

**MAKING DECISIONS IN ADVANCED CANCER:
THE LIVED EXPERIENCE OF WOMEN AND THEIR RELEVANT OTHERS**

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ABSTRACT

This descriptive phenomenology had two purposes: first, to explore the experience of making decisions for women with advanced cancer; and second, to explore the experience for significant others and health care team members as women made their decisions. A plethora of research exists on making decisions during the cancer experience, including research regarding: 1) decision-making styles; 2) factors or determinants which play a role in decision making; 3) information: needs, seeking behaviours, and utilization; and 4) decision support technologies. However, a gap exists in the literature regarding the experience of making decisions. Conversational interviews were conducted with five women and three relevant others for each woman: her primary nurse, her oncologist, and one significant other. Women were also provided with the opportunity to journal in a diary or email their memories of decisions and the surrounding experience. Van Manen's (1990) phenomenology guided the analysis of data. For the women, analysis centered on the four existentials of lived time, lived other, lived space, and lived body, revealing four themes of the lived experience of making decisions: 1) control, 2) influence, 3) normalcy, and 4) vulnerability. Phenomenological analysis on data from the significant others revealed three themes: 1) what used to be, 2) power shift, and 3) 'life on hold.' Themes for the health care team's experience as women made decisions were: 1) emotional detachment, 2) discomfort, and 3) acquiescing. Understanding the perspectives from these lived experiences will assist the health care team to support women, and their significant others, through the experience of making decisions.

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With all my love and respect,

Natasha Lee

Dedicated to

Gordon William Murdoch
January 28, 1928 – May 2, 2002

Gordon, I am learning to listen. Natasha

*When once our heav'nly-guided soul shall clime,
Then all this Earthy grosnes quit,
Attir'd with Stars, we shall for ever sit,
Triumphing over Death, and Chance, and thee, O Time.*
- Milton

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CHAPTER ONE – INTRODUCTION

The term *advanced cancer* is applied to patients in varying phases of disease progression, including during treatment for curative intent and palliative or end-of-life care. The Canadian Institutes of Health Research (2004) state research is usually directed towards a cure for those with a terminal diagnosis, rather than quality of life. However, quality of life issues also affect policy and practice. One of the most stressful aspects of advanced cancer with a major impact on quality of life is the multiple significant decisions that must be made by persons with this stage of disease. However, little is understood about the experience of making decisions when confronted with the diagnosis of advanced cancer.

Despite the plethora of research available on making decisions during cancer, no research has specifically addressed the phenomenology of women with advanced cancer and their experience in making decisions. Literature also does not appear to address the experiences of relevant others when a woman made decisions during advanced cancer. Because cancer is not experienced alone, this research also sought to understand the experience for relevant others when the woman made her decisions. Relevant others include significant others (spouses, children, etc.) and health care team members including oncologists and registered nurses. Understanding these experiences is important to support women as they make significant decisions during the chaos of having advanced cancer. The purpose of this research was to explore the lived experience of

women with a known terminal cancer diagnosis when they made significant decisions and the impact of that experience for relevant others.

Definitions

To facilitate understanding of this specific experience with decision making, the terms *relevant other* and the advanced cancer transition period are operationalized below.

Significant Others versus Relevant Others

This research included four types of study participants: the woman, her significant other, her oncologist, and her primary nurse. For the purposes of this research, the latter three were combined into one term: relevant others. The term significant other is used in the literature to delineate the single, primary source of support: a spouse, partner, eldest child, or best friend. The health care team members are also a primary source of support.

In debriefing with my supervisor, this support was deemed to be equally significant. However, the experience for each group may be different. Thus, the study participants, chosen by the women, are the most significant (referring to spouses, partner, child or best friend) or relevant (nurse or oncologist) persons in the women's lived experience of making decisions. Each term was used when the writing required this specificity.

Definition of Terms Leading to Advanced Cancer Transition Period

Patients with advanced cancer move through a cancer care timeline including diagnosis, progression, and metastases, ultimately culminating in a terminal stage. Advanced cancer is “cancer that has spread to other places in the body and usually cannot be cured or controlled with treatment” (National Cancer Institute, n.d.). The advanced cancer transition period starts when the woman is informed that her prognosis is poor and includes medical cancer treatments. The transition period ends when medical cancer

treatments are discontinued. The inclusion criteria and study timeline was delimited to this transition period.

The current study best described the experience of women within this delimited timeframe. For the researcher, the impetus for this study was meeting a woman who was in this transition. I met her when she would come in for follow up to the clinical trial department at the Saskatoon Cancer Centre. She talked about being at her cottage in the summer time, kayaking, and spending time outdoors gardening. At one appointment, her blood work reflected a change from her normal. These results started a chain reaction of appointments, and diagnostic tests, including a bone marrow biopsy.

The woman and her husband researched the diagnosis, the treatment options including risks and benefits, and the potential outcomes. They both arrived for their appointment to meet their new hematologist, a resident, myself, and the new primary nurse armed with information. When the hematologist came in the room and sat down, the woman took over the interview, an interview that might normally have been directed by the hematologist and the diagnosis. She requested to tape record the interview so that she and her husband would not miss anything and then began explaining what she understood about her diagnosis. Despite hearing her poor prognosis, this woman was able to ask pointed questions about possible treatment options. She told the hematologist she understood she would die.

This situation was enlightening because this woman, after hearing of her poor prognosis, initially decided not to undergo treatment. She was given 24 hours to make a decision because the hospital was holding a bed for her. This woman eventually chose to undergo treatment, but questions remained. What was she experiencing when she made

this decision? Were concerns for her family what led her to continue with treatment? What effect did her decision have on others? What were the thoughts of her relevant others (her husband, her daughter, her nurse, her doctor) when she made the decision? The concern, and therefore, the rationale for pursuing this research, was to understand what it was like to have made this decision. This encounter led to the current study on the experience around decisions for both women with advanced cancer and their relevant others.

Research Aims

This research studied the experience for three groups of people (women, significant others, and the health care team) during this time of significant decisions.

Aim 1: Describe what it is like for women to make decisions when they know they are going to die.

Aim 2: Explore the meaning of the lived experience for these women.

Aim 3: Describe the lived experience of relevant others involved in these significant decisions.

CHAPTER TWO – LITERATURE REVIEW

Van Manen (1990) postulated whether literature should be reviewed prior to implementing a study, arguing that literature could affect analysis. However, at some point, interpretation of the literature is required to further knowledge in the chosen field. This literature review provided a pre-understanding, and defined both concepts and the general experience around advanced cancer and decision making theory. The interviews then focused on the essence surrounding decisions within the context of advanced cancer.

A search of nursing and medical databases revealed no research on the experience of making decisions during the advanced cancer transition period. As well, literature tended to specify symptoms or care settings within the cancer experience. Literature was found on the experience of advanced cancer and making decisions.

The Experience of Advanced Cancer

In studies of the experience of advanced cancer, participants convey the experience of gaining a new identity (Chiu, 2000; Davies & Sque, 2002), their search for meaning in having cancer (Albaugh, 2003; Houldin & Lewis, 2006), and the changes in relationships with relevant others (Houldin & Lewis, 2006; Johansson, Axelsson, & Danielson, 2006).

Gaining a new identity is reflected in a study by Chiu (2000). She studied the concept of transcendence, an ‘evolutionary process’ where one has the “capacity to

reflect, reach out beyond oneself, extend oneself beyond personal concerns, and take on broader life perspectives and purposes” (p. 65). Chiu’s premise is that even if a woman experienced crisis by being diagnosed with cancer, she could learn to live again, and then search for meaning. Women transitioned through suffering, being liberated, being open to death, and finally giving their healing energy to others. Women found meaning by transcending and therefore experienced a different level of self.

This change in identity is also reflected in a grounded theory by Davies and Sque (2002). The core process was ‘reconciling a different me’, which was the experience for women of visualizing their pre-cancer identity then accepting they had changed. The result was being ‘apart’ from a world in which they once lived and looking into that world. The woman’s new world included dealing with the time bomb of cancer recurrence, the positives (inspirational messages) and negatives (impact of breast cancer) from the media, the steadily declining relationships with professionals, and the search for supports who would rescue them from the isolation of cancer. With a final statement on self-transcendence by one of the participants, ‘ordinary people don’t understand,’ (Davies & Sque, p. 589), the authors relate the process of gaining a new identity by transitioning through advanced cancer.

Albaugh (2003) provides a concise thematic description of searching for meaning in illness. Participants spoke of coming to the realization of what was important in their lives, of enjoying the time they had left with their loved ones, and that despite cancer, life was still meaningful. This was an abstract experience of meaning as compared to an operationalized experience, as presented by Houldin and Lewis (2006) in their grounded theory for participants diagnosed with advanced cancer. One domain the researchers

described centered around reframing the experience of having cancer, which included conducting a life review and confronting death.

Along with this search for meaning, Houldin and Lewis (2006) note domains where relationships with physicians and family were impacted. Participants relayed communication with physicians that ranged from hopeful to distressing. They also relayed the need to change how they parented including communication style, time, and content. Johansson et al. (2006) also found a theme related to significant relations where participants expressed the need for networks of support—from spouses to nurses to pets—and particularly resonant communication that provided understanding and responsiveness.

To summarize the literature, the experience of advanced cancer is a journey through initial shock, to acceptance, and finally meaning, that results in a new identity and affects communication and relationships with relevant others.

Making Decisions

Literature regarding decision making with respect to cancer was extensive. Research was focused in four main areas: 1) decision-making styles (Budden, Pierce, Hayes, & Buettner, 2003; Correa-Velez, Clavarino, Barnett, & Eastwood, 2003; Elit et al., 2003; Lantz et al., 2005; Hack, Degner, Watson, & Sinha, 2006; Caldon, Walters, & Reed, 2008; Delgado et al., 2008; Rondanina et al., 2008; Vogel, Bengel, & Helmes, 2008); 2) factors or determinants that play a role in making decisions (Llewellyn-Thomas, Sutherland, & Thiel, 1993; Gilbar & Cohen, 1995; Mansell, Poses, Kazis, & Duefield, 2000; Hinkka et al., 2002; Jansen, Otten, & Stiggebout, 2004; Steginga, Occhipinti, Gardiner, Yaxley, & Heathcote, 2004; Ramfelt & Lutzen, 2005; Elliott &

Olver, 2008; Silen, Svantesson, & Ahlstrom, 2008); 3) information: needs, seeking behaviours, and utilization (Kenny, Quine, Shiell, & Cameron, 1999; van der Molen, 2000a, 2000b; Davison et al., 2002; Pinquart & Duberstein, 2004); and 4) decision support technologies (Anagnostou, Remzi, Lykourinas, & Djavan, 2003; Durand, Stiel, Boivin, & Elwyn, 2008). A small number of studies related the experience of making decisions, not the process. However, this research was not related to the advanced cancer transition period but to treatment in other stages of cancer (Montbriand, 1995; Bottorff et al., 1998; van der Molen, 2000a; Bailey, 2001; Lacey, 2002; Fitch, Deane, & Howell, 2003; Sainio & Lauri, 2003; Halkett, Scutter, Arbon, & Borg, 2005, 2007).

Decision-making Styles

The majority of research in regard to decision-making styles has focused on breast conserving surgery (BCS) versus mastectomy. For this treatment in particular, the survival rates are the same for all the current treatment options, so patients are provided the opportunity to decide their preferred treatment. Caldron et al., (2008) suggest women provided with a choice between surgeries [suggesting an active decision-making style] had less psychological consequences and lower regret. A similar study (Lantz et al., 2005) found that as women took a more active role in making treatment decisions, the rate of BCS decreased. Canadian researchers (Hack et al., 2006) looked at quality of life three years after surgery treatment choice; women choosing to have an active or shared role in treatment decision making had an increased quality of life three years later.

Factors Influencing Decision Making

The second area of decision-making research focused on factors or determinants that affect the process, such as communication. For example, studies include: interviews

with nurses working on a dialysis unit regarding professional boundaries between nurses, physicians, and patients when communicating about decisions (Silen et al., 2008); patients with colorectal cancer reflecting on their own communication (Ramfelt & Lutzen, 2005); and oncologists listing factors that affect their choice of treatment such as attitudes and personal characteristics (Gilbar & Cohen, 1995).

Hinkka et al. (2002) found decisions were affected by physician factors (speciality, experience, values, attitudes, and socio-demographic characteristics) as well as patient preferences and the clinical situation. As patient illness increased in severity, patients desire more information and more involvement in the process (Llewellyn-Thomas et al., 1993; Mansell et al., 2000).

Information: Needs, Seeking Behaviour, and Utilization

The fourth area of decision-making research regarding information needs and information seeking behaviours was found in a review of 97 studies on age-related differences in making decisions related to cancer treatment (Pinquart & Duberstein, 2004). Older adults have a more passive decision-making style and take more time to analyze information to make an informed decision.

Davison et al. (2002) surveyed patients with prostate cancer and their significant others to determine if the “men and their partners have similar information preferences at time of diagnosis.” Lacey (2002) provide a descriptive phenomenology of women with breast cancer. The researcher interviewed women, considered disease free, following treatment about the experience of using decisional support aids during the prediagnosis, diagnosis, and treatment phases. The findings state family support was necessary in making decisions, especially in ‘information seeking.’ However, in the end, the

participants stated the decision was their own to make, not their significant other's.

Van der Molen (2000b) sought to understand issues for people with cancer. The researcher separated three levels of information needs and found themes consistent among those three levels. Her findings revealed issues with self-identity, social support, and processing information. Decision making was impacted by these themes but was not presented as the priority issue. The experience of having cancer, presented in a narrative of one woman (van der Molen, 2000a), meant gaining information to deal with issues around children, friends, finances, and work.

The utilization of information was studied by Kenny et al. (1999), who interviewed 40 women about treatment decision making for early stage breast cancer. The problem for the women was making choices when only part of the information was absorbed, information was difficult to interpret, or the probability (percent chance) was difficult to apply to her situation.

Decision Support Technologies

Decision support technologies (DSTs) include patient decision aids. This area of research was split between technologies that supported the clinician (Anagnostou et al., 2003) in making a decision and those that supported the patient (Durand et al., 2008). One example of a patient supportive aid would be a pamphlet or video on a screening tool such as mammograms.

