MOVING ON:
THE POST-TREATMENT EXPERIENCE
OF WOMEN AND FAMILIES WITH BREAST CANCER

by

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ABSTRACT

The initial period of time after treatment for cancer ends has been described as one of ambivalence and limbo (Halvorson-Boyd & Hunter, 1995; Hurt, McQuellon and Barrett, 1994) – yet few researchers have specifically studied the immediate post-treatment period, particularly from a family perspective. The purpose of this study was to explore and describe what life is like for women and their families in the first six months following completion of adjuvant treatment for breast cancer.

Interpretive description was the qualitative method chosen for the study. In-depth interviews were conducted with eleven family dyads (the woman diagnosed with breast cancer and a family member of her choosing) who were between one and six months post-treatment. The data was analyzed using an inductive approach.

The initial post-treatment period was revealed as a time of transition when families move past the cancer into normal life – a new normal that must take into account the cancer experience. “Moving On” was identified as an appropriate overall descriptor of the experience. Three subthemes – making sense of the experience, managing the threat of recurrence, and rejoining the world of normal – describe the concerns of the women and families and their strategies for managing the post-treatment experience. Six families had a different and more challenging experience post-treatment than the other five families. A variety of factors related to family, treatment, and interactions with health care providers that appeared to contribute to the variations in Moving On are also discussed.

By shedding light on how the first six months following treatment for breast cancer is manifested in family life, this study has implications for health care professionals working with women with breast cancer and their families.
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DEDICATION

This work is dedicated to the many women with breast cancer and their families whom I have had the privilege of working with and learning from over the last several years,

and

To my Dad,
Who has been with me in spirit the last few months of this venture.
I know you’ll be watching as I walk across the stage.
CHAPTER 1: INTRODUCTION

Background

1 in 9. The magic statistic that probably every woman in Canada understands is her lifetime risk for getting breast cancer. In 2000 that statistic translated into an estimated 19,200 women in this country newly diagnosed with breast cancer (Canadian Cancer Society, 2000). The majority of these women will have undergone six months to one year of treatment with the intent of preventing the cancer from ever coming back. For many women, treatment will be successful. For some women it will not. But regardless of the eventual outcome, all of these women will initially finish treatment with the hope that they are cured, and the desire to get on with a normal life. What is this period of time like for women and their families? What is a “normal life” following a diagnosis of and treatment for breast cancer? How do women and their families begin to move forward?

The initial period of time following the completion of treatment for breast cancer has been referred to as neutral time or a time of limbo (Hurt, McQuellon & Barrett, 1994). Treatment for breast cancer takes place over the better part of a year and may involve various combinations of surgery, chemotherapy and radiation. From the moment of diagnosis until the treatment plan is completed, a woman’s life is structured around appointments, and contact with health professionals is frequent. Once treatment ends, this consistent support and structure lessens considerably, with the result that women may feel abandoned (Pelusi, 1997). This is especially significant given that women are often still coping with lingering side effects of treatment. In addition, the unpredictability which is characteristic of the disease – although it may vary, there is always some risk of recurrence – comes once again to the forefront when treatment is over. Women feel vulnerable when “nothing is being done”
(Ferrell, Grant, Funk, Otis-Green & Garcia, 1998a). The result is that the end of treatment is often a time of conflicting emotions and ambivalence – relief that treatment is finished yet anxiety and uncertainty about what comes next (Runowicz & Haupt, 1995). The path from breast cancer patient to breast cancer survivor appears uncharted and each woman must navigate her own course.

Yet each woman is not alone on this path – breast cancer, any cancer, is not an individual’s disease but an experience in which families and significant others are automatically immersed. The effects of diagnosis and treatment have an impact on all aspects of family life – communication, finances, normal patterns of everyday living (Hilton, 1993; Northouse, 1995). Family priorities are often altered and established roles of all family members can be challenged and transformed (Fitch, Bunston & Elliot, 1999). Therefore, it is reasonable to suggest that the initial period of time following the completion of adjuvant treatment for breast cancer is significant for the family as a unit, not just for the woman with the breast cancer diagnosis, and can be best understood from a family perspective.

Despite this, while there is research that addresses a variety of issues related to breast cancer survivorship, and the beginning of research that addresses the experience of families with breast cancer, there is limited research specifically related to the experience of finishing adjuvant treatment for breast cancer – from either an individual or family perspective.

**Statement of the Problem**

Given that the majority of women diagnosed with breast cancer today will become survivors of their disease, nurses have a responsibility to prepare women and families for the experience of finishing treatment. While this period of time is mentioned in the literature as one of confusion and anxiety, there is little research about it specifically. It is often buried in
research related to the overall experience of surviving breast cancer, yet the evidence does suggest that it can be a very significant time in a woman’s journey after a cancer diagnosis. And if cancer truly is a family affair, then the post-treatment period is likely a significant time for family and friends as well. A better understanding of how women and their families experience the initial post-treatment period will assist nurses to provide breast cancer patients and families with the appropriate knowledge and skills to begin to navigate their own course from breast cancer patient to breast cancer survivor.

**Purpose of the Study**

The purpose of this study is to address the gap in knowledge related to this particular phase of the cancer continuum and contribute to the literature on breast cancer survivorship, particularly that which addresses the impact on the family, by exploring and describing the period of time immediately following the completion of treatment for breast cancer from a family perspective. This study will be guided by the question: How do women diagnosed with breast cancer and their families experience the first six months following completion of adjuvant treatment?

**Definition of Terms**

For the purposes of this study, the following definitions will apply:

- **Family** – any group of 2 or more persons that consider themselves to be a family. A family may take any number of different forms or composition as it is the attributes of strong emotional ties, a sense of belonging, and future obligation that are important, regardless of whether the members are related by blood or live in the same physical household. (Wright and Leahey, 1994)
• **Adjuvant treatment** – A course of radiation and/or chemotherapy following initial surgery for a diagnosis of breast cancer. The intent of the treatment is curative. Hormone therapy alone following surgery is not included in this definition.

• **Post-treatment period** – The first six months following the completion of adjuvant treatment

**Assumptions**

1. Women and their families who have finished adjuvant treatment for breast cancer and are beginning to make the transition from patient to survivor have a unique insider perspective on this phenomenon that would be important for health care professionals to appreciate.

2. There may be common patterns or themes within the experience of different families that can inform supportive care and clinical practice.

3. Family life, not just individual members, is impacted by breast cancer and its treatment and therefore the family as a group can speak about this shared experience.

