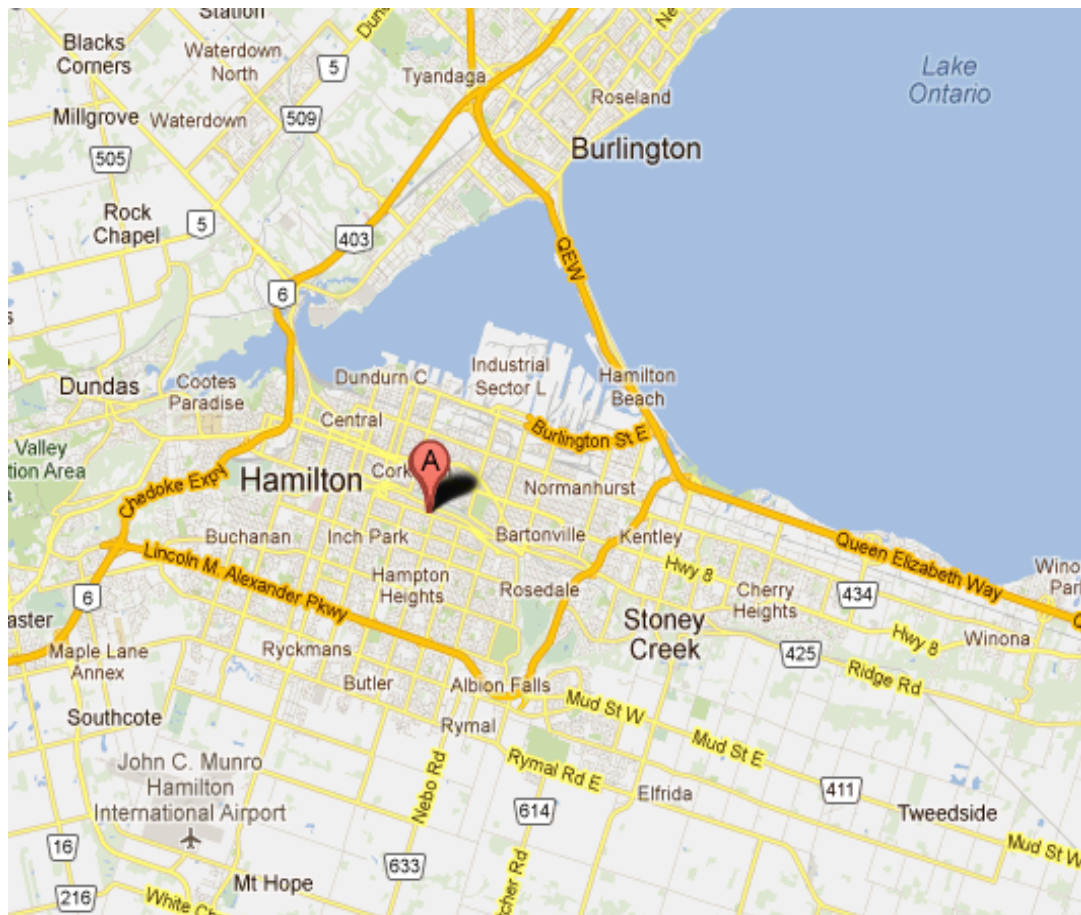


Figure 3.3: Map of area surrounding the JCC (denoted by the letter A), showing access to major roadways (Google Maps, 2012).

3.3 Research Design and Methodology

3.3.1 Social Constructionist Approach to Knowledge

This study uses a social constructionist approach in its view of knowledge generation and insight into the experience of breast cancer patients and their interactions with environments of care. This form of inquiry was chosen because it is principally concerned with figuring out the processes by which people explain, describe and account for themselves in the world in which they live. It places knowledge within the process of social interchange and asks participants and researchers to challenge the objective basis of conventional knowledge (Gergen, 1985). Berger and Luckmann's (1966) seminal work on the social construction of reality describes how:

Man is biologically predestined to construct and to inhabit a world with others. This world becomes for him the dominant and definitive reality. Its limits are set by nature, but once constructed, this world acts back upon nature. In the dialectic between nature and the socially constructed world the human organism itself is transformed. In the same dialectic man produces reality and thereby produces himself (Berger and Luckmann, 1966, p.183).

This approach looks at individuals as constructing varied and multiple subjective meanings of their experiences. Forms of negotiated understanding are significant in social life and are connected with many other activities in which people choose to engage. As Creswell (2007) explains, the goal of research then becomes to rely on how study participants view a situation – breast cancer patients' views on health services and the environments involved in its delivery – where the researcher accepts that a complexity of views of experiences exists rather than narrowing the meaning into a few themes. The researcher is challenged to see things from the view of the participants as the emphasis is

on the meaning of the illness or disease to the individual (Gatrell and Elliott, 2009).

Using a social constructionist approach in a study of the experience of breast cancer care is also appropriate as alongside its biophysical presence, *perceptions* of the disease itself can be socially constructed. As Kearns (1994) points out the thoughts of Foucault, when doctors examine patients, patients are objectified and turned into ‘cases’. The subject is socially transformed and viewed by another (doctor) as an ‘other’ (patient), and as long as disease is observed within humans by others such as health care professionals, perceptions of disease can be viewed as a socially constructed phenomenon (Kearns, 1994). In studies such as this thesis, social constructionism is used because participants are not seen as people who passively attain knowledge about health, but rather people who are “continually engaged in the construction of such knowledge [of health and health care]” (Gatrell and Elliott, 2009, p.30).

3.3.2 *Qualitative Case Study Methodology*

The qualitative approach used to guide this research is that of a case study. This thesis uses Yin’s (2009) work that defines a case study as “an empirical inquiry that investigates a contemporary phenomenon in-depth and within its real life context” (p.18). Here, the Juravinski Cancer Centre represents the holistic *case* that bounds health care uptake and interaction with clinical environments of care (phenomenon) where breast cancer patients are the *unit of analysis*. The study takes the form of a ‘theory expanding’ case study in order to further develop theories of patient satisfaction, adherence to care (health beliefs), and experiences with health care environments, with a specific application to breast cancer treatment (Baxter, 2010).

Using Yin's (2009) conditions of selecting a method, the case study can be identified as conducive to investigating the research question. First, this thesis uses what Yin (2009) describes as a *how* research question to look at the role of cancer care environments in patient satisfaction and health behaviors. The second and third conditions are to determine the degree of control over behavioural events and the focus on contemporary events, which the study uses. Case studies are preferred when looking at contemporary events where behavior cannot be manipulated, where interviews of people involved with the events is the source of evidence (Yin, 2009). This approach has the purpose of giving voice to the patient and the patient experience, to better understand what shapes their satisfaction and attitudes toward adherence to care (Sofaer, 1999).

To breakdown the components of the case study using Baxter's (2010) explanation, the *phenomenon of interest* is the group of breast cancer patients that seek health services at the Juravinski Cancer Centre for their diagnosis. The 'case' to be studied is the Juravinski Cancer Centre. The *local context* impacting the experience of care at the centre and the social construction of perceptions of the environments of care, are the guidelines outlining the organization of the clinical areas, health care providers and staff within the centre, and surrounding facilities (i.e. parking) around the centre. Journey-to-care and use, or non-use, of community services such as support groups, make up the *regional context*. Cancer Care Ontario's strategies and guidelines for their Regional Cancer Centres and Programs as well as the cues to action (e.g. media) that the Health Belief Model identifies, compose the *broad context* (Baxter, 2010). An in-depth analysis of how the centre impacts the cancer care experience is conducted using

qualitative methods (Creswell, 2007).

3.3.3 *Social Constructionism in a Case Study using the Health Belief Model*

The Health Belief Model (see Chapter 2) is the theoretical framework for this qualitative inquiry into the role of the environments in patient satisfaction and attitudes towards care. The model, which theorizes the creation of health beliefs that encourage health action, hypothesizes that an individual's perceptions of barriers, benefits, susceptibility, severity and threat of disease will determine whether they pursue health services for a diagnosed illness (Rosenstock, 1966). In this study, since participants are those that *already* attend the Juravinski Cancer Centre, the health belief model is used to understand the decisions to *continually* take-up health services at the centre. The continuity of adherence as an attitude towards care, for example, is an objective of the study, and it is how interactions and perceptions of the different environments involved in receiving breast cancer care at the Juravinski Cancer Centre impact continued attendance, that the study seeks to find out.

Social constructionism is used as the approach to identify the perceived barriers to care, amongst other perceptions, which may impact continual adherence to care at the centre (e.g. keeping up with follow-up appointments, following therapy schedules). Social constructionism seeks to look beyond conventional barriers to care - such as availability of places at the cancer centre - and to look at barriers that arise when patients interact with the social and physical environments involved in cancer care. Using social constructionism within the theoretical framework of the health belief model seeks “greater *understanding* of the social processes involved in shaping health-related

behaviours and outcomes” (Gatrell and Elliott, 2009, p. 30), where the emphasis is placed on the meaning of breast cancer and receiving treatment, and the task for the researcher is to uncover and interpret the patients’ expressed experience and health behaviors (e.g. adherence attitudes) as ‘rational’ to act in a particular way (Gatrell and Elliott, 2009). The boundaries of the defined ‘case’ make the environments of care identifiable and the social constructed perceptions of disease severity, barriers, benefits, susceptibility and threat of untreated disease, become the points of inquiry.

3.3.4 Participant Recruitment and Sampling

Prior to recruitment of participants, the Hamilton Health Sciences/Faculty of Health Sciences Research Ethics Board approved the project in June 2011. Study protocol and the interview schedule, as well as material for the participants (e.g. information flyer, letter of information/consent – see Appendices A and B) were approved for use in the study. Recruitment of participants used a ‘double-informed’ method of consent. Health care providers at the Juravinski Cancer Centre approached patients they assessed as emotionally and physically fit to partake in this study. Using the flyer provided by the researcher (see Appendix A), the health care provider introduced the patient to the study to gauge their interest. If interested, the patient was then approached in the examination room or waiting area by the researcher, to further explain the research objectives and what involvement in the study required. It was explained to patients that their participation was completely voluntary, that their decision to participate or not would not affect the care they received and that although their responses will be published and presented to different audiences, their identities would be kept confidential. Appointments

to conduct the interview were made on either the same day a participant was recruited – most participants agreed to this – or over the next couple of days when they had another appointment at the centre. This strategy was used to reduce any inconvenience to the patients and potential disruptions to the functioning of the cancer centre.

Purposeful Sampling to select “information-rich cases for study in-depth” (Patton, 1990, p.169) was used as the strategy for selecting potential participants. As Patton (1990) explains, these information-rich cases allow the researcher to learn a great amount about the issues of central importance to the study. Here, the purpose of the research is to understand the breast cancer care experience as it relates to the environments that care is given in, and how these environments can lead to different health beliefs such as the belief that adherence to care can lead to a good prognosis. As a result, those receiving breast cancer care in a provincial-designed cancer centre were sampled and defined as these ‘information-rich cases’. *Maximum Variation* was the type of purposeful sampling used. Participants were defined by their shared cancer site and medical treatment environment. Participants could have been selected from any point in the treatment continuum, at any stage of breast cancer, of varying lengths of experience at the centre, of varying travel distance to the centre, and of any gender or age. The logic behind this strategy was that with a maximum variation group, any common insights that emerge “are of particular interest and value in capturing the core experiences and central, shared aspects or impacts” (Patton, 1990, p.172) of the care environments on patient satisfaction and emerging health beliefs. *Criterion sampling* was also used as health care providers followed a criterion outlined by the researcher, when they referred patients to the study

(Bradshaw and Stratford, 2005).

3.3.5 Study Participants

Table 3.3: Participant breakdown with city or town of residence and corresponding LHIN.

Participant ID	City/Town	LHIN	Distance Travelled to the Centre² (km)
P1	Simcoe	HNHB	67
P2	Simcoe	HNHB	67
P3	Kitchener	Waterloo-Wellington	68
P4	Greensville	HNHB	15
P5	St.Catharines	HNHB	60
P6	Beamsville	HNHB	41
P7	Oakland	HNHB	55
P8	Hamilton	HNHB	6
P9	Hamilton	HNHB	6
P10	Hamilton	HNHB	6
P11	Burlington	HNHB	18
P12	Hamilton	HNHB	6
P13	Burlington	HNHB	18
P14	Hamilton	HNHB	6
P15	Hamilton	HNHB	6
P16	Arkell	Waterloo-Wellington	49
P17	Hamilton	HNHB	6
P18	Hamilton	HNHB	6
P19	St.Anns	HNHB	47
P20	Stoney Creek	HNHB	10
P21	Elora	Waterloo-Wellington	77
P22	St.Catharines	HNHB	60
P23	Brantford	HNHB	42

Informed *a priori* by the existing body of reviewed literature on which the research question and objectives were based (Curtis et al., 2000), the inclusion criteria for

² Distances adopted from chemotherapy scheduling policies of the JCC. When not defined, Google Maps was used and it was assumed that participants would take the shortest route.

participating in this study was that participants had to: i. have a breast cancer diagnosis; ii. be attending the Juravinski Cancer centre for full or partial treatment; and/or iii. be attending the Juravinski Cancer Centre for follow-up care. To ensure experience with the centre as well as to follow a request from health care providers at the Juravinski Cancer Centre, patients who were on their first visit to the centre could not be approached to participate in the study. Members of the Breast Disease Site Team expressed this one requirement since patients are recruited for clinical trials during their first visit, while also being receiving a lot of new information about the centre and their disease. This request was acceptable for the study, as many of the interview questions asked participants to reflect on changes in their experience of the centre, requiring them to have been to the centre more than once. Participants also had to be fluent in written and verbal English to ensure their informed consent (see Appendix B) and comprehension of the interview questions and probes (see Appendix C).

Overall, twenty-three participants were recruited and included in the study: twenty-two females and one male. Participants ranged from having three months of experience of coming to the centre for breast cancer treatment to over 15 years of visits and familiarity. All the participants were either presently completing their schedule of chemotherapy or had already completed it. If the participant was not in chemotherapy at the time of the study, they were either completing a schedule of radiation therapy and/or attending the centre for follow-up visits with oncologists or supportive care providers at the centre. Twenty of the participants lived within the boundaries of the Hamilton Niagara Haldimand Brant (HNHB) LHIN, while three participants lived in areas within the

boundaries of the Waterloo-Wellington LHIN (see Table 3.3).

As literature suggests, the sample size for a case study should be no less than three to five, yet big enough to provide an understanding of variations in experience (Collins, 2010). When originally presenting the research study design to the Breast Disease Site Team in August 2011, the predicted sample size was stated as being twenty participants or until saturation of responses was reached, whichever happened first. To achieve saturation in qualitative data, Collins (2010) instructs that a researcher should continue to collect and analyze data from participants to the point that additional sampling does not provide any new information to be incorporated into thematic categories. After twenty-three interviews, no new insights emerged and each theme within the interview schedule had responses that reflected negative, positive and neutral experiences, to ensure the saturated data was rich, full and complete (Morse, 1995).

During the data collection period, recorded interviews were transcribed verbatim in between meetings with participants. This allowed the researcher to re-familiarize herself with the collected data and have the opportunity to reflect on the insights from the participants, while in the field, to determine how many interviews were needed for saturation of responses. After the data collection period, the researcher did a preliminary organization of the data into themes, categorizing the positive, negative and neutral responses to each question and topic of the interview schedule, to reconfirm that saturation had occurred.

3.3.6 Data Collection: Semi-Structured Interviews

Qualitative semi-structured interviews were used as the method of data collection

to gain an in-depth understanding of the patient experience and the meaning that different events may have for those seeking health care (Frankel et al., 2005). Qualitative interviews have been largely used in health care research to gain patient perspectives on cancer care (Whelan, 1997; Pennery and Mallett, 2000; Cox, 2003; Thorne et al., 2005b; Thorne et al., 2008; Stajduhar et al., 2009 Maddalena et al., 2010). Comparisons of quantitative surveys and qualitative interviews have demonstrated that when seeking to understand the experience and care needs of cancer patients, interviews uncover more expressed experience and impacts of care, than questionnaires (Cox, 2003; Pollock et al., 2011). This form of data collection in case studies is both *targeted* directly to the topic of the research and also *insightful* of perceived causal inferences (Yin, 1999). Using semi-structured interviews helps to define the areas of interest in the study, while allowing the interviewee to pursue an idea in more detail (Britten, 1995). Data collection was modeled after the process outlined by Weston and colleagues (2001), a logical deductive approach, of using *a priori* theory to: i. drive questions; ii. drive the interview protocols; and iii. structure initial levels of the coding scheme (see Appendix D). The interview schedule (see Appendix C) of primary questions and probes, was based on a review of existing literature and the hypothesized relationships in Rosenstock's (1966) Health Belief Model. The interview schedule reflected the constructs and corresponding literature that detailed the different elements of the model. The 'structure' of the questions that still allowed participants to be flexible with their answers, helped to ensure consistency across interviews.

Using the Health Belief Model from the outset facilitated the narrowing down of

possibilities for the questions as well as the analysis that occurred afterwards (Weston et al., 2001). The interview schedule consisted of 18 open-ended primary questions that Dunn (2010) describes as storytelling, opinion, descriptive and structural. Each primary question had at least three probes that were a pre-determined and flexible set of clarification, nudging and form secondary questions to help guide the participants and address the research objectives. The interview schedule (see Appendix C) followed a *pyramid structure* where more abstract and general questions were asked at the end, and the interview started with an easy-to-answer question (e.g. can you tell me how long you have been coming to the Juravinski Cancer Centre?) so the participant can become accustomed to the interview, interviewer and question topics before being asked for deeper reflection (Dunn, 2010).

Before the final version of the interview schedule was submitted with the ethics application, input from the clinical manager and a social worker in the Supportive Care Department at the cancer centre, both well-versed in qualitative research with patients, was requested and received. Prior to submission for ethics board approval, the questions were pilot tested on an upper-level graduate student with qualitative research experience in health care, to refine the interview questions and phrasing of questions, for clarity and structural flow (Creswell, 2007).

Twenty-three semi-structured interviews were conducted one-on-one with each participant by the researcher. Interviews took place in the Supportive Care Department of the Juravinski Cancer Centre during the centre's operational hours and over the course of two weeks in August 2011. On average, three interviews were conducted each day during

the data collection period. After being referred by a Juravinski Cancer Centre health care provider, patients were given a letter explaining the study objectives, researcher's background and type of involvement needed from participants. After being given the opportunity to clarify any points in the study, the patients then signed the consent form. Interviews took place in a private room that was usually a counseling office or booked meeting room. While the interviews were structured as one-on-one where each participant was interviewed individually, there were a few instances where circumstances required a participant's travel companion to remain with them.³ While the researcher preferred to only have the participant in the room, if the participant felt more comfortable having their companion there or if it was the 'norm' for them to have their loved one with them during all aspects of their care experience, they were accommodated and allowed to stay. All the travel companions that stayed in the room during the interview were respectful of the process and did not answer any questions for the participants nor persuade them to change their answers or views.

All interviews, with the consent of the participants, were audio-recorded and stored as digital files and labeled using a code that combined their assigned participant number and their city or town of residence (e.g. P12 Hamilton). This was to ensure confidentiality in both the storage of the data but also in the reporting of the results. The audio files of each interview were then transcribed verbatim to produce a 'rich' data set

³ Companions such as spouses, family members and friends often accompany patients to the cancer centre for emotional and/or physical support. Some go into the examination room or treatment area at the request of the patient. If that was also the participant's wish for the interview, the researcher accommodated the one extra person in the room. This happened in three of the interviews.

that provided sufficient information to address the research question and objectives (Weston et al., 2001).

3.3.7 Data Analysis: Coding

To analyse the collected qualitative data, a thematic coding analysis of the verbatim transcripts from the interviews, was conducted. According to Bradley and colleagues (2007) themes are recurrent unifying statements or concepts about the subject of inquiry that characterize specific experiences of the participants. Theory, such as those on patient satisfaction and resultant health beliefs of care, help to explain, predict and interpret events during the analysis stage. In this stage of the research, theory helps to identify and understand causal links and confounding variables (Bradley et al., 2007). Here, an understanding of patient health behaviors in the realm of cancer care is sought. The causal links and confounding variables are centered on patient experience and interaction with the different environments involved in their breast cancer care.

Coding is used as a method to organize and manage the amount of information rich qualitative data that has been collected (Cope, 2010). The aim of coding, as a method for analysis, is to create a detailed and systematic record of the themes that the interview aims to address and to connect the identified themes and conducted interviews together under a “reasonably exhaustive category system” (Burnard, 1990, p.462). Coding involved creating a codebook (see Appendix D) to facilitate the thematic analysis of the interviews. A codebook is “a tool for the development and evolution of a coding system and is an important means for documenting the codes and procedures for applying them” (Weston et al., 2001, p. 395). The stages for developing and refining this book were

adapted from the works of Weston and colleagues (2001) as well as Bradley and colleagues (2007), and occurred as follows:

1. *Established an organized framework for the codes:* The *a priori* theory and review of literature that was used to develop the interview schedule, facilitated the identification of major themes that the data collection tool addressed. This included: cues to action, perceived barriers, perceived benefit, perceived severity, perceived susceptibility and self-efficacy.
2. *Search for evaluative statements:* A preliminary read through of transcripts and review of researcher's notes during data collection, was then done to look for the macro-codes that emerged when participants spoke of negative, positive and neutral experiences of receiving care.
3. *Search for sub-codes:* Transcripts were searched through again, looking for sub-codes that identified different elements of the social and physical environments, which participants mentioned in their evaluative statement.
4. *Researcher review of codebook:* A first draft of the codebook was made and included the questions, themes, macro-codes and subcodes that were identified. This draft was then reviewed and discussed between the researcher and her supervisor, who was familiar with the collected data. During this step, the meanings of codes were clarified and defined, while redundant codes were deleted from the codebook.
5. *First application of codebook to the data:* Using qualitative organizational software, NVivo 8, the researcher developed an electronic coding structure to

organize the data into different elements of the codebook (trees and nodes). Excerpts from the interviews were coded under the single or multiple codes that applied. Codes were added to the book if they were missed during the initial transcript read through.

6. *Second application of codebook to the data:* After the initial formal coding of the data set and addition of codes to the codebook, the transcripts were read through again in NVivo 8. Codes added in stage 5 were applied to fitting excerpts and already coded excerpts were reviewed to see if they applied to these new codes.

Using NVivo 8 provided a method to store the data so it could be easily accessed and analysed throughout the study. This made it easier to locate needed material and also compare how answers reflected multiple components of the Health Belief Model and led to a particular event (Creswell, 2007). It also facilitated the process of reviewing and adding elements to the codebook. Using this software also helped to improve the rigour of the analysis since it provides “algorithms to identify co-occurring codes in a range of logically overlapping or nesting possibilities, annotations of the text, or the creation and amalgamation of codes” (Pope et al., 2000, p. 115).

3.3.8 Limitations of Research Methods

This study is limited in its generalizability. The research was not conducted with the aim of collecting a breadth of experiences, but rather a rich, in-depth look at a single case. The use of a questionnaire would have allowed for more patients to be included and numerical scores from the questionnaires could have even identified more widespread

‘problems’ with current care. However, questionnaires are not specific or comprehensive enough to provide information about what aspects of the care experience need to be improved and how it can impact the life of a patient (Cox, 2003). Furthermore, if you consider Yin’s (2009) argument that you cannot generalize from a single scientific experiment and that scientific facts are rarely based on just one experiment, you can reason for the benefit of a case study. While the study of a single case cannot lead to any large-scale governmental policies, it can be added to an evidence base alongside other case studies that can inform or support current and future policies and theory.

The Juravinski Cancer Centre also represents just one of 13 Regional Cancer Centres in the province. Although all these centres strive to meet the same targets of care and follow the same guidelines for cancer care, it cannot be said that the quality in which care is delivered at the Juravinski is the same as in other centres. It thus cannot be said that the experience of patients at the Juravinski Cancer Centre is the same of those at other cancer centres such as the Princess Margaret Hospital (Toronto, Ontario) or the Royal Victoria Hospital (Simcoe-Muskoka, Ontario). Rather this study takes a scaled-down look at care in the province, to study just one centre and identify the positive elements of that care environment, in shaping health beliefs and behaviors. Carrying out the study at the ‘case’ level of just one centre, also allows for a greater understanding of *place* in the cancer experience, that may be lost when attempting to record large numbers of locations (Gatrell and Elliott, 2009). As Baxter and Eyles (1997) highlight, the experiences drawn from the participants of qualitative studies are assumed to be bound to “time, people and setting of the particular study” (p. 515).

Additionally, the sample of patients represents just one sub-group of cancer patients. While breast cancer is the most diagnosed cancer among Canadian women, it is one of many cancer sites that are diagnosed every year. While breast cancer patients reflect the experience of cancer patients with relatively longer lengths of treatment and care (approximately five years), they do not reflect the experience of shorter treatment schedules such as those associated with lung cancer. Lastly, since the interviews and consent processes was all done in English, participants were limited only those who could understand the language in both text and dialogue. As clinical signage, cancer information material and interaction with health care providers is primarily in English, the exclusion of non-English speakers meant that their experiences of breast cancer care was also excluded.

3.3.9 Rigour and Evaluation of Qualitative Research

Establishing rigour and evaluating the quality of this study is important to ensure the validity of the findings and the overall applicability of the insights gained. Rigor was evaluated by using the criteria outlined by Baxter and Eyles (1997). *Credibility* of the “authentic representations of experience” (p.512) was addressed through the strategy of purposeful sampling of breast cancer patients and individual interviews with them. This technique was used as the researcher assumed that no single reality but multiple realities exists in the lived experience of cancer care. *Source triangulation* using multiple quotations from different respondents, as will be seen, was used to corroborate identified constructs. By including negative cases for all aspects of the interview schedule as a target for saturation in data collection, an analysis of negative cases could be done to

ensure that all types of experiences – negative, positive and neutral – were accounted for in all theoretical constructs that the interview schedule embodied. *Member-checking* was also done, where an additional researcher read through a sample of the transcripts and discussed possible coding analysis with the primary researcher. Conclusions were also presented at conferences in the Winter and Spring of 2012, where questions that were posed were later used to reflect on the analytical process and conclusions drawn by the researcher (Weston et al., 2001).

While the *transferability* of the study is limited because of its qualitative case study design and restriction to people attending a single cancer centre, the use of ‘thick descriptions’ of the study’s methodology, the results section (Chapter 4) and inclusion of data collection tools as appendices, are available to other researchers who wish to determine the degree to which this research design can be transferred to other contexts (Baxter and Eyles, 1997). In addition to the literature and health behavior theories that informed the development of the interview schedule, research and data collection objectives were also informed by the guidelines and targets set out by Cancer Care Ontario for the delivery of care in all 13 of the province’s Regional Cancer Centres. While the results from this study may not be transferable to other cancer centres in the province, the data collection tool can.

Dependability of the study was ensured through the use of verbatim transcripts of interviews for analysis. Supervisory meetings during the development of the codebook, allowed for the researcher to reflect on the developed codes while also getting input from another researcher who was familiar with a sample of the data, as well as the research

design. Using this technique allowed for the variability in interpretation. Research methods were made explicit and systematically evaluated (Bailey et al., 1999) prior to data collection and analysis, by members of the Breast Disease Site Team at the Juravinski Cancer Centre, the researcher's supervisor and the instructor of a qualitative research methods course. Lastly *confirmability* of the research was done through keeping a research journal with entries done during the data collection period, analysis and presentations at conferences, which tracked the development of ideas and reflections on interviews and recruitment (Baxter and Eyles, 1997).

3.4 Working With Health Care Gatekeepers

The successful carrying out of this study would not have been possible without the involvement of the health care providers at the Juravinski Cancer Centre. While a discussion of the experience of working with gatekeepers could rival the length of this entire thesis, here is a brief discussion on how this relationship impacted the methodology and data collection stages. Initial contact with providers and the structure of the teams they work in, was difficult to determine in the very early stages of the project. As a researcher working within a university, the information made available on the internet is not the most detailed or accessible. It eventually came down to e-mailing the 'best bet' who was a research coordinator for Hamilton Health Sciences with an affiliation to the Juravinski Cancer Centre. Very receptive to the idea of identifying the proper contact, this coordinator was quite helpful in facilitating contact with the head oncologist of the Breast Disease Site Team. Having this team as a part of the recruitment process meant that a variety of patients could be sampled from a variety of clinics and departments in the

centre. Members of the team who successfully recruited participants included: oncologists, nurses, a social worker, a dietician and a genetic counselor. This not only allowed for a greater access to patients but also a professional evaluation of whether patients were physically and emotionally fit to participate in the study, something the researcher could not assess herself.

While engagement with health care gatekeepers is almost critical to the success of a health care study, it is not without its challenges. Working with an inter-disciplinary team of professionals in such a large institution such as Hamilton Health Sciences, means that all research procedures and data collection tools are, rightfully, under their scrutiny. In this study, meetings and e-mail exchanges over the final draft of the interview schedule were made and eventually delayed the submission of the research ethics application to a month after its targeted deadline. Concern over questions about the care environment and accessibility of information and services, were brought up. Some providers thought that interviewees might interpret the questions as being evaluative of the doctors and nurses at the centre. Questions were willingly re-worded to better reflect the research objectives of understanding the role of the *environment* and final approval of the guide was given.