Experience of Making Decisions

A few studies addressed the experience of making decisions (Bailey, 2001; Bottoroff et al., 1998; Halkett et al., 2007; Montbriand, 1995; Sainio & Lauri, 2003). Although the process of decision making was apparent, the meaning of participating in

making a decision seemed to include dependency. Bailey used mixed methods to survey patients with colorectal cancer to determine whether people of different ages and in different functional states were more or less likely to receive a certain treatment. The recently diagnosed participants, awaiting surgery, let the physician choose the treatment because of their own lack of knowledge or experience, and they therefore felt a sense of dependency.

Sainio and Lauri (2003) used questionnaires to understand the amount of participation from cancer patients [unable to determine advanced cancer transition period] regarding treatment decisions and nursing care. The authors looked at factors such as information and relationships with staff. Respondents were asked about specific things such as rest, food, medications, or intravenous fluids (nursing tasks, not symptom management or information). Not surprisingly, patients felt choosing the amount of intravenous fluid was not high on their scale of importance. Findings did reveal that if the relationship with staff was good, patients participated more in making decisions. However, the experience was one of staff making decisions rather than patients being mutual participants.

Bottorff et al. (1998) observed various patients with cancer and HIV/AIDS to develop a grounded theory on the experience of making decisions and nursing care choices in palliative care. They found patients valued the daily opportunity to participate in care decisions. The researchers observed the experience of making decisions when the nurse offered control, attempted to take control, or the patient chose to relinquish control. The authors found five themes related to the process of making decisions including what type of choices were made, the social interactions involved, the need to weigh options,

communicating the choice, and living with the choice. The themes suggest the experience of making decisions during a stay in palliative care meant maintaining a balance between having and giving up control. These three studies seem to suggest patients were dependent upon the health care provider to make decisions.

Dependency on significant others or the health care team to provide the suggested decision path was found in an ethnographic study (Montbriand, 1995). This study developed a decision tree for participants choosing alternative therapy along with their biomedical care or a biomedical path through treatment. Ten themes were found around biomedical or alternative treatment choices. Along with the common concerns about stress, participation in treatment decision making and influence of others on making choices included experiences of secrecy about what was chosen and faith in the particular practice. The researcher carefully chose types of cancer (digestive or respiratory) with high rates of morbidity and mortality; this patient population relates to the women in the current study. The researcher states patients used alternative therapy as a means of being in control. This study did not relate to women in the advanced cancer transition period.

Finally, one phenomenological study in women with early breast cancer describes the experience of making decisions. Halkett et al. (2007) list ten decisions that women made in regards to their breast cancer ranging from those related to the process of making decisions to what meaning would be ascribed to breast cancer. The first existential theme ‘being challenged’ was the experience of confronting cancer despite being terrified. The second theme was ‘getting ready’ for making decisions. The experience included deciding whom to talk to and communicating with health care professionals. The third theme was ‘surviving’, which meant making decisions that would ensure their survival.

The fourth theme meant deciding with whom they would ‘share the challenge.’ The final theme was the experience of questioning their decisions made during treatment, dealing with the possibility of recurrence, and considering breast reconstruction as a way toward normality, all of which were measures to move forward with life. Halkett et al. suggest women have difficulty making decisions when they have not had time to address their concerns of being diagnosed. The difference between this study and the current one is Halkett et al.’s use of a hermeneutic phenomenological method rather than a descriptive one. Their process of analysis included taking the ten decisions and devising themes based on the researcher’s interpretation of that experience. Furthermore, the participants were not in the advanced cancer transition period.

The Effect of a Woman’s Decisions on Relevant Others

Notably, no studies describing the decision-making experience of women with advanced cancer and their relevant others were found. A few studies discussed how the significant other experienced suffering when the other had cancer: as disturbing, but not comparable to the woman (Lindholm, Rehnsfeldt, Arman, & Hamrin, 2002); as emotional anguish in conflicting beliefs (James, Andershed, & Ternestedt, 2007); or as uncertainty and helplessness as a caregiver (Walker, 2002). Another study discussed the effect of anxiety on a nurse’s work when dealing with palliative care patients (Hildén, Louhiala, Honkasalo, & Palo, 2004). This implies patient decisions may affect health care providers; however, no research was found specific to the impact around decisions.

Summary

The literature on the experience of making decisions was strongly grounded in treatment decisions. Each one of these studies addressed portions of the four types of

decision making discussed previously: styles, factors, information, and technologies. These studies also tended to focus on the progression through diagnosis and treatment rather than the issues concerning making decisions. Patient concerns resulted when the amount of information provided by the health care team was not sufficient. In contrast, despite the amount of information given and the sense of dependency a lack of information creates, patients do not always want to participate in making treatment decisions, but are required to make decisions related to changes in their lives. No single study explored the experience of making decisions in women with advanced cancer.

One article reviewed approximately 80 studies and summarized the differences and similarities regarding making decisions in cancer care (Blank, Graves, Sepucha, & Llewellyn-Thomas, 2006). The four areas of decision-making literature presented initially reinforce that *processes* of making a decision have been well researched. However, researchers have also stated that making decisions is complex, and that despite the best developed questions and designs, factors, communication aspects, and relationships impact the patient perspective of a quality decision and the subsequent quality of life.

Decision-making research is difficult to apply to the experience for women with advanced cancer, especially when most prior research involved a newly diagnosed population with curative intent or a population in the final stages of palliative care. The literature review gave focus, a pre-understanding, and explicated the gap on the experience surrounding decisions for women within the advanced cancer transition period.

CHAPTER THREE – METHOD

Because of the limited pre-understanding available in the literature, phenomenology was the best choice to gain understanding of this experience. Van Manen's (1990) use of phenomenology allows for a stepwise analysis as conversational interviews are completed, and provides for a well-formed holistic interpretation that would represent the essence of the experience for women and their relevant others around decisions. For a complete holistic view, van Manen suggests analysis following the lived existentials. These four lived experiences of *body*, *space*, *time*, and *other* intertwine and interact to describe the experience of advanced cancer for women making decisions.

Phenomenological Approach

Phenomenology has different methodological approaches and philosophical underpinnings. Van Manen's (1990) phenomenology was chosen because the method is “relevant to researchers in nursing” (p. 1) and the narrative is used to understand experience. For example, the themes and existentials could provide for greater understanding of the overall cancer experience, yet a practicing bedside nurse could apply these experiences to quality care of a single individual.

The method utilized was descriptive phenomenology where the purpose was to describe the lived human experience. The lived experience is insights into context, thoughts, behaviors, and emotions of the woman and others without first conceptualizing

those insights.

Phenomenology also can illuminate the phenomena the researcher brings to consciousness (van Manen, 1990). This means the researcher chooses the topic that is significant to understanding the lived world. It is important to note that in phenomenology, conscious understanding is always reflection. Phenomenological research does not happen ‘in the moment’ because that moment would be changed by reflection. Women with advanced cancer told their experiences of making decisions as they were remembered.

The goal of phenomenology is to describe and interpret the structures and relationships of data (Guthrie, 1967). The structures, or experiences of participants, represent the attributes of a phenomenon. The attributes, although supplementing the definition of a phenomenon, do not describe the essence (Charles, 2001; Woods, 1975). The reader must ‘see through’ the attributes to the essence (Van Manen, 1990). Van Manen refers to the philosophy of Aristotle and Husserl to define the term ‘essence.’ Husserl’s method of ‘seeing essence’ relayed the necessity to observe and use intuition (Golomb, 1976). Whereas Aristotle’s idea is that essence is understood through perception or ‘grasped’ through reflection (Boas, 1927). If the phenomenon loses one attribute, the essence is lost. Essence, then, is the answer to ‘What is?’

A frequently used analogy in the literature is an image in a pane of glass. To a bird, the essence of a flower is reflected in the window (Sparks, 1981). Whether looking at reality or reflection, the image is the same. However, one of the attributes of a violet lilac is fragrance. Without fragrance a flower has lost its essence. Cunningham (1952) stated that essence is poetry because an inference can facilitate reflection. The image of

the flower in the glass makes one imagine its scent. This suggests that essence should not be defined with a strict, limiting language. Therefore, this research sought the experiences (structures and attributes) inherent in the essence of making decisions during advanced cancer.

Phenomenology studies the nature of an experience or the essence of advanced cancer (van Manen, 1990). In this thesis, the ‘heart’ of advanced cancer is understood through descriptions of its structure; the experience of the four themes. Phenomenology does not explore the factual description of progression through cancer and its treatment. It describes the meaning as the experience is lived fully, rather than, for example, culturally, psychosocially, or quantitatively. Phenomenology is a human science—an explicit, systematic research requiring critique and reflection on the part of the researcher and reader. Essence, meaning, and being human are being attentive and thoughtful. Van Manen states thoughtfulness is “a heedful, mindful wondering about the project of life, of living, of what it means to live a life” (van Manen, p. 12). This assumption fits well with a nurse desiring to understand what it means for a woman to live with advanced cancer for the purpose of providing quality care. This leads to another assumption of phenomenology which is that it focuses on the search for what it means to be human. For women with advanced cancer, a terminal illness provides a singular opportunity to conduct this search. Yet for the nurse, the same opportunity is granted; to fully understand what it means to be a nurse for a woman with a terminal diagnosis. This understanding is ‘poetized’ in phenomenological writing, the findings of which are described by van Manen as follows:

As in poetry, it is inappropriate to ask for a conclusion or a summary of a

phenomenological study. To summarize a poem in order to present the result would destroy the result because the poem itself is the result. The poem is the thing. (p. 13)

Within the words, within the data, and within the narratives from women with advanced cancer are memories. Phenomenology *gifts* understanding. When reading a phenomenology, whether the reader has knowledge of making decisions within advanced cancer or not, the experience seems shared.

Phenomenology was the appropriate qualitative tradition to understand the experience of making decisions during advanced cancer. Literature on making decisions described the steps, the process, and the consideration of pros and cons for coming to a decision. A gap existed in the literature surrounding the research question, “What is it like to make decisions when you’ve been given a life-limiting prognosis?”

Design

Setting

The Saskatoon Cancer Centre (SCC) is an outpatient center servicing central and northern Saskatchewan. Following a diagnosis of cancer, patients are referred to SCC for treatment. Most patients will receive the majority of their care through this center: blood work, x-rays, chemotherapy or radiation therapy, and some supportive care.

Interviews

Participants in this study were offered their choice of setting for the interview. Most were interviewed in a private room in the cancer clinic. Three women were interviewed in their homes. Two significant others were interviewed in their homes. One Registered Nurse was interviewed at the researcher’s home.

Access

Access to the clinical setting was requested in writing to the Executive Director of the SCC (see Appendix B). The Director of Nursing, oncologists, and Registered Nurses who had access to this patient population were approached next by the researcher.

Participants

As this is a phenomenology, a sample size of five to 35 is acceptable (Creswell, 1998). The sample included five women with advanced cancer who received care through SCC and three relevant others for each woman: one Registered Nurse, one physician, and one significant other chosen by the woman.

Inclusion Criteria

Potential participants were adults, 18 years of age or over, and able to give informed consent. Participants were selected regardless of whether or not they chose to continue with treatment or refused further treatment. The physician and nurse team were the first to approach participants. This technique ensured the oncologist and Registered Nurse implied their willingness to be contacted for an interview. The participant was asked permission for the nurse researcher to initiate contact. The researcher gained confirmation of a significant other participant in the initial phone call. The researcher was not aware of any potential participants who had decided to refuse treatment.

There may be significant quantitative and qualitative differences in response to health and cancer diagnosis between men and women (Denton, Prus & Walters, 2004; Hampton & Frombach, 2000), supporting the decision in this exploratory study to focus on one gender. Women were recruited for this study to explore whether the experience I had witnessed with the clinical trial patient was similar to the experience of other women.

Because no previous understanding of a woman's experience of making decisions during a life-limiting prognosis is available, this research is the first step to exploring what it is like for a woman in cancer care.

Topic of Death

The oncologist and nurse team understood the estimated timeline to death was a year when they screened initial participants, even though the participants may not have heard this prognosis. One hematologist expressed concern about the interviews including the topic of death. I clarified I would not broach the topic unless the woman chose to reveal her thoughts. One woman refused to be part of the study. When the researcher phoned her to set a meeting, the woman stated that she understood the questions that would be asked and was "not ready to deal with those thoughts right now."

Ethical Considerations

Approval for this study was received by the University of Saskatchewan Behavioural Research Ethics Board on July 9, 2004 (Appendix A).

Informed Consent

After the initial phone call to each participant (whether woman, significant other, or health care team member), a meeting date was set to go over the consent. All participants who set a meeting date signed a written informed consent at that time and continued with the interview. Two potential participants were mailed the patient consent and the significant other consent for information purposes prior to setting a meeting. One pair brought signed consents back to the meeting and interview. The one woman who refused to participate had been contacted to set a meeting date and explained her reason for refusal during the phone call.

At the initial meeting, the nurse researcher engaged the participant in discussion of the risks and benefits of participating in this study. A copy of the signed consent form was provided for participants (see Appendices C, D, and E). Due to either their prognosis change to advanced cancer or the effects of treatment, this was an emotional time for participants. As the interviewer and an experienced oncology nurse, I was sensitive to the emotions of the participants. Therefore, the participants were reminded psychosocial assistance was available from the Saskatoon Cancer Centre if requested.

As member checking was employed throughout the interview process, no second interview was conducted.

Data Protection

Copies of the transcribed interviews, marked with a participant number only, were on computer disk. A copy of the consent was kept in a separate area.

Data Collection

Data were collected from each participant (woman, significant other, and health care team members) individually. To provide for their comfort in the interview, participants were given the choice of setting. Interviews were one to two hours in length and were completed between July 2004 and January 2005.