**Significance of the Study**

Over the years, treatment for breast cancer has become more successful – more women are being treated at earlier stages of disease, and more women are becoming breast cancer survivors. Given this, it is important to understand as much as possible about what women and their families face when adjuvant treatment ends. Currently, resources and support tend to focus on assisting women and their families to cope during diagnosis and treatment, yet as survivors they will spend more time living after treatment is finished and so have the right to be prepared for that experience as much as possible. The initial period following adjuvant treatment has been identified as a time of confusion and uncertainty – a
study of the perceptions of women and their families may shed light on how the experience is manifested in family life. Investigation into what happens for women and their families in the first several months following the completion of breast cancer treatment may contribute to the development of some preliminary ideas about factors that women and their families think may help or hinder the transition from breast cancer patient to breast cancer survivor. Finally, by conducting this research from a family perspective, the information will contribute to the body of knowledge that guides the care of families with cancer. It may help to identify some aspects of support or information required by families in the post-treatment period and/or illuminate areas of concern that clinicians should target in family assessments during the post-treatment period.
CHAPTER 2: LITERATURE REVIEW

There is limited research focusing specifically on the experience of completing adjuvant treatment for breast cancer from either an individual or family focus. In order to determine the current state of knowledge about the initial post-treatment period, two separate but related bodies of literature will be surveyed. First, this review will focus on the literature related to survivorship issues for those with breast cancer, since that is where information relevant to the post-treatment experience most often seems to be situated. However the focus of research in the area of cancer survivorship is almost always the individual with cancer. Therefore, in order to gain a better understanding of what is known about the family experiences post-treatment, the literature discussing effects of cancer and breast cancer on the family will also be explored.

The Concept of Cancer Survivorship

It is only since the mid 1980’s, as improved cancer treatments and earlier diagnoses led to increased survival rates for persons with cancer, that cancer survivorship began to emerge as an important area in cancer care (Hassey Dow, 1991; Quigley, 1989; Tamlyn-Leaman, 1995). In 1985, Mullan, a physician diagnosed with cancer, was one of the first to bring attention to the issue when he wrote an article for the New England Journal of Medicine discussing survival as a useful concept to describe the experience of living after a diagnosis of cancer. Mullan identified the need to investigate and address the problems of cancer survivors, advocating for research focused on survivorship as a phenomenon in itself, rather than as a "byproduct...of basic research on cancer treatment" (p. 273). Yet even in 1992, Leigh identified survivorship as a "new concept in relation to cancer...[which] has yet to undergo rigorous conceptual development" (p.1476). And in 1995, the area of adult
cancer survivorship continued to be described as emerging, with inconsistencies in its definition and descriptions (Abbey, 1997; Tamlyn-Leaman). For example, the common understanding of ‘survivor’ amongst medical professionals is a person who has lived five years past their initial diagnosis without a recurrence. In contrast, the National Coalition of Cancer Survivors states that “survivorship starts at diagnosis and proceeds along a continuum through and beyond treatment, recurrences, cures, and the final stages of life regardless of the cause. Survivors can be the individual with cancer and/or their family or friend” (Pelusi, 1997, p.1352).

Despite a lack of consensus with regard to defining survivorship as a concept, over the years researchers have responded to Mullan’s call to describe and understand the phenomenon of being a cancer survivor by studying a variety of issues and problems, with people with a variety of cancer diagnoses, using a variety of definitions of survivor. In this next section, the literature pertinent to women surviving breast cancer will be reviewed in order to understand the issues particular to this population.

**Being a Breast Cancer Survivor**

A diagnosis and the subsequent treatment of breast cancer can impact a woman in any number of ways. While no one women will have exactly the same experience as another, there are several issues identified repeatedly in the literature that appear to be common to the experience of surviving breast cancer.

**Survivorship as a Journey**

Cancer survivorship is often portrayed as an ongoing process or journey, regardless of whether one believes the beginning of the journey to be at diagnosis, at the end of treatment, or following five disease-free years (Bushkin, 1993; Hassey Dow, 1990; Leigh, 1992;
Mullan, 1985). This journey is often broken down into a variety of stages or phases. For example, Mullan described three ‘seasons of survival’ based on his personal and professional experience. The acute season is during the time of initial diagnosis and treatment. The extended season is when the basic course of treatment has finished and the patient finds him or herself in a phase of watchful waiting. Permanent survival is when the cancer can be considered permanently arrested.

In a qualitative study exploring the daily lived experience of women who have survived breast cancer beyond 5 years without recurrence, Carter (1993) described a survival process labeled “going through” which involved movement through six phases: interpreting the diagnosis, confronting mortality, reprioritizing, coming to terms, moving on, and flashing back. Carter noted that movement through the phases was non-linear, sometimes simultaneous, and unique to each participant. This study was limited by the broad range in survival time (5-26 years) and the fact that no attempt was made to distinguish differences in experiences at various increments in the survival trajectory.

Pelusi (1997) conducted open-ended interviews with eight women about their experience surviving breast cancer and identified nine theme categories, one of which was named ‘the journey’. In this journey the women traveled from being an individual, to being an individual with cancer, to being a cancer survivor. Features of the journey included that it began at diagnosis, involved ever-changing roles, and was challenging. As with Carter’s (1993) study, the range of survival (2-15 years past completion of therapy) makes it impossible to determine whether a particular experience is related to any particular point in time in the overall cancer trajectory.
Yet, in examining the evolving meaning of cancer for long-term breast cancer survivors, Utley (1999) was able to loosely connect particular meanings of cancer with specific phases in the cancer trajectory. She found that participants expressed the meaning of "cancer as sickness and death" in relation to their early reactions to the breast cancer diagnosis. As participants dealt with their diagnosis and continued through treatment this meaning evolved to "cancer as an obstacle"—something that intruded on life but had to be dealt with. The final meaning, "cancer as transforming" was arrived at as women continued to survive past treatment and experience a greater appreciation for life. Participants in Utley's study varied in length of survivorship from 5-29 years and there was no attempt to determine how long each phase was.

These studies suggest that survivorship does appear to be a dynamic lifelong process with a variety of possible phases or stages, and that cancer survivors tend to identify diagnosis as the beginning of the survivorship journey. However, if one looks at the cancer trajectory as described by Mullan, it is unclear how certain experiences or phases are related to a particular season or point in the cancer trajectory.