While engagement with health care gatekeepers is, overall, largely beneficial, it also means that, to some degree, the health care providers can have a greater impact in the study than the participants themselves. As this study aims to give power to breast cancer patients to express their experience of care, it is partly dependent on a group of professionals traditionally viewed as holding the ‘power’ in health care relationships. It becomes ironic that in order to conduct a study to give patients the power to express their

experience, power must also be given to the very people that play a large role in shaping the patient experience. However, as with any recruitment technique (e.g. posters, advertisements, approaching patients), tradeoffs must be made to ensure the success of a study. Giving consideration to the need to access patients with a specific disease site and to, most importantly, ensure they were emotionally and physically fit to participate, giving providers the power to refer approve all participants by selecting patients to potentially take part, was accepted as a necessary stage in the research process. Also, a presentation the day before data collection began was used to clearly outline to the providers that the study did not seek to evaluate *them* but rather the environments of care that are designed and mandated by decision makers. Team members appeared to understand that expressed negative experiences of the centre would not necessarily be a reflection of the care they provided, but rather the context where the care occurred. Team members also appeared to be genuinely interested in what patients had to say and even offered some of their own insights into the experience.

3.5 Chapter Summary

This chapter outlines the research design and methodology used in the study. Purposeful sampling of participants, with the assistance of health care providers, to conduct semi-structured interviews was outlined. The thematic content analysis of verbatim transcripts and development of codebook were detailed. Steps to ensure rigor in study design and analysis were provided, as well as insight into the experience of working with gatekeepers.

Chapter Four

Study Results

4.1 Introduction

This chapter presents the themes that emerged in the study results, organized by macro and micro codes. The organization of this chapter follows the major components of Rosenstock's (1966) Health Belief Model and Bandura's Social Cognitive Theory. To briefly restate, the Health Belief Model (Figure 4.1) uses four dimensions to understand and predict health behavior by combining individual perceptions with modifying factors to understand the likelihood of a patient taking recommended health actions. Based on an individual's perceptions, the model considers an individual's *energy to act* and their preferred *path of action* during the event of an illness by considering their perception of barriers existing in their path to care.

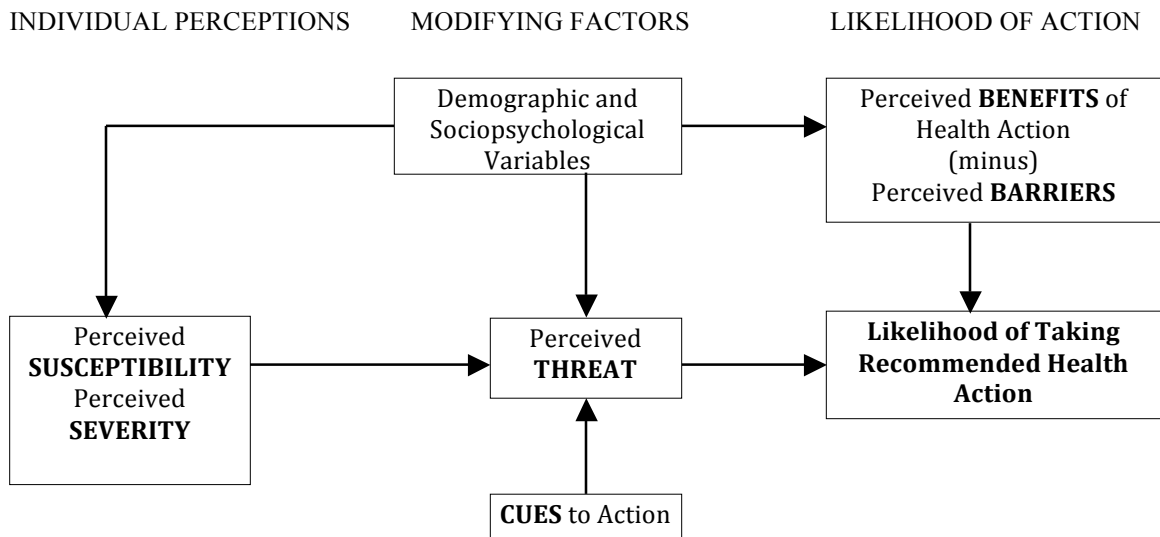


Figure 4.1: Major components of the Health Belief Model (Rosenstock, 1966).

Social Cognitive Theory furthers this model by considering perceived *expectancies* and *incentives*, while setting *self-efficacy* as distinct from outcome expectation by considering an individual’s conviction that they can successfully carry out the recommended health behavior.

Table 4.1: Overall, 932 segments from the interview transcripts were coded and are summarized below using the components of the Health Belief Model as macro thematic categories.

Macro Code	Segments Coded
Perceived Susceptibility	14
Perceived Severity	7
Cues to Action	33
Perceived Barriers (total):	824
<i>i. Physical Environment – Community</i>	69
<i>ii. Physical Environment – Journey to Care</i>	127
<i>iii. Physical Environment – Cancer Centre</i>	167
<i>iv. Physical Environment – Micro-Environment</i>	372
<i>v. Social Environment</i>	89
Perceived Benefits	27
Self-Efficacy	27

NVivo 8 was used to organize the verbatim interview transcripts during analysis. Overall, 932 segments were coded as being relevant to the theoretical framework that is composed of the Health Belief Model and Social Cognitive Theory. Table 4.1 summarizes the results to highlight the frequency of each theme from the framework, as appearing in a segment of the transcripts; some segments were coded under multiple macro codes when appropriate. While counts in the table offer little analytical value to the data itself, it does highlight the relative importance of *perceived barriers* in the social and physical environments involved in cancer care, as being the most popular topic (88% of coded segments) within the interview. Specifically, topics pertaining to the micro-

environment (40%) and area surrounding the cancer centre (18%) were most common in the interviews, a reflection of the interview schedule as well as what patients identified as the most significant environments in their experience of care. For anonymity, in this chapter participants are referred to by the order they were recruited, as well as the city or town in which they reside. For example, quotes labeled as “P16 Arkell” come from the 16th participant in the study, who resides in Arkell, Ontario.

4.2 Perceived Susceptibility

This dimension of the model refers to one’s perception of the illness itself, specifically what having the diagnosis means for their health and how treatment can impact their prognosis and overall wellbeing. Here, three main themes emerged: belief in diagnosis, belief in resusceptibility, and belief in vulnerability. Within the interview schedule, no question or probe directly asked participants about how they viewed their diagnosis, but when asked about keeping up with appointments and journey to centre, participants often answered that the seriousness of their disease and what it meant for their own wellbeing, comes before any considerations of how ‘convenient’ care is in their lives. One participant described her experience of finding out she had cancer a few days before her brother’s wedding and being faced with making a decision within moments of learning of her diagnosis. Upon hearing her test results, she was immediately offered a surgery date for the next day, something almost unheard of in Ontario. She says:

She [doctor] pulled down her mask and she said “I am so sorry, it’s malignant, it is cancer” and she said “I don’t even know if this is ethical, but here I go. You’ve got a great support network. You seem like a bright woman. I know you want this thing out of you. I have a cancellation tomorrow morning at 7 o’clock, if you want it, it’s yours”. So, here I am, I find out I have cancer at 3 o’clock in the afternoon, they pop some Lorazepam in my

mouth, I go home, I freak out and I cry. I have to get up at five the next morning, be up at that hospital in Kitchener for 7, to have this dye pumped into me, drive back to Guelph, go under and wake up at 3 o'clock the next day and the cancer is out of me. – P16 Arkell

She describes her diagnosis and surgery as being a 'whirlwind'. On the day she was diagnosed, she got a call that her results were in and that the doctor had five minutes between two surgeries to meet face-to-face with her. She headed to the hospital thinking that the tumor must be benign because in her mind "who tells you 'you have cancer' in five minutes? Surely to God they have a big white padded room with 20 people and support, so this has got to be good news. Got to be good news." (P16 Arkell). With this in her mind as well as a previous appointment where the doctor told her she had none of the risk factors associated with breast cancer – including age – the diagnosis and offer for immediate surgery sent her through a range of emotions that began with shock. Upon reflecting on her experience, however, she believed acting quickly was best for her own peace of mind as well as her children:

[If] I knew that thing was in me and I had to just wait for my surgery, I would've gone frantic. I really would've lost my mind, so I didn't have any time for that, it just...so by the time I had to tell my kids, I already had this surgery. Like I didn't have to say to them "Mommy's got cancer", I said to them "Mommy had cancer, it's gone now and it's all..." so it was easier for everyone around me too. – P16 Arkell

Another participant believed the stage her cancer was detected at as well as her prognosis for recovery, after surgery, to be 'good' compared to other outcomes, and from that, sought comfort. She compares the stage her cancer was caught in as well as her body's positive response to her cancer treatment, to other patients:

I know, there's some people who have worse cases and you know what, I'm blessed that, you know, they've removed all of mine. I'm blessed because everyday you know someone else has a worse scenario than you have, and you always have something to feel blessed for. And that's what makes you charge on more for your day, right? – P1 Simcoe

It was also common for participants to say they process their diagnosis in the stages that they learn about it and as it progresses. Belief in diagnosis appeared to be an evolving feeling that changed as the cancer and corresponding treatment progressed. P18 from Hamilton, who at the time of the interview had been coming to the Juravinski Cancer Centre for 8 months, talked about her first visit and how things have changed since then and said “I was more interested in actually my diagnosis and what I was going through. And then you kind of deal with things on an ongoing basis when I found out something, that's when I would research it.” (P18 Hamilton).

In addition to talking about belief in their diagnosis, participants also commented on the possibility of their cancer not responding to treatment or even returning (resusceptibility). This was particularly common amongst patients in follow-up care who visit the centre once or twice a year. P5 from St. Catharines expressed her gratitude for the care she has received and the comfort in knowing the centre exists if her cancer were to ever return:

Just very, very thankful for my care that has been given to me here and I feel good and healthy because of it. And hopefully I stay that way. And nothing personal, but hopefully I never have to come back! [laughter] But I know that I can... – P5 St. Catharines

The participant who was quoted earlier talking about her ‘whirlwind’ experience of diagnosis to surgery, also commented on the thought of her cancer returning. Now cancer-free and on follow-up care, she explained how the physical environment of the

Juravinski Cancer Centre serves as a reminder of her diagnosis and everything she experienced during her treatment period. With her routine mammograms bringing her back to the centre once a year, she explained:

I do get a little bit of anxiety when I first come here because I just live, like I never had cancer the whole year, until I get that mammogram. Once I have that mammogram, I have a week wait and then I come back. I do get anxious when I come into the building but nothing because of the building or anybody here but just because the whole horrible experience of right out of left field finding out you've got cancer. – P16 Arkell

When asked about her adherence to prescribed medication when outside of the centre, she again talks about the possibility of her cancer returning and how it can become a driving force to do whatever is needed to ensure it does not return. She explains “I wouldn't not take it. Like I don't know, if this is going to stop cancer from coming back, I'm all over that.” (P16 Arkell).

Lastly, participants also talked about the vulnerability that results from having a breast cancer diagnosis. P1 from Simcoe explained how a friend of hers who survived breast cancer gave her advice about medication and side-effects of treatment. Here, this participant, who at the time of the interview was in the chemotherapy stage of her treatment schedule, talked about being vulnerable to the pain and discomfort that comes as a result of adjuvant therapy. She explained her friend's advice:

she said “do not, you're gonna go through this and this with this drug, and make sure...you're gonna get this type of pain, so make sure you don't walk away without, you know, some medication”...she says “you know, I cried for three days because it hurt so bad so, make sure you've got medication” So hey, what's the sense of having pain if you can have something to relieve it...there's no sense in having pain, right? – P1 Simcoe

Other participants talked about how having a breast cancer diagnosis and receiving

care becomes the most important aspect of your life. A feeling of vulnerability comes from knowing you had a malignant tumor removed from you and knowing that adjuvant therapy at the centre, is critical to being ‘cancer-free’ and reducing the likelihood of recurrence. Participants expressed how vulnerable they felt to the cancer and how beneficial and important they viewed cancer care at the centre to be to their health. P22 from St. Catharines has completed her chemotherapy and at the time of the interview was completing her schedule of radiation therapy. When asked about being able to keep up with appointment schedules and travelling from St. Catharines to the Juravinski, she explained the importance of treatment as “this has been a priority right, for me obviously in the last few months. This comes first so whatever they tell me I’m going to be here [the cancer centre]” (P22 St. Catharines).

4.3 Perceived Severity

In this component of the theoretical framework, perceived severity focuses on how patients view the seriousness of leaving a breast cancer diagnosis untreated. Here patients describe how in the face of uncertainty with a cancer diagnosis, the best thing to do is to follow the advice given by your health care providers. P3 from Kitchener has been coming to the Juravinski Cancer Centre for more than five years and at the time of the interview, had completed her adjuvant therapy and on a schedule of follow-up care. In her experience of coming to the centre and adhering to the medical advice and lifestyle changes when at home, she believed that:

You just follow everything they say and you keep going...Listen to your doctor, yes that’s all you can do and I’ve had no real problems, you know? Besides of course, there’s always different phases you go through...it’s always changing but, like you say, just go with the flow. – P3 Kitchener

When asked specifically about their time at home, participants explained how their perception of the disease and curative potential of medication, encouraged them to follow recommended prescription schedules. Participants talked about the importance of taking their medication and how they tried to forget. P8 from Hamilton who is done her adjuvant treatment and goes to the cancer centre for counseling in the Supportive Care Department, explained how she occasionally forgets and a strategy she uses to make sure she gets back on track. She explained:

I just take it every night, it's beginning to be a habit. Mind you, I forget sometimes but I'll, if I do, I'll take it first thing in the morning because I try not to miss it. But I take it in the morning and I take it late the next night so that it's a good span between. – P8 Hamilton.

When further probed if she would prefer the health care providers at the centre to ask her more often about taking her medication or if she has any problems with the schedule at home, she simply replied “No, because I've been told from the beginning that I have to take it for five years.” (P8 Hamilton). Additionally, participants talked about how the decision to treat a diagnosis and enter a system of cancer care set into motion a series of health care events that required being in medical care environments. One participant describes it as a ‘flood’, saying:

Once you're in that system it's like a flood right? I have the surgery, they get everything, the tumor goes away to be tested or whatever, and I just right away, came down here [the cancer centre], met my oncologist, started my chemotherapy and that was it. It was like boom, boom, boom, done.
– P16 Arkell

Overall, participants appeared to perceive their illness as posing a severe threat to their health. They were also able to make the link between how critical it was for them to

seek treatment for the disease after their initial diagnosis and surgery. Patients did differ in how they viewed their cancer compared to others. Some held the view that ‘it could be worse’ while others use their knowledge of what was to come.

4.4 Cues to Action

Cues to action work as the ‘triggers’ to encourage or discourage people to take or not take recommended health actions. These cues fall under the ‘modifying factors’ section of the Health Belief Model and were identified as existing in both the social and physical environments. Since all the participants in this study were already users of the cancer centre, *cues to action* were considered to be prompts that influenced their initial visit to the centre as well as those that continue to impact their continued usage. Cues were also identified if they impacted health actions in the community environment as well.

4.4.1 Media and Promotional Posters

Participants talked about the role of the media in their knowledge and familiarity with the Juravinski Cancer Centre, prior to their first visit. P14 from Hamilton who has been coming to the centre for her entire schedule of radiation therapy and, at the time of participating, was completing her chemotherapy treatment. When asked about her sources of information about coming to the centre and learning about the health services they provide, she said:

Oh the clinic’s been in the news and you know I’ve often heard of people making comments about the Juravinski Centre ... how they’ve donated money and things like that. So I knew about the Juravinski Centre before I knew about the cancer. – P14 Hamilton

The centre has been in local media over the past two decades for many reasons. Research, quality of care evaluations and, most popularly, the large donations from Charles and Margaret Juravinski to the creation of the cancer centre in 1992 and the redevelopment of the adjacent hospital in 2010. In recent years, the name change of the adjacent hospital, from the Henderson General Hospital to the Juravinski Hospital, has placed the facility in the media bringing attention to its position in Hamilton's health care system. A participant from Hamilton noted this attention as a source of knowledge, saying "Oh we knew a lot about the facility because it was Nora Francis Henderson Hospital and then Juravinski" (P17 Hamilton).

Participants also described the media as being a source of information when they were at home and had questions about their care. Of interest in the study were the strategies participants used when they were outside of the cancer centre setting and had questions related to their care (e.g. managing side effects of prescription medication). The media appeared to play a role in shaping the health behaviors of some participants. While most people would refer to the internet, as will be detailed later, some such as P20 from Stoney Creek, talked about television and print sources. She says:

It's not online because I don't have an online so many times I'll pick up pamphlets when I'm on my way out, I don't usually call back in, I just let it go for the present time but it's not far back in my filing cabinet up here so somewhere along the way I'll be watching for that answer. You know? And I might get it from TV, I might get it from a magazine, or whatever.
– P20 Stoney Creek

Cues to encourage the use of workshops and support groups appeared to be contingent upon a participant's knowledge of them. P22 from St. Catharines talked about

accessing care and support while she was in between visits to the cancer centre. The participant talked about the poster and advertisements she sees while in the waiting room or navigating the centre on days where she has an appointment. She says:

Often times I see they're [Cancer Centre] good at posting things and I'm a person who would read stuff like that. So, I did attend some of the seminars already, in the beginning that I saw posted, through Wellwood or through Juravinski they ran some seminars on chemotherapy and exercise and nutrition and stuff like that. So I did go to a couple of those. So, but I just kind of found those on my own. – P22 St. Catharines

Overall, the above excerpts show that posters and larger-spread media can serve as informational tools for patients undergoing care. News items about the Juravinski Cancer Centre and hospital allow patients to become familiar with the health care environments that are involved in cancer care, before or during their diagnosis. They can also provide information for patients while they are outside of the clinical environment. Posters are also ways to inform patients of the resources that are available to them, that fall outside of their recommended primary care.

4.4.2 Advice from Others

Outside of their cancer care team of health care professionals, participants talked about sources of information and advice from people they knew or connected with after their diagnosis. Advice from others appeared to impact initializing and continuing a health action. P1 from Simcoe talked about seeking advice from friends who have gone through a similar diagnosis and treatment experience. She talks about them telling her what she might expect to happen as well as advice on handling the side effects of treatment and what she should ask for. She says:

I generally talk to my girlfriends that have already experienced it and that's where I get my support because they're like 'yeah, I remember going through that' and 'this is what I did' they'll say and 'this helped me...' and so on and so forth. And you know, with doing that and I come back today, I was able to get a prescription... – P1 Simcoe

Advice from friends who have been through 'similar situations' were also sought regarding the cancer centre itself as well as the treatment experience. As P2 from Simcoe explained, friends who have gone through treatment for a breast cancer diagnosis have reassured her about how positive of an experience it is to go to the Juravinski Cancer Centre:

But I had heard about it previously. I mean, I've had friends who have gone through treatments. Honestly, it's always been good results, good complements that they give with treatment and everything like that.
– P2 Simcoe

Friends have also been a source for reassuring participants and in turn cuing continued action. P21 from Elora talks about consulting a friend throughout different stages of his treatment and explained how she has become the 'go to' person for many.

He says:

I have a very good friend in New York City who is, she works at, she was one of the leaders of the Hastings Centre, the large bioethics centre, and she sort of by accident, through friends, family members and a personal interest, has ended up being the support person for several people with breast cancer. I often check in with her and ask "Is this supposed to happen?" – P21 Elora

Participants spoke of friends and family not only giving them the physical and social support, but also providing advice taken from their own experience and expertise. The advice given to them shaped current and anticipated expectations for the care experience and the cancer centre environment.

4.4.3 Illness of a Family Member or Friend

Participants also cited examples of friends and family members with similar cancer care experiences, when asked about their continued visits to the centre for treatment and care. P18 from Hamilton talked about the experience her and her sister had with their mother who went through a similar diagnosis and sought treatment at the Juravinski Cancer Centre. In this participant's case, comparing her mother's experience to her current one highlighted the improvements that have been made at the centre and its internal organization, giving her confidence that she would have a more positive experience. She remarked that the changes to the centre have created for a much better experience, encouraging of continued visits. She commented on the changes she has noticed to the layout of the cancer centre environment as well as the clinical layouts, that makes the experience of multi-purpose visits, comparatively, easier.

She said:

our mother came to Juravinski four and a half years ago and so we already knew, her pattern was a little different. Her waits were so much longer because I do my lab work and doctor on Friday, they're ready on Monday with my chemo so when I clock-in, they know I'm here, they prepare my chemo. My mother had to come, do her blood work, go downstairs, get a number, her labels for her blood bottles, come up here, sit and wait until they're ready in the lab, then we'd sit and wait for them to test her blood, make her chemo, get called in. And you knew, you were guaranteed here for hours and hours. Her schedule was a lot different than ours so I've experienced it both ways, so for me, it's easy because I went through with her, what she went through. So it's a little different perspective...
– P18 Hamilton

Similarly, P21 from Elora talked about his mother-in-law's experience with cancer care and how 'disconnected' and discouraging the organization of the care

environments was for her experience. He uses her as an example when asked about his experience with the layout of the micro-environments that make up the Juravinski Cancer Centre. He says:

I had moved here recently from Manitoba and I had friends with quite widely disparate experiences in Manitoba. And also my wife's mother recently had a breast cancer diagnosis two years ago and she lives in a slightly more rural area, north of where we live. She lives in Mount Forest and the care provided in that area was quite disconnected... – P21 Elora

Commenting on her familiarity with the cancer centre and the treatment it provides, P16 from Arkell shared a story of how her and her family researched the Juravinski Cancer Centre for her mother-in-law's cancer treatment and how the knowledge gained through that process cued her to attend the centre for her own diagnosis. She says:

My mother-in-law died of cancer three months before I was diagnosed. She had stomach cancer. She was also a nurse and her husband's a doctor, this is my husband's family. And he researched and sort of looked around and decided where the best place for her to go and being in the field he chose the Juravinski. So I never wanted to know about it, but I knew about it and as soon as I got cancer I said "I want to go where Grandma [surname] went".
– P16 Arkell

Friends and family with similar cancer care experiences appear to shape the expectations that the participants have in anticipating their treatment experience and encouraging their continued use of the cancer centre. Through knowing people, who have gone to the Juravinski Cancer Centre, participants grew familiar with the centre and what it has to offer. Comparing their experience to that of someone who had attended the centre years before, appeared to increase satisfaction because participants noted the improvements that have been made to the organization of clinical environments inside the Juravinski. Knowing someone who had a cancer care experience in a different location,

also allowed such comparisons to be made.

4.4.4 Schedule Appointments

The most important factor in cuing health action came down to familiarity and structure of scheduled appointments. Participants commented on how the scheduling of their visits to the centre became apart of their routine and despite their personal schedules, their treatment was their first priority. ‘Routinization’ of care emerged as a main theme for participants to make sense of their experience of receiving care in different environments and to continue their uptake of the care provided at the centre. The scheduling of appointments and knowing one’s own schedule, was encompassed in this theme of visits to care environments becoming ‘routine’. Participants commented on how structured the treatment schedules for chemotherapy and radiation therapy were and how the printed out schedules provided by the centre made it easier to remember when they have to come in. P18 from Hamilton who has finished radiation and at the time of the interview was in chemotherapy, said “It’s very helpful having a schedule printed out for you when you come then you don’t forget anything, which is really good.” (P18 Hamilton). Similarly, P8 from Hamilton made reference to the printouts given by the centre for patient appointments, as she describes:

yeah everything is indicated everywhere like this is Clinic D, Clinic B you know? Things like that. You know? They usually give you a paper, what floor, where you’re going so, if you lose the paper you might have trouble, I always kept them with me, so... – P8 Hamilton

Printed schedules appeared to be cited as the main structured ‘cue to action’ for treatment appointments at the centre. Participants appeared to rely greatly on this for knowing when to come in and where to go. Waiting and receiving the printout for the

next appointment become a part of the micro-environment clinical experience. P2 from Simcoe notes some of the changes that have been made to ease the process and experience of getting scheduled for her next chemotherapy appointment. She noted the changes to waiting time. She said:

I used to come, we'd go through the chemo and I would actually send my sister-in-law to the front counter to get my – they give you your appointment for the next time – and they said that they couldn't give it to her until I was actually done with my chemo. So, I've gone through the chemo, go out to the front and we've usually had about a ten minute wait, ten to fifteen minute or maybe it was ten minutes, while they set up your next appointment. But recently, the last two times I've noticed the doctors give me something and when I come in I give it to them [chemotherapy receptionist] and they actually have it ready for me when I go out and I thought what a great idea, why didn't they do that in the first place, eh? Yeah maybe there was a problem with the chemo, and they can cancel that in a hurry if they had to. But that speeded me up to get out of here, by ten or fifteen minutes so...

– P2 Simcoe

Generally, participants appeared to be accepting of their treatment schedules because they viewed it as something they needed to do. As P1 who comes in from Simcoe explained:

It is what it is, and I know that. It's every other Thursday and that's...I know that and whoever's brining me is quite aware of that and they're fine with that. So, I'm not...I don't...I'm not upset with that at all. I'm totally not upset with that because it's part of my treatment schedule and that's fine. That's not something that I worry about. – P1 Simcoe

Some participants also commented that in addition to having printed schedules of their appointments, they still needed to use their own system and strategies for organizing and reminding themselves about appointments. During the interview with P18 from Hamilton, she talked about going to support centres such as Wellwood as well as programs such as Look Good, Feel Better and learning different strategies such as using a

planner to organize her appointments. She pulled out her planner during her interview and said:

I wrote my own schedule down as well, even though they gave me papers, so I keep organized that way. Actually, I got this book from Look Good, Feel Better and I also like to plan ahead. The one thing I like, and I know they can't do it too far in advance, I like to write down my schedule and I only get it every time I come, for the next visit. I like it a little far in advance because I know I'm gonna be coming here for a whole year, but I write down all my information in this kind of journal.

–P18 Hamilton

Participants, who appeared to be the most accepting of their treatment schedule and need to visit the centre multiple times a week, were those who felt they had the 'flexibility' to do so. Participants were asked how they felt their schedule fit into their day-to-day lives and the most common factor to positive responses was whether participants were retired or had children. For example, P2 from Simcoe says "well luckily I'm retired and luckily I don't have young children. So it really isn't a problem for me. I know I can go home and have my supper and go to bed if I feel like it or...it is very convenient." (P2 Simcoe).

When asked about how travel to the centre and appointment lengths fit into personal schedules, participants often answered that an appointment was an 'all day experience'. Narratives on this topic often included comments on travel time, wait time at the centre, length of treatment administration as well as side effects of treatment (e.g. fatigue, nausea). P1 from Simcoe is one of the youngest participants in the study and also has one of the largest travel distances from home to the cancer centre. She explained how she and her travel companion leave Simcoe in the morning and it is close to dinnertime once they get back. She said:

I'm down for the day. It's a whole day experience. I mean, we get home and yeah you're done. For me, I am not well. I go home, I get my jammies and I go into my bed. That's, I'm not well. When I go home, there's no carrying on with anything ...whoever brings me, they probably go home and it is their supper time . Yeah...so it's a long...it's definitely a whole day. – P1 Simcoe

Similarly, P2 from Simcoe discussed how preparation for an appointments, in addition to travel time and length of chemotherapy appointment, becomes complicated and lengthy.

She said:

we come in from Simcoe so we have to allow an hour and a half. This time I have to take five pills, 12 hours ahead, which is no problem, and then I have to take five pills at 4 in the morning which to be five...five...six hours ahead, pardon me, because my appointment is for 10 o'clock and if I don't get in for 2 hours, if I don't get in until noon and if I've taken these pills at 4...and the trouble is I get up at 6 to be ready for 7, I don't go back to sleep after 4 because you have to take it with food. – P2 Simcoe

Most participants who are in adjuvant therapy and travel in from outside of Hamilton have come to accept that visits to the cancer centre and the side-effects of treatment, make an 'appointment day' an all-day event. While this 'all day' experience in the cancer centre environment can be discouraging of continued attendance, the centre does have a 'Same Day Chemo' policy where participants with a travel distance that is greater than 50 km get priority for other appointments (e.g. blood tests, supportive care, oncologist visits) on the same day as their chemo appointments. As a result, it became apparent that participants who had further distances to travel (e.g. Simcoe, St. Catharines, Kitchener) were more accepting of the full day visits, because they were more common for them. Other participants, mainly those in Hamilton, were more critical of visits that ended up taking longer than they anticipated or changes to timing of 15 to 20 minutes, as

the convenience of the centre being in their city meant that they could do more in their day than just going for their appointments. Some participants commented on unanticipated changes to their treatment schedules. At the time of her interview, P12 from Hamilton had been attending the Juravinski Cancer Centre for 8 months, was done her chemotherapy and was attending the centre for radiation treatments and visits with the genetic counsellor. She commented on how her frequent radiation appointments have been changed in the pasts, and says:

The one thing is with radiation, you can go and swipe in and your appointment might be changed as much as a half an hour from when you thought it was going to be. But they told you from day one that they might switch up appointments and I guess if it was a different day or something, they might call you. Mine were never a different day, but they were like as much as a half an hour or twenty minutes or something and then you got a new schedule every Wednesday so when you look, you had to look at it carefully because you might be, I might have expected it to be in here at 9 o'clock in the morning but in truth I was, I was coming in at 1:30 in the afternoon. – P12 Hamilton

‘Cues to action’ for attending scheduled treatment and follow-up appointments appeared to rely greatly on tangible reminders such as printed out schedules, personal planners and computer systems that displayed appointment times. Participants, who travel from outside of Hamilton and its surrounding cities, appeared to be more accepting of appointments that would take up the whole day. Participants from Hamilton and its neighbouring cities were more critical of appointment delays and unanticipated changes to their schedule because they were less accepting of ‘all day’ visits to the centre. While participants believed in the importance of treatment and following appointment schedules, their most significant ‘cue to action’ appeared to be familiarity and knowledge

of the appointments itself.