Interview Process

Conversational technique guided the interview (van Manen, 1990). Face-to-face interviews with each participant were audio-taped and then transcribed by the researcher. The researcher utilized the fundamentals of an interview, as described by Spradley (1979). Twelve steps were incorporated into the interview, beginning with the greeting and an explanation of the interview process (e.g., the tape recorder). The conversation

progressed to the statements provided in the interview guide (Appendix F). Van Manen argued that for an interview to meet its purpose, the researcher must maintain focus on the aim. To accomplish this he suggests asking “the person to think of a specific instance, situation, person or event. Then explore the whole experience to the fullest” (van Manen, p. 67). Frequently, participants in this study did as van Manen suggested and went off on tangents about their experience in health care or communication issues with others. Throughout the interview, I asked for a specific memory of a time when a decision was made and then asked the participant to tell a story surrounding that decision. Member checking followed with the researcher clarifying and summarizing. The twelve steps ended with friendly conversation and taking leave.

Researcher as Instrument

Guba and Lincoln (1981) suggest the researcher is the instrument in qualitative research. During the interview, the researcher is responsive to cues from the participant, adaptable to the diversity of narratives, focused on gaining a holistic view of the participant’s experience, and aware of the opportunity to expand on a current knowledge base of tertiary, outpatient, and education settings. The meaning of data was fully explored during analysis, opportunity to clarify and summarize happened with member checking, and atypical responses were explored with the diversity of participants (women and relevant others).

Demographics

Demographic information, such as education, culture, religion, and number of children was only collected during the interview as the topic came up in conversation. Table 1 shows the number of data types collected per woman, including diagnosis,

approximate time from poor prognosis to death, and time from interview to death.

Table 1. Data types and timeframe of advanced cancer transition period.

Patient	Data types	Relevant others	Diagnosis	Health Care assigned months to death (without treatment)	Poor prognosis until actual death (mos)	Time from interview to death (mos)
P01	Interview Emails Journal	Husband Oncologist 1	Hematological	3	In remission	
P02	Interview Obituary	Husband Oncologist 2 RN 1	Colorectal		31	11
P03	Interview Diary Phone excerpts Obituary	Husband Oncologist 3 RN 2	Colorectal		30	8
P04	Interview Journal	Husband Oncologist 2	Renal	12	In remission	
P05	Interview Journal Obituary	Daughter refused interview, but wrote letter Oncologist 3 RN 3	Colorectal	4	34	2

Transcription

The researcher transcribed all interviews, journals, and fieldnotes verbatim. This ensured the researcher could be fully aware and immersed in the data, which facilitated analysis.

Journals

The women participants were provided with diaries or journals to note decisions

or experiences. One woman wrote quite extensively in her journal, including Bible passages, poems, and stories to clarify her thought processes during her writing. Women were also given the option to use email as a form of diary. One participant shared articles she had written for support groups and the taped interview with the oncologist from whom she had received a second opinion. Because one participant had shared that she had written her own obituary, obituaries were included in the data if available.

Fieldnotes

Initial interpretations of the interview, comments about the process, and significant observations made by the researcher were tape recorded after each interview. These were transcribed for analysis. This was especially helpful when the researcher met R05 (the significant other who refused an interview) to pick up the mother's diary and a letter written by the daughter.

Analysis

For the narrative to effectively represent a theme, the perspective of the woman needed to be the primary focus. Van Manen (1990) states that, when interviewing, the researcher is required to gather anecdotes with a "keen sense of the point" (p. 69). He suggests rigorous collection, after which the resultant narrative construction should be "trimmed of all extraneous, possibly interesting but irrelevant aspects" (p. 69). Therefore, the narratives of all women were combined into an aggregate: one experience.

Constant comparative analysis was employed as each interview was completed, which ensured that each interview was consistent with the emerging themes. Two questions were asked of each data set to ensure the data were placed in the appropriate theme: 1) what experience is represented in this narrative? 2) what experiences are not

represented in this narrative? Analysis was structured using NVivo 6 qualitative software. Analysis began with ‘free nodes’—free floating concepts that began developing into patterns. Due to the amount of data, I felt I needed a place to start in creating themes that would ensure I was capturing the full experience of the women with advanced cancer. In looking to van Manen (1990) for guidance, six different options for analysis were suggested, and one was chosen that would fully explore the experience around decisions.

As the patterns unfolded into higher-level themes, a third question was added to round out the experience (for the women participants only): 3) what existential is represented in this narrative? Van Manen (1990) discussed the use of four existentials which “can be differentiated but not separated...In a research study we can temporarily study the existentials in their differentiated aspects, while realizing that one existential always calls forth the other aspects” (p. 105). The four existentials are clarified here.

Lived Time (Temporality)

This is subjective time or the person’s way of being in the world (van Manen, 1990). One example is mapping the cancer journey with significant family events. Lived time may include the person’s memories, way of walking, gestures, speaking and what is spoken.

Lived Other (Relationality)

The experience of the lived other existential is the result of relationships maintained in a shared personal space (van Manen, 1990). Two people greet each other with a handshake, but learn about each other in cues and coffee-talk. People strive for community and social interaction, which in turn gives a sense of purpose. When a relationship with another is developed, the individual transcends, searching for the

meaning of existence.

Lived Space (Spaciality)

Each person feels different depending on the space where they walk (van Manen, 1990). Space is not the description of what one sees when walking in a room, for example, but is the feeling invoked of walking in that space.

Lived Body (Corporeality)

Van Manen (1990) states that we approach each other in a corporeal way. We reach to shake hands when we meet someone for the first time. But what is the experience of receiving a wink? There are subtle changes that happen to the body because of the interpretation of that handshake or that wink. If the handshake is limp, the receiver might wonder if there is interest in that relationship. If receiving a ‘knowing’ wink, a colleague might feel confident and sit straighter.

By using the four existentials, the researcher does not just look for one ‘way of knowing.’ For the participants, the experiences were not just around relationships. As noted during analysis, ‘others’ were not always involved in the interaction. The woman could have been looking in the mirror at her body, or describing how she felt in the cancer clinic.

Eventually, the free-floating nodes were collapsed as themes began to develop. All nodes were named using the participants own words. For easy clarification, the description of the existential was visible at all times to ensure the data set could be matched.

A significant amount of data did not seem to fit into any of the three emerging themes (for the women). Each of the three themes came from the perspective of the

women, and therefore the final theme needed to represent the women's perspective as well. In an attempt to explicate what the researcher felt the participants were describing as a fourth theme in this experience, a debriefing session was held with the supervisor. In this session, a mind map was created showing the relationship of each participant to one another. What became clear was the separation between a woman and others. Anything (including others) outside of the woman impacts or influences her experience of making decisions during advanced cancer. However, that influence is what *creates* the feelings exhibited by the themes that had already emerged. What was missing was the woman's impact on the others. The woman's perspective in relation to the themes became more solid. With this realization, the fourth and final theme emerged, and all four themes solidly reflected the woman's perspective of the experience of advanced cancer with a focus on decisions.

Rigour

The six steps suggested by Guba and Lincoln (1981) were followed to ensure the resulting themes and narratives met rigorous criteria. First, a list of interview questions was developed that focused on the study purpose and research question. Second, inclusion criteria were used to select participants. These criteria ensured a case group was added as participants rather than one individual. Third, a set of 'decision-rules' were followed during analysis. The decision rules included the definitions of the four existentials and, as the research progressed, the definitions of the four themes. Fourth, only one researcher analyzed the data so 'reader-analyst reliability' was not an issue. Fifth, instead of a 'confidence scale', I used memo-notes to argue my reasons for placing data in which existential and which theme. Exemplar data were flagged to show higher

confidence. And sixth, ‘reader-analyst reliability’ was checked through debriefing with my supervisor, an experienced qualitative researcher.

Bracketing

Bracketing is a concept specific to this type of phenomenology. Bracketing meant taking everything I knew about a phenomenon and holding it apart (van Manen, 1990). The visual picture that came to mind was of a clear glass jar. Inside this jar was everything I knew about cancer, decisions, and interactions with relevant others. In front of me was a table covered with paper: transcribed interviews, memo notes, journals, and ‘stickies’ with potential themes listed. The computer in front of me was waiting for fingers to type the experience surrounding decisions. Yet all the while, I was required to look at the clear glass jar. I accepted I had previous knowledge while I took in the new knowledge. I accepted I had biases not captured in the new knowledge. The result was the essence of the experience of my participants, not what an oncology nurse researcher might ‘expect’ to find (Guba & Lincoln, 2003). This included: 1) writing memo notes to clarify interpretation versus participant narrative; 2) debriefing with other researchers to understand their perspective of the narrative (thereby separating my interpretation from the narrative again); and 3) asking relevant others about their experience with a particular phenomenon to see if the narrative experienced was global.

Researcher Role

I worked in the clinical trials department of the Saskatoon Cancer Centre. Therefore, only those patients who were not offered or were not in a clinical trial were included in this study. I was not involved in the care of any of the participants. Participants were assured that participating in this study would not affect any of the

health care they received or would receive in their future. As other researchers have suggested (see Koch, 1994; Cohen, Kahn, & Steeves, 2000), the participants with advanced cancer were assured their perceptions would be kept confidential and not shared with their significant other, physician, or nurse.

My experience working with patients with cancer is varied. I worked on the ward in a teaching hospital providing treatment, symptom relief, and palliative care. I have also worked in an outpatient clinic setting in the medical and radiation assessment clinics, chemotherapy and phlebotomy departments, and in clinical trials. Each situation has provided opportunities to become comfortable with people dealing with various diagnoses, various stages of disease and progression, and varying psychosocial states. This provided for a unique experience during the interviews. Due to my comfort with advanced cancer and its treatments, participants seemed unrestrained in their conversations, as there was no need to spend time on unnecessary explanations about advanced cancer itself.

Despite continually reflecting on my reasons for this research and the impact of this process and its outcome on my soul, my family, my friends, and my clients, I am unable to put the experience into words. I can only offer one statement at this moment in time. This research, this writing, is who I am beyond the nurse that I stuffed into that ‘clear glass jar’ (see Bracketing, above). These pages contain more than words.

CHAPTER FOUR - FINDINGS AND DISCUSSION

The purpose of this study was to explore the lived experience of women with a known terminal cancer diagnosis when they made significant decisions. Five female participants who were diagnosed with advanced cancer and whom attended an outpatient cancer clinic agreed to participate in the study. Four women were undergoing active treatment, while the fifth had just stopped treatment and was moving into the terminal stage of her cancer experience. All women had children of teenage years or older. Three women had grandchildren. Four women were married and the fifth was widowed. Each woman was interviewed regarding her decisions and offered the chance to journal any supplemental experiences in a diary or by email. One woman chose to contribute by email; three others wrote in diaries. Four men—the husbands—were interviewed. Three men were proprietors and ran their own business; one was a professional. One female significant other refused to be interviewed; time seemed to be a significant issue for her as she was employed outside the home, she shared caregiver responsibilities for the woman participant, and she had small children. This significant other wrote a letter to the researcher and provided the woman's journal after her death.

Women

The first aim of the study was to describe the experience around making decisions for women with advanced cancer if asked, "What is it like to make decisions when

you've been given a life limiting prognosis?" Their stories revealed four themes: control, influence, normalcy, and vulnerability. Each theme was found to exhibit attributes of all four existentials: lived time, lived other, lived space, and lived body. To facilitate brevity of description and exploration, attribution was one theme to one existential. Women wanted control over the lived time they had left. The lived other experience for women was realizing they had potential to influence. Women reached for normalcy when deciding between lived spaces—those which were safe and those which were chaotic. The lived body experienced vulnerability.

The second aim of the study was to explore those experiences for women. The four themes are presented below, first by definition, then as taken from the interviews with the women in 'data bits.' The purpose of the subthemes was only to clarify further the main themes in order to further develop the experience. Following the subthemes, a narrative is presented. This narrative is aggregated data from numerous women. The researcher only made minimal changes to the wording to ensure grammatical correctness. These narratives are exemplars of the lived experience of each theme for women living with advanced cancer and having to make decisions. As van Manen (1990) suggests, stories convey the lived experience more thoroughly than smaller line-by-line portions. Finally, discussion reveals insights from the interviews and the literature on each theme.

Theme: Control, Existential: Lived Time

Van Manen (1990) suggests lived time is subjective and not the objective measure of a clock. The theme combined with the existential lived time was *control of the time left*. The definition of control was exhibited in the woman's expression of power around making decisions. Subthemes included: options, balance, and buying time (see Table 2).

The participants described their power as a right to investigate options (even when the choices are between two poor alternatives), their ability to balance the extremes in situations or relationships until they were comfortable with the outcome, and the goal to buy valuable time. The narrative that follows, entitled ‘Suicide,’ reflects perceptions of a choice of options: treatment and eventual death or suicide and impending death.

Table 2. Data Bit Examples for Control Themes within the Existential Lived Time

Theme	Subtheme	Examples
Control		<p>“We sort of took the control back into our own hands and said this is what we are doing; this is what we aren’t doing. They give us the information and then we make the decisions... So they were in control in the beginning, but now my husband and I are very much in control.”</p> <p>“The hardest thing for others with cancer is to think, ‘Gee, I hope this is it. Gosh, I wonder...I feel a little twinge...I wonder...ya, I got another little lump.’ I feel for them. I guess it’s always, ‘Is it coming back? Is this it?’ You know, to tell you the truth, I don’t really have that worry. The worst has happened. So I don’t have to wonder whether something worse is going to happen yet. There’s a certain... I think there’s a certain peace about that, such as it is.”</p> <p>“I did get a little more aggressive this summer. I knew that if there was going to be any chance of surgery, the referrals needed to be sent. I asked the oncologist what the surgeon said and he said, ‘Oh, you haven’t heard from him? Then you should phone him.’ I thought, ‘if I’m going to be in control, then I can be in control.’”</p>
	Options	<p>“We have done our research and we have seen other people and we know that there are other options...”</p> <p>“Well, there were no options. It’s either you don’t do anything, you die. Or you come into the hospital and you may die, but it might buy you time. So the option was clear that we were buying time...”</p> <p>“My husband and the oncologist really pushed for me to get a second opinion out of province. I didn’t think there was any point. But they said don’t close the door without listening to the possibilities. The [referring] oncologist’s first question was, ‘Why are you here?’ I felt like saying, ‘That’s it! Sorry! Good question. I</p>

		wonder too. I don't think you have anything to offer me.' But that was the right answer. He was making sure that my oncologist and I were not looking for a cure. He said I had a realistic opinion... No promises, and now, suddenly, I had no expectations."
	Balance	<p>"I have become very selfish, very impossible. I make decisions right now. I want it now, not in an hour. It is different from what I used to do. It's really difficult because I used to spend a lot of time making decisions about, like, what kind of BBQ should I get, and I would look up the consumer reports. Time is of the essence."</p> <p>"I was exhausted. I was on the phone every single day seeing whether somebody had my stuff in front of them, wondering what was happening. But that was the only time that things got a little hairy. And I thought, you know, how can your average person do all of this? I was thinking, If you have to fight like this for everything. How can your average person do this? So, I was a little annoyed at that time, but I calmed down. Because after I got things in place, I said, 'there's no more I can do.' Whatever will be, will be."</p> <p>"I'm feeling so guilty, want to spend more time with the kids, but I also feel obligated to talk to family and friends, because I love them too. How do I divide my time, with whom?"</p>
	Buying Time	<p>"...there is no cure. We were buying time. The question for me was did I want to buy time or did I want to have really good quality right now."</p> <p>"I would always wonder what would have happened. Which if I took the treatment and it didn't work at least I would know that I had given it a shot. We knew what was going to happen if I didn't take the treatment. We still know that it's buying time. I think that is the most difficult thing right now. I just feel like dead woman walking. That sums up how I feel about this disease. I was waiting for the final moment."</p>

Narrative: "Suicide"

I remember sitting in the examining room asking "What are the options?" Well, there are no options. Its either you don't do anything, and you die, or you come into the hospital and you may die, but it might buy you time. There is no cure. The question for

me was did I want to buy time or did I want to have really good quality. I felt great; there was nothing wrong with me. It was summer and I was very tempted. In fact, I kept saying “well, maybe I will go back to the cabin and have a really good time until I die.” I’ve got three months, six months, whatever. If we don’t do anything, I’ll be dead anyway.