Ongoing Physical Symptoms

There are numerous physical changes which can occur as a result of treatments for breast cancer that may continue to impact women even after treatment finishes. These late effects can range from causing mild annoyance to being a significant barrier to day-to-day functioning. Some of the physical changes that have been identified by breast cancer survivors as having a particular impact on their quality of life include: loss of a breast, fatigue, menopausal symptoms, weight gain, and arm problems (Ferrell, Grant, Funk, Otis-Green & Garcia, 1997; Hassey Dow, 1995; Longman, Braden & Mishel, 1997). Even in
women who have survived 8 years without recurrence and report an overall quality of life similar to women their age without a breast cancer diagnosis, sexual functioning related to menopausal symptoms and arm problems related to the original surgery were identified as two areas of continued concern (Dorval, Maunsell, Deschenes, Brisson & Masse, 1998). In my experience, menopausal symptoms and fatigue are two concerns that breast cancer survivors commonly mention in the first few months following completion of treatment and they will be highlighted here as examples of how symptoms can persist even after treatment finishes.

Breast cancer survivors may experience menopausal symptoms for a variety of reasons other than aging. Withdrawal of hormone replacement at diagnosis, chemotherapy-induced ovarian failure, contraindications against hormone replacement following diagnosis, and/or treatment with the antiestrogen tamoxifen can precipitate a variety of menopausal symptoms. The most frequently reported symptoms are hot flashes, joint pain, feeling tired, and trouble sleeping (Carpenter & Andrykowski, 1999; Finck, Barton, Loprinzi, Quella & Sloan, 1998; Ganz, Rowland, Desmond, Meyerowitz & Wyatt, 1998). In a quantitative study of 114 breast cancer survivors examining the prevalence and severity of menopausal symptoms and the relationship between menopausal symptoms and quality of life, Carpenter and Andrykowski found that a higher prevalence and severity of symptoms were correlated with a lower physical and emotional quality of life. However the QOL instrument was not specific to cancer populations or to the impact of menopausal symptoms. This study was also limited in that the assessment of menopausal symptoms was limited to a single two week period, and the sample was fairly heterogenous in terms of time postdiagnosis and postmenopause.
In their study designed to gain insight into the experience of hot flashes as a symptom in breast cancer survivors, Finck et al. (1998), found that women tended to define the severity of hot flashes not by the criteria of frequency that is commonly used by health care professionals, but according to duration, physical and emotional sensations, and the action required to reduce them. The narratives made it very clear that hot flashes disrupt normal activity and lifestyle, and that the more severe the hot flashes, the greater the disruption. What constituted a disruption of normal activity and lifestyle, and whether the women considered their overall quality of life to be affected was not elaborated on. The research suggests that menopausal symptoms can have an effect on a breast cancer survivor’s day-to-day functioning, but it is not clear from the available studies specifically what the impact is at any particular point in the cancer trajectory.

Fatigue is also a common and serious problem for women diagnosed with breast cancer, and although more is known about fatigue in women undergoing treatment than in breast cancer survivors, there is certainly an indication that fatigue continues post-treatment (Mast, 1998a; Woo, Dibble, Piper, Keating & Weiss, 1998). For their study describing the side-effects burden experienced over time by 53 women receiving treatment for breast cancer, Longman et al. (1997) collected data at 3 different periods of time. Time 3 was approximately 5 months after the beginning of treatment, which for patients undergoing the more common breast cancer treatments would be very near the end of the treatment course, or shortly after it finished. Fatigue was found to be the most frequent and problematic side-effect over time. It was in fact more frequent at Time 3 than at Time 1, suggesting a cumulative effect. Certainly the fatigue did not lessen as treatment progressed and came to an end.
Mast (1998a) also found evidence that fatigue persists after treatment. In her quantitative study examining variables associated with fatigue, she collected data on 109 women who were between 1 and 6 years post-treatment. Low to moderate fatigue persisted for all participants and was found to be significantly related to the presence of concurrent illness as well as to treatment with chemotherapy, but not to length of time since treatment or age. This study is limited by the fact that fatigue was measured by a single item - degree of tiredness - for which reliability and validity have not been established. It did not take into account the pattern or consistency of fatigue over time, or its impact on various aspects of quality of life.

Woo et al. (1998) also found long-term fatigue to be related significantly to the initial treatment received, particularly chemotherapy. Contrary to Mast, their findings showed a significant inverse relationship between age and fatigue. All participants had had treatment within 18 months prior to completing the survey, but the relationship between length of time since treatment and fatigue was not explored. There is evidence that fatigue can be an ongoing problem for survivors of breast cancer, although how that fatigue manifests itself at specific points in the cancer trajectory has not been well explored.

Fatigue and menopausal symptoms have been highlighted as two concerns that women often experience post-treatment, yet there are others. The point is not to list them all here but to note that dealing with ongoing symptoms and changes related to the diagnosis and treatment of cancer even after treatment is finished can be a common experience for breast cancer survivors.
Transcendence

A third common experience related to surviving breast cancer is a profound type of change which might be called transformation or self-transcendence and involves an increased understanding of self and a broadening of life perspective (Carter, 1993; Fredette, 1995; Pelusi, 1997; Thibodeau & MacRae, 1997; Utley, 1999; Wyatt, Kurtz & Liken, 1993). This goes beyond any changes themselves to include the meaning of the changes and the significance of cancer in the survivor's overall life experience. It has been described as a coming to terms with various aspects of being a cancer survivor; a learning of new ways of being that facilitates moving on (Carter, 1993; Nelson, 1996).

Many women come to a point where they are able to view their cancer as having benefited them to some extent by facilitating positive experiences and changes in their lives. For example, in her qualitative study of older women who are long-term survivors of breast cancer, Utley (1999) found that as participants came to the realization that they were surviving, they had a greater appreciation of life and eventually experienced a positive, transforming effect from the crisis of cancer. All of the participants in this study were women over the age of 65 and therefore there is a possibility that age and life experience contributed to how the women viewed their breast cancer experience.

Yet, in a phenomenological inquiry into the experience of 45 breast cancer survivors ages 29-75 at diagnosis and ranging from 3-31 years post-treatment, Thibodeau and MacRae (1997) also found that the majority of their participants reported positive life changes resulting from their cancer. In her study aimed at understanding concerns and coping, Fredette, too, found that women often coped by finding meaning in having cancer, and that the meaning was often expressed in terms of a gift that provided a perspective on what is
really of value in life (1995). The participants in this study also varied in age from 48-68 and in length of time past initial diagnosis from 8-30 years.