4.4.5 At-home Adherence

Participants were also asked about adherence to lifestyle changes and medication at home. Prompts that cue health actions outside of the cancer centre and within a participant's community are important to understand patient compliance with their prescribed cancer care. When at home, cues to action for taking prescriptions come from written instructions given by health care providers as well as the prescription bottles themselves. When asked about taking prescription medications at home, P1 from Simcoe explained a time when she started a new drug:

they make sure you know your schedule and have a schedule they give you at the beginning. You take two in the morning, because for three days you have to take more of your steroids and stuff like that. I was up in the middle of the night taking drugs to prepare for today... And then you know for two more days you're taking them but they make sure you have a schedule there at the beginning so that's very helpful so that you can look at that and say "oh yeah, okay, I've got to take two tonight, two in the morning, tomorrow two at night, two in the morning, two at night," so...it's written right there in front of you as well as when you get your bottle it's written on there. So twice over.

– P1 Simcoe

Beyond written instruction, participants also talked about strategies and reminders they have developed over the years to help them remember their medication. P17 from Hamilton who has been coming to the cancer centre for 15 years and is currently on follow-up care, described how her pill-taking coincides with her pet's feeding schedule.

She said:

See with me, it's crazy but, my cat gets fed at four, so when I feed my cat at four, I remember that it's time to take my pill because she meows all the time, so, that's how I remember. And it was once when I was away that I forgot it was 4 o'clock so I didn't take it, I took it the next day so...because I forgot.

– P17 Hamilton

Overall, participants described that when at home their ‘cues to action’ depended greatly on the written reminders and instructions given to them while at the cancer centre or with their pharmacist. Some participants described how taking prescription medication has become apart of their everyday life and as a result different parts of the day can trigger a reminder to take their medication.

4.5 Perceived Barriers in the Physical Environment

The perception of barriers existing or not existing within environments of care can greatly impact a patient’s overall experience as well as their decision to continue with a health action. This section looks at the existing barriers identified by participants as well as positive aspects of the environment that prevent barriers from existing (e.g. barriers to information mitigated by positive attitudes of health care providers). Parts of the interview schedule focused attention on what patients perceived as barriers that existed or did not exist when accessing and being within physical environments of cancer care (i.e. clinics, waiting rooms, support groups). Participants were asked about their perception of how accessible environments of care were, as well as elements of the physical environment that impacted their experiences of receiving care. As explained by the HBM, perceived barriers are weighed against perceived benefits in a cost-benefit analysis that determines the likelihood of a health action occurring. If barriers within environments of care are perceived to be greater than benefits that stem from being within these environments, initial use and continued use may not take place. This thematic area of the interview schedule provided the most insight into the role of the environment in cancer care. For organization, this section will be divided into the four environmental scales:

community, cancer centre, interior micro-environment, and the journey-to-care from home to the cancer centre.

4.5.1 Community Environment

A. Experience with Family Doctors and other Health Care Providers

When anticipating their experience in the cancer centre, some participants said they based their expectations on what they had already experienced with other health care providers in their community; participants' experiences in the cancer centre environment were impacted by their past experience in their community. P16 from Arkell talked about past experiences at hospitals and with her family doctor when she said how great the interaction and accessibility of health care professionals is at the cancer centre. She said:

everyone [at the Juravinski] I've seen has been so tremendously helpful. Not patronizing. I find a lot of home, like family doctors or like at local hospitals, they're busy, they're arrogant, they sort of treat you like "oh you're an idiot. What do you mean?" You know? I don't get that experience here at all. It's all about education and they just completely want you to understand. They pick up on even if you look a little confused they say "now you don't get that, let's go through it again" and, so that part's, I would always come to a teaching hospital. – P16 Arkell

Similarly, P12 from Hamilton talks about a frustrating experience after she was initially diagnosed where she was trying to access her family doctor and surgeon in her community and was unable to get the information she needed. She talks about how things got much better once she got out of the care environments in her community and to the cancer centre:

it was like "oh no, don't bother me [family doctor]" I made appointments with him and he can't and his office called me back and said "oh he's got something, he's got a meeting he has to go to we have to cancel your appointment," until I finally said "you're not cancelling anymore of my

appointments, it's either that or find me another doctor"... when I went to go see the surgeon to get the report and everything he goes "oh well, this is what happened, it's worse than we thought, okay? Goodbye" I was out the door "we'll give you a call to get to the Juravinski". I'm going "what's worse, I don't know" and that was after his secretary had said "oh no, your report's really good". So like, I was a bit of a mess for awhile. I must say that once I did get to the Juravinski and got to talk to my doctor, things were much better.
– P12 Hamilton

B. Connecting the Home Environment with the Cancer Centre

Participants were also asked about their connection and contact with the cancer centre when in their home and community environments. These questions were mainly concerned with how participants accessed information and got their questions answered while they were at home and in between visits to the centre. The purpose of these questions was to understand accessibility to the health care providers at the centre, when not physically there. It demonstrated the connection of the home care environment to the cancer centre environment. The most common strategy to get needed clarification and information was to use the 'call-in' numbers that the cancer centre provides for patients to reach their different health care providers when at home. P23 from Brantford explained that:

the first day we arrived we were given a piece of paper with our oncologist's, like the JCC phone number and their extension so we can contact them. Sometimes there is a bit of a, there can be a two day turnaround time to actually get a response back but if it's an emergency they're pretty good at you know, getting back to you right away. – P23 Brantford

This service allows the participants to feel they still have access to the centre when not physically there and to assist patients when they are at home. P11 from Burlington who had been coming to the cancer centre for almost three years and was attending the centre for follow-up care at the time of participation, recalled the period of time when she

was completing her chemotherapy and would feel the side-effects while at home. She used the call-in service and was able to connect with the providers. She said:

I did have questions about – because I did have, I was having a heck of an issue with one of the bouts of chemo – and like calling in and speaking to the nurse is just like fantastic. Yeah, so they're ...like you may not get them like that [snaps finger] but knowing that she's reliable to call you back, absolutely. – P11 Burlington

Participants who used this service also commented on the availability of different types of providers and how the person to speak to depends on the question that needs to be asked. P13 from Burlington explained:

Well it depends on the question. If it's a question of relevance to my medical practitioner, I call her. Simple as that. You know, and I either talk to her attending you know, whoever her students or her nurse or her assistant or whoever you wanna call it. Or I talk to her or him. – P13 Burlington

Some opted not to use the service but to seek the information they needed, when not at the centre, within their community. Participants mentioned health care providers in their extended family and circle of friends as well as local pharmacists as sources of information. Others would say that they would wait until their next appointment to get their answers, especially if they did not perceive the matter to be 'urgent'. Some participants talked about 'saving up' questions and writing them down for their next appointment. P21 from Elora explained how he reflects on the urgency of the question and will usually decide to wait. He said:

we [he and his partner] reflect on a question we intended to ask, it's sort of like, well do we need the answer now or can we wait two weeks? So far, the only things we've called in about are the things that say "if you have this, call us" so that's what I mentioned to you before. We've kind of stopped doing that. I mean, if we have a high fever you bet, I don't even know if we would bother calling we'd just make sure we do or don't have phaedra neutropenia

so, it's ...there haven't been situations where we've needed to get a more urgent answer in a shorter time frame so...– P21 Elora

Another alternative was for participants to collect written information from the centre and support services to refer to when at home. Pamphlets, books and recommended websites can turn home environments into care environments allowing patients to find the answers to their questions about medication, lifestyle changes and handling treatment side-effects using suggested sources of information. Participants mentioned that upon arrival to the centre, patients are provided with a package of information that they can consult along various stage of their treatment, when at home. P14 from Hamilton says:

They gave me a whole bag of pamphlets when I first came to the Juravinski Centre and when I first got them I did go through them and that and I've gone back to them a few times, you know, to check up on things that I had a question about. And yup, the pamphlets usually answered it for me.
–P14 Hamilton

P1 from Simcoe explains how using this collection of information and having it in her home, can help her to understand and handle the side-effects of her treatment when she is away from the centre. She says:

I have all the information because in my first appointment they [cancer centre] gave me, they gave me information on everything...I have all the printed information that I keep in a folder so I can look it up and say "Oh ok right, now that's gonna cause that, that and that" and "okay, I have this drug and that's gonna take this away" and I have all the printouts on that because they're really good at giving you the printout on what it's gonna relieve.
– P1 Simcoe

Similar sentiments were shared by P6 from Beamsville who said she supplemented her use of the call-in services with written material, saying "I got lots of pamphlets and things that they gave me. Lots of information on almost everything that I need" (P6 Beamsville). While many had trusted these sources of information that had been

recommended or given to them by their health care providers, some did make a point to clarify their understanding of the information on their next visit. P15 from Hamilton explained how she double-checks the information she finds online because she is not always certain that it is meant for her. She said:

[I] always came back and asked the doctor or the nurses, my team, what I found out because sometimes you can get information on the internet that doesn't actually compare to what you're going through. So you have to verify that. So it's always better to come back and double check with the team.
– P15 Hamilton

Overall, participants suggested different ways that they stay connected with the care they receive at the cancer centre when at home in their community environments. The call-in service was the most used form of staying connected and turning the home into a cancer care environment by being able to consult with health care providers via the telephone. Recommended informational materials were a way to continue care and adherence to recommended health actions, while at home. Some sought information from people within their community such as friends, family members and pharmacists that they recognized as having medical expertise that was relevant to their diagnosis. Others assessed the 'urgency' of their questions and would often just wait until their next visit to the cancer centre.

C. Medication At Home

One way that care environments are created within the home occurs when patients are required to take prescribed medicine in preparation for an appointment and/or between appointments. 'Barriers' to taking up and continuing this health action can be created and prevented depending on a patient's understanding of their medication

schedule and instructions for administration. P7 from Oakland commented on the clarity of explanations the health care providers at the centre gave her about taking her medication at home, and said “once they explained it, it was pretty self-explanatory, if there were side-effects or if I needed something because I had an infection or whatever...yes, they were very good” (P7 Oakland). Participants also cited using their introductory information packages as ways they could understand their prescribed regimens, a way to prevent ‘barriers’ to understanding medication in the home environment.

D. Use of Support Groups

Questions asking participants about the use and knowledge of support groups generated much discussion on their perception of suitability, self-assessment of need and location, which then translated to their overall decision to attend. Support groups are not required elements of cancer care but are suggested and advertised by health care providers. As P15 from Hamilton said, “they [cancer centre health care providers] brought it up. They talked about it if you needed it. If you felt you wanted something like that, they gave you the options. So everything was there for you if you wanted it, it was up to your discretion.” [P15 Hamilton].

Overall, the majority of participants did not actively attend any support groups in their area, but all participants confirmed that they knew of at least one group they could use. Some participants explained that they knew they existed and even though they did not use the support groups simply they still view it as a future possibility. P1 from Simcoe says, “I haven’t, no. But maybe in the future I might. You know, I know it’s out there and

I'm not afraid to, it's just at this point, I'm just too tired and I, generally don't feel well enough to go out and do, sit and chat. It's not on my agenda." (P1 Simcoe).

A unique perspective on the non-use of support groups was provided by P16 from Arkell who described how she could understand other people's use of them but would never go herself. In her mind, attending support groups and entering that environment was almost a way of prolonging your cancer experience and making it apart of your identity. To her, she did not view support groups as a way to move on from cancer, she viewed it as just the opposite: a way to continue to make it your reality. She explained:

I've always been of the mind set, like you know what, I did not sign up for this. I don't want to learn the camp song. I don't want the t-shirt. I don't want everything I own covered in pink ribbons. This is something like the flu, I had it, I'm done. I'm not the big celebrator of being a survivor. You know, and for me that's, and I totally respect the people that it is, like some people are "I'm a survivor" is part of who they are. But I don't tell you I got through the flu or that I conquered tonsillitis. So I'm not, so no, I don't seek out cancer groups and cancer lectures and...I'm not interested. And again, I don't mean to be negative about that. For some people that's a real lifeline for them and I respect that, but for me I need to move...I don't want to remember it, I just rather be done with it. – P16 Arkell

The most common reason cited for not using community support groups was that participants felt they did not 'need' them. P3 from Kitchener succinctly explained that she has not been using them because "I've found that I haven't needed anybody or anything because everything's been going really smoothly. So I haven't needed anybody or any support groups so, I didn't bother with it." (P3 Kitchener). Personal circles of support that are made up of family, friends and fellow patients were a common reason for participants to believe they did not need to use the groups. A common answer to questions about support groups expressed by P19 from St. Ann's who simply said "I don't believe I

needed any support because I had my own support, so I'm fine.” (P19 St. Ann's). Having your friends and family make up your support group instead of a formal one within the community, was much more preferred as P5 from St. Catharines describes it as 'fortunate' when she said:

I know I have had people who have said to me that there are other support groups if you need them. I have been made aware of them, let's put it that way. But I've been very fortunate that I've had a great support group in my family and friends and I just haven't needed it. – P5 St. Catharines.

P7 from Oakland similarly described that having your personal network of support, rather than using community resources, was 'fortunate' but it was also comforting to know formal groups did exist. She said “I am a very, very fortunate person. I have family, friends, I mean I just have the best support system anyone could ever have, and I didn't really feel I needed anymore, you know? But I knew that there was here if I did.” (P7 Oakland).

An additional 'barrier' to using community support groups was the perception that existing groups were not suitable to the participants. P1 from Simcoe cited the age of support group members as a reason why she did not use them. She specifically refers to a group near her home that she does not use and explained “the thing about that group is that it's a bunch of older ladies...but there's also one in Brantford which is about a half hour or so away from me that are a bunch of younger ladies.” (P1 Simcoe). Age similarly played a factor in the support group experience of P16 from Arkell. She talked about going to a support group but then decided to never go again. Earlier she was quoted as saying she found support groups to be a reminder of her diagnosis and opted not to go.

Here she goes on to describe the facts and realities a younger woman, in her opinion, has to face when attending a breast cancer support group. She said:

I did go to one, this doctor that I saw today, she ran a Life After Breast Cancer clinic thing and I went to that, and I have to say, again, respectfully, I know a lot of people put a lot of time and energy and a lot of work went into that whole day for all of these women and I found it totally depressing. You know what I didn't like, when you get breast cancer as a young woman, most of the stuff that you are told is about how you're going to go into menopause and that just what menopause is and it's just frightening. Like when you're a young woman, you don't want to hear that your vagina's going to be dry, and that you're not going to want sex and that you're going to bloat up, and that you're going to gain 50 pounds. Like, it's hard enough to get through the fact that you had a chunk of your breast cut out and in some cases your whole breast removed, and this whole day of everybody revisiting this fact that everything went back to menopause and all that's going to happen. And I walked out of there and my husband said "You are never going to one of those things again." Like never. – P16 Arkell.

The perceived 'formality' and 'structure' of support group environments, were also highlighted as barriers to using support groups. P8 from Hamilton describes what she would prefer support groups to be like. Her ideal support group would include anyone who needs cancer support, not just breast cancer patients. She said:

I know that they have like pensioners centres, where older people can go and just like, old age people and they can just go and just play cards and stuff like that. And I think that they're should be a centre similar to that where's it's like a drop-in place, and as it builds, and I'm sure it would build, something like that but for cancer victims, you know? Because I think everybody with cancer experiences something different because everybody's cancer was different, right? It doesn't matter if it was Leukemia or some sort of foot cancer, breast cancer, skin cancer, whatever. All the cancers are different and everybody experiences different things with it and different moods with it and everything... And talk about other things as well, family and whatever, but just to get into to knowing each other and knowing that the support of each other is there all the time. Because I got that feeling from doing the walks. Cause the people were so, so, so close. Like it was almost like it didn't matter who they were. You were walking with them, you felt like you knew them forever... Like an open house thing. Even if it was the bottom of the church or something where they have coffee and stuff and everybody take care of

their own, you know? Like take care of the place... it's [cancer] a thing where people who have never had it, have never experienced it, don't really know...you don't really know until it hits you unless, well, even taking care of somebody is not the same as having it...you'll have to really experience it to really know what the effect does to you...even a place where people who are going through taking care of their parents or something who have it, the cancer or something, can go. They can just sit and talk and see how other people feel and get ideas. – P8 Hamilton

In addition to perceptions of need and suitability, distance appeared to serve as a barrier for people to take up support groups. Location matters. P1 from Simcoe was earlier cited as saying that age composition of the group (i.e. younger vs. older ladies) deterred her from going as the group of 'older ladies' was the one closer to her home. She did express a desire to join the group of younger ladies who were further away but then said "if I felt like traveling and right at this moment, I am not well enough, too tired, so that's an option at this point" (P1 Simcoe).

P17 from Hamilton explained how she attended Wellwood Resource Centre in Hamilton but stopped going when it moved locations. She says that "they [Juravinski Cancer Centre] told me that they [Wellwood] would help me out so that's how I went. But since they moved to Chedoke, I haven't been there yet...because they're further away." (P17 Hamilton). P21 from Elora, lives outside of the HNHB LHIN and has one of the greatest travel distances to the centre, of all the participants. While he travels to his neighbouring LHIN for treatment, he views travel time to be a barrier for support group usage and said, "I think it's Wellsprings or there's a Wellness Clinic in KW as well, maybe one here we just didn't see this as the logical place for the support groups, because of the travel." (P21 Elora).

Overall, participants cited a number of 'barriers' as reasons for not using or

continuing to use a support group. The main reason for many was that they perceived themselves to have sufficient support amongst the family and friends as well as no additional ‘need’. While everyone said they knew of at least one support group that they could use, very few actually used them. ‘Suitability’ for one’s self, in terms of age composition of group, formality and structure of the environment, deterred some from using the support services. Distance, trip time and willingness to travel were also cited as barriers for use of support groups.

E. Unavailable Community Resources

Participants were also asked what resources they wished their cities had to assist patients when they were outside of the Juravinski Cancer Centre and within their communities. Hats, prosthesis and clothing were suggestions given by two participants who believed there was not enough available where they lived (Simcoe and Hamilton). P22 from St. Catharines believed her community was lacking a more diversified variety of supportive services. Specifically, she highlights the need for education on personal fitness. She said:

for fitness, there’s kind of a lacking because I am a person who works out everyday and I have had trouble finding out like what should I be doing now? Like now, you know, in terms of the cancer that I have, there doesn’t seem to be a lot of knowledge, I think, because it’s kind of a new field. Like how exercise and what’s safe and what isn’t during treatment and beyond. I’m having trouble... I mean, there’s someone here [Hamilton] but we just have nothing in Niagara, like absolutely nothing. No support in that way at all that I’m aware of or that I’m able to find. – P22 St. Catharines

4.5.2 Journey-to-Care Environment

Travel from a patient’s community to the cancer centre can produce a variety of positive and negative experiences. ‘Barriers’ along the way can play a significant role in

determining a patient's experience of cancer care at a regional cancer centre because the uptake of care can cause them to continually drive the same distances and routes from their communities. The interview schedule asked participants about their travel experiences and familiarity with their route, with the purpose of identifying potential barriers to continued health action.

A. 'Border' of Two Places

For participants living outside of Hamilton, it is common for them to be given the option of two different centres to receive their treatment and follow-up care. Some participants explained how, geographically, they live on the 'border' where they could travel in two different directions and get to two different cancer care environments. Some participants decided to come to the Juravinski Cancer Centre because it cut down on travel time. P11 from Burlington discusses how she had the choice to go to the cancer centre at Credit Valley Hospital in Mississauga or to come to the Juravinski Cancer Centre, and said "I had a connection in with Credit Valley Hospital, as well for as a possibility for treatment and it was like "well, which way do I go?" For traffic wise, this ended up being much, much better. Much better." (P11 Burlington). P2 from Simcoe had a similar experience saying "Well my surgeon actually gave me the choice of either London or Hamilton. And I chose Hamilton because it's about 15 or 20 minutes closer" (P2 Simcoe).

The perceived 'reputation' of a centre also helped participants choose between two centres. P5 from St. Catharines chose to come to Hamilton because she had not heard positive comments about the centre closer to her. She said:

there is a type of, I guess, cancer centre in our local hospital, but you know I just always said, I always hear, well not bad stories, I shouldn't say that I don't mean to be talking negative about my own city, but I just don't think it's up to the same grade of care as it is here. And it is so easy for me to come here, and thank God that I am of the age or the health ability that I am able to get here on my own. And it's no big deal so I find it very easy to get here...
– P5 St. Catharines

Another participant from St. Catharines, P22, shared a similar decision process but also commented on how she had heard great things about the Juravinski Cancer Centre, and said:

I just knew, you know, not from personal experience but from hearing other people, that the Hamilton Health System is far better than St. Catharines. And not to be negative, but St. Catharines doesn't have the greatest reputation, especially right now the Niagara health system. Since that was offered, I saw this as an opportunity. – P22 St. Catharines

B. Travel Start Point

To understand a patient's journey to care, participants were asked what point they usually travel to the cancer centre from (e.g. home, work). The majority of participants said they come straight from home. This was always the case for participants who were retired or said they had taken a leave of absence from their work. Some, such as P7 from Oakland who heads to the centre straight from home to ensure she is on time, have more specific reasons for why they start their journey-to-care from their home. She said, "generally, I come straight from home for this and I guess I don't wanna get tied up doing anything so I do things at home, if I need to go anywhere I probably do that after the appointment. I don't want to be late." (P7 Oakland).

A smaller group of participants said they came to their appointments straight from their workplace, but made a point to say that it was because the companies they worked

for were ‘flexible’. P20 from Stoney Creek says that in the earlier years of her treatment when she still worked, she had the flexibility to work around her appointments. She said “I was working in the type of profession that I could schedule my own appointments, so you work around it. That type of thing.” (P20 Stoney Creek). Offering a different perspective, P16 from Arkell who owns her own business and now comes to the centre for follow-up care, said “Yeah, I’ll go in and get the girls [employees] organized and make sure everybody’s okay and then head down.” (P16 Arkell).

Two participants said that their start points depend on the purpose of their appointment (i.e. follow-up vs. chemotherapy). P18 from Hamilton talked about being able to work through her period of radiation therapy and not during chemotherapy. She said:

Oh when I did radiation, I came from work. I didn’t have problems with radiation so I was very lucky. I could go to work and they were great at giving me near end of day appointments. They were always on time. They were great. Sometimes they took me before my appointment was even there and I worked in the mornings and then I came to radiation in the afternoons so that was great for me. I didn’t have problems. I couldn’t work through chemo though. Physically impossible for me. – P18 Hamilton

P11 from Burlington who was on followup care during the time of being interviewed, explained how she currently travels from work which actually makes her journey-to-care longer.

She said:

Now, it’s from work. At the time of treatments, it was from home. So, I’m actually travelling further to come in because I live in Burlington but I work in Oakville, so. Yeah it’s not too bad though. I try to time it, like I said, as late

as possible in the day but I don't want to be hitting rush hour traffic coming in, so it's kinda mid-afternoon, is when I kinda try to aim for.
– P11 Burlington

P18 from Hamilton was the only participant who said that she travels to the centre from neither her home nor work. Her sister lives within walking distance of the Juravinski Cancer Centre and Hospital and on days of her appointment, she goes over to her house.

She said:

Well you see it's easy for me because my sister comes and picks me up from home, I don't live too far, we park, we're able to park at her house which is just down one of the streets right inline with the hospital. And then we walk here, so my timing is very good, yeah. – P18 Hamilton

C. Familiarity with Route

Participants commented on their familiarity with the travel route to the cancer centre as a way to ease the burden of traveling to the centre. They talked about their familiarity with the physical and built environments as they traveled from their starting point to the cancer centre. As previously mentioned, participants ranged from having three months of experience of coming to the centre for breast cancer treatment to over 15 years of visits and familiarity. None of the participants described their travel route to care as being 'complicated', as most participants expressed a great deal of familiarity. P1 from Simcoe said "I can do it in my sleep now. No it's not a bad time getting here for us, from Simcoe to here ...it's highway six. I can't say there's a bad time getting here." (P1 Simcoe). Similarly, P3 from Kitchener described the ease of travel with "we've come here last five years, winter, summer, and of course they keep the roads really good, so we really have no problem...not really hold ups or anything." (P3 Kitchener).

Most participants described their travel to the Juravinski Cancer Centre as ‘straight forward’. P7 from Oakland described how well she knew the directions and how it would be easy to explain to someone else from her area how to get to the centre. She said:

yeah it isn't difficult. It's really kinda straight, like how you get here. It's...and even if you're explaining to someone like how to get here? The explanation is really good, like you know from our place, it's you know from Brantford you get on the 403, get on the Linc, turn on Wentworth, turn on Concession, you're there. You know, check out for the white area [laughter].
– P7 Oakland

P21 from Elora was the participant with the furthest travel distance and considered the travel route to the centre to be ‘easy’. He said, “it’s quite easy for us [his partner and him] to get to. We come down highway 6 and get onto the 403 and then come across a few blocks and then up past St. Joe’s and up the mountain.” (P21 Elora).

D. Transportation

Transportation to the cancer centre was a key factor in the experience of journey-to-care. Participants were asked how they get to the cancer centre and if they have ever taken public transportation or private cars to get to the centre. None of the participants said they have ever taken public transportation, and one said she once used a taxi. The general view on public transportation, especially while actively receiving adjuvant therapy, was that it was just too strenuous of an activity. As P12 from Hamilton described, “I would never consider it [public transportation] when I was taking chemo or radiation, and the public transportation for me, would’ve been more trouble than it was worth.” (P12 Hamilton). She was also the only participant who said she had ever taken a

taxi to the centre, and explained why she did not like to. She said, “I just feel like they’re completely germ-laden. When I was on chemo, I was really conscious about germs.”

All the participants either drove themselves or had a friend or family member drive them. It became apparent that driving in a personal vehicle to the cancer centre was seen as most essential to receiving cancer care at the centre and overcoming any ‘barriers’ that could occur during the travel experience. Some participants made a point to mention how they have preserved their independence throughout their treatment experience. Whether they believed it provided a continued sense of empowerment after diagnosis or whether it was from a sense of guilt to ‘impose’ on someone. P9 from Hamilton, who had been coming to the centre for 7 months at the time of her participation and was completing a round of radiation, was asked if she drove herself or came with someone else, she said “No, I’m okay to drive and do my thing. I don’t like putting people out unless it’s like really, really, really, really, really necessary and it hasn’t been, so it’s fine.” (P9 Hamilton). P20 from Stoney Creek who has been coming to the centre for over 14 years, highlighted the feeling of independence that comes with still being able to drive herself. She said:

I have been driving since I was 19 years of age and that’s a lot of years. So you know, you’re independent, you have your own wheels and away you go. But I suppose down the road when I’m no longer driving, public transportation or family would then kick in and help you, you know? I’d like to think – P20 Stoney Creek

P7 from Oakland also expressed a desire to maintain her independence but also said that there were certain stages of her cancer care where she would have to accept offers from her friends and family and have them drive her. She said:

I am just surrounded by wonderful people so ...and there are times where I think, you know? “Hey, don’t take my independence away, I wanna drive” [laughter]. So for radiation I have been...yeah I’ve probably driven two-thirds of the time and had friends and you know sisters that have driven me as well, I have two sisters so...I just didn’t...because for chemo I had someone drive me every time because that’s what I was told I should do, and that was once every two weeks...but everyday, and I think I didn’t really wanna bother anybody. I had lots of offers to drive and I’m very, very fortunate but...yeah there’s something about getting behind the wheel of your own vehicle you know? – P7 Oakland

P3 from Kitchener commented on how being able to drive a personal vehicle can facilitate the continuity of her care by keeping her connected with her same doctors. She explained:

I’m in Kitchener and I think that they have all the cat scans and all the machines. But I’ve started coming here, five years ago is where they sent me, so I don’t even bother with there’s...I know it’s [Kitchener] a lot closer but you hate to change your doctors right? So we just keep coming here, so as long as we can...if we can’t drive, then maybe I’ll have to stay in Kitchener probably...but as long as you’re driving, you have no problem with coming here. – P3 Kitchener

Participants felt that driving themselves or being driven by a friend or family was essential to their journey-to-care experience. Public transportation was not viewed as an option due to the tiring nature of adjuvant therapy. Maintaining one’s independence and asking for assistance only when needed, was both important and empowering to some participants. It was common for participants to say the nature of their appointment determined whether they drove themselves or had others drive them.

E. Volunteer Drivers

Through the Canadian Cancer Society and community-based volunteer organizations such as the Cancer Assistance Program, patients at the Juravinski Cancer Program can book volunteer drivers to drive them to and from their home when they have

an appointment at the centre. These programs have the potential to assist patients to overcome any travel barriers that they may have (e.g. no personal vehicle, unwell to drive) for traveling to the centre. Regardless of whether they used it or not, some participants considered the programs as a way that makes the centre more accessible to get to from communities outside of Hamilton. As P6 from Beamsville explained, “there’s all kinds of ways of getting here if, there’s drivers. In Beamsville we have community living that does that, if you can’t, if you don’t have a drive, yes there’s things set up to get you here.” (P6 Beamsville).