I think that is what made the decision making so much easier. The alternative was so black. It wasn’t like breast cancer where you might get away with doing nothing. But in this situation you knew you wouldn’t get away with it. This could be an opportunity. But that was the balance, an opportunity to kill you or definite death. Those were the two decisions starting the actual treatment process. Intellectually, taking treatment was the right decision because there wasn’t any other decision.

If I had decided the other way, I would always wonder what would have happened. Whereas if I took the treatment and it didn’t work, at least I would know that I had given it a shot. I feel so good, I would just hate to give up. If I felt sick, if I felt anything, then maybe! It sounds kind of like suicide if I just sit here and do nothing.

I was hoping for some kind of miracle. But it didn’t happen and it didn’t come. I did make the decision on my own.

Discussion of Control in Existential Lived Time

The experience of lived time for women in this study was revealed in two ways. First, the lived time experience was revealed in stories about what they ‘would rather be doing’; the data bits show the women talking about moments in summer, buying a BBQ, or being with the children. The lived time experience was also revealed through the value of time between the moments of life and death. Both were revealed in the narrative where the woman was required to balance her options and take control of how she lived in the

time left, valuing life by taking every opportunity to live.

The experience of having control thrust upon them was evident in all the women's stories. For example, one of the participants appeared vulnerable when her significant other made a series of comments. He told the oncologist he would do anything, go anywhere, and pay anything to fight this cancer. The emphasis on 'anything' suggested nervousness and a desire to bargain for his wife's life. This desperation revealed the magnitude of the distance between the two decisions: fight or suicide. Because of his expression of emotions, nervousness, and bargaining, the husband showed his vulnerability and placed his wife in control. She possibly felt obligated to continue treatment for her husband. Women made statements such as "treat, treat, treat" or "I don't want to die." Women vacillated between balancing the lived time measured by treatment and the value of being full of life.

Women seemed incredulous at being offered nothing as an option to treatment. Initially, they did not believe 'no treatment' was a decision. Although cancer was killing them, there was an expectation to have a series of options spanning years. After telling the story out loud, women seemed to realize that choosing between treatment and no treatment was the decision. Despite the obvious lack of positive alternatives, women seemed to appreciate even having the choice between two evils. Here, the word suicide emerged. Two participants related that if they were going to die anyway no matter what option was chosen, doing nothing would still have seemed like giving up or committing suicide.

The options were so black and were in conflict with how they were feeling physically. They did not feel sick; women were working, kayaking, taking care of kids

and running small businesses or sitting on numerous committees. A contrast existed between the present life and time versus what the health care team was suggesting. Despite that contrast, women still pondered the decision. One oncologist urged a woman to make a decision in twenty four hours because a hospital bed was being held. The urgency possibly influenced that particular woman to take some time. She reflected on her summers at the cottage, spending time outdoors, the sun shining, and the quiet lake. What a perfect day for kayaking. The question she asked herself was “If I’m going to die in a few months, why not spend it at my favourite spot rather than in a hospital being ill from side effects?” She revealed her decision-making process, which included thinking about her quality of life. Here, the decision became hard. Her options were to enjoy the rest of the summer, not being affected by side effects of treatment, or to spend the summer in a white-washed room feeling nauseous.

Van Manen (1990) states that lived time is having a perspective of life to come. Women decided against, what they perceived, was suicide. There was value in the time that was left, even if the future was shorter. They had weighed the options, took control, and made a decision that was right for them: to buy time.

Research on the lived experience of having control of their time left for women with advanced cancer making decisions was scarce (Fegg, Wasner, Neudert, & Domenico Borasio, 2005; Thorne, Hislop, Kuo, & Armstrong, 2006). However, several research studies describe the experience of losing control or the attempt to achieve control during the cancer experience (Roberts, Brown, Elkins, & Larson, 1997; Markovic, Manderson, Wray, & Quinn, 2004; Coyle, 2006). For example, Fegg et al. (2005) studied personal values, such as power and security, for patients with advanced cancer receiving palliative

care to compare the difference between satisfaction with life and physical functioning. The findings revealed control was not important to palliative care patients. However, the authors suggest one reason may be that their participants were not being treated for curative intent. Conversely, other research (Roberts et al., 1997; Coyle, 2006) found that when in palliative care, women feared or grieved their loss of control. Contrary to this research, women with advanced cancer in the current study balanced alternatives when in control, and did not consider themselves out of options, as reflected in the subtheme of control.

Markovic et al. (2004) suggest that when patients perceive death is inevitable, such as in gynaecological cancer, there is no open decision making and women are deprived of their autonomy. Despite being diagnosed with ‘the end,’ patients in the current study still stated there was a choice to make, even if that choice had an option that seemed like suicide.

The participants in this study suggested information was helpful in having control over the time left. This is similar to findings of a study of 200 men and women with cancer by Thorne et al. (2006). Thorne et al. (2006) state “having information was associated with having power, choice, or control in relation to some aspect of the disease, whereas not having information implied powerlessness or lack of control” (p. 323). Participants calculated and played the odds, especially in relation to the success of treatment or the chance of survival, wanting to beat the odds and make it past a predicted timeframe. More research is needed to determine if information, and in what form, will assist women with advanced cancer maintain their perception of control in the time they have left.

Theme: Influence, Existential: Lived Other

The existential of lived other was about interactions between people and what was learnt from that interaction (van Manen, 1990). Influence, therefore, involved affecting a relationship or situation to attain the best outcome for a decision. A woman might exert influence and try to gain control. She may overtly or covertly use power in an attempt to gain her voice.

The following exemplar data bits (Table 3) reflect the awareness that arises from interacting with another. Women began to realize they had power. Frequently, women seemed certain of their power and either overtly forced others to affect a decision or covertly attempted to sway the other. Either use of this influence was an attempt to make others realize the women needed assistance and perceived their voice was not being heard. Women felt they made the decisions and desired others to realize their voices should be the loudest. The narrative, ‘Losing It,’ revealed the experience of women overtly and covertly influencing their husbands. What resulted was a sense that despite the intensity of the interactions, women still perceived they had lost their voice.

Table 3. Data Bit Examples for Influence Themes within the Existential Lived Other

Theme	Subtheme	Examples
Influence		“If I hadn’t got along with my oncologist, I don’t know whether I would have made the same decision. I mean, which is really funny because I thought I was putting my life in my hands but I found out when I got there, I saw him once in four months. And that was just because he happened to be stepping in. I had told the transplant coordinator that I had a very difficult time with doctors. I didn’t suffer people who didn’t treat me like a reasonably intelligent individual and she said, ‘I’ll make sure you get this particular oncologist.’ That connection between the doctor and patient is very important.”
	Overt	“We had a situation where I wasn’t quite confident and comfortable in my oncologist. But we were making a decision to get a second

		<p>opinion out of province. And that was a very difficult decision for us to make... My husband...he said to me, 'this decision is yours, I cannot make this decision for you.' As I wanted him to. I said, 'Well, you make the decision.' And he said, 'No.' So, I made the decision on my own and I decided not to get a second opinion in this case..."</p> <p>"It was important for me to talk to my husband about some of the decisions that he might have to make in the future with me no longer around. I had always displayed a leadership role in our life together. It helped me to feel that I was in some way helping him to feel OK about what he faced. I was concerned about how he would reach out and continue with his life."</p>
	Covert	<p>"Originally, my oncologist had said, 'You are too old for this treatment. I won't do one on you. It's not very successful.' In my mind, this treatment was dismissed within the first month. Now, either she got to know me, or my condition, I don't know. But I ended up having the treatment."</p> <p>"Just because you're dealing with cancer doesn't mean that you have to feel like it or act like it. I use make up still. I don't hang around in my pajamas and my housecoat all day. It's good for my children to see this. It's very good for my children to see me looking the way I do. It gives them a little more support, a well feeling. They aren't concerned about Mom dragging her bum around all day."</p>
	Voice	<p>"I'd still have to make my decision and tell them in the end. I want to tell them here in the living room."</p> <p>"I kept on saying to my husband, 'I could have had this time at the cabin. Instead, you are putting me through this...'"</p> <p>"The oncologist had already told me that the cancer had grown. I told my son that. I guess he just had to make sure."</p>

Narrative: "Losing It"

This summer, I was going just absolutely bonkers. One morning, my husband was going on a business trip. He hadn't gone a half a hour and I just went berserk. My kid phoned me and said, "Mom, I'm coming right away." By the time they took me to the doctor, I was just totally spun out. I wanted to get off the wheelchair while the wheelchair

was going. I just wanted to get away from everybody. My husband flew in and flew back out again. He's the only one that can settle me down. So, now everybody knows that he's got a wife that's losing it. You know?

I want to grow closer and not spend so much time fighting. It doesn't mean that I've quit parenting, although my husband does way more of that now.

Sometimes I'm mad at him for not being more sensitive. There was this time that I was talking to my husband about my diet. I want to start eating strictly, but it's hard. He says, "yeah, but it's your life we're talking about". Then he eats all sorts of things in front of me...

Discussion of Influence in Existential Lived Other

Women told stories about relationships with different relevant others, and this revealed the effects of cancer on those relationships. Women desired to make an appropriate decision, as these decisions would affect the way cancer impacted relationships. A discernable difference exists between having control and having influence. The study participants did not feel they had control over another person. However, they described attempting to influence another to gain power over the situation. Similarly, they felt controlling another person's thoughts was not possible, yet the interactions between two people seemed to influence thinking.

Women described the lives of their families including the occupations of husbands and children and the activities in which kids and grandkids were involved. When the stories shifted to the women, they talked about what they could do within the limits of cancer, side effects, and treatment. Decisions that were once family oriented now needed to be centered on the woman. The woman was required to make decisions

around visiting family and friends or taking ‘holidays’ based on how she was feeling or what appointment was next. This was where women seemed to choose to exert influence; they wanted to be part of family decisions, appreciated being included, but needed to ensure the appropriate decision included their limitations.

One woman decided she could visit her husband’s family out of province, but overtly influenced her husband into getting a hotel so she could have a quiet place to rest. Two other women expressed desire to travel further but complained of the impact of timing for treatment and known side effects, and that the disease itself prevented getting health insurance. The impacts of these factors were the women’s overt reminders to their husbands that trips were limited.

Another woman frequently called her husband at work. To relay her decision that she did not want to be alone, she voiced her melancholy until he came home. On one occasion, as described in the narrative, she overtly influenced her husband, daughters, and the health care team by going ‘berserk’ until her husband returned to her, and her medication to control pain was modified.

One key example of overt influence was a woman deciding whether to take alternative treatment along with her chemotherapy. She and her husband brought information printed off the internet to her appointment with her oncologist. She attempted to communicate her desire to work with him in coordinating both treatments. In the end, she was only able to influence him to allow her to continue with alternative treatment on her own. This is a clear delineation between attempting to influence and having control. She overtly pushed the oncologist, yet he remained in control of treatment decisions.

Covert examples of influence seemed more adept at revealing the lived other existential. Table 3 includes an example of a woman realizing her oncologist had changed her mind, and continued with treatment based on their interactions. The lived experience of learning something about oneself in interactions with another is apparent in the woman's confusion over the change in approach by her oncologist. She seemed to understand she had influenced the oncologist, and she decided to continue with treatment.

The second example of covert influence illustrated a different approach. Whereas the first example was a woman not understanding how she had exerted power, the second was a woman understanding she had power and attempting to covertly influence her family. The decision to present a positive front was expressed by two women in this study. Despite knowing the grim outlook, they chose to keep their home environments safe.

The subtheme of voice reflected the outcome of the woman's attempts to influence. If she expressed her influence, and decided to continue with treatment or not, her family were satisfied. In moments when women seemed to have less influence, they made comments such as "I've told them that," "I keep saying," or "the decision is still mine in the end."

The decisions in the theme of influence surrounded gaining an awareness of the self after interacting with others. Women valued family relationships and desired attention from their families with busy lives. Women seemed to struggle over whether to exert influence on their significant others. However, the theme influence and existential lived other also revealed the experience of women who sometimes felt they were not being heard.

Research into influence spans topics such as patient participation in making decisions, patient empowerment, and the patient as a consumer of health care.

One potential example of a woman's ability to influence others overtly was a study by Norcross, Ramirez, & Palinkas (1996). The authors state women are "more likely than men to seek and utilize health care, possess greater knowledge about health, be compliant with a therapeutic regimen, and monitor the health and safety of others as well as own health" (Norcross et al., ¶2). The findings of their study supported their hypothesis that women influence men to seek health care.