These studies suggest that for some women there may be a concurrent positive growth experience associated with the challenges and complexities of cancer diagnosis and treatment. However, it is not clear from this research how the occurrence of transformation is related to a particular point in the cancer trajectory, the length of time a person has survived, or to other factors such as personality or age.

Uncertainty

A fourth experience common to breast cancer survivors, and the final one that will be discussed here is that of uncertainty. Due to the nature of the disease, the outcome of a cancer diagnosis and its subsequent treatment is never predictable. This uncertainty, including fear of recurrence, thus becomes a key feature of the survivorship experience and may be a significant source of psychological and spiritual distress for cancer survivors (Ferrell et al., 1998a; Pelusi, 1997). In their quality of life research, Ferrell et al. (1996), and Ferrell et al. (1998a) found that the women’s greatest areas of distress were in the psychological domain, particularly with regard to fearing a recurrence of their cancer. In the spiritual domain, uncertainty was the greatest source of disruption.

The relationship between illness uncertainty, fear of recurrence and emotional well-being was further explored by Mast (1998b) in her quantitative study of 109 breast cancer survivors from 1 to 6 years post-treatment. She found that symptom distress and fear of recurrence contributed strongly to illness uncertainty, which in turn contributed to emotional distress. This study is limited by the fact that the scale used to measure uncertainty was not originally designed for use with cancer survivors.
In a phenomenological study designed to provide insight into the experience of living with uncertainty after a breast cancer diagnosis, Nelson (1996) uncovered five themes of uncertainty. Uncertainty was found to be dynamic, varying over time in the survival trajectory. In addition to the usual negative consequences of uncertainty such as anxiety, positive aspects such as optimism, freedom, and intrigue were described by her participants. This may have been influenced by the fact that while all the participants in Nelson’s study were between 2 and 6 years post-treatment, not all were disease-free.

The research supports uncertainty as a common experience for breast cancer survivors, yet just how this uncertainty impacts on day-to-day living and exactly how it fluctuates over the cancer trajectory is not clear.

According to the research described up to this point, the experiences of uncertainty, transcendence, dealing with ongoing physical symptoms, and the sense of being on a journey are common to many women who have survived breast cancer for a varying amount of time. Are these experiences more likely to occur at any specific time in the cancer trajectory, or is there a specific time in which breast cancer survivors can expect certain experiences? For many women undergoing treatment for breast cancer, the goal is to finish treatment – the expectation being that life will then get easier. This next section will explore what the literature has to say about what women experience after their treatment for breast cancer finishes.

**The Immediate Post-treatment Period**

The period of time immediately following the completion of treatment for breast cancer has been portrayed as stressful for women both in the lay literature and by health care professionals through case studies and clinical experiences. Books such as *To Be Alive: A*
Woman's Guide to a Full Life After Cancer (Runowicz & Haupt, 1995) and Dancing in Limbo: Making Sense of Life After Cancer (Halvorson-Boyd & Hunter, 1995) discuss the real-life experiences of surviving cancer. Written by cancer survivors, both of these books talk about the initial post-treatment period as a time of conflicting emotions and confusion. With treatment complete survivors experience relief that it is over, yet also a sense of loss—a loss of focus and a sense of purpose. Hurt, McQuellon and Barrett (1994), suggest the concept of "neutral time" and the safety signal hypothesis developed by Martin Seligman may help to explain the anxiety that can accompany the time immediately after treatment ends. Illustrated by a case study, they hypothesize that patients feel anxious and alone when they no longer have the regular supportive contact with their health care providers, and due to the nature of cancer also have no safety signal to indicate that the disease will not return. Based on his personal and clinical experiences, Mullan (1985) described the extended survival period as beginning when the person "...has terminated the basic, rigorous course of treatment and enters a phase of watchful waiting..." (p. 272). According to Mullan this is a period characterized by physical limitations and a fear of recurrence; an unpredictable time when the diminishing support of health care professionals leaves a void for many cancer patients. Despite the acceptance of these beliefs, only a few researchers have identified themes related to end of treatment issues in the breast cancer population, and only one article was found that specifically studied that particular period of time in the cancer journey.

In Pelusi's study described earlier (1997), she identified nine theme categories which were developed into an essential structure of the experience of surviving breast cancer. Within the theme of abandonment, women described feeling abandoned by their health care team: "They were there all the time for me during the treatment, but once it was over they
gave me no direction on where to go from here or what it would even be like..." (p. 1345).
Health care professionals were considered an important source of support and security during treatment, but criticized for not offering the necessary guidance to prepare survivors for the future (Pelusi). The women in the study also experienced a sense of abandonment of their life prior to the cancer experience. This was further described as not being able to return to what had been their "normal" life pre-cancer, even though others expected it, because the cancer had taken it away. "Normal" was now something different than what they had previously known. Because the women in this study were all a minimum of 2 years post-treatment, the initial post-treatment period descriptions were based on their recollections.

The completion of treatment was found to be a particularly stressful time and a source of psychological distress by Ferrell et al., (1998a), in their descriptive study evaluating the quality of life of twenty-one breast cancer survivors. Some of the main issues of concern that the women in the study identified that arose at that particular point in their journey with cancer included: uncertainty, fear of recurrence, and physical changes related to cancer treatment (Ferrell et al., 1997, 1998a).

A study by Ward, Viergutz, Tormey, deMuth and Paulen (1992) was designed to further explore whether women with breast cancer experience psychological distress specifically at the completion of adjuvant treatment, and if so how is it manifested and what factors might predict it. Thirty-eight women with breast cancer were assessed on the first day of the first chemotherapy cycle, then one week and 6 months after completion of chemotherapy. Severity of psychological distress was assessed with the Center for Epidemiologic Studies Depression Scale (CESD) and a specific question asking the women if they felt a safety net had been lost when treatment was over. Other instruments were used to
identify particular problems after treatment was completed, the patient's perceived illness timeline and efficacy of treatment, and the number and severity of side effects experienced during the last cycle chemotherapy. Only the CESD and the Side Effects Checklists had established validity.

Results indicated that of the 38 participants, only 11 (29%) stated they felt as though a safety net had been lost when their chemotherapy treatment ended. Since 66% of the women went on to receive radiotherapy following chemotherapy, it would be useful to know whether those who answered yes to the safety net question were among the group not carrying on to further treatment. The CESD score at time 1 was determined to be a significant predictor of feeling that a safety net had been lost – in other words, those who felt a safety net had been lost had been more depressed since the beginning of treatment than those who did not. Regardless of the answer to the safety net question, 71% of the women reported nonphysical problems such as emotional distress, anxiety, preparing for the future, sadness, and depression at the completion of chemotherapy. The Problems Checklist was not completed again at time 3 (6 months post completion of chemotherapy) so it is unknown whether these issues continued to be problems for the women.