These programs are advertised at the centre and pamphlets about them are included in introductory information packages. All participants mentioned being aware of the service and regardless of whether they used it, mentioned that they find comfort in knowing that it was an available option for themselves and fellow patients. P22 from St. Catharines explained how she has never had to use the service because of her great ‘support system’ but knows someone who has and takes comfort in knowing it is available. This is important when understanding ‘barriers’ that may compromise continued health action. While participants may not view themselves to presently face any travel to care barriers, because of being able to drive themselves or have others drive them, they do know that if it were ever to become an issue (i.e. barrier) they can use this available service. She said:

thankfully I’ve never had to because I have a good support system. People always been very gracious to offer to drive, so...yeah there’s always been someone available. I mean I’ve known about that. Actually I have a friend who does use the drivers so I know, she’s had good experience. I’ve known in the back of my mind that it’s a backup, which is comforting to know that they’re available. – P22 St. Catharines

Similarly, P7 from Oakland talked about having family and friends willing to drive her, but being conscience of the potential of becoming a ‘burden’. She, too, found the option to use the services as a source of comfort when thinking of the uncertainties of her treatment and progression of her diagnosis. Although she has yet to use any of the programs, she is confident that they will be there if and when she needs them. She said:

I had called the cancer society in Brantford because I didn’t want to become a burden to anybody and I thought, just incase I need a ride, especially because I didn’t know...you don’t have a clue what hasn’t happened already, how things will go. So yes, I had received information, I did sign-up. I never used, used the Cancer Society for drivers or anything because ...yeah, I’m truly fortunate. – P7 Oakland

P11 from Burlington also connected her anticipated use of the services with the uncertainties of her treatment. When asked if she had ever used any of the programs, she said “Yes, I did register with them cause I didn’t know at the time, how things would be going. So I was registered with them, but I never had to utilize them so.” (P11 Burlington). Providing a different perspective, P23 from Brantford who had just finished chemotherapy at the time of the interview, talked about how she actually uses one of the services but believes that once her treatment stops and she is coming to the centre for follow-up visits, she will be able to drive herself. She said, “I still have one treatment that I’m still on so, I still use a driver for that but otherwise if it’s just a doctor’s appointment and it’s nothing major, than I’ll just come on my own.” (P23 Burlington).

When discussing the volunteer driver programs with participants, the concept of ‘need’ came up quite often. Participants would assess their own need and needs of others, for the service, when explaining their use and nonuse. All participants were asked if they

had used any of the services in the past. P10 from Hamilton said “No, nope. I figure, it’s a much needed service, there are people who need it more than I do so... if I’m able to get here myself, that’s how I get here.” (P10 Hamilton). Similarly, P8 from Hamilton assessed herself as having ‘no need’ for the services because she was capable of driving herself. She said “I don’t need them. There’s more people worse off than I am that needs that so I wouldn’t want to take up a space. If I needed it yes, I would use it but I don’t. I’m quite capable of getting some place myself.” (P8 Hamilton). Having it as an option if the ‘need’ for the services ever came up, was comforting to know, as P15 from Hamilton said “I was always able to get somebody from my family and friends, so I didn’t need that...It was an option. It was open to me if I needed it, but I was fortunate enough if I, I didn’t have to...” (P15 Hamilton).

Whether they used them or not, participants were very cognizant of other patients’ needs for the services. P5 from St. Catharines, who has never used the services, talked about her mother having to rely on a volunteer driver to get to her appointments in Hamilton. She said:

I haven’t but I know people who years and years ago, years ago, my mother did. She used to come all the way up here. Well it wasn’t Juravinski then, it was just The Henderson and I remember, probably because my dad was working, I suppose, I know she had to rely on Cancer Society way back then for drives. So I know they do it and I know people that have done it and they always speak so highly of that...so I can only go by hearsay but I haven’t had to do it myself. – P5 St. Catharines

As participants recognized the challenge of frequently attending the cancer centre during treatment, they also came to understand the barriers that fellow patients may face. As P15 from Hamilton described, there was this idea amongst participants that if

they used the service that they may be potentially depriving someone else. She said, “I know there’s a lot of people who do use it, so if I don’t need to take somebody away from somebody who does need it”. (P15 Hamilton).

One participant who used the service explained that it was her preferred way of transportation because of the convenience it creates while at the cancer centre. Since volunteer driver programs pick patients up at the main entrance to the centre, it can be viewed as more convenient than coming in a personal vehicle. Patients, particularly those completing chemotherapy, talked about fatigue and other side-effects of treatment and how particularly strenuous the walk from the centre to the different parking areas can be, after treatment. Having a volunteer driver pick patients up at the main door can make for a better experience as patients do not have to negotiate the different parking environments as well as the city environment if they parked in a municipal lot or street parking. When asked to describe her most positive experience of coming and receiving cancer care at the centre, P23 from Brantford talked about the times she used the service. She said:

Probably using the drivers because they pick you up at the door, they bring you down, they’re very pleasant. I’ve had a couple of scary drivers that kind of concern me in terms of their driving habits, but they bring you right through the door and especially when you’re going through chemo you’re feeling like crap as it is. I don’t have to worry about parking, they tell you where to meet them and they’re right there and they bring the car right to the front of the building again and then you’re in the car and you’re gone, so...
– P23 Brantford

Experiences with the different volunteer driver programs can also vary because of the different policies they may have. P12 from Hamilton shared an experience where her radiation therapy appointments would get rescheduled or moved back, the day of, and how it would

impact the scheduling of her volunteer driver. She said:

So the problem with changing appointments is that I had already booked my volunteer drivers and then I had to re-book them once on short notice. They were really good to me at Cancer...CAP, Cancer Assistance Program, they switched it for me, but I have heard that the Cancer Society doesn't do that for you. You need three business days period, they won't switch it up. I don't know that's true or not. So that kind of thing is problematic for people who have volunteer drivers, is when they switch appointment. – P12 Hamilton

Volunteer driver programs provide a way for participants to overcome some of the present or anticipated 'barriers' involved in their journey-to-care, and can be encouraging of continued pursuit of cancer care as it provides assistance. While most participants reported not ever using the services, it did become apparent that knowledge of the programs provided an invaluable source of comfort when patients considered the future of their treatments and the uncertainties that lay ahead. The 'barriers' that exist within the environments involved with a participant's journey-to-care (i.e. not having a mode of transportation, not having a driver post-treatment visit) can also impact their continued uptake of health care, and in knowing that these services exist, participants can begin to overcome travel issues that may prevent them from receiving care.

F. Travel Companions

Most participants discussed having friends and/or family members accompany them during their journey-to-care to the cancer centre. Participants, however, differed on their reasons for having these people come with them. As mentioned before, some participants rely on family and friends to drive them to their appointment. Having a travel companion can be a form of physical support providing assistance to the patients. P10 from Hamilton explained how having someone drive in with them can be relaxing

because they can deal with matters such as driving directions and finding parking. She said that “when someone drives me, my husband drives me, than I don’t have to worry about anything. Yeah...just if a family member drives, it’s a lot easier.” (P10 Hamilton).

Similarly, P8 from Hamilton talked about having her niece drop her off and coming back later to get her, and said “Yeah, it was a good experience. Just so, when I come with her than I don’t have to park right? She just takes off and does what she has to do and comes back and gets me.” (P8 Hamilton). Having someone drop you off at the entrance as opposed to walking from a parking space can make a difference in the experience of care. As P12 from Hamilton described, “Well, mostly through my chemo treatment I had a friend or my son drive me. After the first couple, I couldn’t have driven by myself, even if I wanted to because, quite frankly, the walk over from the parking, was enough.” (P12 Hamilton).

Alternatively, some participants expressed that their travel companions provide social support more than anything else. P7 from Oakland talked about how travel companions, regardless if they were the driver or not, can make the experience of cancer care that more enjoyable. She said:

I think the best experience is having somebody that...whether or not they drive or come with me, makes the time go by quicker. If there’s any thoughts that I’ve always felt comfortable saying what I’m thinking or what I’m concerned about or whatever, makes it go a bit quicker. – P7 Oakland

P3 from Kitchener, who at the time of the interview had been coming to the centre for 5 years, explained that her husband has always accompanied her to her treatment and follow-up appointments. She explained that in more recent years, her husband has been experiencing chronic hip pain and depending on the events of her visits (i.e. having to

visit multiple clinics on different floors in a given day) he has to use a wheelchair. She explained how her husband developed Alzheimer's a year ago and cannot drive to the centre but still comes along with her to all her appointments. She said:

Oh I drive, he's [spouse] got early Alzheimer's ...so he doesn't drive for at least the last year...because first, you know, you have early Alzheimer's, he could drive for the past year...you know he gets a little mixed up so...can't trust him [laughter]. So I always drive when we come here. – P3 Kitchener.

On the day of her interview, P23 from Brantford was meeting with a genetic counselor. She explained that her sister drove her to the centre so she could drive her back in the case of 'bad news'. She said, "she [sister] drove because I didn't know what the results of the genetic testing was going to be..." It was also common for participants to praise loved ones for being so dedicated to their treatment schedule and insisting they come with them. As P21 from Elora explained, "I don't think my wife would ever allow me to come without her with me [laughter]. She's a wonderful person and she loves me dearly."

The use of travel companions for the journey-to-care was cited by many as being almost essential to a positive experience of care. For some, it is for physical support to actually get to and from the centre. When parking areas and travel between parking and the centre are involved, it can also become essential for some that experience fatigue and side effects of treatment. For others, in addition to physical support, travel companions provided important social support ranging from occasional visits to accompaniment for every appointment.

G. Negative Travel Experience

Participants were asked to describe their 'worst experience' of traveling to the

cancer centre. The purpose of this question was to isolate aspects of the environment that make this experience and to see how they could exist as ‘barriers’ to continued access of the centre, depending on how manageable and persistent participants felt the situation was. Two participants mentioned construction sites as being apart of negative travel experiences. P1 from Simcoe described an area along her regular route to the centre that consistently has construction disrupting the flow of her travel. She said, “You know, there’s the little blips of, what’s it, Upper James is covered in, it’s just cuckoo with construction. That’s the only thing that’s stupid...that’s the only thing that I don’t like. That’s all I got. The rest is fine. It’s just that stupid construction which I don’t think is going to get done before we’re done” (P1 Simcoe). Similarly, P22 from St. Catharines described her only negative travel experiences as being when she encounters the occasional construction on her drive back home. She said:

I think just getting back on the Queen E everyday. That’s tough right now because of the construction and just that merging, that’s a difficult...and we’re pretty experienced drivers but I would think for some people who aren’t really comfortable driving on the highway that would be a scary thing everyday but for us it’s...that’s the worst part probably. Once I get past that spot on the highway... driving here is not usually an issue, it’s all, it’s pretty much a good experience all the time. It’s driving home. That’s difficult just because of the construction right now [Summer 2011] – P22 St. Catharines

City traffic, once participants were out of their own community and driving through downtown Hamilton, was the most common example of negative travel experiences. As P4 from Greensville described, traffic in downtown Hamilton is generally accepted as something that any driver needs to deal with. She said, “it would be nice if there was a quick and easy way to get here, but there isn’t. You just have to drive through the city and come through the traffic” (P4 Greensville). Traffic has become a

particularly stressful aspect of travel to the centre, especially when patients are worried about missing their appointments. P7 from Oakland described a time when traffic made her late, and said “I’ve gotten traffic, stuck in traffic a couple times, thinking ‘Oh boy, I hope they don’t say too, you’re too late, too bad’ but no, getting here, no, it’s fine.” (P7 Oakland).

Participants also described attempts to deal with traffic or at least the potential of it. P11 from Burlington talked about passing active train tracks on her route to the centre.

She said:

Getting caught by a train down at Kennelworth type of thing and having to wait for it, that’s probably, I’d have to say the worst, I think. Cause we tried a few different routes and kinda experimented with, and found a few different shortcuts as we could have. – P11 Burlington

P22 from St. Catharines explained how she asked the centre to schedule her appointments earlier in the day because of her experiences with traffic. She said:

at first, the radiation schedule was a little crazy at the beginning because they had me coming in at the end of the day. So for driving home that made it difficult because it was busy on the highway and I did mention that and it seemed like they, whether the schedule’s already in place or not, they seemed to accommodate that, and the appointments got earlier which was really helpful.. – P22 St. Catharines

Another way of dealing with the stress caused by traffic is to adjust your departure time to leave extra time for delays caused by traffic and to even avoid it to begin with. Coming in from Elora, P21 talked about having an early appointment and said “You have to leave a little bit more time in the mornings because there’s more traffic,” (P21 Elora).

Most participants, however, could not describe a particular negative travel experience that stuck out in their memory. Instead, when asked about it they commented

on what they thought a negative travel experience could result from. Having appointments in ‘rush hour’ was presumed to be a cause of a negative experience by P13 from Burlington who usually had her appointments during the day. ‘Wicked snowstorms’ in the winter was recognized as most likely leading to a negative experience by P11 from Burlington who completed treatment during the winter but managed to avoid extreme weather.

H. Stops in Hamilton

Participants were also asked about any stops they make while in Hamilton, on their travel to the centre or on their way back. Participants who made stops on the way over appeared to do so only if it was on their way. P9 from Hamilton said “I think maybe once or twice I might have stopped at the mall on the way over [laughter]. Because I go right by the mall, but other than that I don’t think.” (P9 Hamilton).

P2 of Simcoe, who found the visits to be enjoyable for herself as well as her travel companion, provided the most insightful experience of making stops in Hamilton during travel experience to the centre. She talked about how after a day of being at the centre, going into a shop where people do not know you as a ‘cancer patient’, can be quite comforting. She said:

we stopped at a couple, like a garden shop one time and we wandered around for a half an hour because I felt like it. And then we were still home for supper, home by 5 o’clock. So that was probably the best experience. When we were later than that, you just don’t feel like stopping. And it’s kind of nice to go into a store because it’s a whole different world, they don’t know you’re sick, they don’t care. And it’s nice for the person that drives me too. I often feel bad for her, it’s longer for her than me. – P2 Simcoe

Experience of the city environment through stops in Hamilton did not appear to play a significant role in the journey-to-care experiences of participants. Some talked about occasional stops in the city while most participants expressed being more concerned with heading out before traffic started, wanting to go straight home or making it back to work.

4.5.3 Cancer Centre Environment

A. Reputation

Participants were also asked about any experiences they had that were a result of the site of the cancer centre. Most participants expressed that they had some familiarity and knowledge that the centre existed in Hamilton, prior to their diagnosis. The theme of ‘reputation’ emerged when participants were asked about their knowledge of the centre and what they did to learn more about it, once they found out they were going there for treatment. Living close to Hamilton, P11 from Burlington talked about how she knew the centre existed but had not had any experience at the centre until she needed to. She said, “I would say, really, I guess I sort of kind of new it was here. But I never set foot in it, didn’t really know too much about it until I talked to a surgeon, so that was about it.” (P11 Burlington). Living a bit further away, P1 from Simcoe talked about previous knowledge of the centre from two close friends who had gone there for treatment and spoke of its great reputation that drew her to the centre. She said “my surgeon said to me, he says “I’d like you to go to the Juravinski Centre” right? Certainly I could have said, “you know, I prefer to go to London”. I heard great things about the Juravinski so I was

like, “yeah sure”. Both of my girlfriends were treated here and they were very happy with the results.” (P1 Simcoe).

A few participants expressed familiarity with the cancer centre environment because of experience prior to their diagnosis. Prior to her breast cancer diagnosis, P5 from St. Catharines had received treatment for melanoma at the centre and had gained familiarity with the area of the city and the centre’s surroundings, before coming for her breast cancer care. P15 from Hamilton, used to work as a nurse at the Juravinski Cancer Centre. As previously mentioned, the Juravinski Cancer Centre has made media headlines over the years from their conducted research and large monetary donations, and as two participants pointed out, the media had increased their knowledge of the site, prior to their first visit.

B. Coordination

Highlighting the geography of the centre’s location in the city compared to the location of other health care providers, patients commented on their perception of ‘coordination’ between different health care environments. A lack of coordination between the centre and family doctors was expressed by some of the participants. P18 from Hamilton talked about the lack of transitional information for patients going to the centre. She explained how family doctors appear to be disconnected with the centre in terms of information they can provide their patients.

She suggested:

when you go to your family doctor, they should have little packages of information to help you in that process before you get to your medical oncologist or you’re surgical oncologist because she’s or he is your first step. I was diagnosed in the end of November and I didn’t even know what to look

up or do which I wanted to be informed before I came, and I didn't know anything. Now my family doctor she was helpful because she used to work here. But for other people, you're sitting there, you're thinking and wondering and kind of stressing in some ways until you come and see your doctor. Which took weeks because mine happened during Christmas. They have shut downs here at Christmas and I wish I had a lot of that information from the get-go, from my family doctor. And I think that would be very helpful.
– P18 Hamilton

P12 from Hamilton shared a story of asking her family doctor for a referral to talk to a counselor because she had limited family and friends in the area. She explained how it was not until she got to the centre that she got to talk with a social worker there. Her family doctor was unable to help her. She said:

it was really bad. And when I got here and I finally got in to see [Social Worker] she said “you know he could have referred you, because you had already been diagnosed, he could have referred you directly to us at then” which would have been wonderful. Even after the first time I had talked to her, she said “You want another appointment because you know....” And I said “ No, I'm fine,” I said, “but I like talking to you”. So just incase I have an issue, I'll have one more. But he [doctor] didn't know that, he kept saying “oh when you get to the Juravinski...” – P12 Hamilton

Additionally, P21 from Elora said that he had observed that most of his test results at the centre do not get sent to his family doctor. He highlighted that in his experience, the centre being separate from family doctors creates ‘silos’ of activity that involve the same patient. He also talked about the impact these silos have on communication and said “There is a little bit, there seems to be a bit of a breakdown in communication and actually Dr. [oncologist] the radiation oncologist was quite helpful about this. He said “no, no, we do in fact still function as separate specialties”. So it's not perfect, things still fall between the cracks and so on.” (P21 Elora).

Other participants commented on the perception of connection between the Juravinski Cancer Centre and the adjacent Juravinski Hospital. P15 from Hamilton spoke highly of how connected the two care environments were, when speaking about a time when her chemotherapy did not go as planned. She said, “when I was going through the chemo my platelets crashed, twice. So I had to be hospitalized. And they were right there, they were amazing. The first time was very, very scary but the second time I knew what was happening and they were there like immediately. So, I can’t thank them enough.” (P15 Hamilton). P23 of Brantford perceived the two health care environments to be rather disconnected, through her experience of getting a some blood work done. She said:

I have a complaint about the interaction with the JCC and Juravinski Hospital. The computers don’t talk. So for example, I had blood work that had to be done because I developed a blood clot so I’m working through the Thrombosis Clinic at the hospital and they wanted something done with some blood work. Well I brought it over here because I was having blood work done anyways and the clinic here said “No we can’t do that. You have to get the order through your oncologist.” I was like “You’re connected. The two are connected buildings.” So that was a problem. – P23 Brantford

C. Entry Ways

Different entryways to the Juravinski appeared to also impact how patients experienced the environment that the centre was placed in. As mentioned before, some participants, by preference or necessity, get dropped off and picked up at the main entrance of the centre. P14 from Hamilton commented on how congested the area around the main entrance gets, as some people idle their cars rather than dropping people off right away. She described:

Sometimes, at the front of the building where people drive up the ramp and drop people off, sometimes that’s not, controlled to well sometimes. Sometimes people are double parked and you’re kind of waiting in line a little

bit to, to get out and it's kind of congested there sometimes. It doesn't last very long but you know, it's you know, that's just about, and that's really not all that bad. It's not like you're sitting there, waiting for 20 minutes or half an hour, it doesn't happen like that. It's only just for a few minutes but it does seem to get very congested sometimes but I mean it's busy here so...

– P14 Hamilton

Similarly, P8 from Hamilton shared her experience of her niece dropping her off and having to wait to get out of that area. She described it as her 'worst time' at the centre and how the congestion can be particularly distressing. She said:

Actually today when I came, my niece was, she pulled up to let me out, and I was already out of the car and some woman was behind her, just laying on her horn and I thought, like what's your problem? This is not the emergency centre so if it's an emergency you shouldn't even be here, right? This is where you drop people off, right? And she [niece] couldn't get back out because somebody was in front of her, so this woman was just laying on her horn, like what's your problem. Yeah, it wasn't like she was gonna park there because she was leaving, she was going some place. But, that was the worst time

– P8 Hamilton

Despite these experiences, participants who mentioned using the main entrance described it as being 'convenient' for their arrival and drop-off by whoever drives. The drop off area by the main entrance allowed for travel companions and volunteer drivers to continue with their day and go find cheaper parking in a municipal lot. It was also beneficial to those who found it difficult to walk beyond the centre after a chemotherapy appointment. Choice of entryway (i.e. main door vs. side door) also appeared to depend on the nature of the visit to the centre. Participants shared strategies they would use to navigate their entry into the centre that depended on their schedule for the day. As mentioned before, visits to the centre often entail multiple appointments in different areas. P7 from Oakland talked about how her choice of entryway has changed and said:

The majority of the time, I come through the side door. Now, when I was coming for chemo I would come in through the front because I was going for blood work and just happened to be...now if somebody brings me and drops me off near the front of the door, obviously I come in through the front.
– P7 Oakland

D. Location

Participants were asked how convenient they found the location of the centre to be and many differed on how they assessed ‘convenience’. P1 from Simcoe considered the centre convenient because of the different parking options that were available in that area of Hamilton, while P20 from Stoney Creek considered it convenient because of where it is located on the mountain. She said, “I would say it’s very. It’s right here in the centre of the mountain and it should be easy access, north, south, east and west to come here.” (P20 Stoney Creek). P13 from Burlington considered the location ‘convenient’ because of how it organized care into one location. She said:

So, everything was here, everything was scheduled here. I had every treatment here. You know? Maybe I would’ve explored it more if I was doing like, well a few of my friends did half their treatments their and half their treatments here. Maybe it would be different, I would’ve explored Burlington more as far as their different resources, but I didn’t have to. – P13 Burlington

Other participants acknowledged that while they consider the location to be convenient, it could be because they live in Hamilton or at least close by and as a result recognized how it may not be convenient for others. For example, P10 from Hamilton said “I think, as a general, we are very fortunate to have a cancer centre this close. I mean personally, it takes me fifteen minutes to get here, I couldn’t imagine driving into Toronto everyday or people that come from far.” (P10 Hamilton). Similarly, P12 from Hamilton discussed how living in the city makes the centre convenient and said “The centre is

convenient in terms of the amount of time it takes me because I live downtown, so I just take the mountain access up and because I live near Bay St. so it's really easy to get here in terms of the access". (P12 Hamilton).

Those who considered the location of the centre 'inconvenient' cited having to drive through the traffic of the city as the main reason. As P4 from Greensville said, "it would be nice if there was a quick and easy way to get here, but there isn't. You just have to drive through the city and come through the traffic" (P4 Greensville). The frequency of visits, especially while actively on adjuvant treatment, was cited as a factor that further complicated the inconvenience of the location. Despite perceptions of 'inconvenience' some participants praised their experience of care and said they would overcome their perceptions and continue to attend the Juravinski Cancer Centre for care. P11 from Burlington expressed this sentiment best when she said "it would be nice to have it local [in Burlington] so if it meant giving up the phenomenal care I had here, just so I could be in Burlington, no I'd bypass that, thank you very much" (P11 Burlington).

E. Centre as a Reminder of Cancer Care Experience

Regardless of experience, participants showed gratitude for the centre and the care it provided. To some participants, the Juravinski Cancer Centre is seen as a good place for a difficult situation. As P7 from Oakland described so well:

this is one great place for people that are in a very stressful time in their lives and they do everything here to make you feel comfortable, and make you understand what's going on, and keep you informed. I honestly can't say enough, especially the team that worked with me, and are still working with me, they're just wonderful people. So that's, that's my comments.
– P7 Oakland

Similarly, P10 from Hamilton expressed her gratitude that such a place exists and

said “it’s a life altering experience, but you just, you know, thankfully you have a centre that can look after you. You have to be thankful it’s ...everyone’s working for you know, your best interest.” (P10 Hamilton). P14 from Hamilton furthered this sentiment and said “They’ve helped me through a very big step in my life and helped my get through it, you know. I’m happy to be, I’m happy that there’s a place like this for me to be. I wish there wasn’t a place like this and we didn’t have to use it but I’m pleased” (P14 Hamilton).

F. Parking

The most common ‘barrier’ and poor experience that participants talked about was parking in and around the Juravinski facilities. Parking was commented on by all participants in the study (n=23). Perceived ‘accessibility’ of the adjacent parking garages was probed by one of the questions in the schedule. Most participants had similar comments such as P11 from Burlington who described them as “fairly easy to get in and out of”. Few felt the opposite. P2 from Simcoe commented that “The elevators are out quite often” which can be particularly challenging because the garage has four floors. P16 from Arkell described the lot directly beside the centre as:

pretty old and rickety. It’s hard to, it’s falling down for one thing. It’s hard to, it’s nerve racking, you can see it’s all crumbling and those ramps are really tight. I drive a big van and it’s, I have Honda Odyssey and it’s, but other than that I mean, I don’t know it’s a parking lot, I don’t really, it is what it is.
– P16 Arkell

P23 from Burlington commented on the complexity of the paying system and said “It’s confusing learning how to pay for it. You go back to your car and then you come down and no you have to pay first.” (P23 Burlington).

Half of the participants commented on the poor availability of parking spots in the garages as well as the surrounding area. P11 from Burlington talked about how it can be rather stressful to search for a spot when she comes in for an appointment. She said “I have had the odd time where at Poplar, I’ve had to circle a few times, and then the stress level starts going, it’s like I have an appointment, I gotta get in there, where am I going to park?” (P11 Burlington). P15 from Hamilton furthered this sentiment by saying the availability of parking is an issue that reaches far beyond the garages belonging to the Juravinski Hospital and Cancer Centre. She believed the availability of parking is a constraint placed upon the patients due to the centre’s location. She said “I’m used to this parking, but there’s not enough parking. That’s the problem, the area doesn’t have enough parking. That’s you know, that’s not something that the hospital can rectify, it’s the area and it’s all over.” (P15 Hamilton).

Participants commented that the location of the centre provides multiple options for places to park, beyond the two garages managed by the Juravinski health care centres. This provides options for patients to park outside of the garages. P14 from Hamilton said “we’ve been very fortunate. We’ve always got a parking spot either in a spot on the brow at the back of the hospital or over on Upper Sherman. We’ve always gotten a parking spot there” (P14 Hamilton). Many other participants also talked about finding parking spots along the escarpment and down residential streets.

The most common negative experience about parking at or near the Juravinski Cancer Centre was the price of parking. 19 out of 23 participants made specific comments about the price being a negative aspect of their care experiences. P7 from Oakland talked

about how the cost of parking can be quite costly and impact her choice of where to park.

She said:

I am self-employed, my husband is self-employed. Once I had my surgery, there is no benefits, no nothing. So it is draining financially, we're coping, but...when you walk out of here it's you know, through radiation it's alright because ...well added up it probably you know? Well, I think "okay, can I make it a \$3.25 day because it's within the first half hour or .." [laughter].

– P7 Oakland

Participants were most critical of how the cost of parking 'adds up' throughout the course of care. P11 from Burlington described the cost of parking as the 'worst part' of her care. She said:

someone who hasn't got any income that's coming in and having especially radiation five times a week for six weeks, like it's a killer. It's absolutely brutal. Whether they can do something along those lines, for people who are having to come, because that was the worst part of it, I found.

– P11 Burlington

The parking garages at the cancer centre offer different parking passes that provide a small discount when bought in bulk. While these provided some relief to the participants, they still involve some strategizing. P11 from Burlington explained, "we ended up getting passes. We tried different types of passes depending on when I was going through the radiation versus the chemo, type of thing." (P11 Burlington). Some participants, such as P20 from Stoney Creek, believed that "if you're coming to the hospital for health care that [parking] should be free". P15 from Hamilton offered a different take on the cost of parking by highlighting how unfair the prices seemed for the family and friends of patients. She said:

I think it's outrageous what they charge to park for the stuff and to turn around and what they charge for patients and family... Well when one of their

family's in here and they're taking out their time to help and support to be there with that family member, and then turning around and having to pay the outrageous prices they have to pay for parking, I think it's going overboard now. – P15 Hamilton

Recognition of other people's ability to pay for parking was a sentiment also shared by P21 of Elora who shared his observations of fellow patients in the waiting room. He said:

fifteen bucks. We can [he and his partner], as it turns out, afford it, but a lot of people man, it's not...so you see them checking their watch and rushing out to put money in the thing [meter]. I don't know what the solution to that is. I guess, it seems strange that you have to finance some of the important parts of your operation [health care facilities] on the backs of patients, many of whom are, especially if they have cancer and are elderly, they just don't have a whole lot of cash... – P21 Elora

The majority of participants viewed the price and availability of parking to be a problematic aspect of the cancer care experience for themselves, other patients, as well as friends and family. Availability and even the need to charge, was considered by some to be a reflection of where the centre is located and the amount of people that use the hospital and/or cancer centre. Parking prices, in the garages or on the street, were viewed to be high as well as unmanageable over the course of care.