Bishop and Yardley (2004) suggest control over the use of complementary treatment is actively negotiated between cancer patients and their health care professional. This suggests their participants from cancer support groups sought the opportunity to influence their medical professional in making decisions regarding complementary therapies. A similar experience was found for one woman in this study.

Melander Wikman and Falthom (2006) developed a grounded theory where one half of the model was patients moving through a traditional medical model of compliance and subordination and the other half was patients moving through the individual model of being empowered to demand. They suggest "patient empowerment has changed from patient influence to self-control and self-decision making" (Melander Wikman & Falthom, 2006, p. 30). This grounded theory suggests the process to 'negotiating their way to health' begins with influence and leads to having control or power to make decisions.

In a study on understanding the meaning of expressing a desire for a hastened death, Coyle and Sculco (2004) found triggers for expressing this desire included loss of

autonomy, worthlessness, and being a burden to others. The result is that expressing desire for death is a communication tool. Coyle and Sculco found patients desired to be seen as other than ‘that patient,’ ‘that diagnosis,’ and ‘that procedure’ in a meaning entitled “A way of drawing attention to ‘me as a unique individual’” (p. 704). The authors related that one patient expressed desire for hastened death as the only method of communication that worked to get people to hear. This is reflected in the current study’s subtheme of ‘voice.’

Another meaning, “An attempt at manipulation of the family to avoid abandonment” (Coyle & Sculco, 2004, p. 704), was revealed in one participant who had involved his family in all his care decisions, including his desire for hastened death. The outcome was that by involving the family, he made them realize how vulnerable he was because of his dependence on them. This ensured his family never left him alone again. This seems to present a similar situation to the woman’s narrative, ‘Losing It’. These expressions of influence draw concern to the patient as well as highlighting the impact on the recipients: the families and caregivers.

Theme: Normalcy, Existential: Lived Space

The existential of lived space was the worldview of a particular person in a particular environment. For example, people felt more comfortable in a space that was familiar, such as home, work, or school. In the theme of normalcy, women study participants described finding themselves required to look at what would be their ‘worst case scenario.’ At what point would it be difficult to handle everything the cancer experience was throwing at them? Knowing the worst, women described their experiences of chaos: difficult decisions and situations that seemed unbearable. This was

compared to the moments when the women were able to find calm or find safety.

Unfortunately, the ‘new normal’ found in the calm moments was always tempered with something negative. It seemed as if there was never a static normal, but women were always striving for normalcy. Table 4 presents data from participants who experience normalcy in relation to space. One exemplar narrative, entitled ‘Pizza Party,’ is presented, where a woman describes her spatial experiences of hearing a cancer diagnosis, both for her in the hospital and for her children at home, and deciding how to tell others in as normal a manner as possible.

Table 4. Data Bit Examples for Normalcy Themes within the Existential Lived Space

Theme	Subtheme	Examples
Normalcy		<p>“When will I wake up and things will be 100% normal.”</p> <p>“We are trying very hard to keep life as normal as possible.”</p> <p>“It was a rough night. Things feel like they’re in slow motion. Why can’t my life be back to normal? I feel like I’m slipping into a state of despair. I am falling off a cliff in slow motion and some days I wish I was at the top and other days I wish I was at the bottom. I’m tired, I’m tired. I must not continue to feel sorry for myself. I have a lot to be grateful for.”</p>
	Calm/safety	<p>“I’m sitting on my bed writing and outside I’m hearing snowmobiles going up and down the back alley. It brings back memories. We used to snowmobile with the kids all winter long. I want to go up to the cabin. Soon, really soon. I want to go on the snowmobiles. I want to enjoy the heat of the wood burning stove and from the outside enjoy the smell.”</p> <p>“There are things I do to forget I have cancer. I have a nap or sit and read a book or watch television. There’s not much to watch but (laughs) I like sitting here watching cartoons when my grandsons come over.”</p>
	Chaos	<p>“My back hurts. More pain. Physical therapy with no relief. Massage therapy with no relief. I see the Chiropractor and I am rocking in pain. I start crying. He says, ‘If you were my wife, I’d take you straight to</p>

		<p>the hospital.’ I leave there in agony, crying so hard that I’m sure I frightened off half his clientele. I get to the car and my daughter phones her Dad, ‘Pick me up,’ I cried. I’m ready to finally go to the hospital. The doctor there remembers me. Thank goodness. We were serenaded by a drunken fellow with his guitar. He sings about his girlfriend from Assiniboia. My husband and I laugh hard.”</p> <p>“Nightmares, screaming, crying, everything is the way it used to be until I wake up and feel this pain of the huge incision that goes from bottom front to middle back and fifty some stitches. I start crying some more because I want to go back to sleep and dream again that my life is normal. I have all these confusing thoughts. How is my husband coping? How are the kids dealing with this? They cry a little bit; I cry a lot. The Social Worker says this is normal too, ‘After all you’ve been told you’re dying.”</p>
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Narrative: “Pizza Party”

Still in the hospital; sent for a cat scan. Next morning my husband and my sister go downstairs for a drink or something. A gang of doctors enters my little cubicle (don’t have a room for me yet) and say the reason you have pain in your legs and back is because you have a tumour. Instant shock. This is a problem; you will need surgery. Major surgery. This is serious. “Well, how serious?” I hear someone asking without realizing it was my own voice. “Very serious,” the stranger said. I ask him what it is, even though I already know the answer. Cancer. It’s systemic. What? What does that mean? It has spread, spread from somewhere else. I’m all by myself. No one beside me to shield the words. They start to penetrate. Tears are flowing. I can’t ask the question, but finally it comes out in interrupted format. “What does this mean?” I say. Metastatic cancer, one year. They leave, I think they say, “I’m sorry,” and they’re gone. My husband and sister come back to me and I’m crying. “What’s the matter?” It’s cancer. They said I’ve only 1 year to live. See the total shock in their eyes, but I don’t remember what they say. I’m thinking, thinking, thinking. Yes, this is a problem. How do we tell the

children...? We think of a way that we can tell the kids. We think okay, we'll order in pizza, have ice cream, cake.

Discussion of Normalcy in Existential Space

Each one of the women's stories related to the essence of how they felt in a particular space. Van Manen (1990) states "We become the space we are in" (p. 102). For space to affect life, there needs to be meaning in a particular space. Cancer was the landscape. Cancer invaded the home environment, gave perspective to the woman's social interactions, and certainly revealed the way the woman experienced day-to-day events as trips to the Cancer Clinic defined her days. The experience of decisions in normalcy was around finding a safer space.

When walking into a room, the first thing noticed was placement of objects in relation to other things: the pictures on the wall, no door, bright windows, clean counter, big table, and chairs with thick cushions. Yet the essence of that space was how it felt: comfortable. The converse is exhibited in the narrative. A woman sitting on a gurney in a blue hospital gown in a corner cubicle being stared at by a flock of medical people. Her shock and anxiety seem apparent with her description of the space, let alone the message received in that space. This dichotomy was reported by participants frequently, for example, painful moments that led to hilarious laughter, or nightmares and screaming that roll over into dreams. Lived space was created where it was experienced.

The experience of day-to-day existence, the normal that women seemed to be looking for, was found in comfortable space. As per Table 4, women were safe in their bedrooms or on a couch and felt calm when spending time with family, watching TV, or reminiscing. Yet these moments were few, as evidenced by comments such as trying to

keep life as normal as possible. A comment suggests normal, for these women, currently does not exist.

One example of a calm versus chaotic environment was a woman waiting for the results of her next CT scan. She believed chemotherapy was not helping; the cancer was growing. She expected her oncologist was going to ‘dump’ her to be on her own. She sighed, “so this is it,” and resigned herself to the worst possible outcome. In the safety of her home, she became angry and debated the knowledge of her oncologist with statements such as, “his guess,” “I’ll show him,” and “he has no idea.” The words she used to describe her oncologist suggested she perceived him as aloof, just full of facts. The lived experience of this clinic space was cold and unsupportive. She described the fast-paced clinic life. She had experienced a litany of cancer news reports—good and bad—then was out the door in 15 minutes. After each appointment, she was often left confused, having more questions than when she started.

The experiences of chaos seemed to have violent shifts. Table 4 includes an example where one woman described her decision to go to emergency with such severe pain that a chiropractor, her daughter, and her husband needed to be involved. Yet once past those moments, where pain and prognosis are uncertain, the woman searched for someone that made her feel safe. She found a doctor that remembered her. When that space started to calm, she described her new level of normalcy: being serenaded in the middle of the emergency department.

Another woman experienced a normal life event during her chemotherapy treatments: the death of her mother. A sense of desperation, or chaos, arose around losing her mother: her major support system. The difficulty in attending her mother’s funeral

was not grief over that loss, but having the friends and relatives associate the living cancer patient with the dead cancer patient. ‘Everyone’ at the funeral approached her and offered help and prayer, boosting her spirits. She decided she might ‘heal.’ Normalcy seemed attainable. This promise disappeared when the vomiting started again. She described her cancer with words such as pain, black, and getting worse. In this woman’s instance of space, her narrative merged the chemotherapy experience with a funeral experience. Loss, physical discomfort, frustration, and hopelessness marked her cancer journey.

As the advanced cancer worsened, as the options dwindled away, the swirling winds of chaos surrounded the woman—a tornado increasing in intensity. She felt protected while in the eye of the storm. It was calm. Yet if the woman stepped out of the eye, she entered chaos. This was the irony of normalcy. There were moments of calm in deciding to maintain a normal support system of friends, family, and faith, yet deciding to move away from that safe normal space (moving out of the eye of the tornado) would throw her back into chaos. Realizing there was a tornado of chaos caused by advanced cancer was the experience of striving for normalcy.

Literature regarding normalcy is extensive. Although no research studied the existential space, the concept of space is, surprisingly, prevalent (Peteet, 2000; Carter, 2003; Ferrell, Smith, Ervin, Itano, & Melancon, 2003; DeMarco, Picard, & Agretelis, 2004; Thorne, Bultz, & Baile, 2005; Ahlberg & Nordner, 2006; Atkins, Bell, Hartley, & Payne, 2006; Houldin & Lewis, 2006; Ussher, Kirsten, Butow, & Sandoval, 2006; White & Verhoef, 2006; Kennedy, Haslam, Munir, & Pryce, 2007; Mitchell, 2007; Piggin & Jones, 2007; Hjorleifsdottir, Hallerg, Gunnarsdottir, & Bolmsjo, 2008). Only one study

thoroughly explored the experience of normalcy and placed that experience within a process for patients with advanced lung disease (De Vito Dabbs et al., 2004).

Ahlberg and Nordner (2006) found that participants benefited from support groups because the sharing of emotions provided a sense of normality. The authors suggested that if patients are not receiving the psychosocial support they need, patients decide to turn to groups for support. Alternatively, Ussher et al. (2006) studied the differences between support from close relationships versus groups. In their study, participants found the support group experience challenging and the normalizing experience came from outside the support group. Therefore, although the support group provided a ‘service,’ it did not appear to help women to move between ‘normal’ and supportive experiences.

Although no research described the particular existential, space was a recurring concept. The incidence of normalcy in the literature will therefore be discussed here within the spaces represented. Researchers commonly elucidate the impact of cancer on the patient’s experience of home. Frequently, patients decide to make an effort to maintain normalcy that includes balancing family, cancer treatments, other commitments, and the effects of symptoms on significant others and routines (DeMarco et al., 2004; Houldin & Lewis, 2006; Hjorleifsdottir et al., 2008). One difficult decision was requesting care from family members, including children (DeMarco et al., 2004), when women had once been the caregiver. Part of that reversal in caregiver role was to ask for protection from spouses, who could be ‘gatekeepers’ between children and friends (Mitchell, 2007). Bennett, Laidlaw, Dwivedi, Naito, and Gruzelier (2006) found women purposefully decided to socially isolate themselves because it was less stressful than

dealing with friends and family. One woman in the current study related her experience of coming home from hospital to cards, letters, friends, family, and the phone ringing off the hook. She decided not to answer the phone and stated that even her teenagers agreed.

Piggin and Jones' (2007) example of the effect of symptoms on life was their study of the experience of patients living with a fungating wound. One woman stated it was not the cancer that stopped her from being a mother but the wound, because that was the reason she could not go swimming with her small child. The researchers suggest patients with cancer can strive to be normal, yet still feel different. Decisions related to the effect of chaos on safe space included one woman refusing a cancer treatment so she could be well enough to cook for her children at Thanksgiving. The chaos was reflected in her concern about her cancer growing while she took time to create normal for her family.

The experience of being in treatment was studied by Mitchell (2007). Of eight themes, ‘striving for normality’ was primary. The author states all aspects of life were affected by chemotherapy and the experience of normality was the patient’s evaluation of what could be accomplished, specifically, “routine activities, such as gardening, housework, visiting, celebrating, hobbies, driving and simply being involved in life” (Mitchell, p. 42). The experience of being in treatment space rather than in ‘life’ is corroborated by a grounded theory on the experience of normalcy for patients after a lung transplant (De Vito Dabbs et al., 2004). The core process of the theory was ‘striving for normalcy’ and involved four stages leading from naiveté to vulnerability, through discovery to insight. The authors state “to live with ‘normalcy within illness,’ sickness may be distant but the management of the disease must be foremost. Chronic illnesses...

require attention in order not to have to pay attention” (De Vito Dabbs et al., p. 1482).

This statement seems to reflect the sentiment of the women in the current study. Women can decide to have moments of calm, and there are also chaotic moments. It is not a new level normal, it is normal attached to cancer—a normal that requires vigilance and a continual change.

Striving for normalcy is being able to put cancer in its proper context. Atkins et al. (2006) suggest there is a ‘space between’ cancer and a normal life with complementary therapies being within that space. I would argue the ‘space between’ is actually the focal point of the treatment focus, such as the cancer clinic or support groups, and the social focus, such as home and work. It appears that those who can make decisions that move chaotic space to safe space are striving for normalcy.