There is currently a small amount of evidence to support the idea that completing treatment for breast cancer can be a difficult and stressful time for women. Yet over the years there has been increasing recognition that a diagnosis of cancer affects not only the person being diagnosed, but also those who have significant relationships with that person – spouse, children, extended family, friends. Even in the literature on breast cancer survivorship that focuses on the individual experience, relationships and social support are consistently identified as being important components of quality of life in persons with cancer (Ferrans,
1994; Hassey Dow, Ferrell, Haberman & Eaton, 1999; Lee, 1997; Wyatt and Friedman, 1996). For instance, Ferrell et al. (1997), and Ferrell, Grant, Funk, Otis-Green & Garcia (1998b) found that the women’s greatest concern in the domain of social well-being was related to the impact of breast cancer on the family. This next section will focus on the state of the literature with regard to the effect of cancer on the family generally, but also looking for specific references to the post-treatment period.

**Cancer and the Family**

Despite the mounting evidence of the importance of family in the cancer survivor’s journey, there has not been a parallel growth in the amount of research related to the cancer experience from the family perspective. Over time, this lack of research has been identified and written about by several researchers (Kristjanson & Ashcroft, 1994; Lewis, Ellison & Woods, 1985; Northouse, 1984).

As early as 1984 Northouse published a review of the literature on the impact of cancer on the family organized around three phases of the cancer journey: the initial phase, the adaptation phase, and the terminal phase. General problem areas for families in each stage were identified based on the available empirical research and, where that was limited, clinical papers. In the adaptation phase of cancer the following three problem areas were identified: adjusting to changes in roles and lifestyles, meeting the needs of well family members, and living with uncertainty. Northouse concluded that there is a gap in research related to the impact of cancer in the family and that it is particularly large in the initial and adaptation phases of the cancer experience. In addition she noted that there is a need for studies that include both patient and family members concurrently in order to “provide information on how the reactions of one family member influence the reactions of other
family members, and how their varied coping strategies help or hinder one another's adjustment” (1984, p. 236).

Lewis, Ellison, and Woods (1985) echoed the concerns of Northouse in their exploration of the impact of breast cancer on the family, identifying very little empirical evidence documenting how families adapt to breast cancer after the initial diagnostic and treatment period. Drawing on clinical papers on breast cancer, cancer, coping with chronic illness, and the limited available empirical studies on families and breast cancer, they identified a set of conceptual themes that may characterize a family's adaptation to breast cancer: powerlessness, ambivalence, interdependence, uncertainty, role restructuring and resiliency. Preliminary results of their longitudinal study of 126 families whose mothers had nonmetastatic breast cancer identified children's perspectives of their mothers' illness, as well as the nature of demands of the illness experienced by the women and their spouses, reinforcing the view that how families adapt to breast cancer is complex and multi-dimensional.

Even as late as 1994 there was indication of an inadequate amount of family cancer research in specific areas. Kristjanson and Ashcroft (1994) reviewed approximately 200 clinical papers, research studies, and theoretical writings written between 1970 and 1991 that focus on the family's cancer experience. They divided the literature into four categories: developmental stage of the family, cancer illness trajectory, family responses to cancer, and health-care provider behaviours. Of particular relevance here is their conclusion regarding the literature in the cancer illness trajectory and family responses to cancer categories. They concluded that while there is evidence that the family's experience with the cancer illness changes over time, the majority of this research has focused on the diagnostic, acute and
terminal stages of cancer. They found no research that describes the concept of rehabilitation from a family perspective. While the literature on family responses to cancer was the largest category reviewed and documented a variety of family needs and experiences, Kristjanson and Ashcroft identified several areas that could benefit from further study – two of which were social support for families at various stages of the illness trajectory, and health changes in family members and the health of the family as a unit. Overall they concluded that further research to address questions concerning the family’s experience at different stages of the cancer illness trajectory is warranted, and that more attention must be paid to a variety of family structures, as well as social and cultural factors.

The call for increased research on families and cancer has been met with a number of studies addressing the impact of cancer specifically on the spousal or partner relationship. Germino, Fife and Funk (1995) studied 412 patients with various types of cancer and 175 partners. As part of a larger study on the adaptation of patients and spouses at four specific stages of the illness trajectory (time of diagnosis, period of first remission, first recurrence, and period of metastatic disease) they administered a variety of instruments measuring psychosocial adjustment, specific sources of social support, dyadic adjustment, coping strategies, emotional response, cognitive response, and personal control. Two major findings were that it became more difficult for partners to adjust to the stress of cancer as patients progressed through the illness trajectory (especially with the development of recurrent or metastatic disease), and that social support from all sources correlated significantly with the adjustment of partners. They also found that partners experienced greater anxiety and depression than patients, although the point in the illness trajectory in which this occurred was not reported.
Douglass (1997), in a smaller quantitative study with 73 couples with cancer examining the relationship between mutual spousal support and psychological health status of patients and spouses, found that each member of the marital dyad gave and received support but spouses perceived significantly less interpersonal support than did patients. Similarly, in a qualitative study of nine husbands of women diagnosed with early-stage breast cancer, Samms (1999) found that husbands continued to have unmet needs at the end of treatment and expressed a need for help in the recovery phase with regard to 'getting back to normal' and helping their wives regain their health. While none of these researchers included same-sex partners in their studies, their findings do suggest that significant others are affected by the diagnosis of and treatment of their spouse's cancer, and that there is a need for more family-focused care in oncology nursing.