4.5.4 Micro-Environment

A. Appointments

The Juravinski Cancer Centre is made up of multiple clinic and supportive care areas for cancer patients. As previously mentioned, a visit to the centre can include multiple appointments throughout the centre. Appointment schedules appeared to be the main 'cue to action' for the uptake of cancer treatment and care at the centre. Interested in how the scheduling of these visits impacts the experience of care at the micro-

environment level, participants were asked about their appointment experiences at the centre. Participants commented on the complexity of their treatment schedule and how it had them coming to the centre at varying frequencies. P18 from Hamilton described her treatment schedule since her lumpectomy and said:

And then through the month of...the end of March and all of April, I had radiation. And then, starting May 16th, I've been here every other, well, every Friday for lab and doctor, no every other Friday, and then every other Monday for chemo. And then I started my Herceptin, so for one week I came three Mondays in a row. Yeah...well it's alright. And this is my last Paclitaxel, and then I will come every three weeks for Herceptin.
– P18 Hamilton

The theme of the clinics being 'accommodating' to patient preferences for appointments, also came up when talking about the convenience of visiting the centre. Participants appeared to be divided on how accommodating they viewed the centre. Some described the centre as "really good" (P23 Brantford) and "flexible" (P9 Hamilton). P23 from Brantford talked about how they make efforts to coordinate her appointments on the same day. She said, "if I had one appointment scheduled and then another appointment scheduled and it's like a day apart, if I call them, they will do their best to coordinate it so I'm coming one day." (P23 Brantford).

Others perceived the centre as not being able to accommodate their preferences. P14 from Hamilton talked about her period of radiation therapy and trying to get morning appointments. She said:

when I was going through the radiation, I did request morning appointments and the girl said she would try to accommodate me as much as I could, but I didn't, I didn't get much morning appointments, it was, most of them were early afternoon. Which kind of broke up my day a little bit which kind of, you know, she explained to me that they had to make appointments for 400 people a day, so. You know, I'm just one of the 400. – P14 Hamilton.

B. Familiarity with micro-environment

To further understand how the micro-environment impacts patient experience, participants were asked questions that drew upon their familiarity with the environment by asking them about their experience of navigating within and between the different clinics and departments. The majority of the participants reported that they had grown familiar with the layout of the clinic and departments over the course of their treatment. Repeat visits to the centre and the same clinics, increased the participants' knowledge of the layout and helped with their navigation. P11 from Burlington shared the same view that many participants had and said "I'm used to doing it now but the first time it's like am I going the right way?" (P11 Burlington). She also shared an experience where she was a bit too used to going to the same clinic that she did not notice the location for her appointment had changed. She said:

I had one mix-up when I was coming to see one of the radiation oncologists, cause the first time I saw him was in one clinic and then the next few times I saw him in a different clinic and then when I came back for my appointment I just assumed, I guess I didn't really read the instructions, but he was operating out of a different clinic so I just had to switch floors is all I had to do, but that kinda took me by surprise. – P11 Burlington

Temporary disruptions such as construction, also appeared to impact how familiar patients were with the area, as well as their experience of navigation. P15 from Hamilton talked about her experience of getting to the radiation therapy clinic and said:

they were doing construction down when I was here for radiation. So I don't know what it's like now. I haven't been back down there, but it was a little bit confusing at the time because you had to go through tunnels and bypass...so that was a little different, but I'm sure it's fine now. – P15 Hamilton

Some participants commented on how signage for the clinics made navigation easy

and said different areas in the centre were ‘clearly marked’. P8 from Hamilton explained that “everything is indicated everywhere like this is Clinic D, Clinic B you know” (P8 Hamilton). Participants also spoke about the availability and positive attitude of people who worked there to help them navigate the area when they needed assistance. P16 from Arkell talked about how she has never had any bad experiences navigating through the area because everyone is so eager to help people find where they need to go. She said “that everybody’s pretty ...you even have to look just a little bit confused and somebody steps right up “Can I help you? Can I direct you? Can I ...” So I’ve never had any frustrating experiences.” (P16 Arkell). Some participants went further to elaborate that not only are they appreciative of people’s willingness to help, but that ‘willingness’ becomes a source of comfort as they know they can always get assistance when they need it. P5 from St. Catharines explained:

If I go to some place that I haven’t been before, I know I’ve always got the great, all the volunteers are great and they go out of their way to direct you to wherever you need to go...they’re most anxious to help you. All you have to say is ‘Do you know where...’ and they’re right on it, so I think they’re a great bunch of people. – P5 St.Catharines

For some, as P18 from Hamilton pointed out, having someone with you who is familiar with the centre can ease the burden of navigating and finding your way. Her sister, who works at the cancer centre, comes with her to every appointment. When asked about how she finds navigating the centre, she explained:

If I had to do it on my own, I’d have to think about it. But because I’m with her [sister], she knows her way around so I didn’t have a problem. But you know something? If you ask someone that works here, they’d be very helpful in letting you know how to get around. – P18 Hamilton

Easing the challenge of navigation is the organization of the centre. Two participants made it a point to comment on how organization impacts the experience of care at the centre. P21 from Elora described the Juravinski Cancer Centre as “well organized and mostly integrated functioning centre that was fairly welcoming”. P4 from Greensville said there is ‘no hassle’ at the centre, when she explained:

Well the most surprising thing was how well orchestrated everything was. It was, I mean, you didn’t have to wait and there was no hassle. It was, it was very smooth, compared to other doctor’s office visits or clinic visits, it’s much streamlined, much more streamlined. – P4 from Greensville

Navigating the centre and perceptions of its organization appeared to impact patient experience at the micro-environment level. Clear signage, helpful staff members and familiarity with clinics appeared to make more positive experiences of time at the centre.

C. Waiting: Rooms and Time

Participants were asked about their time spent, after check-in, waiting for scheduled appointments as well as the areas they waited in. The purpose of these questions was to understand the role of waiting room environments and wait time, in the patient experience of receiving care at the centre. Most participants made it clear that time spent waiting for their appointments made up a large part of their experience at the centre. P2 from Simcoe believed it could make the difference between a ‘good’ and a ‘bad’ day. She said:

Today has gone good. Yes, probably one of the better days... Because the waiting time was a lot less...it would be nice if we didn’t have that two hour wait. It’s discouraging when you come. Like, we’re here for 8:30 this morning and normally it’s been 6 o’clock by the time we get home. And that’s a long wait... – P2 Simcoe

When asked about her experience so far on the current day (i.e. ‘How has today gone so far?’), P1 from Simcoe also brought up how ‘time’ can impact experience. She said “Good...Everything’s been on time. You know we got here right on time and everything’s gone (*snaps fingers*) right on time, tickety boo. We’ll see how we get back there [chemotherapy] and waiting time.” (P1 Simcoe). Waiting in an area surrounded by other patients can also be an environment that induces anxiety for some patients. P1 from Simcoe who was completing chemotherapy at the time of the interview said about her time in the waiting room “I am starting a new drug today, so, you know, it just makes you a little anxious.” (P1 Simcoe). Of all the ‘types’ of appointments at the centre, chemotherapy has the longest wait time and the largest and most used wait area. When she talked about waiting for chemotherapy, P18 from Hamilton said “It feels longer than what it really is, but I think it’s because you want to get it over with you know? Just get plugged in and go [laughter].” (P18 Hamilton).

Participants also expressed that checking-in, on time, for your appointment and having to wait became an expectation for them. While the length of the wait can vary, the actual need to wait was consistent. Referring to her chemotherapy appointments, P1 from Simcoe said “pretty much the norm for me waiting is about two [hours] to get in for my chemo.” (P1 Simcoe). Some of the participants talked about the wait time being different depending on the clinic within the centre. Those who had been coming to the centre for years most often noted this. P5 from St. Catharines who finished her radiation and chemotherapy and goes to the centre for follow-up care, explained how her wait time has changed over the years with her treatment schedule. She said:

When I first started coming here, I can remember waiting for an hour or over an hour...but I can't say that's happened in a good long time now. I would say, I don't even know if I wait for half an hour. Like once you get into the lobby, the main area, I don't think I'm there any more than fifteen minutes maybe? You know? And then you get into the examining room and then the nurse comes, another few minutes for Dr. [Name]...no, I don't think I'm in and out of the whole procedure for more than an hour...or less, sometimes.
– P5 St. Catharines

Arriving to the clinic and seeing the number of patients in the wait room can also served as an indicator to some participants, about if and how long they would be waiting. Participants commented on lineups and crowded waiting rooms, especially on the Monday after a long weekend, being indicators of longer waiting times. As P21 from Elora explained:

So for blood, it's anywhere from one minute to 15 to 20 minutes and we've discovered, quite by accident, that when your chemo's on Tuesdays then, if it happens to be a Tuesday after a long weekend, which it has been now, twice and it will be one more time, you're just out of luck because you get everybody from Monday bumped into Tuesday, of course some into Tuesday some into Wednesday so it's a longer, much longer wait. So we waited up to two-and-a-half, two-and-three-quarters hours and it's been as short as an hour. – P21 Elora

Being able to 'anticipate' the wait also appeared to impact the experience of patients in the waiting rooms. P22 from St. Catharines explained how being told to 'expect a wait' can ease the experience of waiting. She said:

We were told to expect a long wait, which we appreciated because I would bring along music or a book, we just knew we were in for a wait...there's always a sign "extra long wait" for us that was normal but we were prepared for it so, you know we just kind of rolled with it. – P22 St. Catharines

With the opposite experience, P2 from Simcoe shared a time where she was told there would not be a wait because her chemotherapy length was longer than normal. She explained how they ended up waiting and it led to a poor experience:

I knew it takes three hours for the chemo, and the doctor had said to me “you’ll probably get in right on time”. Because it is a three hour [appointment] getting that chemo. So the first time we came all gung-ho thinking “oh great, we’re going to get in, we’re going to get in, if we get in at 10 o’clock we’re going to get out of here at a decent time”. And we didn’t get home ‘til 6 that night because we had to wait. And they kinda indicated “no, you’re more up to getting in on time” So that was, yeah, our expectations were we were going to get out early and it was later than ever. Yeah, that was kinda disappointing – P2 Simcoe

Participants said that the nature of their centre visits (e.g. follow-up with an oncologist, chemotherapy appointment) made their waiting room time vary greatly. As P14 from Hamilton explained, a follow-up or review appointment with an oncologist has a relatively shorter waiting time than a chemotherapy appointment. She said:

Well if I’m just going to Clinic D to see Dr. [Oncologist] or Dr. [Oncologist] I’m usually in to see the doctor with a half an hour of my specified time, but it’s a different story in the chemo suite. It can range anywhere from waiting for maybe a half an hour to maybe three or three and a half hours to get in.
– P14 Hamilton

A small group of participants shared instances where they had an unexpected ‘no wait’. Occasionally, appointments run ahead of schedule and depending on when a patient arrives, they can be taken in before their actual appointment. Patients who had experienced this appeared to appreciate when this happened and expressed how it made the appointments a more positive experience. P22 from St. Catharines explained “If I get there [radiation clinic] early, they’ll just kind of slip me in and get my appointment through if the next person’s not there. So, sometimes I’m leaving before my appointment even starts. That didn’t happen today, but you know, they were just a little busier today” (P22 St. Catharines).

What also emerged from conversation on wait times was a general understanding

amongst most participants about why appointment delays occur. As reported by the participants, the chemotherapy area has the longest and most frequent wait times. The areas where treatment takes place as well as the waiting room, are all open spaces where patients can see other patients. As a result, participants incorporated what they observed in treatment and waiting areas, into their understanding of why wait times occur. P2 from Simcoe talked about observing “chemo spills, they had a few of those, people on holidays, a patient has a reaction so they spend longer with that patient” (P2 Simcoe). When talking about wait times, P11 from Burlington said “from what I witness, that’s where there’s a patient issue, people not taking their meds when they’re suppose to take their meds, before they go in and then they have to wait, it’s just ...kinda pushes everything back” (P11 Burlington).

What became clear was that none of the participants thought that delayed appointments and long wait times were the fault of any of the staff members and health care providers. When asked about her wait time, P23 from Burlington said, “I know that’s not necessarily the fault of the staff, I know there’s problems with the pumping system sometimes...” (P23 Burlington). P21 from Elora also said “We understand very readily why there are waits at the chemo suite, we know it has nothing to do with the nurses playing cards and so forth. It’s just the nature of the types of, I mean my veins are sometimes, are very uncooperative.” (P21 Elora).

Having a companion in the waiting room appeared to make for a positive experience. As P12 from Hamilton described:

Well, I was lucky that I had a friend come with me every single time. One of my girlfriends, you know, would come with me. So you know, I had

somebody to chat with ...we'd chat and we'd read. But there were lots of people who sitting there all by themselves and looking pretty dejected about having to sit there. – P12 Hamilton

P15 from Hamilton talked about initially coming by herself but later she started bringing people with her. She said “When I came here before and found out, I was by myself. I don't recommend that. But then after that I had support from my family, my friends, my grandchildren.” (P12 Hamilton).

Participants were also asked about their experience being amongst other patients while waiting for their appointment. The lineup of chairs in the chemotherapy waiting room was cited by one participant as a way to foster conversation amongst patients. P14 from Hamilton said “you really can't help but to start talking to someone in there because of the way the seating is and everything and I think that's good sometimes, to talk to other people.” (P14 Hamilton). Others expressed how the waiting room provides a way for patients to learn from each other. P7 from Oakland shared that “The one day, somebody liked the way I wore my scarf and she wanted to know how I did it. So the next thing you know it became like a whole area, I did help, I showed her and then another woman and then the other woman.” (P7 Oakland). P9 from Hamilton, however, appeared to have a different experience with conversation in the waiting room. She said “They're [other patients] quite quiet. Everybody more or less keeps to themselves unless they strike a conversation with another patient saying “Oh what are you doing here?” that kind of stuff but usually they're pretty quiet.” (P9 Hamilton).

The experience of spending time in the waiting rooms can be made up of different ways to occupy time. Half the participants said they always thought ahead and brought

‘things to do’. Most common was bringing a book or periodical to read while waiting, and in chemotherapy, bringing food was also common. P21 from Elora explained at the chemo suite I bring lots to read, I have an iPad that I can read stuff on or I have books. So we [him and his partner] read, we bring a lunch we sit and eat lunch together.”

(P21 Elora).

Others commented on the availability of ‘things to do’ in the waiting room, that are provided by the Canadian Cancer Society as well as the cancer centre. P1 from Simcoe explained that

there’s all kinds of books there which I have some at home that my sister-in-law has to donate and all kinds of magazines. Like, I’m impressed by how much they provide here. That’s awesome. Like, my husband picked up a book the first time we were here and read it and we brought it back so somebody else could read it. Yeah they definitely provide you with lost of literature which is good. Yeah they’re really good with that. – P1 Simcoe

Continuing the conversation of wait room experience, participants were asked about what they thought about the physical design of the waiting room and how it translated into their experience of waiting. Some participants said there was ‘good scenery’ in the chemotherapy waiting area. P23 from Brantford mentioned the impact of the nature scenes that are displayed in the different areas. She said “I actually like the video screen that is up with the nature, but I’m an outdoor person so I find that very calming.” (P23 Brantford). P22 from St. Catharines compared the chemotherapy area to the radiation area and talked about the difference space and lighting can make on the overall experience. She said:

I think the chemo suite’s really comfortable. Like I was impressed by the size of it and the amount of room and it’s nice, like I appreciate how bright the places are and it’s a really nice atmosphere. I do find the radiation waiting

area a little bit tight, but you know because you don't have to wait as long, is not as big of a deal. – P22 St. Catharines

Criticisms of the waiting areas centered around noise level and the amount of people. P10 from Hamilton talked about the amount of people waiting for chemotherapy and the occasional shortage of chairs. She said, “There was one seat left for me to sit and I feel badly for those that are coming behind me because there was nowhere for them to sit. And if I give my seat up, you know I don't mind, but where would I go? I think seating is an issue and sometimes noise.” (P10 Hamilton). Noise level also becomes an issue in crowded waiting areas. Patients are given a number when they check-in for their chemotherapy appointment, and are called by this number when there is an available machine. P2 from Simcoe talked about how difficult it can sometimes be to get your number. She said “It's always been full when I've been here and ...you can't hear them call your numbers sometime so you really have to listen for them to call the numbers, especially if you're at the far end of the room.” (P2 Simcoe). Similarly, P18 from Hamilton said “Yeah a lot of people, especially older people, can't hear them [receptionists]. They call numbers, three, four times.” (P18 Hamilton).

D. Privacy

Patients were asked if they felt the different areas in the cancer centre were conducive to their preferred levels of privacy when it came to interacting with health care providers and staff members at the centre. Participants provided a mix of responses in this area of the interview schedule. Some believed that their interactions were ‘private enough’ and that people made efforts to have it that way. P1 from Simcoe discussed her interaction with a nurse the day of the interview and said “it was quiet enough and private

enough in there because I had to talk about you know, some new drugs” (P1 Simcoe). P12 from Hamilton commented on the numbering system in chemotherapy and said “They call you by number, they don’t address you by your name, which I guess, puts a lens and a level or privacy to it.” (P12 Hamilton).

More than half of the participants believed that there was no privacy during most of their interactions. This, however, was not necessarily viewed as a negative experience. As P1 from Simcoe said about the questions her and her partner had for their nurse:

For us it was like, you know what everybody here is doing the same thing, getting the same thing, so for us it was like, it didn’t bother us because you’re all getting a treatment of one sort or another, maybe not the same actual chemo but we still felt fine talking. Yeah, I didn’t feel like we needed to go into a private area or anything like that. – P1 Simcoe

Most of the participants who felt there was no privacy at the centre, also felt like there did not need to be privacy. It became apparent that participants felt a certain level of comfort being in a cancer centre because everyone who visited either had cancer or was with someone who did. Being in waiting rooms with other cancer patients and their loved ones, appeared to decrease the need for private areas to discuss certain matters. P18 from Hamilton said that she does not pay attention to the people around her when she needs to discuss any issues or questions she has. She said “You know, you kind of tune out when you’re going through that” (P18 Hamilton).

Issues of a lack of privacy came about when talking specifically about medical procedures at the centre. P12 from Hamilton shared an experience from her radiation therapy period of treatment where the presence of a technician compromised her sense of privacy in the treatment area. She said:

when you're getting your radiation treatment ...sometimes the machine would stop and... the tech support person goes into the control room where they do this and they put some code in or something and then the machine will start again. So there was a couple of times where, and you can't move, you can't move a millimeter because then they would have to start the set up all over again and you're lying on this very uncomfortable bed, and I thought it was fairly frequent, and the thing about privacy though, is you're on a monitor so they can see you, and the person who comes in, the tech, I've never asked them if they turn the monitor off, I don't think they could because they have to be able to see me, the person who comes in as the tech, they can see you and I used to have to keep saying to them "could you please pull my gown over, you know, this side because you don't need to have my gown, like I don't need to be lying there completely exposed," and most of them were pretty good about it, but they have to have a tech do it but it's still a non-medical person that's coming into the room. I found that more irritating in terms of privacy, than anything else actually. – P12 Hamilton

This sense of feeling 'on display' during treatment was also shared by P16 from Arkell. The layout of the treatment area for chemotherapy is a large room with reclining chairs and gurneys along the perimeter. While this layout appeared to be a source of comfort for some, it can also create a negative experience for others. She said:

I felt like in those early days I was the one people were looking at saying "Oh that poor person, she'd bald, she's..." so I didn't like being on display in those days... and then I was in the circumstance where I was looking at sick people and I was feeling really sad because I remember being like that and I knew how bad they were feeling, so I didn't like to see that. Like it didn't make me feel any better seeing these poor people, you know? ...I hated that giant big room where you can see all these people, because you're so freaked out and so scared and to know that they're somebody feeling the same way, it's overwhelming. I wish the chemotherapy could've been way more private. I would've wanted to be in a room by myself, with a TV and whoever I brought for my support. I don't want to see people all lying around on their beds...that was probably the most disturbing for me. You're like sitting in a giant gymnasium. It's like a big sick bay...and you're looking into people's eyes when they're getting this stuff and you, you know because you're going through it, what they're going through and that was, exhausting. – P16 Arkell

E. Information Needs

For many, the micro-environments of the cancer centre have become an

education environment where patients can learn and have their information needs met. As P5 from St. Catharines explained about the centre:

[The health care providers] could explain everything to me, either verbally or through written information, directed me as to places to go for wigs and prosthesis and things like that...chemotherapy, I understood, I totally understood my choices there, how they would...what the pros and the cons were about my choices, what would happen with the medication, as far as how I would feel afterwards. I was totally aware of what was going to happen to me and what would happen afterwards and if somebody wasn't verbalizing it, I had pamphlets had all kinds of information. – P5 St. Catharines

Familiarity with the environment inside the cancer centre as well as the health care providers and staff of the centre, appeared to provide a source of comfort for patients to ask questions they have. With routine visits to the centre, patients gain familiarity about where they should direct their questions. P12 from Hamilton talked about getting details from her oncologist on the main floor and asking radiation-related questions to her therapists in the basement. She said:

my doctor, fantastic, I mean he has his spiel if you like and it's basically you know, he said "are you a detail person?", I said "yup" so you know he has, like he'd tell the next person who is detail, basically the same kind of thing because it's, you know, "you're gonna have this kind of treatment, this is going to happen, blah, blah, blah, blah". The radiation therapists were all very forthcoming with their answers. – P12 Hamilton

Even though they felt comfortable to ask, some participants said that they did not discuss issues or ask questions because they would simply forget what they needed to know. For some, such as P22 from St. Catharines, the waiting room area and the initial minutes of being in the examining room, is an opportunity to reflect and try to remember any questions. The Interactive Symptom and Assessment Collection (ISAAC) is provided in the waiting area and is usually done after a patient has completed their check-in. As.

P22 from St. Catharines shows, this tool can help patients to remind themselves of some of the symptoms they have been having at home, right before meeting with their doctor.

She said:

even those surveys [ISAAC] which we do before, they have us do the survey. I appreciate those because it also helps you sit and think before you go into the doctor. Like remind you of things [laughter]. Because sometimes I go over a two or three week period, you might have forgotten oh yeah, I might not feel this now but I did, so before you see the doctor it helps to remind you where you've kind of been in the last, since the last time you saw the doctor. So I found those helpful. – P22 St. Catharines

When asked about 'sources of information' at the centre, some participants cited examples of material throughout the centre. Some participants such as P22 from St.Catharines spoke about the centre being "good a posting things and I'm a person who would read stuff like that" (P22 St.Catharines) when referring to workshops. Similarly, P9 from Hamilton talked about not needing to request information and said "Sometimes I will walk by and there's little brochures and I pick them up and if it catches my eyes, like the Life After Breast Cancer that they're having in September, that kind of stuff. So you really don't, I don't specifically have to ask. They're always willing to give you information" (P22 St. Catharines).

At the centre, there is a library for patients to use and find material on their diagnosis and treatment. Use of this learning environment appeared to vary amongst participants. Those who did say they have used it appear to be highly satisfied with their experience as well as the material they can take away. P18 from Hamilton talked about her experience of using the library and getting information from the librarian, to use at home. She said "The library here is very helpful, they have tons of books and stuff like

that, we have visited there before. I go to the cancer dot, oh you know what, I don't know it off the top of my head, sorry, but she gave me Canadian sites. And that's what I'm looking for, Canadian sites." (P18 Hamilton). Reasons for not using the library ranged from not knowing it existed to simply not having the time. As P2 from Simcoe explained "usually by the time we're through here [chemotherapy], we just want to go home. You know what, I've never been in it..." (P2 Simcoe).

F. Sources of Comfort

At the micro-environment level, participants cited aspects of their experience that provide a critical level of comfort to their time spent at the centre. 'Familiarity with place' and the idea that, with time, you grow to know what to expect, appeared to impact the patient experience of being inside the centre. P7 from Oakland described this familiarity and said:

Not that I feel this is my second home but, by all means I'm feeling more comfortable and there's familiar faces, you know? Which you know, whether it be staff or even patients, you know, who are coming. A lot of familiar faces and there is something to be said about doing something repetitiously, you know? Because yeah it's not as a frightening experience as it starts out to be because you know where everything is, you begin to know the people and you find it, it's not as horrible that...it's much easier to handle when you know what you're expecting than wondering what to expect. So everything's been good. Has it been a blast? I wouldn't say...I wouldn't go that far [laughter].
– P7 Oakland

4.6 Perceived Barriers in the Social Environment

Aspects of the social environment also appeared to impact the way participants experience their breast cancer care. 'Anticipated experience' for the centre was a theme that emerged when discussing the period of time between a participant finding out they needed to go to the centre and their first visit. P22 from St. Catharines described an early

interaction with staff at the centre and how the positive experience of that only continued when she go to the centre. She said:

from the time that they called to say “You’re coming here, here’s the directions...” like the people on the phones were great, like they’ve always been pretty good and then our first meeting here, they kind of find out what your needs are and then there’s people in place, it seems right away, to kind of deal with any issues you might have like insurance, drug coverage and things like that. So yeah, I mean we were just blown away, from the beginning, of how good the care was here. – P22 St. Catharines

As mentioned when talking about the ‘community environment’, some participants expressed that their experience of care in the communities shaped their expectations and experience of care at the centre. For P8 from Hamilton her experience with a social worker in the supportive care department was relatively much better than the experiences in her community. She highlighted how the quality of interaction she has at the centre has encouraged continued uptake of supportive care at the centre. She said:

like my visits with [Social Worker] as well. Like, she never ever cuts me short. I know there’s sort of a limit on time you have, I mean you can’t sit here all day because there’s other people, right? But it’s not like ‘Hey, sorry, you’re finished, now go’ because there are other people who do it that way. And no, she’s not like that, she’s very, very good. I like her and I’ve been offered by my doctor in the office that she’s in, they have counseling as well and I prefer to come here. – P8 Hamilton

‘Other people’s attitudes’ also came about as a way the social environment impacts the patient experience in physical environments of care. P1 from Simcoe talked about positive experiences at the cancer centre and in the different treatments areas because “nobody makes you feel like ‘oh you’re sick’. You know? It’s not that.” (P1 Simcoe). When speaking about coming to the cancer centre, P16 from Arkell explained how the staff and providers make for a good experience of being there and said “I’m constantly

amazed by how pleasant everybody is. It's kinda weird to have the worst experience of your life but it's kinda fun to come here because everybody's so attentive, so it's a strange mix of emotions." (P16 Arkell).

The relationships people built at the centre provided a great source of comfort for participants who were in treatment. Most notable was the praise participants had for the nurse and Canadian Cancer Society volunteers in the chemotherapy suite. Participants explained that the anxiety and side-effects felt by completing the chemotherapy, were eased by the great attitudes of the people they encountered there. P1 from Simcoe explained the comfort she felt with her nurses and said:

Those chemo nurses, I have to say are fabulous nurses and I always make sure that I compliment them, because you know what? They're in there doing such a fabulous job and I always tell them, I say, because the one lady said to me "You know what? I'm happy to come and do my job because I know that I am helping somebody" and I said "absolutely, there's no reason to be in here, being unhappy, because you're in here doing something wonderful for me" and that's what she said "I feel like, I'm doing something wonderful for you because I feel like I'm helping you get better" and she said "I love my job!". And isn't that something wonderful to hear for someone sitting there saying "I love my job because I am helping you." – P1 Simcoe

P7 from Oakland praised her interaction with volunteers during her chemotherapy and explained how they fostered such a positive atmosphere for the suite and most importantly a good experience. She said:

the volunteers, I mean some of them are a hoot, you know? 'Oh yeah, you're getting apple juice? You know you look more like a Merlot kind of person' [laughter]. And there was one elderly lady that, and I look like the type, so she would tell me like you know jokes? So whatever, which just makes it all for a pleasant experience for not a very nice disease – P7 Oakland

4.7 Perceived Benefits

To predict the likelihood of action, the HBM considers how people perceive the benefits of completing health actions such as adjuvant treatment and follow-up care. This section of the model focuses on how someone perceives the feasibility and effectiveness of taking up a course of action. While the perceived barriers represent the ‘costs’ of recommended health actions in cancer care, this dimension represents the ‘benefits’ that people consider in their analysis for deciding on taking action. P13 of Burlington talked about the benefits of making lifestyle changes recommended by different health care providers. She explained:

You know, if you’re taking better care of yourself, you know, from what I’ve heard cancer feeds on fat. Cancer feeds on sugar. So if you had some classes where you know, a person that’s, I mean, I lost 17 pounds. My doctor said “you know what, it might be a good idea for you to lose 15 pounds”. Why should I lose that 15 pounds? Go to a class that tells you, you know, cancer feeds on this, some classes that you can learn to take better care of yourself. Not a health club. Not you know, just where you can go and get information on that stuff. Alternative care. – P13 Burlington

Similarly, P12 from Hamilton shared the same view on the benefits of diet changes, but felt that the supportive care environments as well as the clinical environments involved in her care, did not do anything to encourage this belief. She explained:

Nobody [at the centre], nobody has talked about diet. The only time I ever heard anything about diet was at the chemo education class which happens an hour before your first chemo, which I don’t, I think it’s wrong. I think it should be the week before or something so if you do have other questions, you can pose them, hopefully, before you go for chemo or you have time to digest the information and it doesn’t seem like, okay you go and sit in class and you hear this stuff and you go and get chemo. I think they mentioned something about sustaining a balanced diet or something or you know, sometimes, no it wasn’t that. Sometimes people have issues with taste and

stuff like that, or nausea, but nobody's really talked a lot about diet.
– P12 Hamilton

Overall, the 'perceived benefit' that appeared to be the most influential in getting participants to continually attend the centre for treatment, was the perceived effectiveness of medical treatment. P1 from Simcoe explained her view of her medical treatment and said "You know what... I'm coming here to make myself better so it could only be a good experience. I have a good positive attitude and you have to do that right? In order to get better, you have to have that positive attitude" (P1 Simcoe). P5 from St. Catharines talked about the trust she had in her doctors and said:

I've always been somebody who's put my faith in my doctor and doctoring staff. You get that good feeling, you either don't have a good feeling about your care caregiver and you want to move on or you do have a good feeling and you wanna stay and you trust them to be giving you the information that you need, which has been the way I've always felt. – P5 St. Catharines

The perceptions participants had about the benefits of recommended lifestyle change and medical treatment appeared to impact not only the patient experience in their care environments but also continued uptake of health actions such as diet, exercise and adjuvant therapy. Participants recognized that the health recommendations given to them held great benefit for their own prognosis and became a push to overcome any perceived barriers of getting treatment and adhering to other recommendations.