Theme: Vulnerability, Existential: Lived Body

The application of the experience of body is difficult in oncology where the disease and the treatment have significant impact and visibility. However, the lived experience of vulnerability, for this study, was not the effect of these changes on the body, just as lived time is not the measure of a ticking clock. Lived body is revealed in the awareness that arises from a physical interaction. Van Manen’s (1990) example was being blown a kiss. When the girl received the kiss, she blushed. What was revealed was the message—flushed cheeks—that she liked the boy in return. A cancer example was a woman feeling so well she could travel throughout the province and go for coffee with her friends, despite receiving a treatment that caused neuropathy of her feet. She only felt the tingling and pain when she sat down to relax at the end of her day. What was revealed was her vulnerability in a steadily deteriorating body. The theme of vulnerability,

therefore, was defined as feeling powerless to make decisions and being victimized by cancer and its treatment. The vulnerable body was revealed in two ways (see Table 5): first, in corporeal interactions with others by worrying over what others would say when they saw the effects of cancer treatment; and second, in regret about whether the right decision has been made to preserve the outer aspect of body over potential cancer growth. The narrative, entitled ‘Over My Dead Body,’ revealed vulnerability and its subthemes: being towered over by the oncologist, forced into decisions that seemed high risk and might be regretted later if infection occurred.

Table 5. Data Bit Examples for Vulnerability Themes within the Existential Lived Body

Theme	Subtheme	Examples
Vulnerability		<p>“The cancer in my lung has reduced somewhat. I’m back on the same chemo again. Just a lucky shot. I don’t know if this is going to work. It’s not classed as working for my type of cancer. I think my oncologist is pulling at straws. Using me as guinea pig.”</p> <p>“Some days it’s a conscious effort to get up. I have to get into the shower, do it first thing in the morning, because if I don’t then sometimes it doesn’t happen. There are days that I would love to lay in bed all day. I do have some down days.”</p> <p>“He said to me, ‘You have to think about whether you want to continue chemo.’ There is a point where I will say enough is enough. I will have to choose which is the worse of two evils. I’ve had a couple of days where it’s been that serious, where my feet were frozen. It’s when I stop and put my feet up when I feel it. That’s when it starts to hurt. It sounds bizarre, but that’s the way it works.”</p>
	What will they say?	<p>“I’m ready to cut my oncologist loose. I’m feeling today that I won’t choose any more treatments. My children will be angry. I feel more confident to win this battle with alternative therapy. Must remember not to play the part of the VICTIM. But play the part of the VICTOR. This has helped me so much with fighting the battle.”</p> <p>“I do feel like I’m forcing myself to eat sometimes. With the</p>

		<p>liquids it's not too bad, but the solids, they need to put it in the blender: roast, gravy, and potatoes. It doesn't taste bad, just different. I'm supposed to eat bananas, which I used to love, then I got to the point I just couldn't even look at one. So I just didn't even bother. Its hard be...the only thing that's hard is not being able to get up and walk around myself. That's the worst part of it. I don't know what my sister is going to say when she sees me 'cause last time we went out for lunch (laughs). The trouble is I go out and order something and wouldn't be able to eat it."</p>
	Regret	<p>"I had some spotting. It would only come and be there for a couple days and then it would be gone. So I never went to the doctor. I really regret that. I'm really stubborn. This has been very difficult for me. I hate doctors. I hate going to the hospital. I hate taking pills. I really think, if I would have gone sooner my outcome would be different."</p> <p>"I wouldn't do that again. I would have more tests, more examinations, more done than that. Three years later, I had it again. I know I wouldn't have done that again. One devil got away. Now it was real, really real."</p> <p>"I was so happy that I didn't have to have chemo. It's a double edged sword. You are happy that you didn't have chemo because your week is going to be wonderful, but in the same breath, you're thinking, 'Well, is that going to cause internal problems with my cancer?' Then you think, 'Oh maybe it's spreading now because that chemo's not in there.'"</p>

Narrative: "Over My Dead Body"

The two times that I was really ill, I was going nuts. One time, I had septicemia, and they were really wondering if they were going to pull me through. I should have realized when the oncologist was at my feet for about an hour that there was something wrong. But anyway, they put me into the observation unit and I said, "I can't be here because of all these germs." I was going on and on. Then she was going to put a catheter in and I said, "Over my dead body! You are not going to put a catheter in because I will, for sure, get infected!" I made the oncologist come to me. I said, "I want her to tell me to

my face, because I want to argue with her.” Of course, I was really quite weak, but I was going to argue not to have a catheter! I said to her, “This is too dangerous to put a catheter in; I will get an infection.” She said, “This is the least of our worries right now.” And she was right, and she was so good. She held my hand because it was not very pleasant.

Discussion of Vulnerability in Existential Body

The experience of vulnerability in relation to making decisions was the resultant expressions when the body was seen by others. The decisions all relate to whether the woman hid her body. She questioned whether she chose the treatment that would reduce the symptom impact on her body, made the right decision to get out of bed, get dressed, wear a wig, or go out for supper. Her questions such as “What will they say?” and “Will I regret this later?” revealed her existential experience.

Another participant spoke of desiring to enjoy a good meal. For her wedding anniversary, she decided to accept her husband’s invitation. However, having a vulnerable body meant deciding on such basic needs as whether the smell of food was nauseating, whether the glass of wine would end up in vomit, whether the hors d’oeuvres would create constipation and therefore pain, and whether the energy it took to get dressed up was worth the time out. In the case of this couple, after deciding that her body felt good enough to go out, the bigger concern was what people in the restaurant might say if her body revealed the cancer.

Other women were worried about what others would say when the body revealed cancer. Women’s lived experience of making decisions regarding their bodies were centered on whether or not to keep the cancer hidden. One woman decided to go grocery

shopping with a kerchief over her bald head rather than a wig and experienced being caught by a stranger. She was standing in line, oblivious to everything around her, when a woman behind her assumed cancer and began to give advice. She had decided not to wear a wig for two reasons: 1) she felt the wig was uncomfortable, and 2) she disliked explaining her reason for having no hair to others. She used the words ‘fake and phony’ to describe the experience of wearing her wig *for* others. Everyone knew she had cancer. She might as well keep up *their* reality. She seemed frustrated by this interaction. Instead of being the provider for her family, bringing food home, she was singled out as someone needing help because she was wearing a kerchief, because her body communicated vulnerability. This seemingly simple decision of whether to wear a wig or not became a contentious issue over her body’s existential place in this world.

One woman expressed regret in deciding to wait to enter the health care system. She had blood, ‘spotting’ in the toilet for a couple days, then it was gone. This was an initial symptom of the cancer recurrence. She described not wanting to ‘give herself up’ to the disease. She needed to feel that the symptoms would go away; she felt fine. She was certain the cancer would work itself out. The severe increase in pain led her back to the hospital. The shoulder x-ray revealed her cancer had progressed, and was a significant moment.

One woman progressed through her disease until she received a colostomy. When running her hands over her body, she realized there was no opening to wipe, but instead felt a new moist lump where flat soft skin should be on the tummy. She called the appliance a ‘purse’: an accessory, an item, an object to dress up an outfit, to carry important information. It was outside of her, not part of her, yet she decided to give it

importance. The significance of the purse was her perception that she could have chosen to have surgery and treatment sooner in her cancer journey. She was reminded that ‘one little devil’ metastasized and led her to this poor prognosis. Her colostomy was her lived experience of regret.

Surprisingly, literature regarding the concept of vulnerability around decisions in advanced cancer is limited. However, authors use inconsistent language, and therefore the concept of vulnerability is often not thematically addressed. For example, the word ‘vulnerable’ is traditionally used in terms of marginalized populations, such as children, cultural groups, or the elderly (Chouliara, Kearney, Worth, & Stott, 2004).

Imes, Clance, Gailis, and Atkeson (2002) relate the therapy experience of three cases, two with terminal cancer. One participant related the anxiety of disappointing her family because she was on disability due to her cancer. She was also fearful of meeting new people because she would have to see their reaction to her diagnosis. She decided to solve the problem, inherent in interacting with others, by socially isolating herself. These were similar to the experiences expressed by the women in the current study.

Still other women are more immediately concerned with vulnerability from the cancer itself, deciding to believe what the cancer is doing on the outside must be a reflection of what it is doing on the inside (Piggin & Jones, 2007). The theme ‘living with a body that cannot be trusted’ (Piggin & Jones) was expressed in sentiments by women in the current study. For example, women decided to take a break from treatment, but realized that break meant an opportunity for the cancer to grow. As well, one woman stated she could feel the cancer growing inside.

The body betraying the woman physically and interpersonally was also a theme in research by Morse, Bottorff, and Hutchinson (1995), the only study utilizing van Manen's phenomenological method, which revealed the experience of vulnerability as the lived body. The authors found the person was reflected as "victim, patient, case and sufferer" (Morse et al., p. 15) through the themes of a body that is 1) 'dis-eased', 2) disobedient, 3) deceiving, 4) vulnerable, 5) violated, 6) enduring, 7) betraying, and 8) resigned. These findings are similar to the women's descriptions of the lived body.

Finally, one study on the decision-making process for Chinese women (Lam, Fielding, Chan, Chow, & Or, 2004) documented the experience of participants who were concerned about the impact of cancer on the lives of their friends and family. The decision whether or not to accept treatment was related to the visibility of cancer. The example, a hidden mastectomy scar, decreased the need for the woman and her family to acknowledge her cancer to others. In contrast were symptoms or side effects such as alopecia, which must be explained.

These experiences extrapolated from the literature suggest the disruption in body image often affects a patient's well-being, causing the patient to question their self-identity and therefore their worthiness as contributors in their families, social groups, or society [often explicated as 'being a burden'] (Blinderman & Cherny, 2005; Piggin & Jones, 2007). These vulnerable moments affect the experience of making decisions as revealed in the theme 'What will they say?'

Lam et al. (2004) stated that regret relates to the decision-making style (active, collaborative, passive) of women, suggesting that if women did not have the control they desired, regret about the decision was more likely. However, the authors also extrapolate

from Zeelenber, van Dijk, Manstead, and van der Pligt (as cited in Lam et al.) who suggest instead that women may choose not to have control, which means they do not have responsibility for the decision or outcome, and therefore cannot regret a decision made by another. The current study neither confirms nor denies either suggestion, but adds to the understanding of regret in the experience of vulnerability in making decisions.

In summary, the four themes of control, influence, normalcy, and vulnerability reveal the experience surrounding decisions for women with advanced cancer. Women were in control over cancer, its treatment, and effects in an effort to gain time. Women had potential when they influenced others to gain a better quality of life. Women lived in a space between chaos and safety to achieve normalcy. Women were disrupted by a changed body image, questioned their sense of self and their worthiness to society, and revealed their vulnerability in their experience of making decisions.

Relevant Others

The third aim of the current study was to describe the lived experience of relevant others involved in the woman's significant decisions. Relevant others for the woman included a significant other, her oncologist, and her registered nurse.

Significant Others

As stated previously, only four significant others consented to an interview. Three themes were revealed and begin to reflect a picture of the impact of the women's decisions making on others.

What Used to Be

Husbands found they were becoming aware of changes in how the women were making decisions. The data revealed a change between how the husband-wife team had

previously come to decisions and what was currently happening. The following data excerpt represents this changed relationship:

One area we didn't come to agreement on right away is what to tell the kids and when to tell them. I've always been one to say that what we know, they should know. We shouldn't be hiding anything from them. My wife felt otherwise. Some of this is going to be difficult. We have to learn how to support each other on those things.

My wife has been a very independent person and I've allowed her to be that way. We had a great relationship in our independence, but there are times when we have to come together and grow on each other's weaknesses.

I really respect my wife's decisions. I usually go along with them. Sometimes I should stand up for myself a little bit more but that's not in my nature.

When it came to deciding on treatment, we said we would wait and think about it. That's the way we used to work. I thought the treatment option was the one to take and I know I would have used that, or simply made my opinion known. I think I would have tried to influence my wife to come around to that way of thinking.

It appeared that husbands were struggling with the change in communication between themselves and their wives. On one hand, men attempted to remain firm, stating

they would push for the decision they knew to be right. On the other, men seemed to realize they could not go back to what used to be, and accepted change or hinted that they allowed the change to happen.

Power Shift

Significant others sensed a change in power. For example, the husbands gained awareness that their wives were not revealing every decision. However, they remained confused as to why their wives were not sharing the decisions. The following are data examples of this theme:

I'm always the passive one and I give in, until it gets to the point of having to be tough with something and I have to get to the point of being angry. Then I'll put my foot down and say, 'OK, we're going this direction and we're doing this'.

She made the decision. She's always accepted the fact that she could die very quickly. She's always given me the impression that she's accepted this. I don't know if she's just hiding her true feelings from me so that I don't get carried away?

Like we have no idea what she's going through because she never sits there and tells you. I don't know why she doesn't say something. Maybe she figures we can't handle it or something.

These examples revealed a shift in power from being an equal in decisions to having information kept a secret.

'Life on Hold'

The significant others described how the women's decision making resulted in putting their life on hold. The normal, comfortable, safe, lifestyle did not exist and was missed.

My life is on hold right now and it will remain on hold until we can make decisions at home. I had to have someone else take over the community groups I lead. There were a lot of outside things that I had to say no to because I had to prioritize my life and my life right now is my wife. I had to take over the role of 'stay-at-home Mom' and make decisions with school things that I had never really participated in before. It was tough, for the first while, to get to know those things. Your whole life changes, whether you like it or not.

The biggest decision is that we would have to live a totally different lifestyle, because she's so sick. She just doesn't have the gumption to get up. It was really forced on us. I didn't want to change. I want my lifestyle the way it was before. Because of the severity of their illness, women were deciding to stay home, not work, not parent, and frequently, not get out of bed. Societal expectations of being the provider and being the parent took control and meant that going to the cabin, getting lots of sleep, and having 'down days' took a lower priority. The seemingly polar extreme of this example should not be taken lightly. Despite the words chosen, these male participants were revealing familial sacrifices within the personal context. Therefore, these themes are enlightening and possibly reflect some societal changes. For example, the language that

men speak as compared to the women in this study seemed to have different meaning (e.g., ‘I allowed her’, or the man being required to be the ‘stay-at-home-Mom’).