But by focusing on spousal relationships the previous studies have ignored the fact that a family may be more than a couple, and often includes children. Yet, the number of studies focusing on the impact of cancer on the children in a family has been somewhat less than those examining the spousal relationship. Lewis and Hammond (1992) studied 111 child-rearing mothers with breast cancer on three occasions at four-month intervals using standardized measures of psychosocial adjustment in order to assess the impact of the mother's breast cancer on her family during rehabilitation and to determine the processes families use to adjust to the illness over time. The women averaged 27.4 months since diagnosis with a range of 1 to 9.5 months from last course of chemotherapy or radiation. Results indicated that a family's adjustment to the mother's breast cancer changes over time in two areas: there are decreased illness-related demands, and the marriage relationship improves. However, measurements of the mother's level of depressive mood, the family's
coping behaviour, and the total household's level of psychosocial functioning remained stable over the three time periods studied despite fewer illness-related demands and improved marriage quality. Reporting on data obtained from 40 of these same families (mothers with breast cancer and their partners) with school-age children aged 6-12 years only at Time 1, Lewis, Hammond and Woods (1993) confirmed the relationship between illness demands, depressed mood and marital quality. They also suggest that the mother's level of marital adjustment directly affected the quality of relationship with her child but that for the partner it was the family’s overall coping that impacted on his relationship with the child. In addition, they found that family coping behaviour significantly affected the psychosocial functioning in the child. It is important to note that only the parents participated in both of these studies and therefore childrens’ functioning is based on the perspective of the parents rather than a direct assessment of the children.

In a report on a qualitative study designed to explore the experience of being a mother with cancer, Fitch et al. (1999) interviewed 47 mothers with a variety of different types of cancer and children ranging from 4 – 18 years of age. All of these mothers were described as living with disease, but it was not clear how long from diagnosis or treatment they were, or even if they were still undergoing treatment. Preliminary results indicated that the impact of the cancer led to changes in roles and relationships for the women, which in turn created demands in the family unit. Mothers described tensions around not giving enough to their children and not living up to their usual way of caring for their families but this was strictly the perspective of the mothers, not of the children or families.

While all of the described research is useful in understanding the cancer experience for individual family members and generally supports the idea of cancer as a family affair, it
does not take into account the family as a unit and therefore it does not present a truly holistic picture of the impact of cancer on the family. As well, it ignores the idea that ‘family’ can no longer be defined in the traditional manner of ‘parents and children’. While they are few in number, a few researchers have addressed this issue with studies involving a variety of family members together.

Thorne (1985) explored the experience of the “ordinary cancer family” in a qualitative study where family was “defined by the patient as whomever he or she considered to be family” (p.286). Thus the participants included a variety of spouses, adult children, and other kinfolk. Families were interviewed as a group, reflecting the underlying assumption that cancer has an impact on family life as a whole, rather than simply on the lives of individual family members. She found that these families tended to focus on the normalcy in their lives rather than the cancer. The strategies use by the families to retain normalcy varied widely – what made the strategies successful were not the strategies themselves but rather how closely they conformed to each family’s philosophy and belief system. These findings suggest that families do indeed have a shared perspective of their experience of cancer. As well, what works best for any given family is probably best determined by the family itself.

Using a definition of family similar to Thorne’s, Green (1986) employed both quantitative and qualitative measures to investigate family behaviour with regard to changes in responsibility distribution and use of support systems during the first year of living with cancer. The sample consisted of a variety of partnered and non-partnered families with and without children living at home where the adult female had been diagnosed and treated for breast cancer. Results reflected a collective family perspective and showed that in all families prior to diagnosis the adult female member later diagnosed with cancer held more
total responsibility for family activities than any other family member or support network members. Subsequent to diagnosis, during treatment and recovery, there was a redistribution of some responsibility to other family members, relatives and friends although by the time of the second interview 6-12 months later the distribution of workload had returned to prediagnostic patterns. This confirms that the initial diagnosis of and treatment for cancer in a family is disruptive to the family as a whole, yet it also suggests that families themselves know how they can best cope with this disruption.

More recently, Hilton (1993, 1996) studied the experience of women with early-stage breast cancer and their families in the first year following diagnosis. As with the two studies described earlier, families were a mix of partnered and non-partnered, with and without children. Families were interviewed five times from time of diagnosis to twelve months post-diagnosis. Initially, three themes were identified around issues, problems, and challenges and their impact on family members: taking care of the cancer, family patterns, managing other issues. While the initial diagnosis and treatment was identified as the time of most difficulties, issues and concerns continued to arise for the families throughout the first year. For example, in the ‘taking care of the cancer’ category, the two subcategories of uncertainty, and tests, treatments and accompanying physical and psychological effects continued to be an issue to some extent for most families at one year after surgery/diagnosis. Next, Hilton (1996) described the process of normalization as an important coping process for these families over the first year. It is important to note that what constituted normal, and the importance of being normal, were different for different families. Yet in all families, cancer produced at least a temporary change from a family’s normal state, requiring varying degrees of shift and disruption in family life. While many families experienced a minimal
disruption and were able to return to prior normal patterns soon after treatment ended, other families experienced greater degrees of physical and emotional disruption which continued beyond the end of treatment, and even beyond the first year for some families. A variety of strategies such as maintaining or returning to usual patterns, minimizing disruptiveness, and reframing negatives to be more positive were used to get back to normal. These were influenced by factors such as the family experience with illness, flexibility and adaptability of the family, and congruency of family member views. Hilton’s work illustrates that the effect of a cancer diagnosis and treatment can continue to influence family patterns and family life even after treatment is finished. In addition, it underscores the complexity of families, and thus the importance of whole family research in studying the impact of cancer on the family.

While the amount of research related to the impact of cancer on the family in the post-treatment phase is limited, there is enough to suggest that it is worth looking at more specifically. In addition, there is also enough evidence to support the underlying assumption that cancer has an impact on family life as a whole, rather than simply on the lives of individual family members, and therefore research using a broad definition of family and involving family members as a group is warranted.

**Conclusion**

In this chapter, two separate but related bodies of literature have been reviewed in order to understand the current state of knowledge with regard to issues for women and their families in the initial period following the completion of treatment for breast cancer. From the breast cancer survivorship literature it is clear that women continue to experience concerns related to uncertainty and ongoing physical symptoms. They often liken their
cancer experience to a journey with various phases or stages, and may identify some positive outcomes related to it. In addition, there is suggestion that there may be some specific issues of abandonment and fear of recurrence immediately after treatment is finished. It is less clear how these various concerns, phases and outcomes manifest themselves in daily life, particularly in the period of recovery immediately following the initial treatment.

From the family cancer literature, it is obvious that diagnosis and treatment for cancer in one family members affects all family members individually as well as family life as a whole, and that as for the individual patient diagnosed with the disease, this impact can continue even after treatment is finished. However, specific research involving the family as a unit, as well as studies focusing on the post-treatment experience or recovery/rehabilitation phase for families, are limited.