4.8 Self-Efficacy

After applying the HBM to identify the factors involved in predicting the uptake of recommend health action in cancer care, consideration of patients' perceptions of self-efficacy is necessary. This component of the analysis, from Social Cognitive Theory,

considers a patient's conviction that they can successfully carry out the health behavior required for an outcome. No question in the interview schedule directly asked participants about their personal beliefs of being able to carry out recommended health actions. Themes of self-efficacy still came up as participants talked about the importance of 'being your own advocate' and having a 'circle of support'.

For many, their 'circle of support' made up of friends and family was critical to overcoming challenges of travelling to the centre and having emotional support for the events of a visit to the centre. P11 from Burlington talked about the importance for patients to build their own circle and said:

you kinda build your own support group. People that can be available for driving type of thing, or just people to talk to and somebody to check in with, you know, another friend that I walked with on a regular basis. It's was just more about building your own little circle to me. And family, absolutely.
– P11 Burlington

Participants believed that the success of treatment and care was ultimately their own responsibility. Whether it was getting questions clarified or seeking out resources, the majority of participants held the view that it was their responsibility to do so. P23 from Brantford explained: I've been quite an advocate on my own in that. So I write down questions that I think of while I'm away and bring them in and they're very good at going through the list and answering them for me so. Because chemo brain, I would forget half of them" (P23 Brantford). Similarly, P21 from Elora talked about his belief in a patient's role and how it is the most important factor for successful treatment. While he credited the centre for encouraging this he also believed that they needed to make greater strides to allow patients greater access to information and involvement in decision-

making. He said:

the patient should be a full and active participant. Now if they don't want to see results and look at the records, that's fine, they should have a right of access without any question... I'm not your average patient but many of your average patients are actually quite bright, involved who wanna know about themselves, it is their body so, the cancer centre needs to get with the 21st century, on that issue. When it's all finished and done, I'm probably, in a very gently way, will raise it with them. It needs to change...You want them [patients] to have access to their records because they're the people who are going to help save your butts. Really, seriously, they'll notice things and you know, that's been my experience over and over. Patients want to help us [doctors] and we're just not very comfortable letting them help us. You know, it's, I sort of get it but I mostly don't get it. I cannot understand why we wouldn't tap into every possible source of intelligence, goodwill, energy you know? – P21 Elora

Perceived self-efficacy to be successful at carrying out recommended health actions is important for patients to continue to seek and uptake care, as it builds their confidence that they can. While patients may see the benefits of treatment, supportive care and follow-up care, it is their overall belief that they can overcome any perceived barriers that will ultimately lead to their initial and continued uptake. Support circles and belief in being one's own advocate appeared to be critical to participants to believe that they can successfully pursue and undergo health recommendations.

4.9 Chapter Summary

This chapter presents the results of data analysis. The qualitative data was organized using the main dimensions of the Health Belief Model as well as Social Cognitive Theory to understand the role of different care environments in the initial and continued uptake of breast cancer care. Perceived susceptibility and perceived severity of breast cancer diagnoses appeared to be a motivating factor to seek out treatment and follow recommended health actions provided by health care providers. Belief in one's

diagnosis and seriousness of leaving the diagnosis untreated appeared to shape how participants viewed the importance of seeking health care at the Juravinski Cancer Centre. Acting upon the advice of others as well as having a structured schedule of care appointments emerged as the main ‘cues of action’ for participants to go to the centre.

‘Barriers’ to care and continued uptake of recommended action were identified at four geographical scales. When participants are at home, away from their health care providers, following complicated prescription schedules can pose a barrier to adherence. The cancer centre’s ‘phone-in’ service as well as the provision of written informational material, appeared to be a way participants could overcome this barrier and continue with their care in between visits to the centre.

Travel to the cancer centre appeared to be aided by having a personal vehicle to complete the travel and was facilitated by travel companions, volunteer drivers and familiarity with the travel route. Negative travel experiences were mainly shaped by traffic and construction. The reputation of the Juravinski Cancer Centre was highlighted as a way for participants to become familiar with the centre and also shaped some of their care expectations, before their first visit to the cancer centre environment. The exterior environment of the cancer centre impacted the patient experience of participants, mainly because of the parking availability and costs. Having the centre located away from their family doctor also impacted the participants’ care experiences because of the lack of coordination and communication between their different providers.

The micro-environment, made up of the different clinics, appeared to have the largest impact on the patient experience of participants. Familiarity with the environment

was something most participants said grew over time and eased their experience of navigating the different areas of the centre. Privacy, for most, was not an issue in the micro-environment as many participants felt a sense of comfort and ease being around other cancer patients. Noise level and amount of people in treatment waiting rooms, however, was raised as a concern for some participants who described them as ‘too crowded’. Attitudes of other people as well as the anticipation of cancer care experience appeared to ease the patient experience of participants as the caring attitudes of nurses and volunteers made for a pleasant patient experience. Patient perceptions of the benefits of treatment and care as well as their ‘self-efficacy’ to complete it, were also highlighted as driving factors behind the continued uptake of health care services.

Chapter Five

Discussion and Conclusion

5.1 Introduction

This chapter begins with a discussion of the identified themes that impact health actions in cancer care. This section then moves to discuss the perceptions of barriers that exist in the physical environments of cancer care, drawing from patient experiences of the journey to care, care in community settings, as well as the placement and internal organization of the Juravinski Cancer Centre. The social environment that factors into the experience of received care is then discussed to create an understanding of how attitudes and interactions impact experiences of treatment and supportive care. A discussion of patient beliefs in cancer care then follows to highlight the role of personal perceptions in promoting and cuing health actions. The contributions of the study and policy implications of its emergent results will then be outlined to identify the theoretical, practical and methodological impacts of the research. Lastly, study limitations and areas for future research will be discussed.

As identified in the literature review (Chapter Two), the purpose of this study falls within the research agenda of health geography and incorporates a multi-disciplinary body of literature in its understanding of patient experiences of care. Patient satisfaction, adherence to cancer care, the role of the patient in the experience of care, as well as the different environments in which cancer care occurs, were areas of the literature that this study drew upon. The study identified ‘care environments’ within communities where patients live (e.g. support groups, patient’s homes) and the micro-environments of the

Juravinski Cancer Centre (e.g. chemotherapy suites, follow-up clinics, the supportive care department). The geographic location of the cancer centre (e.g. placement in the city, parking facilities), as well as the environments involved in the journey to care are also focused on to create a deeper understanding of the cancer care experience.

Rosenstock's (1966) Health Belief Model (HBM) and Bandura's Social Cognitive Theory comprise the theoretical framework of the study, to understand the role of experiences in care environments shaping attitudes towards continued health actions such as adherence to treatment. The HBM hypothesizes the relationship between a patient's perceptions of actions and its resultant outcomes. Broadly speaking, if the outcome of a health action outweighs its perceived challenges, then a patient will continue to take up the health action to benefit from the perceived outcomes. Looking specifically at the social and physical environments involved in cancer care, allows for consideration to be given to modifiable aspects of care that can be conducive to encouraging continued usage of cancer treatment and supportive care services.

5.2 Cuing Cancer Care Health Action

The perceived severity of a breast cancer diagnosis was identified by the participants as a main 'driving force' behind the initial and continued uptake of cancer care at the Juravinski Cancer Centre. The willingness to keep up with appointment schedules and traveling varying distances to the centre appeared to be encouraged by how severe a threat participants believed their diagnosis to be to their health. Participants also discussed belief in their cancer returning or not responding to treatment, especially those in follow up care, as causing them to adhere to prescribed care.

Overall, the participants identified their breast cancer diagnosis as posing a significant threat to both their present and future health. Participants demonstrated a strong belief that medical treatment and prescribed care is critical for treating their cancer, and expressed a strong faith in the cancer centre being able to provide needed health services for their present diagnosis and in the event of a recurrence. As studied by Hall and colleagues (2008), knowledge about breast cancer and perceptions of health care are associated with how patients view their diagnosis and also the development of a fatalistic attitude towards the diseases. Breast cancer fatalism – the belief that cancer is a ‘death sentence’ – has been shown to result from inaccurate knowledge of survivorship and the treatment experience. Belief that the treatment could be worse than the disease itself can lead to such fatalistic attitudes amongst breast cancer patients (Hall et al., 2008). Participants in this study appeared to not have such fatalistic attitudes; they appeared to have great faith in the cancer centre and treatment experience, as well as the potential impact it will have on their health outcome. The level of comfort and gratitude that participants expressed for the centre suggest that the cancer centre environment factors into the positive outlook participants have towards their disease. This outlook translates into the belief that treatment could lead to survivorship, encouraging continued uptake of care at the centre. It can be said that the perceptions participants have of their disease and the centre can help to prevent the development of fatalistic attitudes amongst the participants.

Belief in diagnosis and the perception of the severity of leaving the disease untreated also appeared to translate into a strong adherence to prescribed medication

schedules and lifestyle changes, for participants when they were in the care environment of their homes. Participants explained that their perceptions of the disease and rationale behind taking prescribed medication encouraged them to follow prescribed health actions when outside the cancer centre environment. For some, knowing that they would need to take the medication for years after their diagnosis to treat their current diagnosis and to prevent recurrence, was enough of an impetus for them to take their medication and to also ensure they understood their instructions.

The component of ‘time’ as a factor to increase adherence to breast cancer care diverges from the arguments of Kirk and Hudis (2008) who believe that adherence to breast cancer treatment is becoming increasingly complex as the use of long-term hormonal treatment is changing the perception of breast cancer towards that of a ‘chronic disease’ causing adherence to decrease over time. While this may be true for adherence to care in other settings (e.g. appointments at the cancer centre), the knowledge that medication needs to be taken for five years (or longer) appears to be a driving factor for the participants to adhere to medication regimens at home. Additionally, the participants appeared to have an understanding of the effects of long-term medication schedules on their prognosis and this appeared to encourage their commitment to prescribed medication when at home. As identified by the American Society of Clinical Oncology (2009) as well as Kirk and Hudis (2008), grasping the clinical importance that commitment to daily treatment regimens will have on clinical outcomes, is one of the most cited factors for increasing adherence and maintaining commitment over time.

Participants also addressed the Juravinski Cancer Centre’s presence in local and

regional media as being an influence in their initial decision to seek care at the centre. Newspapers and television news networks appeared to provide a way for participants to become familiar with the centre and what it has to offer, before their first visit and to increase their perception of the centre being able to treat their diagnosis. Additionally, some participants mentioned knowing family members or friends who have had a similar diagnosis and some of whom have been treated at the centre. Overall, these allowed patients to become familiar with the Juravinski Cancer Centre before ever entering it and also increased their confidence in the centre being able to treat their diagnosis. Participants' initial perceptions of the cancer centre and what it could mean for their diagnosis reflects what DeMiglio and Williams (2008) describe as one of three viewpoints of *sense of place*. Knowing and being aware of the centre before visiting it for their own diagnosis, participants demonstrated a “sense of place as cognitions of place” (DeMiglio and Williams, 2008, p. 18). Here, the expressed views and experiences of participants demonstrated how one can establish a sense of place for a health care environment, by what they know and hear about the place without ever actually having an encounter. Before experiencing their own cancer care at the centre, participants explained that having knowledge of the cancer care experience at the centre and the potential for a good prognosis through stories from the media and loved ones, helped them to become familiar with the environment before their initial visit.

The routine nature of appointments appeared to be the most significant factor impacting compliance, especially amongst participants who were completing chemotherapy during the period of data collection. ‘Routinization’ – fixed times and

predictable intervals – of care appeared to be the most effective reminder of appointments at the centre as well as a way to increase familiarity and ease for the journey to care. Knowing their schedules ahead of time, participants appeared to be more accepting of the scheduling demands of treatment as they felt they were still able to keep to other schedules in their lives. This can have a positive impact on the patient experience of cancer care when considering the psychosocial impact that the act of going to the cancer centre can create. Pennery and Mallet's (2000) discuss that during active treatment, cancer centres become 'safety nets' for breast cancer patients as they are having frequent contact with specialists and other health care providers to treat their diagnosis. The routine nature of visits, especially those that are frequent can begin to take on a comforting role for some patients as they feel reassured they are getting the medical attention they need. For others, the frequent visits can have the opposite effect where those who have scheduled appointments more often than the patients around them, view it as an indicator that their health is not reverting back to 'normal'. The routine nature of frequent appointments can become such a part of the cancer experience that while patients are often relieved to finish all of their treatment, it is a recognized phenomenon that they can also experience feelings of anticlimax because their long period of contact with care has come to an end and follow up appointment are few and far between (Pennery and Mallett, 2000).

5.3 Community Experiences of Care

Participants also highlighted experiences within their community settings that have indirectly and directly impacted their experience of breast cancer care. Participants

mentioned that past interactions with health care providers in their community shaped what they expected their experience with providers at the cancer centre to be. Regular visits to their family doctors and initially discovering they had breast cancer were the most common experiences participants brought up when asked what their expectations were of the centre, before their first visit. Experiences in the community during the period of time between learning about their diagnosis and going to the cancer centre after surgery, appeared to be the worst experiences for some participants. It appeared that participants were much more satisfied with their providers at the centre, than those in the community. In some cases, participants had a sense of relief once they came to the centre and had a more positive experience with providers who seemed more patient, knowledgeable and friendly. For some, coming to the cancer centre meant important questions and concerns could finally be addressed through interaction with the different providers or even just the availability of printed information and resources. Coming to the centre and being amongst other diagnosed patients, also opened up a much-needed informal avenue of information and camaraderie with people who could relate.

Participants talked about how these experiences in the community shaped their expectations of the doctors, nurses, and staff at the cancer centre. Expectations varied amongst the participants, as did their experiences accessing and interacting with health care providers in their communities. This is consistent with the work of Speight (2005) who found that patients attach values to different attributes of treatment or service that are unique to their own individual experiences. Patients establish what they value in care based on their experiences of receiving it. This finding is particularly important to

understanding patient satisfaction amongst the participants in the study because it demonstrates how two geographically different environments of care (e.g. family doctor's office and the cancer centre) can produce different experiences and shape expectations. Patient satisfaction can be generally described as how an individual's experience compares with their expectations of care (Speight, 2005). This is not to say that patient satisfaction amongst the participants was a result of poor experiences with providers in their community, but rather, it is a reflection on how patients positively experience their cancer care and the quality at which care is delivered. Coming to the cancer centre and experiencing treatment and supportive care appeared to meet and/or exceed the expectations of the participants and also shaped what they value in their cancer care.

Another explanation for the differences in care experiences at the community and cancer centre geographic levels, is that Regional Cancer Centres provide a unique experience of health care. The positive experiences and instances of exceeded expectations of care at the centre, may also be a reflection of the unique organization and delivery of care at the centres, that differ from the organization and delivery of care of family doctors and hospitals. Similar to a family doctor, patients go to the centre with scheduled appointments and overtime begin to build expectations of their wait and experience with the different providers and staff members. Unlike a visit to their family doctor, however, patients at the cancer center do not always have the same health care provider especially with nurses. Regional Cancer Centres also differ from hospitals because the centres are outpatient facilities and do not provide acute care; in other words, patients know ahead of time when they will go to the centre and are only there during

regular business hours so they can expect to leave the centre by end of day. Also, visits to the centre are more frequent and scheduled in advance allowing patients to plan ahead and around other activities. As mentioned before, frequent and predictable schedules assist patients in developing routines and familiarity with care environments that not only become encouraging to following recommended health actions but also increases the ease at which care is pursued and experienced.

The most direct role of geography in the patient experience of breast cancer appeared to be the theme of lack of coordination between the Juravinski Regional Cancer Centre and family doctors in patients' communities. A disconnect in communication and information between the cancer centre and some community family doctors appeared to be an area where some of the participants were dissatisfied with their care. Most often, this disconnect appeared to occur when participants were being referred to the centre by their family doctor who had little information about the centre to provide to the participants. It was also expressed that family doctors appeared to not receive test results or much other communication from the cancer centre while patients were completing treatment. Participants felt they had to serve as the 'bridge' of communication between their family doctors and the centre, highlighting that the centre being geographically separate from family doctors can create 'silos' of care in the health care system through a breakdown in information transmission. This result demonstrates that while patients can overcome the challenges involved with accessing geographically distant environments of care to treat a cancer diagnosis, the communication between their providers as well as information resources, are not always able to overcome the distance and communicate to

provide a seamless experience of care.

The implications of this existing and perceived communication disconnect was that some participants experienced a poor transition from being diagnosed to being treated because some family doctors lacked resources, such as information packages, to introduce patients to their diagnosis, potential treatment experience and the Juravinski Cancer Centre. These results also suggest the centre has little connection with some family doctors within the region/LHIN. This highlights how geography can impact the patient experience of care as patients who are expected to travel to different locations to received health care, interact with providers that do not always communicate with each other. While Regional Cancer Centres provide a very centralized location for cancer care, it is also challenged to connect with the different community health care providers of their patients, which exist at varying geographies.

This highlighted area for improvement is important to address as a lack of information can cause many to adopt a fatalistic attitude towards their disease (Hall et al., 2008). While many of the participants expressed a positive attitude towards treatment and the impact it could have on their prognosis, it is important to address this area of dissatisfaction for future patients who may not be able to maintain such an outlook on care. The period of time between diagnosis and first visit to the centre for treatment can be a critical time for such an attitude to develop. With inadequate information from a family doctor, the time spent before a patient's first appointment at the centre can be a critical time when attitudes develop from misperceptions, inaccurate information and overall lack of knowledge of different aspects of care. Early education about breast cancer

is important for dispelling any misperceptions or addressing any anxiety patients may have that can potentially affect their pursuit of cancer care (Hall et al., 2008).

The main impact on adherence behaviors when in the home environment were the direct and indirect connections that participants maintained with the cancer centre in between appointments. Schedules and side effects of prescription medications, as well as recommended changes to diet and physical activity were all areas of cancer care that participants mentioned needing clarity about when at home. The centre's call-in service appeared to be a critical point of connection for participants to continue with recommended health actions when at home, as participants called in when they had questions about their medication, diet or symptoms. The frequent usage of the service by participants demonstrates their confidence in their health care provider's expertise to provide the information they needed, complimenting the findings of previous work by Leydon and colleagues (2000). Participants explained how the service allows them to have access to the health care providers they strongly trust, when not physically at the cancer centre. This finding complements existing literature that identifies competent and knowledgeable staff at cancer care centres as being a vital information resource for patients (Rowlands and Noble, 2008). Participants also felt that the call-in service provides the same access to health care providers as they have when they are actually at the centre, because through the service they can request to speak to specific providers just as they would during a visit to the centre.

The availability of the call-in- service, and, more importantly, the participants' usage of it, provide a way for health care providers to maintain contact and provide

critical information to patients outside of appointments. Ensuring that patients take their oral medication during their period of cancer care is an ongoing concern for oncologists who lose control of medication administration when it is no longer in the clinical setting but rather the patient's home (American Society of Clinical Oncology, 2009). Demanding and complex dosage schedules of medication can decrease adherence when at home, but the call-in service provides a way for the participants to address any confusion they may have to continue their adherence to medication. Additionally, as discussed before, cancer centres and continued interaction with health care providers become comforting 'safety nets' to patients. In between appointments, this call in service has the potential to assist patients in feeling a continued connection to these 'safety nets' and trusted sources of information.

Considering the geographical layout of regional cancer centres in the province, patients' distances to the centre vary. As Milligan and Wiles (2010) argue, 'proximity' and 'distance' to a health care centre are not simply spatial but also reflect emotional closeness. A health care provider may be a physical distance away at a cancer center, but their involvement in providing care and support can make them emotionally proximate (Milligan and Wiles, 2010). The connection to the providers that participants feel when they are at home and use the service, facilitates this emotional closeness in between appointments. It allows a way for two spatially separate care environments to have a connection and for patients to still access the support of providers even when physically distant from them.

For others, a more indirect method of maintaining a connection to the centre when

at home, was to use the printed material and website suggestions that they received from providers at the centre. The use of this information is also critical to continued adherence at home because it provides patients with multiple information sources that have been recommended by the health care providers. This finding compliments existing literature that demonstrates clinicians can and do have a critical role in providing their patients with information and helping them to identify and evaluate resources that can meet their informational needs (Wengström, 2007; Chen et al., 2008; Rowlands and Noble, 2008). This allows oncologists, nurses and supportive care providers to ensure patients know what they need to when outside of their care interactions. The variability amongst participants to seek information in different ways (call-in service vs. printed material), converges with the literature that finds high variation in preferences for the amount, timing, provision and delivery of information in cancer patient populations (Whelan et al., 1997; Leydon et al., 2000; Hack et al., 2005; Wenger, 2007). Access and usage of written information is critical to patient education as written information in the form of books and pamphlets have been identified as modifiable factors to increase breast cancer knowledge, and can be used by patients and providers to address uncertainty (Chen et al., 2008; McCormack et al., 2011).

Support groups are additional environments outside of the cancer centre and within a participant's community, where care can be *potentially* experienced. Most participants reported not using support groups, confirming findings from a previous study involving cancer patients at the same centre (Whelan et al., 1997). The participants that did report using support groups provided valuable insight into the impact of experience

on continued usage. Age, perceived ‘formality’ and distance appeared to be deterrents for continued usage of support groups, as these factors appeared to impact the level of comfort of participants. The younger participants, who also reported initial use of the groups, commented on the age of the other attendants and how they felt they could not relate to the topics (e.g. menopause) being discussed. For one participant, the conversations about going through menopause was particularly difficult as she was still struggling to accept that as a young woman, she was diagnosed with breast cancer and the effects of surgery on her self-image. For another younger participant, distance and age of members in nearby support groups also factored into her decision to continue attending. She was faced with going to a closer group for older women or traveling further away to be in a support group for younger women. She decided to do neither.

Perceived formality regarding who can attend (e.g. spouses) and how specific the support was (e.g. metastatic breast cancer patients vs. all cancer patients) appeared to determine continued usage for some of the participants. It appeared that some preferred to go to more informal environments that fostered general socializing and mutual support with other people, regardless of breast cancer diagnosis, because it provided a more relaxed environment where conversations were not solely about cancer. As passionately expressed by one of the participants, these groups and gatherings of only people with breast cancer, while helpful, can be a constant reminder that you are living with the illness. It appeared that, for some, these support groups and activities appeared to have the opposite of its intended effect as they became negative reminders that they were ill and left some users feeling upset once they left. This finding diverges from other studies

such as Montazeri and colleagues (2001) who have found support groups to improve psychological well-being by decreasing levels of depression and anxiety amongst breast cancer patients.

Overall, the participants rarely used the support groups and cited having sufficient support from their family, friends and fellow patients at the centre as their reason for not using the groups. For those who did report attending a support group meeting or workshop, the likelihood of them returning was small. None of the patients reported continued usage beyond a few visits, because of poor experiences. The participants that used the support groups and were dissatisfied also reported having their own network of support amongst their family and friends and expressed that they only tried the groups because they thought there was something more the groups could provide. This finding compliments the study of Hegleson and colleagues (2000) who found that peer support groups for breast cancer patients can be helpful for women who lacked support from their partners or health care providers, yet provide negative experiences for women who had high levels of support outside of the groups. As is suggested in the literature, people with high levels of support from their loved ones could have negative experiences in the support groups due to the frequency and depth they are used to talking about their cancer when with loved ones versus when with people they just met (Hegleson et al., 2000).

The insights from the few participants who had experience going to support groups suggest that the structure and makeup of the groups could be modified to encourage usage and become more conducive to a positive experience. The infrequent usage of the support groups by all of the other participants, however, and their reasons for

not attending, confirmed the findings of a previous study that suggested patients find sufficient information and support amongst their care providers, friends, families and other patients, seeing no need to seek out organized groups (Whelan et al., 1997). To encourage increased usage and a wider appeal, a more convenient, informal and diverse environment can be online support groups where participants do not feel the pressure to participate (e.g. post a message, read a message) and can select only the information they want to know (e.g. that which applies to them). These online groups have been shown to be empowering for the breast cancer patients that use them, while also reducing the barriers posed by location, other participants and topics of conversation (Winzelberg et al., 2003; van Uden-Kraan et al., 2008).

5.4 Experience of Journey to Care

With the organization of Regional Cancer Centres placing cancer care at different locations throughout the province, many of the participants found themselves having to choose between two different centres to receive care. Being on the ‘border’ of two centres’ catchment areas was common for participants living outside of Hamilton and Burlington. As discussed before, while perceptions of care cued participants to initially place their confidence in treatment and encourage their uptake of health services, it was the reputation of the cancer centre that made some participants choose to attend the Juravinski. The theme of ‘reputation’ when discussing the choice to attend the Juravinski Cancer Centre is important as the perceived reputation of a health care centre can shape a patient’s expectations of care. As discussed earlier, expectations not only impact initial uptake of care and confidence in health services, but also patient satisfaction once

throughout the course of treatment, as well as supportive and follow-up care. Some participants talked about wanting to come to the centre because they had a friend or a family member who had received care there. As the participants demonstrated with their insights into reasons for their decision, the cancer care experiences and satisfaction of these participants have the potential to impact the usage of the centre by future patients.

For most participants, travel to the cancer centre starts from their home, while travel from work or another point was rarely reported. This finding reflects the current lifestyles of most participants (e.g. retired) or the necessary changes (e.g. leave of absence from work) some participants had to make. For participants, traveling from the same place to the cancer centre increased familiarity of the route for themselves and those that came with them, once again highlighting the impact of ‘routinization’ on the care experience. Knowing travel starting points is important for the centre itself for shaping and reinforcing policies they have. The Juravinski Cancer Centre has a ‘same day chemotherapy’ policy where participants with a travel distance of 50 kilometers or greater, are given first priority for scheduling chemotherapy appointments on the same day as other appointments in the centre (e.g. blood work, genetic counseling, oncologist). This finding also reflected the time commitment that an appointment involves and the priority it takes in a patient’s day. Many participants on chemotherapy said part of the reason they come straight from home is because they do not have the time or energy to do anything else on the day of their appointment. This begins to reflect the experience of treatment in the day-to-day lives of the participants as the journey to care and actual appointments involve a significant commitment that can define the rest of a patient’s

activities for the day. Additionally, knowledge of where patients are traveling in from can be used to understand the organization of the LHINs and inform strategies for locating future cancer centres that recognize the challenges patients face.

When talking about the actual travel to care none of the participants found their route to be complicated and explained their increased familiarity with directions as they had more and more appointments. This is important when understanding continued uptake of care at regional cancer centres. Considering the multiple health services located at the centre as well as the varying distances participants must travel for different appointments, ease of travel can make for a more positive experience of the journey to care. It suggests that over time, the burden of navigating to the centre lessens and is one less barrier faced during travel.

Despite familiarity with route however, having a personal vehicle was considered essential to be able to receive care at the centre. Public transportation and hired vehicles (e.g. taxis) were not seen as options for travel, especially during adjuvant therapy. Participants explained that taking public transit was just too strenuous of an activity. All the participants either drove themselves or had a family member or friend drive them. Participant appeared to perceive their ‘mobility’ to access care as a function of being able to drive themselves or have available transportation. This finding agrees with existing literature that looks at the effects of geography and spatial behavior on health care utilization. Having a driver’s license and use of provided rides are both factors that have been identified as playing a role in attending appointments for chronic care (Arcury et al., 2005). When considering the length of breast cancer treatment as well as the travel

required to access the centre, continued access to transportation appears to greatly factor into continued access to care.

The theme of ‘independence’ also emerged from the views of some participants. Maintaining the ability to drive themselves and not having to depend on others, was very important for a sub-group of the participants because it meant they could work on their own schedule (e.g. not have to worry about someone else’s availability) and not put others out. One participant even mentioned that driving herself was something she has done since 19 and it only felt normal to continue to do so. This finding agrees with existing literature that has shown that patients who drive themselves to appointments value the feeling of independence as it is produced amidst the lifestyle changes brought on by diagnosis and treatment (Payne et al., 2001). While their care and progress with treatment may not be wholly in their control, transportation was viewed as an area where some participants could possibly maintain some form of control and normalcy.