Although each husband spoke for one to two hours, these themes are limited by the small sample size and the fact that most of the interview was directed around the experience of the woman. As well, no literature was available to expound the experience of significant others relating to the impact of decisions made by women with advanced cancer. Future research should investigate this experience for both men and women in the significant other role.

Health Care Team

The current study also sought to understand the experience of health care team members around decisions made by women with advanced cancer. Two female oncology nurses were interviewed, one female haematologist, and two male oncologists. This complement of formal caregivers covered all five women participants. The three themes that emerged from the data were: emotional detachment, discomfort, and acquiescing.

Emotional Detachment

The health care team is affected personally by the patient. As well, they are affected by the patient’s negative perceptions, or mistrust, of them or the health care system. When women made decisions, the participants described becoming emotionally detached. Detachment often resulted from disagreeing with the decision; sometimes detachment was a method to prevent bias as the woman made her decision. Despite all attempts, being emotionally detached at all times was difficult. The following data examples reflect this theme.

The role I play is to provide information without getting emotionally involved in her case. It is not possible to cry for everybody that has metastatic disease. So I have to be very isolated from that emotional experience and I give the facts and figures and options. My role is to be honest and give the straight forward answer.

My feeling was, if I had been her, I would never have gone for that treatment. But I tried not to let that show in my conversation to her and just let her make the decision. I wanted to give her a good chance to make up her mind. I was afraid of being too biased. So I was trying to keep that hidden.

I have a very sad feeling when I go home. Even though it would seem that after seeing so many patients in a day it might not affect me that much. I think it still does.

I do try and cut off my emotions. You have to do that. This is part of your training. We have emotion, but if you involve your emotion with patient care it will affect our patient management. I told you that I have some attachment with her, but I have been working with her for a long time. Unfortunately... she doesn't want to give up. She should probably be supportive care. I don't know. I try to be as professional as possible.

The difficulty with being taught to detach and being in situations that require detachment is that often the emotions seep through. Whether from the multitude of patients, the severity of their diagnoses, the experience of the oncologist and nurse, or the complement

of supporting team members, completely preventing attachment may not be possible.

However, remaining unbiased while the patient makes their decision is expected.

Discomfort

The health care team participants described perceptions of expected timelines and patient behaviours. They felt uncomfortable when the women did not fit those expectations or when they did not feel they understood the women's needs. Ultimately, they stated their primary goal was to support the patient. The following data experts reflect this theme.

I stood up and gave her this big hug and she was like a board. She wasn't accepting of the hug. I felt a bit uncomfortable. She wasn't as receptive to my hug as I was hoping that she would have been. If that would have been me, I would have melted. I would have just bawled my eyes out. She just stood there. It was kind of funny. For myself, I felt like that was appropriate and that's what I had to do at that time. Kind of for her, but for myself too. I've got one patient who won't leave without a hug from me. That's expected.

I had the saddest thing. I have a young patient, with young children and she would not say one word to her children about her cancer. I was just blown away. That would so not be me. I guess that's her way of coping and dealing with cancer. I thought, is it my right to say that I think it's important her kids know? Who am I to say? It was scary. I guess it's her prerogative. That's none of my business.

When she looks back and sees what she's been through... Like, I would have thrown in the towel a long time ago. Who needs all this coming and going? This is the way her life is. You really have to admire her. I want to crawl into bed and put the covers over my head, block everything else out. How does she keep going?

The diversity of the women's reactions to being diagnosed, receiving treatment, recurring, and progressing varied with each woman and each stage. Experience helped the health care team member provide appropriate support. However, occasionally there were instances where the woman made a decision that lay outside what the health care professionals perceived as normal. Those experiences represented possible moments of discomfort during nursing care.

Acquiescing

In the participants' view, the oncologist's job was to treat, and the women wanted all options. The data in this study suggest the experience for the health care team was to focus on what the patient felt was the best option and to acquiesce the decision making to the women. The following are data examples of the theme of acquiescing.

Other oncologists might not have asked for that drug. They might have just said there are no other options. Every oncologist is different. Some are more aggressive, some work from active care through supportive care. I feel the patient should make the decision. They should have all the information about the options. If she was really deteriorating, not doing well, then that's a different thing. Then I wouldn't...

She probably only heard about 2% of what I said (laugh). I was pretty blunt about it. Pretty up front. I made it look pretty bleak for her, but on the other hand, I let her know that without chemotherapy she would be palliative and probably looking at maybe a month or two. I tried to be as unbiased as possible and leave it up to the patient. Patients know themselves well enough that they'll choose one way or another.

Decisions are a mutual agreement. We are all part of a team. I tell them the options. I said that my inclination would be to treat you because you still have good performance status. They didn't want to go to best supportive care. If I know it's not going to work, I'll tell them the options; getting a referral, or just doing nothing. For some patients who are not doing well, I really feel that it would be pushing. So, if the patient pushed, then I would advocate for the next treatment. Despite what the oncologists felt were in the best interests of the women or was the best research available, sometimes a participant decided to continue with treatment. The health care team then acquiesced to the woman's wishes to continue with treatment.

The three themes that emerged from the data seemed to reveal an overriding sense of resistance to becoming too involved, either with the women, or in her decisions. One concern exists from this series of themes. The oncologists participating in this study did not seem to communicate their personal experiences and dilemmas with other oncologists and chose not to debrief with family and friends. One oncologist stated:

It's hard to go home at the end of the day. It's not just her [the patient] I think about. Sometimes it's really depressing. The younger the patient, the harder it is. I

do talk to my wife. But I don't want to. I don't want to tell her that I'm down. I try to be happy and keep the good and bad separate. I don't want to bring it home. So, I keep it to myself.

This choice to not communicate with others is contrary to nursing where reflective dialogue is assistive in debriefing and critical thinking leading to clinical decision making (Crathern, 2001; Cohen & Erickson, 2006).

Research suggests physicians continue to aggressively treat because they have concerns communicating the end of options (Friedrichsen & Milberg, 2006). Further research could investigate whether this lack of communication is the resultant experience around a patient decision at this terminal stage, or the emotions associated with the patient transition to the terminal stage.

Summary

A woman's lived experience is comprised of body, time, space, and other. This research explored the experience of making advanced cancer decisions as defined by these four components. Advanced cancer was one context of a woman's life. Within that context, she experiences moments of control, influence, normalcy, and vulnerability when making decisions. The experiences chosen for writing in the current study are depicted in Figure 1, below. Important to note in this figure, and one limitation of this writing, is the arrows suggest movement of the themes among the existentials. Readers could note the sixteen potential representations of themes paired with existentials.

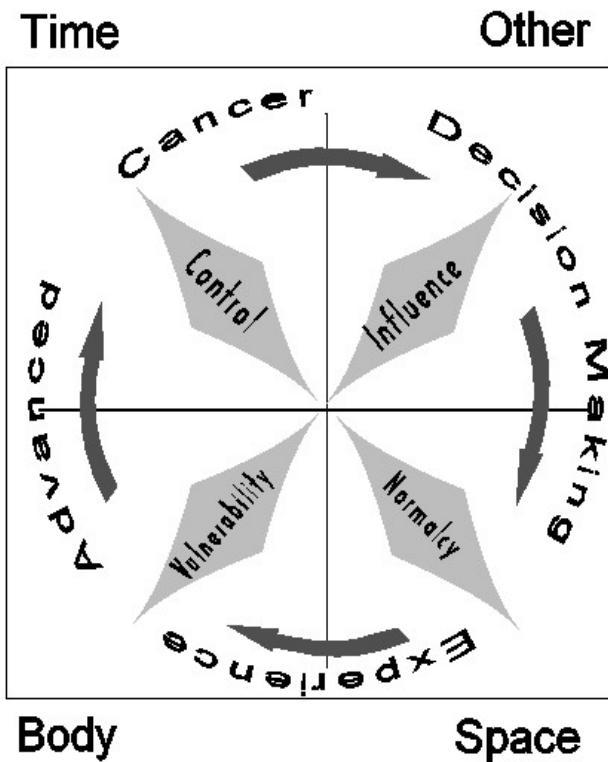


Figure 1. Visual representation of the woman's experience of making decisions during advanced cancer.

This figure represents the findings: the exemplar experience of the five women participants. Within time, the measure of life lived, women found control—the power to make decisions over treatment and cancer. Moments of measured time included holidays at the cottage or a child's graduation. However, within the lived experience of advanced cancer, one measure of her time became the moment when the woman chose to buy more time—to live in the life she has left, rather than certain suicide. Within lived other, the learning through interacting, women found influence: the ability to sway thoughts. Opportunities to influence included eliciting others to decide on alternative treatment, parenting, or family gatherings. Within lived space, the awareness of emotions evoked from the environment, women were striving for normalcy. Women experienced calm or

chaos, which often affected decisions. Within lived body, the learning about self through interactions with others meant women felt vulnerability. This was often experienced in how the side effects of treatment stopped women from participating in life. Where women seemed to ricochet between experiences of power to chaos, relevant others seemed to have generally negating experiences.

The current study has provided insight into the experience of three groups of participants. The essence of making decisions during a life-limiting prognosis was revealed through the experiences of women, their significant others and health care team members.

CHAPTER FIVE

Conclusion

Four emerging themes of the participant's experience in making decisions in the advanced cancer transition period were: control, vulnerability, influence and normalcy.

Control was exhibited in the woman's expression of power around making decisions.

Van Manen (1990) states that lived time is having a perspective of life to come. Women decided there was value in the time that was left, even if the future was shorter. Influence involved affecting a relationship or situation, either through overt or covert use of power, to attain the best outcome for a decision. The theme of influence revealed women's values, their struggles over whether to be an influence and the experience of not being heard. Women seemed to strive for normalcy which was between the experience of chaos and the moments of calm and safety. The women's narratives revealed that normalcy possibly exists between treatment and social supports. The theme of vulnerability was defined as feeling powerless to make decisions and being victimized by cancer and its treatment. This vulnerability was reflected in their body image and sense of self.

For the significant others, their experiences included reminiscing about what used to be, the shift in power within their relationship with their wife, and the sense that life was on hold. For the health care team members, themes included emotional detachment from their patient, acquiescing to the decision made and sometimes discomfort with the patient-health care team relationship. The relevant other themes reflected the impact of a

woman's decisions. Similarities also seem to exist between these themes and the original encounter.

The purpose, of applying phenomenological method, is not to better define a concept, but to come to a greater understanding of how a common definition was applied. Schmitt (1962) stated, "We are not stipulating what a certain terms [sic] means...Instead we discover what a certain phenomenon is like, and thereby explicate the terms which have always been applied to this phenomenon" (p. 105). For example, the discussion sections on control, influence, normalcy and vulnerability all included previous researchers' attempts to clarify these concepts according to their practice area. Each of these four themes has their own definitions in common use. Alternatively, this phenomenology explained the use of these themes in relation to the experience of advanced cancer for women and their relevant others.

The experiences of these women, the attributes of control, influence, normalcy and vulnerability, were exposed to create a common understanding. The purpose of this phenomenology was to understand the experiences for women, significant others and health care team members. Having acknowledged the distinctions and similarities between these experiences, nurses may unify research related to these attributes and begin to answer their questions about improving the cancer experience for their patients.

Factors Influencing the Study

This study encompasses the experience of five women, five significant others, and their health care team members. As with all qualitative research, these experiences cannot be generalized to another group of women with advanced cancer as they are specific to the context and experience of the participants of this study.

Furthermore, the sample was limited to participants whom the oncologists felt would be appropriate. Recruiting a larger sample may have been possible; however the purpose was to recruit groups through the oncologist/nurse team to ensure health care team member participation. A further limitation is the setting. Participants were interviewed as outpatients, either in the clinic or at their homes/workplaces. The research may have revealed different meanings for participants admitted to acute care.

Van Manen's (1990) assumptions state that phenomenology searches for meaning when participants have reflected. This was one opportunity for participants to share their burgeoning consciousness of making decisions. As with all research, a second interview may have provided deeper or different understanding.

Implications for Nursing Practice

The findings reveal the perspective of women with advanced cancer, specifically how the women felt in relation to making a decision. Although the findings are specific to the participants and the context, women with advanced cancer may have a heightened awareness of moments of control, influence, normalcy, and vulnerability in regards to making decisions. Although more research is needed, knowing the experiences for women in the transition stage can help nurses provide relevant support. For example, during moments when a woman is particularly vulnerable due to symptoms, nurses could initiate phone calls to offer support rather than waiting for the patient to initiate.

The women's decision-making experience had an impact on relevant others. Knowing the potential impact of a woman's decisions, nurses have opportunity to provide support for significant others. Although no template for how to interview exists, the themes from significant others provides nurses with an emerging awareness. The

findings, therefore, provide some guidance as to what to be aware of when interviewing significant others and the need to ask them “What is the best way to support you?” The health care team was also affected by a woman’s decisions, providing insight into the response of nurses and doctors to women’s decision making. This insight will help the health care team realize their own responses and their own needs for support as caregivers of persons with advanced cancer.

Implications for Nursing Research

A shift in power was suggested by themes for the women and significant others in this study. A power shift is the action of transferring control from one person to another. For the women in this study, the experience was of being in a position of power, not the transfer between positions; or, in the broader sense, the transfer between themes. For the significant others, however, the experience seemed to be the action; the transfer of power.

Nursing literature reveals the need for a power shift in relationships between physicians and nurses, and physicians and patients (i.e. shared decision-making). Literature outside nursing discusses power in relation to gender, economics and health. For example, Cowan, Bommersbach and Curtis (1995) stated that decision-making and perception are measures of power for men and women. Harvey and Thorburn Bird (2004) found that women feel powerful, or in control, when they make decisions or are autonomous. Kahn (1984) suggests when women demand power, men feel that loss. Basu (2006) developed a model showing a household (man and woman) is a collective where the power changes gradually as needs or preferences change and vice versa. Finally, Forssen and Carlstedt, (2001) found that the spousal relationship seems like a working environment where that power differential influences health. Each one of these examples

raises new *nursing* research questions about the *transfer* of power related to making decisions for women and men, in and out of spousal relationships during advanced cancer.