A qualitative research project studying women and their families as a unit during the immediate post-treatment period will shed light on this particular experience and complement and add to the existing knowledge related to survivorship issues for families with breast cancer.
CHAPTER 3: RESEARCH DESIGN

The choice of research design or method for a study is based on what is most appropriate to address the goal of the research and answer the research question. A qualitative approach was chosen for this study for a variety of reasons. Qualitative methods are generally considered useful when little is known about the subject of interest – although there is a reasonably good-sized body of knowledge related to cancer survivorship in general, there is a relative lack of information specific to what women with a breast cancer diagnosis and their families experience during the immediate post-treatment period. Qualitative methods facilitate the exploration of a subject from an insider’s point of view or emic perspective, based on the belief that those who have experienced a particular phenomenon or issue have the best ‘take’ on the experience. In this study the perspective of the women and their families who have experienced the post-treatment period was sought for that very reason. Furthermore, qualitative research is usually conducted in a naturalistic setting with little if any attempt to control all the variables, resulting in an exploration of all facets of the problem. This is important in a study such as the one being described here where there are likely to be a variety of issues arising for women and their families within the context of completing adjuvant therapy.

Within the qualitative arena there are a variety of traditional methods that have been used in nursing research. The most common are grounded theory, ethnography and phenomenology – yet the roots of these methods, their philosophical underpinnings, are in disciplines other than nursing. For this reason, Thorne, Kirkham, & MacDonald-Eames (1997) suggest that strict adherence to these traditional methods does not always meet the needs of nursing, and that it is time to explore noncategorical research approaches that reflect
the philosophical and theoretical foundations of our own profession. The approach they propose, interpretive description, was chosen as the method for this study because it can "contribute directly to the understanding of how people experience their health and illness and what nursing can do to make a difference" (Thorne et al., p.173). Furthermore, it follows the general principles of qualitative research for analytic frameworks, sample selection, data sources, data analysis, and rigor and thus ensures the means to create credible nursing research.

Selection of Participants

In this study, sampling was guided by the theoretical or purposive approach commonly used in qualitative research. Thorne et al. indicate that "theoretical sampling makes a useful contribution to the design of an interpretive description for the purposes of nursing knowledge development" (1997, p.173). In order to facilitate an appropriate sample, participants are selected according to their knowledge of the phenomenon being studied and their ability to communicate about it (Morse, 1991; Morse & Field, 1995). As the study progresses, the researcher may make deliberate sample decisions based on the need to obtain maximal variation on the themes identified during analysis, or to explore one or more of the themes in greater depth (Morse, 1991; Sandelowski, 1995a; Thorne et al., 1997).

In this study the family system is the unit of analysis, and therefore it was decided that participants would be groups of two or more people who define themselves as family according to the attributes of strong emotional ties and a sense of belonging and future obligation. Further criteria for participation included:
1. one female family member (the identified patient) has completed adjuvant chemotherapy and/or radiation therapy for breast cancer not less than 1 month or more than 6 months prior to the first interview.

2. identified family members are aware of the cancer diagnosis.

3. patient and identified family members understand and speak English fluently.

4. patient and identified family members live in the Lower Mainland.

Members of the Fraser Valley Cancer Centre health care team caring for women diagnosed with breast cancer were asked to identify possible participants from their registered patient list, according to the above criteria. The clinic nurse or oncologist approached the patient (and family if present) first and briefly explained the nature of the study. If the patient/family was willing, the researcher was introduced at that time. The researcher then provided the possible participants with information about the study, answered any questions, and requested participation. Patients who attended clinic alone were encouraged to take the consent form and information letter (see Appendix A) with them in order to discuss it with their family. The researcher then contacted the family by telephone to determine agreement to participate. Once families agreed to participate in the study, appointments were made for the first interview in either the home or the clinic depending on the family’s preference.

In research involving families, there is a possibility that family members may be reluctant to participate in interviews, or that women may have difficulty identifying family members to participate. The definition of family as it is used in this study was explained to possible participants, and the researcher offered to speak individually with any family member to address questions or concerns about the research process. It is possible that
participation may enhance understanding between family members about the impact of completing adjuvant treatment for breast cancer, and because family members often wish to learn more about each other’s needs (Moriarty, 1990, as cited in Moriarty & Cotroneo, 1993), this was explained as a potential benefit of the research process. Informed consent of each family member participating was obtained.

In order to ensure an adequate sample, the sufficiency and quality of the data is considered, rather than the size of the sample (Morse, 1991; Morse & Field, 1995). Sampling is complete when there is enough data to develop a full and rich understanding of the experience – that is, there are no gaps, no new themes are emerging, and identified themes and all variations have been fully explored and confirmed (Morse, 1991; Morse & Field, 1995; Sandelowski, 1995a).

The final sample consisted of eleven family dyads, each composed of a woman who had been diagnosed with and treated for breast cancer and one other person she considered to be ‘family’. Although the researcher had hoped to have some family groups of more than two people, this turned out to be difficult logistically for many of the families. The family member was a daughter in two cases, a female best friend in one case, and a male spouse/partner in the remaining eight cases. Participants ranged in age from 7 to 83 years, with a median age of 50 years. Amongst the families, the time that had elapsed between the woman’s last day of treatment and the research interview varied from 4 to 21 weeks, with the majority being 10 weeks or less post-treatment. Of the eleven diagnosed women eight had undergone lumpectomy and three had had a mastectomy, one with immediate reconstruction. Five families then went on to experience both chemotherapy and radiation treatment, five experienced radiation alone, and one experienced chemotherapy alone.
**Data Collection**

Data was collected through an in-depth interview with each of the family dyads. Interviews were audiotaped and transcribed. The interviews were guided by several open-ended questions, examples of which are shown in Appendix B. Open-ended questions are appropriate in this type of qualitative research where it is important that participants speak of issues that are of concern to them rather than what may be considered important by the researcher. However, in later interviews questions may be altered to further explore issues that have been identified frequently in the data from initial interviews. Revised trigger questions used in later interviews are shown in Appendix C. While participants were informed that second interviews may be conducted with all or selected families to verify or expand on initial data, or to verify emerging analysis of the data, time constraints did not allow for this.

Because arranging interview times that accommodate schedules of all family members participating in an interview can be difficult, the researcher was prepared to conduct interviews in the evening and on weekends. The family’s home was suggested as the location of the interview as it offers both convenience and privacy for families (Moriarty & Cotroneo, 1993), although if the family preferred to meet elsewhere interview space was arranged at the Fraser Valley Cancer Centre. Only one family chose this latter option.