Volunteer driver programs are also an option for participants to be driven to the cancer centre from their homes. There appears to be an increase in awareness of the programs available to patients at the Juravinski Cancer Centre. All the participants in this study were aware of that the services were available to them even if they did not use them. This result shows an increase in awareness as an earlier study of patients at the centre reported that knowledge of the programs amongst the centre’s attendants was 75% (Whelan et al., 1997). These programs are important for the act of receiving care at cancer centre because, even though many do not use them, they still provide a reliable option for traveling to and from care.

The theme of ‘other patients’ needs’ emerged as the main reason for why participants did not use the service. Recognition that other patients may not have any other options for transportation and that using the service could potentially deprive someone else was the main rationale for not using the programs. This confirms the findings of Leydon and colleagues (2000) where *charity* towards other patients is expressed in the recognition that resources have to be shared amongst many patients. Participants also expressed that even though they did not use any of the services, the knowledge of it being there was comforting because they knew there was always another option if their current driving arrangements changed. This shows that the service can impact the patient experience of even those who do not use it. While participants currently had a mode of transportation to the centre, they were aware of the challenges they could face if they could no longer drive themselves or have a loved one take them. Knowing that the service was available was a source of confidence for patients, to continue to access care, who expressed the uncertainty of future treatment and their body’s response (e.g. ‘I’m okay to drive now, but once chemotherapy starts, that could change’).

Companions emerged as a popular topic of conversation in the interviews. While some mentioned the presence of a family member or friend as being necessary for physical support in the journey to care (e.g. driving), it was apparent that for most patients, companions provided a great deal of emotional support on the journey. It appeared that having a family or friend accompany them to the centre made the travel time go by more quickly, provide support on the way back in the case of ‘bad news’, and

for some who were used to having someone come with them for the early periods of care, it became a way to maintain normalcy.

Identifiable factors within the city environment that led to negative travel experiences were traffic, weather and construction, all of which agree with previous literature (Haynes et al., 2006). What this study did uncover was that patients were able to separate their negative travel experiences from their experience of cancer care, by realizing that all of the aforementioned elements were a function of the act of travelling and being in a city environment, and not the cancer treatment or centre itself. Participants appeared to view these negative aspects of travel as something they would encounter with any trip to the city, regardless of whether the trip was for cancer care. Experiences with traffic did cause some participants to appreciate appointments that did not coincide with ‘rush hour’; however, overall it was not a negative enough experience for any of the participants to insist on appointments at certain times of the day. Alternatively, the city environment also provided positive travel experiences for some. The availability of stores and services in the city allowed some patients to have a more pleasant experience. Going into a garden store or health foods grocer appeared to be a means of ‘escape’ from the day’s events for some participants. Stopping over at a store on the way home allowed some participants to have a break from the atmosphere of the cancer centre before returning to their homes and parting ways with their travel companions.

5.5 Locating a Regional Cancer Centre

While participants expressed gratitude for the centre and explained the task of traveling to the centre as ‘something you have just got to do’, variations existed in how

participants evaluated the ‘convenience’ of the centre. Being located on the Niagara Escarpment made the centre seem ‘convenient’ for some participants because of the implications the location had on access routes (e.g. Mountain access from the downtown core) and different parking options. The centre was further described as ‘convenient’ because it houses a variety of cancer care services in one location. The physical organization and layout of the centre’s exterior also appeared to factor into the patient experience. The main entrance and side entrances appeared to ease travel to the centre and also shaped strategies, such as using the side door if they had a follow-up appointment in Clinic D, participants used when coming to the centre for different appointments. For participants that were dropped-off for an appointment, the main entrance drive-through provides a convenient way to enter the centre and meet a driver after an appointment. The main entrance was most significant for when participants experience exhaustion and nausea after chemotherapy and found the task of walking to the parking garage or surrounding parking areas particularly burdensome. For others, the multiple entryways became a way to navigate the centre based on the nature of the appointment. Using the side entrance for a visit to the follow-up clinic versus the main entrance for a visit that started with blood work, allowed some to find the most direct route to the area in which they needed to be.

The most common cause of ‘poor experience’ and ‘barriers’ participants talked about surrounded the issue of parking in the centre’s garages and on nearby streets. Availability, accessibility, and cost of parking were the most common themes. While participants felt the adjacent parking garages were easy to get in and out of, broken

elevators, narrow laneways and a lack of vacant spots, appeared to complicate the experience. For some, this meant a delay in entering the centre causing stress over potentially being late for an appointment. In rationalizing the issue of parking, it was apparent that some participants believed that the lack of parking availability was a constraint placed upon patients by the location of the centre. Located beside a hospital in a mixed residential and business area, was perceived as a constraint to the amount of space available for parking facilities.

The price of parking was, for many, a negative aspect of their care at the centre. Having to pay for parking influenced where some participants decided to park (e.g. parking garage vs. timed street parking). Using the parking garages is the most expensive option but is also most convenient for getting to the centre. For some, parking in the adjacent garages is considered ‘essential’ when considering the fatigue that results from chemotherapy. Street parking and municipal lots are much cheaper options but involve a longer walk to the centre and are limited by time (e.g. one hour maximum). While many chose to use the street parking in the residential areas or the metered parking in the blocks surrounding the centre, it also meant that they had to be cognizant of their time while in the centre. For some, this involved trips to move the car or add change to the meter.

The cost of parking was expressed to be ‘financially draining’ because of the frequency of visits to the centre. As previously mentioned, many participants were retired or on a leave of absence that meant they already had to manage on a fixed income. It was apparent that this was a source of stress for most participants. The results demonstrate a greater need for the cost and availability of parking to be recognized as a significant

burden for patients and a potential barrier to continued adherence to care. When considering the cost of travel to a regional cancer centre and the loss of wages some patients were already experiencing since being diagnosed, the cost of parking can become a source of further stress.

Studies have shown that patient satisfaction with financial aspect of care is positively associated with adherence in cancer care (Sherbourne et al., 1992; Hall et al., 1993). In particular, patients' out-of-pocket expenses are being increasingly recognized as a significant aspect of the patient experience and access to care, both of which impact patient satisfaction. The study findings that parking costs, amongst other costs, posing a financial burden on patients has been recognized elsewhere (Kim, 2007; Lauzier et al., 2011). While participants demonstrate a strong belief in the effects of treatment on their diagnosis and appear to be willing to continue to take up treatment services regardless of costs, it should not be concluded that financial burdens on patients should go unaddressed. It has been shown that while cancer patients may be willing to accept the costs associated with treatment during the early stages of care, they may make sacrifices with mental health services and later occurring palliative care (Kim, 2007).

Lastly, many participants showed a great deal of gratitude for the centre and the care it provides. The centre appeared to become a place of comfort for many people experiencing a very stressful and life-altering medical diagnosis. Participants considered themselves fortunate to have access to such a place. While Regional Cancer Centres can be initially daunting for newly diagnosed patients, it can soon become a place of comfort for patients as they begin to associate the environment with becoming 'better' and being

surrounded by health care providers that are there to help patients become and stay cancer-free.

5.6 Micro-Environment Experience

Inside the cancer centre appeared to be the most significant care environment in the patient experience. Similar to the ease of travel that resulted from the familiarity with route, participants spoke about navigation of the centre becoming easier as their knowledge of where clinics were and the best ways of getting there (e.g. elevator, stairs) increased with their number of visits. As previously mentioned, the cancer centre provides a variety of medical and supportive care for cancer patients, which are distributed across multiple floors and wings of the building. Increased familiarity with the location of different clinics and departments as well as clear signage around the different patient areas were identified as ways in which the physical environment impacts the patient experience at the centre. The expressed ease at which patients get to different areas of the centre, demonstrates one less barrier that exists to challenge a patient's uptake of care. Familiarity with place, gained from multiple appointments and used to ease the burden of navigation, adds to the understanding of micro-geographies of care in hospitals, in order to understand place in multiple ways (Parr, 2003).

Waiting rooms appeared to be the most significant micro-environment in the patient experience of the cancer centre. Through comments on waiting times and the scheduling of multiple appointments of different areas of the centre, it became apparent that a large portion of the cancer centre experience is spent in the waiting areas for the different departments and clinics. For some, the length of time spent waiting for an

appointment to start, was the difference between a ‘good’ and a ‘bad’ day. The most significant wait was in the chemotherapy waiting area, which ranged from 30 minutes to 3 hours, and became the ‘norm’ for a visit. Wait times are just one of many factors that have been recognized as influencing patient satisfaction with cancer care (Sherlaw-Johnson et al., 2008). Time spent in waiting rooms can significantly impact the patient experience as these rooms are often the first impression of clinics and can therefore indicate to patients the characteristics of the health care providers that practice within them (Crooks and Evans, 2007).

While all the participants would prefer not to wait, most understood why their appointments were often delayed and were therefore accepting of the wait. Participants mentioned observing instances where other patients did not take their preparation medicine, chemo spills occurring, patients having reactions to the therapy, and mixing machines being out of service. With the open-concept layout of the chemotherapy treatment area, participants were able to observe the different events that cause appointments to be delayed and were therefore accepting of their wait times, because they perceived the events to be unpredictable and uncontrollable. This finding confirms the results of a similar study done by Pennery and Mallett (2000) where cancer patients found the wait time acceptable either because it was short or they believed it to be necessary and unavoidable. This also highlights the discussed theme of *charity* towards other patients that Leydon and colleagues (2000) have found as participants recognized the delay in their appointments as being a result of the needs of other patients. The participants recognizing that they were in the “same boat” as other patients appeared to not only help

many to understand the cause for the delay in their appointments, but to also express camaraderie and compassion towards others and thus feel content to wait their turn for much needed health services.

The waiting room itself appeared to produce a variety of experiences for the participants as it provided a welcomed opportunity to connect with other patients. Participants explained how the organization of the room (e.g. layout of chairs) fosters conversation and relationship building. For some who feel anxious right before an appointment, conversations in the waiting rooms have become a good distraction. The waiting areas provide an opportunity for patients to learn from each other about resources and treatment experiences. This turns the waiting rooms into an informal support environment for patients that can also include their accompanying friends and family members (Crooks and Evans, 2007). As identified earlier, for some of the participants, the formality of community support groups can prevent them from attending. While waiting for their appointments, participants can engage in a form of support with other patients. Most importantly, conversations with other patients while waiting have been shown to increase the knowledge of patients, especially those who are newly diagnosed (Chen et al., 2008). The waiting room also facilitates opportunities for companions (e.g. spouses, children, friends) to connect, as their experience of accompanying someone along their cancer care journey can also introduce new experiences for them.

The level of comfort participants felt amongst other patients proved to also have an impact on the participants' perceptions of privacy in the different clinics and waiting areas. While most participants felt that there were areas of the centre that lacked privacy,

it was not necessarily considered to be a negative aspect of their experience or even one that they wanted to change. Knowing that those who surrounded them were either cancer patients or companions of cancer patients, made the participants feel they were comfortable to talk about private matters with health care providers and ask questions, in open spaces. The apparent attitude was that everyone could learn from each other, and therefore each other's questions. Where participants did feel uncomfortable with a lack of privacy was when they felt they were 'on display' during treatment. Having non-medical professionals in a room during treatment (e.g. machine technicians) and watching others receive chemotherapy was a source of discomfort for a small group of participants. These results reflect the variations in patient preferences for privacy and can be modified by giving patients the choice of which part of the clinic they receive their treatment (e.g. private suite versus open area with recliners).

Some participants discussed poor experiences in the waiting room that resulted from a shortage of chairs and a high noise level. The overcrowding of the chemotherapy waiting room appeared to be a result of delayed appointments. This, in turn created a louder noise level where some participants mentioned not being able to hear their number being called. This identifies a modifiable aspect of the area. While delayed appointments may be unforeseen, adding additional seating area to the room could potentially ease the waiting experience.

A small group of participants commented on the architectural design of the waiting room and identifying nature sceneries, lighting, open spaces, and the size of waiting rooms as creating a calming atmosphere. Architectural design and the quality of

interior spaces have a potential therapeutic value to the patients that use them as they have the potential to shape the senses of well-being of patients within them (Crooks and Evans, 2007). Lighting in health care settings has been shown to enhance mood, especially when used to reflect the time of day (e.g. natural lighting reflecting the progression of time) (Devlin and Arneill, 2003). Arneill and Devlin (2002) found that waiting room design can impact a patient's perception of the quality of care. Rooms that were nicely furnished, well-lit, decorated with artwork, and warm in appearance resulted in a more positive perception of the quality of care. In comparison, rooms with outdated furnishings, were dark, decorated with poor quality reproductions or not artwork at all, and were cold in appearance resulted in poorer perceptions of the quality of care. These participants that commented on the design and aesthetics of the waiting rooms confirm the findings of a large body of therapeutic landscape literature that has shown the positive effects of health care environment design on patients (Crooks and Evans, 2007).

The waiting rooms in the cancer centre also appeared to take on the role of a promotional and educational space. For example, participants mentioned attending events, such as the Juravinski Cancer Centre's *Life After Breast Cancer* biannual conference, that they had seen posted in waiting areas. This is consistent with existing literature that recognizes waiting rooms as ideal places to effectively transfer information to patients (Ward and Hawthorne, 1994). The waiting rooms also proved to be a place to prepare people for their medical examination (Tanner, 2002). This was most evident when participants discussed the Interactive Symptom and Assessment Collection (ISAAC) tool available on computers in clinic waiting rooms and is usually completed prior to entering

an examination room. Participants mentioned how the tool helps them to reflect and remember any questions they may have for their health care providers. The placement of this tool and the demonstrated effect it had on some participants agrees with the existing literature that identifies the waiting room to be a critical environment for reflection and mental preparation before entering into an interaction with health care providers (Tanner, 2002).

Educational environments extended beyond the waiting room at the cancer centre. Participants who mentioned using the patient library located near the main entrance, appeared to be satisfied with their experience as they found the librarian and the available take-home materials to aid in their understanding of diagnosis and treatment. Entering the centre meant having the opportunity to access a critical source of information. For many, the centre was their most ‘trusted’ source for information. Participants expressed that, with time, their confidence to ask questions and knowledge of who to direct them to, facilitated having their information needs met. Different floors of the centre (e.g. the basement for radiation, second floor for supportive care) began to represent different areas of expertise where participants went to seek different health care providers. This provision and access to information is significant to patient education and experience of care because it is critical in dispelling misperceptions about breast cancer that can produce negative attitudes towards treatment (Hall et al., 2008).

Participants seeking information on their own empowers them to control the amount of information they receive and from whom they get it. This is important because as research has identified, the ‘right’ amount of cancer care information varies greatly

amongst patients (Whelan et al., 1997; Leydon et al., 2000; Hack et al., 2005; Wenger, 2007). Patients vary in their desire for information that is beyond the ‘basics’ of their diagnosis, treatment options and side effects (Leydon et al., 2000; Hack et al., 2005). Too little or too much information can evoke fear and uncertainty that can ultimately affect health care behaviors (Leydon et al., 2000). Patient perceptions of whether their clinical environments are encouraging of questions by making providers available for questions outside the appointment time, is a recognized contextual factor in the patient-provider relationship and experience with interaction during clinic visit (Stacey et al., 2009). In providing patients with a cancer care environment that is conducive to information seeking behaviors (e.g. making health care providers accessible for questions, patient library), the centre appears to recognize different patient needs.

5.7 Social Environments of Cancer Care

Attitudes of health care providers, staff, and volunteers appeared to be an important aspect of the social environment that impact the cancer care experience. The caring attitudes and relationships participants built with people at the cancer centre impacted how the physical environment was experienced. Communication and interaction with health care providers can have a profound impact on the experience of cancer care. It has been shown that for cancer patients, communication can have an impact on disease outcomes because of how it facilitates comfort, inclusion, hope and clarity in the treatment experience (Rowlands and Noble, 2008). Quality, length of interaction, and perception of providers’ caring attitudes, appeared to impact how participants experience one-on-one appointments with health care providers and lead to expressions of

satisfaction with care. These results agree with a large body of patient-provider communication literature. The expressed satisfaction participants had with their interaction with nurses confirms the findings of Radwin and colleagues (2004) who found cancer patients held their nurses in high regard when they perceived them to be knowledgeable and have caring attitudes.

Oncologists, who made a point to assess the information needs, learning styles and feelings of their patients were also discussed by patients as being apart of a positive experience at the cancer centre. This is consistent with existing literature that identifies addressing individual goals, using different presentation styles, frequency of imparted information and open negotiations as being conducive to patient ‘needs’ for understanding diagnosis and treatment (Hack et al., 2005). Providing patients with the opportunities to talk about their feelings about their diagnosis, has been shown to be positively correlated with patient satisfaction (Eide et al., 2002; Walker et al., 2003). Participants also noted how supportive care appointments never felt rushed and how that encouraged their continued uptake of counseling appointments. This, too, agrees with current patient satisfaction literature that links unrushed appointments to increased satisfaction. Rushed conversations and perceived efforts to limit the length of interaction can make patients feel dismissed and ‘written off’ by health care providers (Stajduhar et al., 2009).

5.8 Belief in Cancer Care

Encouraging their uptake of cancer care, participants’ beliefs in the benefits of recommended health actions (e.g. treatment, lifestyle changes, adherence to medication)

and self-efficacy appeared to play a significant role in their health behaviors. Through knowledge and met information needs, participants appeared to have a strong understanding of the medical and psychosocial health rationales behind adjuvant therapy, supportive care and other recommended health actions. Participants demonstrated a clear understanding that the relationship between benefits of treatment and a good prognosis, outweighed any challenges or barriers that existed within the process of seeking and receiving care. Many viewed treatment, medication and lifestyle changes as what needed to be done to get better. This agrees with existing literature that discusses a patient's knowledge and understanding of their treatment affects their compliance to medication and treatment regimens (Cameron, 1996).

Participants expressed self-efficacy – the belief that one can successfully carry out an action – as they were willing and believed they were capable of pursuing recommended health actions if it meant they would 'get better'. For many, they ultimately believed in the need for patients to be their own advocate and that the success of their was their own responsibility that could be eased by a circle of support. This is supportive of Bandura's concept of self-efficacy where he believes outcome (e.g. the uptake of care) is often reliant on judgments of self-efficacy. For example, participants: demonstrated efficacy expectations (e.g. 'I am able to travel to the centre and receive treatment'), which led to a behavior (e.g. going to the centre for treatment) and processed outcome expectations (e.g. 'If I travel to the centre to receive treatment, my health will most likely improve) (Grembowski et al., 1993). The presence of this belief amongst the participants is quite encouraging for positive health behaviors. In a comparative study, Grembowski

and colleagues (1993) found that adults with high efficacy expectations have better physical and mental health than those with low efficacy beliefs because they believe in their personal ability to pursue care.

5.9 Contributions

5.9.1 Practical Contributions

This study highlights the role of geography in the breast cancer care experience. When considering the delineation of LHINs and distribution of Regional Cancer Centres throughout Ontario, the presence of geography becomes clear, as patients access care environments that range from their homes and extend throughout their community and to different medical facilities. Geography narrows down the options for which Regional Centre a patient attends and also what resources are available to them in their community environments. Geography becomes most apparent when understanding the experience of travelling to care and the location of the cancer care environment. The Juravinski Cancer Centre draws a number of patients from all over the HNHB LHIN and as the participants in the study showed, the neighboring Waterloo-Wellington LHIN, highlighting the physical distances patients travel to access care in a centralized location.

An objective of this study was to identify areas of success and possible improvement in the current environments of care through the expressions of satisfaction and dissatisfaction of the participants. The cancer centre appeared to be a great source of comfort for participants to have faith that the necessary resources were available for them to ‘get better’. The centre also has a lasting effect on the mindset of participants, providing a sense of ease when they consider the likelihood of their cancer returning. The

centre also appeared to achieve success with its strategies for knowledge translation and dissemination. Using the waiting room spaces, providing introductory packages of information and having additional resources located in the library and throughout the centre, are all effective strategies to provide patients with reputable sources that can assist their understanding of care when in and outside of the centre. The provision of personalized printed schedules also appeared to be an effective memory aide for participants to remember appointments and keep track of their cancer care.

The friendly attitudes and compassion of the health care providers, staff and volunteers at the centre appeared to be a great source of comfort for a patient population undergoing a life-altering diagnosis. Their encouragement of participants to ask questions and seek information, as well as their personalized interactions, appeared to be a great achievement amongst the people at the centre creating a positive social environment. The comfort participants felt with their providers and trust they had in the knowledge they could provide, carried into the community environment and was reflected with the high usage of the centre's call-in service. The study demonstrated support for the continuation of this service and the positive effects it had on facilitating adherence to care when outside the environment of the centre.

This study also highlighted two areas for possible improvement. The perceived lack of coordination between the centre and community health care providers and, most importantly, the effect this lack of communication had on the patient experience suggests an area of improvement. The participants highlighted two main periods of care where they believed the centre lacked in its efforts to communicate with their family doctors.

The first was the period of time between learning of their diagnosis and their first visit to the centre, while the second period of time was throughout adjuvant therapy where family doctors appeared to know little details about their progress. The second area of improvement is the parking costs and availability that participants appeared to be highly dissatisfied with. The study was able to further demonstrate the financial burden associated with receiving care and the necessity for parking in close proximity to the cancer centre.

5.9.2 Theoretical Contributions

This research adds to the understanding of patient satisfaction by emphasizing the role of care environments on the patient experience. The organization of the cancer centre facilitated the accessibility of health care providers to patients and demonstrated what a critical information resource they were. Where previous literature has identified the patient needs and information communication as factors a patient uses to assess their satisfaction with care, these results highlight the role of care environment in meeting patient needs and serving as an educational environment. The study also highlighted how *familiarity* with different environments involved in care (e.g. cancer centre, route of travel) can lead to patient satisfaction. With time, participants explained how they increased their familiarity with travel routes, clinical layouts, health care providers, staff, sources of information and waiting rooms.

The study also adds to the understanding of patient adherence to care when in the home environment. The use of the cancer centre's call-in service demonstrated the impact of continued connection to health care providers when at home on adherence to

medication. Communication over the telephone provided a way for participants to clear any confusion they may have that may impact their adherence at home. The study highlighted how providers can maintain control over patient adherence beyond the boundaries of the cancer centre.

5.9.3 Methodological Contributions

The study also presents a successful application of Rosenstock's (1966) Health Belief Model in a *curative* setting. The model was originally designed to understand population uptake of preventive and diagnostic health services; however contemporary applications use it to understand a patient's uptake of prescribed therapies. The model is designed to conceptualize the likelihood of taking recommended health action. When applying the model to a patient population recruited during a visit to the centre, the 'recommended health action' of cancer care has already been taken. The model was thus used to understand the likelihood of *continued* health action in cancer care. The study also confirmed the role of the social cognitive theory (self-efficacy) in the HBM, because of the demonstrated effect that confidence in one's ability to carryout a health behavior can have on continued uptake of care. Self-efficacy is not a part of the original 1966 HBM, but was later added to recognize one's confidence to complete a health action (Rosenstock et al., 1988).

Participants appeared to be very satisfied with the care they received and the geography of health services. Identified on three environmental levels – community, cancer center, micro-environment – participants expressed how their satisfaction and resultant attitudes towards breast cancer care were impacted by different environments of

care. The study was able to successfully explore patient perceptions of care and the environments in which they experienced it. The expressed satisfaction with the current organization of care can be used to develop a set of indicators that can be used to appraise future cancer care designs. Overall, the study adds to the conversation of patient-centered care by highlighting geographical and environmental considerations that need to be made in future planning.

5.10 Policy Implications

The views of the participants provide great insight into the experience of the organization of cancer care in the province. The objectives and results of this research reflect the goals of CCO as identified in the *Ontario Cancer Plan 2011-2015*. An identified strategic priority area in the plan is to “continue to assess and improve the patient experience” (CCO, 2011). This thesis helps to inform current and future strategies to help patients navigate the cancer system and manage their own journey through treatment. As participants expressed an overall satisfaction with their care and experience, the results from this study are able to identify what ‘works’ in the current system of care. Strategies for information provision and availability, as well as call-in services that allow patients to stay connected to the centre while at home, are just two approaches to care that appear to be effective. Overall, the results show great support for the current policies created by CCO that oversee the delivery and organization of care at Regional Cancer Centre, are conducive to positive patient experiences.

The participants expressed comfort in knowing that volunteer drivers and free-of-charge arranged transportation is available to them. This appears to support the design of

care that is outlined in the *Cancer Act, 1990* as section 5 states that the program of cancer care in the province must include “the transportation of patients and escorts to its treatment centres or to the hospital of the Institute for diagnosis, treatment or investigation”. While many did not use the service, they supported the need for it and the positive role it plays in helping fellow patients and potentially themselves one day.

Policies governing parking at the cancer centre and coordination between the centre and community health care providers, however, appear to be in need of improvement. The parking situation and expressed dissatisfaction with it in the patient experience, is indicative that policymakers are not cognizant of the journey to care experience. Specifically, the distances and frequencies at which patients must travel to the centre, as well as side effects of treatment, have made it essential for patients to get to the centre in a personal vehicle. It is important for patients, especially those on adjuvant therapy, to have affordable parking that is in close proximity to the centre. The cost and availability of parking appeared to be a cause of financial and physical stress for most of the participants. Regional Cancer Centres such as the Juravinski are constrained to charge for parking for reasons that include being located adjacent to a hospital (as set out by CCO) as well as the parking structures of the cities they are located in. For current cancer centres, programs providing financial support or subsidies are needed, as a cancer diagnosis introduces many out-of-pocket expenses for patients, many of whom are retired or on a fixed income from taking a leave of absence from work. While some assistance programs do exist, it is apparent that patients may not be aware and thus it should be woven into the information that is introduced to patient when they are diagnosed.

Efforts must also be made to better coordinate the communication and interaction between the Juravinski Cancer Centre and community health care providers. The compilation and distribution of information packages that can introduce patients to the centre, possible treatment and support resources, *before* going to their first visit, can ease the stress some feel between diagnosis and their first visit. The need for reports and greater communication between the centre's providers and family doctors, should also become a priority area to address this perception of a lack of coordination.

5.11 Limitations and Future Research

This study is not without its limitations. The study is limited in its generalizability in two ways. First, 23 participants do not provide a representative sample of breast cancer patients in the province. While they provide a depth of insight into the experience of breast cancer and breast cancer care, they do not represent a breadth of experiences in the province. In order to use qualitative interview methods for data collection, limits were placed on the sample size. There is the possibility that some experiences and attitudes towards care were not captured. Second, the study is locally contingent as it looks at patients and experience at one out of 13 Regional Cancer Centres in Ontario. While all the centres are overseen by CCO and strive to meet the same set of goals for care, the communities they serve and their physical geography patients travel, vary amongst the users of the centre. The different locations of the centre in the province mean that patients in Ontario experience different travel to care experiences and interaction with the cancer centre city environments.

The research is also limited due to its inclusion criteria of English speaking

participants. Language can play a potentially large role in the experience of care. Navigating the journey to care can be a different experience for patients who do not speak English and are pursuing cancer care in a primarily English-speaking city. It can also have significant implications on communication with health care providers, as well as the understanding and pursuit of information. Designing a study of patients who attend a Regional Cancer Centre who do not speak English as their first language can uncover areas of success and improvements for delivery cancer care to an increasingly diverse population.

Additionally, travel companions and support networks of friends and family members appeared to play a large role in the experience of care for many of the participants. A future research area could be to include these members in the study sample with patients. As participants expressed emotions ranging from gratitude and guilt for bringing companions along, the patient experience might be improved by responding to the experiences and insights of accompanying family and friends. As also discovered, some of the participants had previous experience with the centre as they were once the travel companions of another cancer patient before their own diagnosis. With an aging population in Ontario, some of the companions who currently accompany a patient to the centre, may one day face a diagnosis themselves or know someone else who would. Their experience at the centre may influence their expectations of care if they were to ever receive a diagnosis or support someone else who does.

5.12 Conclusion

Overall, this study presents insight into the experience of breast cancer care under

the organization of Regional Cancer Centres and community environments of care for breast cancer patients. The experience with different cancer care environments, the perceptions of outcomes of care and disease severity, as well as views of self-efficacy appeared to be conducive to creating attitudes that encourage the uptake of recommended health actions. With patients expressing satisfaction with the care they receive, the Juravinski Cancer Centre appears to provide a positive model for the organization of cancer care. The navigable physical environments of the clinics and departments, as well as the positive social environment created by health care providers, staff, volunteers and fellow patients; appear to create an environment conducive to patient satisfaction. With cancer diagnoses projected to increase with the aging population in Ontario, it is important to maintain a system of care that is responsive to the identified needs of patients. Such a system must be conducive to providing a positive patient experience, by recognizing the geography of cancer care that spans multiple environments. A more seamless, rather than disjointed, system is needed to connect these environments and therefore ease the uptake of health actions.

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APPENDIX A: INFORMATION FLYER



***PARTICIPANTS NEEDED FOR
RESEARCH ON EXPERIENCES OF COMING TO THE JURAVINSKI
CANCER CENTRE FOR BREAST CANCER CARE***

We are looking for volunteers to take part in a qualitative study examining the environmental factors that influence the patient experience at the Juravinski Cancer Centre (JCC).

I am a graduate student completing my Master's degree in Geography at McMaster University and have partnered with Supportive Care at the JCC to conduct this study.

If you choose to participate, you will be asked to talk, one-on-one, in an interview with myself about your past and present experiences of coming to the JCC and attending here for treatment and/or follow-up care. You will also be asked about your experiences in seeking and accessing support services. The interview will take place in a quiet room, here at the cancer centre. This will take approximately 30 minutes and will be a one-time only conversation. You may choose to withdraw from the study at any point.