Although the woman's experience is presented as a linear progression from control to vulnerability, and interaction inferences are possible, this research described and explored the meaning of the separate concepts rather than the interaction between concepts. Potential future research questions include: Is there a process or interaction between the themes for women? Are there links between themes for women, the health care team, and the significant others? When a male is placed in the position of patient with advanced cancer, do the same themes (control, influence, normalcy, vulnerability) surface in regards to making decisions? Further, if women were in the significant other role, would those themes apply? For health care team members, do their themes apply whether the patient is in the advanced cancer transition period or in another stage?

More research is needed to determine what would be supportive for significant others and health care team members. As van Manen (1990) suggests, phenomenology does not provide an answer, but further clarifies the question.

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APPENDIX A – ETHICS APPROVAL



UNIVERSITY OF SASKATCHEWAN BEHAVIOURAL RESEARCH ETHICS BOARD

<http://www.usask.ca/research/ethics.shtml>

NAME: Muriel Montbriand (Natasha Murdoch)
College of Nursing

Beh 04-116

DATE: July 9, 2004

The University of Saskatchewan Behavioural Research Ethics Board has reviewed the Application for Ethics Approval for your study "The Experiences Around Heuristic Decisions of Patients with Advanced Cancer and Their Relevant Others" (Beh 04-116).

1. Your study has been APPROVED.
2. Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Committee consideration in advance of its implementation.
3. The term of this approval is for 5 years.
4. This approval is valid for one year. A status report form must be submitted annually to the Chair of the Committee in order to extend approval. This certificate will automatically be invalidated if a status report form is not received within one month of the anniversary date. Please refer to the website for further instructions
<http://www.usask.ca/research/behavrsc.shtml>

I wish you a successful and informative study.



Dr. Scott Bell, Acting Chair
University of Saskatchewan
Behavioural Research Ethics Board

VT/ck

Office of Research Services, University of Saskatchewan
Room 1607, 110 Gymnasium Place, Box 5000 RPO University, Saskatoon SK S7N 4J8 CANADA
Telephone: (306) 966-8576 Facsimile: (306) 966-8597
<http://www.usask.ca/research>

APPENDIX B – APPROVAL FOR ACCESS



SASKATOON CANCER CENTRE

20 Campus Drive, Saskatoon, Saskatchewan, Canada S7N 4H4
TELEPHONE: (306) 655-2662 • FAX: (306) 655-2910

April 26, 2004

Natasha Hubbard Murdoch, B.SN.,CON.
Nursing Staff, SCC and Student, College of Nursing

Dear Natasha,

Thank you for sharing your research proposal with me. I wish you good luck in this endeavour and I look forward to reading your thesis.

You have my permission to conduct this research in the Saskatoon Cancer Centre and to have access to patients who receive treatments here.

Sincerely,

David Popkin
David Popkin, B.Sc., MD., CM., FRCS.
Executive Director, Saskatoon Cancer Centre

Cc : Dr. Muriel Montbriand, Assoc. Professor, College of Nursing
Mr. Ivan Olfert, Assoc. Exec. Director, SCC.
Ms. Denise Budz, Head Nurse, SCC.
Mr. Vaughn Runquist, Director, Health Records, SCC

HEALTH RESEARCH
20 Campus Drive
Saskatoon, SK S7N 4H4

HEAD OFFICE
Suite 400, 2631 - 28th Avenue
Regina, SK S4S 6X3

TREATMENT
Allan Blair Cancer Centre
4101 Dewdney Avenue
Regina, SK S4T 7T1

TREATMENT
Saskatoon Cancer Centre
20 Campus Drive
Saskatoon, SK S7N 4H4

**PREVENTION AND
EARLY DETECTION**
952 Albert Street
Regina, SK S4R 2P7

APPENDIX C

PATIENT CONSENT FORM

You are invited to participate in a study entitled The Experience Around Decision-Making for Patients with Advanced Cancer and Their Relevant Others. Please read this form carefully, and feel free to ask questions you might have.

Researcher: Natasha Hubbard Murdoch
Graduate Studies, College of Nursing, University of Saskatchewan.

Phone: (hm) (306) 382-9871 or (wk) 655-2986
Email: jedimom@shaw.ca **or** nmurdoch@scf.sk.ca

Purpose and Procedure: The purpose of this research is to understand the experiences around decisions made by a woman with advanced cancer. The main focus is on the woman's decisions. The secondary focus is on the experience of the relevant others when the woman makes her decisions. If you are a woman and you have recently learned that you have advanced cancer, you may choose to participate in this research. The researcher would like to interview you twice in regards to the decisions you make after hearing about your advanced cancer diagnosis. A personal journal will be provided to you so that you may make notes, in between the interviews, about any decisions you make or information that you feel may be useful to this research. If you wish, you may also choose to email your stories, about decision-making, to the researcher. The two interviews may take between 1 and 2 hours each. The time frame for collection of all data is six months.

Potential Risks: It is possible that the interview, journal, and email topics may bring up stressful memories and decisions. You may speak to your designated Social Worker in the Psychosocial Oncology Department at the Saskatoon Cancer Centre at any time regarding these topics or the study. If the researcher, or other health professional, determines that you are overly upset during an interview, a referral will be made to the Psychosocial Oncology Department and you will be asked to discontinue with the study.

Potential Benefits: You may not receive any direct benefit from participating in this study. Other patients, registered nurses, and health care team members who read the final study results may benefit from this research.

Storage of Data: You will be identified, as a number, on all research material, except the consent form. Interview tapes and the corresponding transcribed data and the personal journals will be stored in a locked cabinet, in the College of Nursing, for 5 years separate

from the consent forms. You will be identified as a number on the research material. Emails will be copied to CD and all identifying names and addresses removed.

Confidentiality: The results of this study are partial requirements for the Master of Nursing program at the University of Saskatchewan. The results will be compiled into a thesis. Journal articles will be written from the results and presentations are planned with the Cancer Centre staff and Graduate Nursing students. No patient names or identifying information will be written or presented. The written format of this study suggests the use of direct quotations to support the findings. However, all identifying information will be removed. All other findings will be presented in aggregate. For the participant with advanced cancer, your perceptions will be kept confidential and will not be shared with your relevant other, doctor, or nurse.

Right to Withdraw: You may withdraw from the study for any reason, at any time, without penalty of any sort. Withdrawing from this research study will not affect any of the health care you receive, or may receive, in the future. If you withdraw from the study at any time, any data that you have contributed will be destroyed. If the study is extended longer than anticipated, you will be asked if you wish to continue.

Questions: If you have any questions concerning the study, please feel free to ask at any point during the interview. You are also free to contact the researcher at the numbers provided above if you have questions at a later time. This study has been approved on ethical grounds by the University of Saskatchewan Behavioural Sciences Research Ethics Board on (insert date). Any questions regarding your rights as a participant may be addressed to that committee through the Office of Research Services (966-2084). Out of town participants may call collect.

Please indicate if you would like to be informed about the study results.

Consent to Participate: I have read and understood the description provided above; I have been provided with an opportunity to ask questions and my questions have been answered satisfactorily. I consent to participate in the study described above with the understanding that I may withdraw my consent at any time. A copy of this consent form has been given to me for my records.

(Signature of Participant)

(Date)

(Signature of Researcher)

APPENDIX D

SIGNIFICANT OTHER CONSENT FORM

You are invited to participate in a study entitled The Experience Around Decision-Making for Patients with Advanced Cancer and Their Relevant Others. Please read this form carefully, and feel free to ask questions you might have.

Researcher: Natasha Hubbard Murdoch
Graduate Studies, College of Nursing, University of Saskatchewan.

Phone: (hm) (306) 382-9871 or (wk) 655-2986
Email: jedimom@shaw.ca **or** nmurdoch@scf.sk.ca

Purpose and Procedure: The purpose of this research is to understand the experiences around decisions made by a woman with advanced cancer. The main focus is on the woman's decisions. The secondary focus is on the experience of the relevant others when the woman makes her decisions. If you are a significant other, you may have been chosen by a woman in your life with advanced cancer. You may choose to participate in this research. The researcher would like to interview you once to learn about your experience when the woman with advanced cancer in your life makes decisions. A personal journal will be provided to you so that you may make notes about any decisions you make or information that you feel may be useful to this research. If you wish, you may also choose to email your stories, about your experiences to the researcher. The interview may take between 1 and 2 hours. The time frame for collection of all data is six months.

Potential Risks: It is possible that the interview, journal, and email topics may bring up stressful memories and decisions. You may speak to your designated Social Worker in the Psychosocial Oncology Department at the Saskatoon Cancer Centre at any time regarding these topics or the study. If the researcher, or other health professional, determines that you are overly upset during an interview, a referral will be made to the Psychosocial Oncology Department and you will be asked to discontinue with the study.

Potential Benefits: You may not receive any direct benefit from participating in this study. Other patients, registered nurses, and health care team members who read the final study results may benefit from this research.

Storage of Data: You will be identified, as a number, on all research material, except the consent form. Interview tapes and the corresponding transcribed data and the personal journals will be stored in a locked cabinet, in the College of Nursing, for 5 years separate from the consent forms. You will be identified as a number on the research material. Emails will be copied to CD and all identifying names and addresses removed.

Confidentiality: The results of this study are partial requirements for the Master of Nursing program at the University of Saskatchewan. The results will be compiled into a thesis. Journal articles will be written from the results and presentations are planned with the Cancer Centre staff and Graduate Nursing students. No names or identifying information will be written or presented. The written format of this study suggests the use of direct quotations to support the findings. However, all identifying information will be removed. All other findings will be presented in aggregate. Your perceptions will be kept confidential and will not be shared with your relevant other, doctor, or nurse.

Right to Withdraw: You may withdraw from the study for any reason, at any time, without penalty of any sort. Withdrawing from this research study will not affect any of the health care your partner receives, or may receive, in the future. If you withdraw from the study at any time, any data that you have contributed will be destroyed. If the study is extended longer than anticipated, you will be asked if you wish to continue.

Questions: If you have any questions concerning the study, please feel free to ask at any point during the interview. You are also free to contact the researcher at the numbers provided above if you have questions at a later time. This study has been approved on ethical grounds by the University of Saskatchewan Behavioural Sciences Research Ethics Board on (insert date). Any questions regarding your rights as a participant may be addressed to that committee through the Office of Research Services (966-2084). Out of town participants may call collect.

Please indicate if you would like to be informed about the study results.

Consent to Participate: I have read and understood the description provided above; I have been provided with an opportunity to ask questions and my questions have been answered satisfactorily. I consent to participate in the study described above with the understanding that I may withdraw my consent at any time. A copy of this consent form has been given to me for my records.

(Signature of Participant)

(Date)

(Signature of Researcher)

APPENDIX E

HEALTH CARE TEAM CONSENT FORM

You are invited to participate in a study entitled The Experience Around Decision-Making for Patients with Advanced Cancer and Their Relevant Others. Please read this form carefully, and feel free to ask questions you might have.

Researcher: Natasha Hubbard Murdoch
Graduate Studies, College of Nursing, University of Saskatchewan.

Phone: (hm) (306) 382-9871 or (wk) 655-2986
Email: jedimom@shaw.ca **or** nmurdoch@scf.sk.ca

Purpose and Procedure: The purpose of this research is to understand the experiences around decisions made by a woman with advanced cancer. The main focus is on the woman's decisions. The secondary focus is on the experience of the relevant others when the woman makes her decisions. You may be a physician or registered nurse for a woman with advanced cancer and you may choose to participate in this research. The researcher would like to interview you once about your experience around the decisions your patient made after hearing about her advanced cancer diagnosis. A personal journal will be provided to you so that you may make notes about your experiences or information that you feel may be useful to this research. If you wish, you may also choose to email your stories to the researcher. The interview may take between 1 and 2 hours. The time frame for collection of all data is six months.

Potential Risks: There is no demonstrable risk for you in this research.

Potential Benefits: You may not receive any direct benefit from participating in this study. Other patients, registered nurses, and health care team members who read the final study results may benefit from this research.

Storage of Data: You will be identified, as a number, on all research material, except the consent form. Interview tapes and the corresponding transcribed data and the personal journals will be stored in a locked cabinet, in the College of Nursing, for 5 years separate from the consent forms. You will be identified as a number on the research material. Emails will be copied to CD and all identifying names and addresses removed.

Confidentiality: The results of this study are partial requirements for the Master of Nursing program at the University of Saskatchewan. The results will be compiled into a thesis. Journal articles will be written from the results and presentations are planned with the Cancer Centre staff and Graduate Nursing students. No names or identifying

information will be written or presented. The written format of this study suggests the use of direct quotations to support the findings. However, all identifying information will be removed. All other findings will be presented in aggregate. Your perceptions will be kept confidential and will not be shared with your patient, their relevant other, or your team members.

Right to Withdraw: You may withdraw from the study for any reason, at any time, without penalty of any sort. If you withdraw from the study at any time, any data that you have contributed will be destroyed. If the study is extended longer than anticipated, you will be asked if you wish to continue.

Questions: If you have any questions concerning the study, please feel free to ask at any point during the interview. You are also free to contact the researcher at the number or emails provided above if you have questions at a later time. This study has been approved on ethical grounds by the University of Saskatchewan Behavioural Sciences Research Ethics Board on (insert date). Any questions regarding your rights as a participant may be addressed to that committee through the Office of Research Services (966-2084). Out of town participants may call collect.

Please indicate if you would like to be informed about the study results.

Consent to Participate: I have read and understood the description provided above; I have been provided with an opportunity to ask questions and my questions have been answered satisfactorily. I consent to participate in the study described above with the understanding that I may withdraw my consent at any time. A copy of this consent form has been given to me for my records.

(Signature of Participant)

(Date)

(Signature of Researcher)

APPENDIX F – INTERVIEW GUIDES

Interview Guide for the Women

1. Tell me about the decisions you have made in the last few months.
2. Pick one decision that is memorable and tell me all your thoughts and feelings about that particular experience.
3. Tell me about the people most involved in that decision. Tell me what you remember about that decision and the involvement of each person.
4. Tell me all the things you felt and thought when you were told you have advanced cancer, while you made decisions, and after you made these decisions.

Interview Guide for the Relevant Others

1. Tell me about your feelings and thoughts when you knew _____ had advanced cancer.
2. Tell me about one memorable time in the decision making. Tell me about your particular experience in that decision.
3. Tell how you saw your role in _____'s decision making.