Your participation is confidential. Your name, as well as any identifying information, will not be used in the study report. The insights provided by you and other participants can help us better understand the environmental factors that influence the patient experience.

This study has been approved by the Hamilton Health Sciences/McMaster Faculty of Health Sciences Research Ethics Board (HHS/FHS REB).

Please contact Supportive Care at the Juravinski Cancer Centre if you are interested in learning more about the study.

(905) 387-9711 ext. 64315

APPENDIX B: LETTER OF INFORMATION AND CONSENT FORM



July 2011

LETTER OF INFORMATION / CONSENT

A Study of Environmental Influences on Patient Satisfaction and Attitudes towards Breast Cancer Care

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Purpose of the Study

In this study we want to explore what influences your satisfaction and attitudes to breast cancer care. Specifically, the influence, on satisfaction, of the cancer centre's clinical environment, its location in the city and the opportunities for support in your community, are of interest. In engaging with women who have formerly or currently receive treatment for a breast cancer diagnosis, we can give voice to their lived experiences and the realities of breast cancer care in the province. Results from this study may go on to better design and deliver cancer care by recognizing the needs and concerns of women who have experience with treatment. With your input, such a study can help to identify what works with the current system and what could use an improvement.

What will happen during the study?

You will be asked to take part in a onetime interview conducted by the principal investigator. The interview will be guided by a series of questions that will encourage you to reflect on your experience

of cancer care so far and to highlight areas that you are satisfied and dissatisfied with. The questions are open-ended, meaning they do not have a set of answers to choose from and also that there is no 'right' or 'wrong' answer. Topics will include: your journey to the cancer centre, the utilization of support resources in your community and your experiences in and around your appointment time. With your permission, the interview will be tape recorded so it may be transcribed later, and will take approximately 30 minutes.

Potential Harms, Risks or Discomforts:

It is not likely that there will be any harms or discomforts from participating in the interview. At times, reflecting on your experiences may cause you some emotional distress. You do not need to answer questions that you do not want to answer or that make you feel uncomfortable. We can pause for any needed breaks and you can withdraw at any time. There will also be a supportive care clinician available that you may speak with. Your well-being takes priority over the data collection and this study. I describe below the steps I am taking to protect your privacy.

Potential Benefits

The research will not benefit you directly. The insights provided by yourself and other participants can work as an indicator of the effectiveness of the current system of breast cancer care, and highlight any areas that need improvement or that you believe to be neglected. This could help the province as well as the cancer centre to ensure they deliver the best possible care by providing environments and using strategies that are encouraging of successful treatments.

Confidentiality

You are participating in this study confidentially. I will not use your name or any information that would allow you to be identified in any write-ups, presentations or distributions of the results. No one but me will know whether you participated unless you choose to tell them. The information you provide will be kept in a locked desk cabinet where only I will have access to it. Information kept on a computer will be protected by a password. Once the study has been completed, the data will be destroyed.

Participation and Withdrawal

Your participation in this study is voluntary and it is your choice to be part of the study or not. If you decide to be part of the study, you can decide to withdraw, at any time, even after signing the consent form. If you decide to withdraw, there will be no consequences to you. If you do not want to answer some of the questions you do not have to, but you can still be in the study. Your decision whether or not to be part of the study will not affect your continuing access to any services or aspects of care.

Information about the Study Results

I expect to have this study completed by approximately March 2012. If you would like a brief summary of the results, please let me know how you would like it sent to you.

Questions about the Study

If you have questions or need more information about the study itself, please contact Kimberly Devotta by phone (905-525-9140 ext. 20440) or by e-mail (devotk@mcmaster.ca), or Dr. John Eyles at eyles@mcmaster.ca.

CONSENT

SIGNATURE OF PARTICIPANT

I have read the information presented in the information letter about a study being conducted by Linda Learn of Supportive Care and Kimberly Devotta of McMaster University. I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.

I understand that if I agree to participate in this study, I may withdraw from the study at any time. I have been given a copy of this form. I agree to participate in the study.

Name of Participant (Printed) _____

Signature: _____ Date: _____

1. I agree that the interview can be audio/video recorded.

Yes.

No.

2. Yes, I would like to receive a summary of the study's results.

Please send them to this email address _____

or to this mailing address: _____

No, I do not want to receive a summary of the study's results.

SIGNATURE OF INVESTIGATOR

I have discussed this study in detail with the participant. I believe the participant understands what is involved in this study.

Name of Investigator (Printed) _____

Signature: _____ Date: _____

This study has been reviewed by the Hamilton Health Sciences/McMaster Faculty of Health Sciences Research Ethics Board (HHS/FHS REB). The REB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call The Office of the Chair, HHS/FHS REB at 905.521.2100 x 42013

APPENDIX C: INTERVIEW SCHEDULE

Interview Guide

This interview is an opportunity for you to reflect and share your thoughts on the care you have received so far, and any hopes you have for the future of your treatment experience. I will be asking you some questions to guide our discussion, namely those that concern your experiences of getting to the Juravinski Centre as well as your experiences in and around your appointments. I am also interested in how the experience of your appointment can impact how you follow treatment plans at home and your overall satisfaction with the care that you receive. Your answers will in no way be traced back to you, and will simply be pooled with the input of other women so it may be used to come up with some recommendations for the current program of care. Insights that you provide can help to ensure that current and future systems of care are inline with what patients want and need. While your insights into cancer treatment are greatly valued by researchers, decision makers and health care providers, my primary concern is that you feel comfortable with me and the questions being asked. You can simply say ‘skip’ if you do not want to answer a particular question. If at any time you would like to pause for a break or stop completely, I am more than happy to oblige. If you have any concerns or doubts after the interview and would rather not have your answers used, I will not use them.

1. Can you tell me how long you have been coming to the Cancer Centre? Can you give me a brief description of your cancer centre visits so far?

Probes:

- i. What were your first expectations about visits to the JCC? Was there anything unexpected about your visits? Has anything changed?
 - ii. Do you, presently or in the past, enter any visits with particular expectations? (If so) are these usually met?
 - iii. Anything surprising? (positive or negative)
2. How has the day gone so far? Can you describe it for me? What, if anything, have been the most noticeable changes since your first visit?

Probes:

- i. Is there anything you hope will change? Stay the same in future visits?

I'd like to talk more specifically about your experiences at the centre.

[MICRO-ENVIRONMENT (INSIDE THE CENTRE)]

3. Do you enter through a parking garage or through the front door? Do you find it easy to navigate to the different areas of the centre when entering? during your appointment? When you leave?

Probes:

- i. Are areas clearly marked?

- ii. How familiar are you with the different clinics?
 - iii. What do you do/have you done when you need more directions to navigate the area?
4. In terms of waiting for your appointment once you arrive at the centre, how long do you have to wait? Does it vary?
- Probes:
- i. Do you usually get called in close to your appointment time?
 - ii. What do you think of the waiting area? It's privacy? The centre in general? What do you usually do while waiting? What *can* you do while waiting?
 - iii. Any comments on the area? TV screens? Lighting? Seating area? General atmosphere? Art work? Access to written materials while waiting
 - iv. Do you have to go to other parts of the centre for treatment or care? How long do you wait there?
5. How does the environment affect your ability to communicate with different staff members here? (incl: porters, volunteers, receptionists, etc)
- Probes:
- i. Would you prefer that to change?
 - ii. Do you think it *can* change?
 - iii. Is there anything you would hope they'd keep the same?
6. How does the environment help your ability to understand treatment? (learning and asking questions)
- Probes:
- i. What is it that *affects* your ability to understand?
 - ii. What is it that *helps* you to understand?
 - iii. Is the setting and length of your appointment sufficient to discuss any concerns?
7. What are your 'go to' sources for information/clarification of your treatment?
- Probes:
- i. What effects does that have on your ability to understand?
 - ii. Do you call the clinic? Refer to any literature you've picked up?
 - iii. Do you have any other sources?
8. What have been your sources of information about coming to the JCC, attending appointments, accessing internal and external resources (eg: Supportive Care, Canadian Cancer Society)
- Probes:
- i. Do you ever lookup explanations online? Ask a friend or family member? Talk to people in your support group? Internet, written material?
 - ii. Did these sources provide you with the information you needed?
 - iii. How would you have liked to receive the information? Was there information you didn't receive that you would have liked to receive?

iv. Which ones do you trust the most?

9. Are you able to talk about your at home medication, in your appointment?

Probes:

- i. What in the setting makes this *easier* to do?
- ii. What in the setting makes this *harder* to do?
- iii. What would help you?

10. Did you seek information about accessing resources from health professional staff here?

Probes:

- i. Do you get the opportunity and time to address any concerns or questions you may have?
- ii. Have you ever left wishing you addressed certain concerns?
- iii. Is it ever because you forget to ask or tell the health professional about it?
- iv. Feel uncomfortable asking?
- v. Lack of privacy?

One of the areas I am also interested in learning about is your journey to the clinic
[CANCER CENTRE ENVIRONMENT (LOCATION OF THE CENTRE)]

11. How did you get here?

Probes:

- i. Is this how you usually get to the centre?
- ii. Was it a good or bad experience?
- iii. Do you ever come with a friend or family member? Use public transportation? Canadian Cancer Society driver, other volunteer agency, Taxi company?
- iv. Is this how it always is or does it change sometimes? Under what conditions does it change?
- v. What, if any, is the most difficult aspect of getting to the Juravinski Centre?

12. Overall, would you consider the centre convenient and easy to access?

Probes:

- i. Does it fit in with your day-to-day schedule?
- ii. Does this ever impact your choice of appointment time?
- iii. Is this difficult to schedule?
- iv. How would you describe its convenience to other places you may frequent on the same day as your appointment?

13. Do you or have you ever used the on-site parking? How do you find the parking facilities to be?

Probes:

- i. Accessible? Is it easy to get in and out?
- ii. Price?

iii. Does this, in anyway, impact how you schedule your appointments?

14. Do you usually head to your appointment straight from home, work or another place?

Probes:

- i. Is there a reason for that?
- ii. Do you schedule your appointment around errands, or errands around your appointments?

15. Can you describe your best experience of getting to your appointment?

Probes:

- i. Why was this better than all your other trips?
- ii. Is that something rare or does it happen often? Did it have anything to do with the distance you travelled?
- iii. Do you think it had anything to do with the location of the centre?

16. Can you describe your worst experience of getting to your appointment?

Probes:

- i. What, exactly, do you think contributed to that experience?
- ii. Is that something you can easily change? Did it have anything to do with the distance you travelled?
- iii. Do you think it had anything to do with the location of the centre?

I am also interested in the resources available to you, outside of the Juravinski; namely, those available in your community and around where you live and work.

[COMMUNITY ENVIRONMENT (URBAN/RURAL)]

17. Are you aware of resources (i.e. support groups) for people with cancer? Any Breast Cancer specific ones?

Probes:

- i. Can you name them?
- ii. Have you used them? Now? For what?
- iii. How did you find out about these?
- iv. How has your cancer support group helped you cope with treatment?

18. Is there anything you would prefer the city to have, to help patients such as yourself?

Probes:

- i. Do they make enough resources available?
- ii. What would you want them to add?

Thank-you very much for your time. Your participation is greatly appreciated. Please know that your responses will remain confidential and will in no way compromise your care here. Is there anything else you'd like to share about your experience so far?

APPENDIX D: CODEBOOK

Cues to action

Cues to action\advice from others

Cues to action\advice from others\family
 Cues to action\advice from others\friends
 Cues to action\advice from others\on-line
 Cues to action\advice from others\patients

Cues to action\at home adherence

Cues to action\at home adherence\prescription instructions
 Cues to action\at home adherence\prescription schedules

Cues to action\illness of family member

Cues to action\Media

Cues to action\posters and advertisements

Cues to action\scheduled appointments

Cues to action\scheduled appointments\all day
 Cues to action\scheduled appointments\Complicated
 Cues to action\scheduled appointments\Complicated\must be flexible
 Cues to action\scheduled appointments\easy to follow
 Cues to action\scheduled appointments\easy to follow\easy to accomodate
 Cues to action\scheduled appointments\unanticipated changes

Perceived Barriers

Perceived Barriers\Physical Environment

Perceived Barriers\Physical Environment\Cancer Centre
 Perceived Barriers\Physical Environment\Cancer Centre\Architecture
 Perceived Barriers\Physical Environment\Cancer Centre\Architecture\Changing
 Perceived Barriers\Physical Environment\Cancer Centre\Architecture\Updated
 Perceived Barriers\Physical Environment\Cancer Centre\Associated with cancer
 Perceived Barriers\Physical Environment\Cancer Centre\Associated with cancer\anxious
 Perceived Barriers\Physical Environment\Cancer Centre\Associated with cancer\good place for a bad experience
 Perceived Barriers\Physical Environment\Cancer Centre\Associated with cancer\gratitude such a place exists
 Perceived Barriers\Physical Environment\Cancer Centre\Comprehensiveness
 Perceived Barriers\Physical Environment\Cancer Centre\Coordination
 Perceived Barriers\Physical Environment\Cancer Centre\Coordination\With family doctor
 Perceived Barriers\Physical Environment\Cancer Centre\Coordination\With Juravinski hospital
 Perceived Barriers\Physical Environment\Cancer Centre\Coordination\Within centre
 Perceived Barriers\Physical Environment\Cancer Centre\Entry Ways
 Perceived Barriers\Physical Environment\Cancer Centre\Entry Ways\Congestion
 Perceived Barriers\Physical Environment\Cancer Centre\Entry Ways\Construction and parking determines
 Perceived Barriers\Physical Environment\Cancer Centre\Entry Ways\Convenient
 Perceived Barriers\Physical Environment\Cancer Centre\Entry Ways\Depends on visit
 Perceived Barriers\Physical Environment\Cancer Centre\Location
 Perceived Barriers\Physical Environment\Cancer Centre\Location\Convenient location (general)
 Perceived Barriers\Physical Environment\Cancer Centre\Location\Convenient location (general)\Convenient location if you live in Hamilton
 Perceived Barriers\Physical Environment\Cancer Centre\Location\Inconvenient
 Perceived Barriers\Physical Environment\Cancer Centre\Location\Will go regardless
 Perceived Barriers\Physical Environment\Cancer Centre\Parking
 Perceived Barriers\Physical Environment\Cancer Centre\Parking\Accesibility

Perceived Barriers\Physical Environment\Cancer Centre\Parking\Availability
 Perceived Barriers\Physical Environment\Cancer Centre\Parking\Complex system
 Perceived Barriers\Physical Environment\Cancer Centre\Parking\Different options
 Perceived Barriers\Physical Environment\Cancer Centre\Parking\Expected or used to it
 Perceived Barriers\Physical Environment\Cancer Centre\Parking\Frequency of visits
 Perceived Barriers\Physical Environment\Cancer Centre\Parking\Justice issue unmanageable
 Perceived Barriers\Physical Environment\Cancer Centre\Parking\Price
 Perceived Barriers\Physical Environment\Cancer Centre\Reputation
 Perceived Barriers\Physical Environment\Cancer Centre\Reputation\After you become a patient
 Perceived Barriers\Physical Environment\Cancer Centre\Reputation\Always knew of it
 Perceived Barriers\Physical Environment\Cancer Centre\Reputation\Family doctor
 Perceived Barriers\Physical Environment\Cancer Centre\Reputation\Family member
 Perceived Barriers\Physical Environment\Cancer Centre\Reputation\Friend
 Perceived Barriers\Physical Environment\Cancer Centre\Reputation\Media
 Perceived Barriers\Physical Environment\Cancer Centre\Reputation\Previous experience
 Perceived Barriers\Physical Environment\Community
 Perceived Barriers\Physical Environment\Community\Experience with family doctor or surgeon
 Perceived Barriers\Physical Environment\Community\medication at home
 Perceived Barriers\Physical Environment\Community\medication at home\complicated
 Perceived Barriers\Physical Environment\Community\medication at home\easy to follow
 Perceived Barriers\Physical Environment\Community\questions at home
 Perceived Barriers\Physical Environment\Community\questions at home\ask someone else
 Perceived Barriers\Physical Environment\Community\questions at home\call-in
 Perceived Barriers\Physical Environment\Community\questions at home\next appointment
 Perceived Barriers\Physical Environment\Community\questions at home\refer to info at home
 Perceived Barriers\Physical Environment\Community\support groups
 Perceived Barriers\Physical Environment\Community\support groups\bad experience
 Perceived Barriers\Physical Environment\Community\support groups\distance or location matters
 Perceived Barriers\Physical Environment\Community\support groups\never sought
 Perceived Barriers\Physical Environment\Community\support groups\no need
 Perceived Barriers\Physical Environment\Community\support groups\suitability
 Perceived Barriers\Physical Environment\Community\Unavailable resources
 Perceived Barriers\Physical Environment\Journey to care
 Perceived Barriers\Physical Environment\Journey to care\'border\' of two places
 Perceived Barriers\Physical Environment\Journey to care\Familiarity with route or city
 Perceived Barriers\Physical Environment\Journey to care\Familiarity with route or city\Complicated
 Perceived Barriers\Physical Environment\Journey to care\Familiarity with route or city\Straight forward
 Perceived Barriers\Physical Environment\Journey to care\Familiarity with route or city\Varies
 Perceived Barriers\Physical Environment\Journey to care\Negative travel experience
 Perceived Barriers\Physical Environment\Journey to care\Negative travel experience\accidents
 Perceived Barriers\Physical Environment\Journey to care\Negative travel experience\construction
 Perceived Barriers\Physical Environment\Journey to care\Negative travel experience\time or distance
 Perceived Barriers\Physical Environment\Journey to care\Negative travel experience\traffic
 Perceived Barriers\Physical Environment\Journey to care\Negative travel experience\weather
 Perceived Barriers\Physical Environment\Journey to care\Stop in Hamilton
 Perceived Barriers\Physical Environment\Journey to care\Transportation
 Perceived Barriers\Physical Environment\Journey to care\Transportation\Driving is essential
 Perceived Barriers\Physical Environment\Journey to care\Transportation\Public transportation
 Perceived Barriers\Physical Environment\Journey to care\Transportation\Taxi
 Perceived Barriers\Physical Environment\Journey to care\Travel companion
 Perceived Barriers\Physical Environment\Journey to care\Travel from
 Perceived Barriers\Physical Environment\Journey to care\Travel from\Depends on appointment
 Perceived Barriers\Physical Environment\Journey to care\Travel from\home

Perceived Barriers\Physical Environment\Journey to care\Travel from\other
 Perceived Barriers\Physical Environment\Journey to care\Travel from\Someone else's place
 Perceived Barriers\Physical Environment\Journey to care\Travel from\work
 Perceived Barriers\Physical Environment\Journey to care\volunteer drivers
 Perceived Barriers\Physical Environment\Journey to care\volunteer drivers\available option
 Perceived Barriers\Physical Environment\Journey to care\volunteer drivers\different programs
 Perceived Barriers\Physical Environment\Journey to care\volunteer drivers\Nature of appointment
 Perceived Barriers\Physical Environment\Journey to care\volunteer drivers\nEEDED SERVICE
 Perceived Barriers\Physical Environment\Journey to care\volunteer drivers\nEEDED SERVICE\accessible
 Perceived Barriers\Physical Environment\Journey to care\volunteer drivers\nEEDED SERVICE\convenience
 Perceived Barriers\Physical Environment\Journey to care\volunteer drivers\no personal need
 Perceived Barriers\Physical Environment\Journey to care\volunteer drivers\other people are more in need
 Perceived Barriers\Physical Environment\Micro-Environment
 Perceived Barriers\Physical Environment\Micro-Environment\Appointment
 Perceived Barriers\Physical Environment\Micro-Environment\Appointment\accomodating
 Perceived Barriers\Physical Environment\Micro-Environment\Appointment\convenient
 Perceived Barriers\Physical Environment\Micro-Environment\Appointment\convenient\current lifestyle
 Perceived Barriers\Physical Environment\Micro-Environment\Appointment\convenient\necessary changes
 Perceived Barriers\Physical Environment\Micro-Environment\Appointment\length
 Perceived Barriers\Physical Environment\Micro-Environment\Appointment\not accomodating
 Perceived Barriers\Physical Environment\Micro-Environment\Appointment\schedule complexity
 Perceived Barriers\Physical Environment\Micro-Environment\Information needs
 Perceived Barriers\Physical Environment\Micro-Environment\Information needs\amount of information
 Perceived Barriers\Physical Environment\Micro-Environment\Information needs\asking questions
 Perceived Barriers\Physical Environment\Micro-Environment\Information needs\asking questions\afraid to ask
 Perceived Barriers\Physical Environment\Micro-Environment\Information needs\asking questions\comfortable to ask
 Perceived Barriers\Physical Environment\Micro-Environment\Information needs\asking questions\Don't know what to ask
 Perceived Barriers\Physical Environment\Micro-Environment\Information needs\asking questions\forget to ask
 Perceived Barriers\Physical Environment\Micro-Environment\Information needs\assessment of information needs
 Perceived Barriers\Physical Environment\Micro-Environment\Information needs\Sources
 Perceived Barriers\Physical Environment\Micro-Environment\Information needs\Sources\family doctor or surgeon
 Perceived Barriers\Physical Environment\Micro-Environment\Information needs\Sources\friends and family
 Perceived Barriers\Physical Environment\Micro-Environment\Information needs\Sources\HCPs
 Perceived Barriers\Physical Environment\Micro-Environment\Information needs\Sources\internet
 Perceived Barriers\Physical Environment\Micro-Environment\Information needs\Sources\need to be told what exists
 Perceived Barriers\Physical Environment\Micro-Environment\Information needs\Sources\other
 Perceived Barriers\Physical Environment\Micro-Environment\Information needs\Sources\other patients
 Perceived Barriers\Physical Environment\Micro-Environment\Information needs\Sources\staff
 Perceived Barriers\Physical Environment\Micro-Environment\Information needs\Sources\venues at centre
 Perceived Barriers\Physical Environment\Micro-Environment\Information needs\Sources\venues at centre\library
 Perceived Barriers\Physical Environment\Micro-Environment\Information needs\Sources\venues at centre\posters
 Perceived Barriers\Physical Environment\Micro-Environment\Information needs\Sources\venues at centre\waiting room

Perceived Barriers\Physical Environment\Micro-Environment\Information needs\Sources\written material
 Perceived Barriers\Physical Environment\Micro-Environment\Information needs\timing of information
 Perceived Barriers\Physical Environment\Micro-Environment\Navigation
 Perceived Barriers\Physical Environment\Micro-Environment\Navigation\clearly marked
 Perceived Barriers\Physical Environment\Micro-Environment\Navigation\companion is familiar
 Perceived Barriers\Physical Environment\Micro-Environment\Navigation\familiarity
 Perceived Barriers\Physical Environment\Micro-Environment\Navigation\voulnteers or staff
 Perceived Barriers\Physical Environment\Micro-Environment\Organization
 Perceived Barriers\Physical Environment\Micro-Environment\Previous experience
 Perceived Barriers\Physical Environment\Micro-Environment\Privacy
 Perceived Barriers\Physical Environment\Micro-Environment\Privacy\Discussions
 Perceived Barriers\Physical Environment\Micro-Environment\Privacy\Lack of is not a bad thing
 Perceived Barriers\Physical Environment\Micro-Environment\Privacy\no privacy
 Perceived Barriers\Physical Environment\Micro-Environment\Privacy\no privacy\can't talk in private
 Perceived Barriers\Physical Environment\Micro-Environment\Privacy\no privacy\sick and on display
 Perceived Barriers\Physical Environment\Micro-Environment\Privacy\Procedure rooms
 Perceived Barriers\Physical Environment\Micro-Environment\Privacy\tune people out
 Perceived Barriers\Physical Environment\Micro-Environment\Sources of comfort
 Perceived Barriers\Physical Environment\Micro-Environment\Sources of comfort\encouraging of questions
 Perceived Barriers\Physical Environment\Micro-Environment\Sources of comfort\familiarity with place
 Perceived Barriers\Physical Environment\Micro-Environment\Sources of comfort\noise level
 Perceived Barriers\Physical Environment\Micro-Environment\Sources of comfort\non-hospital feel
 Perceived Barriers\Physical Environment\Micro-Environment\Sources of comfort\other patients
 Perceived Barriers\Physical Environment\Micro-Environment\Sources of comfort\routine nature
 Perceived Barriers\Physical Environment\Micro-Environment\Sources of comfort\same boat
 Perceived Barriers\Physical Environment\Micro-Environment\Sources of comfort\same doctors or nurses
 Perceived Barriers\Physical Environment\Micro-Environment\Wait Time
 Perceived Barriers\Physical Environment\Micro-Environment\Wait Time\anxious
 Perceived Barriers\Physical Environment\Micro-Environment\Wait Time\Avoidable
 Perceived Barriers\Physical Environment\Micro-Environment\Wait Time\expected
 Perceived Barriers\Physical Environment\Micro-Environment\Wait Time\no wait
 Perceived Barriers\Physical Environment\Micro-Environment\Wait Time\understandable reasons
 Perceived Barriers\Physical Environment\Micro-Environment\Wait Time\varies
 Perceived Barriers\Physical Environment\Micro-Environment\Waiting Room
 Perceived Barriers\Physical Environment\Micro-Environment\Waiting Room\Companion
 Perceived Barriers\Physical Environment\Micro-Environment\Waiting Room\Don't like to talk to others
 Perceived Barriers\Physical Environment\Micro-Environment\Waiting Room\Everyone talks
 Perceived Barriers\Physical Environment\Micro-Environment\Waiting Room\Everyone's quiet
 Perceived Barriers\Physical Environment\Micro-Environment\Waiting Room\Experience
 Perceived Barriers\Physical Environment\Micro-Environment\Waiting Room\Experience\Bring things to do
 Perceived Barriers\Physical Environment\Micro-Environment\Waiting Room\Experience\Good scenery
 Perceived Barriers\Physical Environment\Micro-Environment\Waiting Room\Experience\Lineups
 Perceived Barriers\Physical Environment\Micro-Environment\Waiting Room\Experience\Mixed statements
 Perceived Barriers\Physical Environment\Micro-Environment\Waiting Room\Experience\Neutral
 statements (observations)
 Perceived Barriers\Physical Environment\Micro-Environment\Waiting Room\Experience\Things to do
 Perceived Barriers\Physical Environment\Micro-Environment\Waiting Room\Experience\Too crowded
 Perceived Barriers\Physical Environment\Micro-Environment\Waiting Room\Experience\Too loud
 Perceived Barriers\Physical Environment\Micro-Environment\Waiting Room\People watching
 Perceived Barriers\Physical Environment\Micro-Environment\Waiting Room\Uncomfortable
Perceived Barriers\Social Environment
 Perceived Barriers\Social Environment\Anticipated experience
 Perceived Barriers\Social Environment\Anticipated experience\comparison to experience elsewhere

Perceived Barriers\Social Environment\Anticipated experience\stories heard
 Perceived Barriers\Social Environment\CB analysis
 Perceived Barriers\Social Environment\Community support groups
 Perceived Barriers\Social Environment\Community support groups\Age
 Perceived Barriers\Social Environment\Community support groups\Diversity
 Perceived Barriers\Social Environment\Community support groups\Formality
 Perceived Barriers\Social Environment\Community support groups\Participants
 Perceived Barriers\Social Environment\Community support groups\Previous experience
 Perceived Barriers\Social Environment\Other people's attitudes
 Perceived Barriers\Social Environment\Other people's attitudes\HCP in general
 Perceived Barriers\Social Environment\Other people's attitudes\Individualized care
 Perceived Barriers\Social Environment\Other people's attitudes\Patients
 Perceived Barriers\Social Environment\Other people's attitudes\Patients\Them to ('I recognize their need')
 Perceived Barriers\Social Environment\Other people's attitudes\Patients\To them (talkative)
 Perceived Barriers\Social Environment\Other people's attitudes\Specifically
 Perceived Barriers\Social Environment\Other people's attitudes\Specifically\Family doctors
 Perceived Barriers\Social Environment\Other people's attitudes\Specifically\Nurses
 Perceived Barriers\Social Environment\Other people's attitudes\Specifically\Oncologists
 Perceived Barriers\Social Environment\Other people's attitudes\Specifically\Supportive Care
 Perceived Barriers\Social Environment\Other people's attitudes\Specifically\Volunteers

Perceived Benefits

Perceived Benefits\Effectiveness of lifestyle change

Perceived Benefits\Effectiveness of medical treatment

Perceived Benefits\Effectiveness of medical treatment\Effectiveness of spiritual beliefs

Perceived severity (expectations incentives)

Perceived severity (expectations incentives)\Knowledge of diagnosis

Perceived severity (expectations incentives)\Knowledge of diagnosis\surgeon or family doctor

Perceived severity (expectations incentives)\Seriousness of leaving disease untreated

Perceived severity (expectations incentives)\Seriousness of leaving disease untreated\adherence to lifestyle change

Perceived severity (expectations incentives)\Seriousness of leaving disease untreated\adherence to medication at home

Perceived Susceptibility

Perceived Susceptibility\Belief in diagnosis

Perceived Susceptibility\Belief in resusceptibility

Perceived Susceptibility\Belief in vulnerability

Self-efficacy

Self-efficacy\Be own advocate

Self-efficacy\circle of support

Self-efficacy\circle of support\family

Self-efficacy\circle of support\fellow patients

Self-efficacy\circle of support\friends