Conducting interviews with groups or families has certain challenges and requires specific skills of the interviewer. Two of the most important skills identified by Figley and Nelson (1989, as cited in Wright & Leahey, 1994) are basic interviewing skills and the ability to establish rapport. In a family interview, rapport is facilitated by the nurse assuming a position of neutrality or curiosity, where she is allied with no family member and every
family member at the same time (Wright and Leahey, 1994). In addition, the nurse should provide structure and actively involve each member of the family in the interview. Moriarty & Cotroneo (1993) recommend the following qualifications for family researchers: 1) understanding of family functioning theories, 2) strong family interviewing skills, and 3) skill in referring families for further help when necessary. As an experienced oncology nurse the researcher is familiar with family nursing theories and in conducting therapeutic interviews with people with cancer and their families. While the purpose of a research interview is different than in a therapeutic interview, the application of basic family interviewing skills were similar. The consultant on the researcher’s thesis committee, an experienced family nurse and researcher, was available to provide advice and support to the researcher regarding family interviewing.

Detailed and accurate field notes can be an important supplemental source of data, and are necessary for a successful qualitative study (Morse & Field, 1995). In this study, field notes were written after every interview and any other contact with participants in order to place the interaction in context. Observations and general impressions about physical setting, nonverbal communication, or other nuances and subtleties of the interaction were recorded.

**Data Analysis**

In qualitative research, data analysis take place concurrently with data collection, and is an inductive rather than a deductive process. Interpretive description requires the researcher “to come to know individual cases intimately, abstract relevant common themes from within these individual cases, and produce a species of knowledge that will itself be applied back to individual cases” (Thorne et al., 1997). A variety of analytic techniques and
processes were employed in order to achieve the desired results. These included repeated immersion in the data interspersed with strategic immersion in the field and constant comparison of data to emerging themes and patterns in order to get a sense of the whole, as well as to discern commonalities versus eccentricities (Thorne et al.). Rather than a line by line sorting and coding of data which can result in a proliferation of words that are contextually and analytically empty (Sandelowski, 1995b), analysis of the data in this study focused on what Morse & Field (1995) describe as the four sequential processes integral to qualitative research: comprehending, synthesizing, theorizing and recontextualizing.

Since this study takes a broad view of the family and who is considered family, the sample was heterogeneous – a variety of relationships existed amongst the participants. It is recognized that this added a dimension of complexity when analyzing the data, yet using a narrow definition of family would have been contrary to the philosophy of family nursing embraced by the researcher. Northouse (1995) notes that in order to provide a comprehensive view of the family “some attempt must be made to include at least the family member with the illness and one other family member to examine the mutual effect that they may have on one another” (p.141).

**Ethical Considerations**

Ethical approval to conduct this study was obtained from the University of British Columbia Behavioural Sciences Screening Committee for Research and Other Studies Involving Human Subjects. Approval was also received from the Regional Operations/Cancer Care Leader of the Fraser Valley Cancer Centre.

In order to protect potential participants from coercion, initial contact with families meeting the study criteria was made by the clinic nurse or oncologist. Potential participants
were provided with written and verbal information about the purpose and process of the study, and given an opportunity to ask questions of the researcher. The researcher spoke directly with each family member in order to minimize the risk of individual family members pressuring other members to participate. They were advised that participation was entirely voluntary, and that non-participation would in no way affect the care or treatment they receive in the cancer centre. In addition, participants were informed that they could withdraw from the study at any time, refuse to answer any question during the interviews, listen to/read their own tape/transcript, and have any responses deleted from the tapes or transcripts of the interview if they so requested. Voluntary consent was obtained from each family member individually by asking them to sign a consent form at the beginning of the first interview.

Participant anonymity and confidentiality was maintained by removing identifying information from the transcripts, and keeping audiotapes, transcripts, and field notes in a locked cupboard. Access to data was limited to the researcher and her thesis committee, and the audiotapes will be erased upon approval of the final report. When study results are published, every effort will be taken to ensure that no information is included that could identify a particular participant. Participating families will be provided with a summary of the study results.

Every attempt was made to ensure participants' safety during the interviews. If any participant appeared upset or overly tired, the researcher offered to stop the interview. During two interviews, participants did become upset but only in one did the participant elect to have the interview stopped. After a short break the participant voluntarily opted to continue with the interview. Participants were also informed that a referral to the FVCC
Patient and Family Counseling program could be made at any time should they wish to explore issues further or seek intervention. While no participants requested a specific referral, one person indicated they might seek counseling on their own and accepted the phone number of the FVCC Patient and Family Counseling department.

**Rigor**

The need for rigor, or trustworthiness, in qualitative research is critical if there is to be confidence in the findings. In particular, Thorne et al. believe that “attention to rigor in the process and the reporting of that process is critical to an interpretive description” (1997, p.175). The four criteria for trustworthiness identified by Lincoln and Guba (as cited in Morse & Field, 1995) are: credibility, applicability (auditability), consistency (fittingness), and confirmability. In this study, a variety of strategies were employed to operationalize the trustworthiness criteria.

The researcher documented the research process and recorded decisions and insights during data collection and analysis in order to create an audit trail. A reflective journal was kept where the researcher documented her own thoughts, feelings, or personal or professional beliefs and values which may have influenced or biased the research process or findings. Theoretical sampling ensured representativeness of the data, and sampling continued until no new themes emerged from the data in order to ensure completeness. All interviews were conducted face to face by the same researcher both to ensure consistency in interviewing and facilitate rapport with participants. While raw data can, when necessary, be validated and clarified directly with the participant(s) who was the source of the data, this strategy is insufficient as a credibility check (Thorne et al., 1995). Instead, draft descriptions and beginning conceptualizations created from data representing the entire sample were brought
back to a few participants for their critical review. This allowed the researcher ample opportunity to ensure that the interpretations were grounded in the data.

**Summary**

Interpretive description was chosen as the research design for this study because it is in keeping with the nature of the research question and “represents a credible means by which to develop clinical knowledge with significant nursing science applications” (Thorne et al., 1997, p.173). Participants were selected according to specific criteria and the principle of theoretical sampling. Data collection and analysis proceeded concurrently, with the intent to both know individual cases intimately as well as extract common themes. A number of strategies were employed to ensure trustworthiness of the findings, and ethical issues were appropriately addressed to maximize safety for the participants.
CHAPTER 4: PRESENTATION OF FINDINGS

In this chapter the findings from the interviews with eleven family dyads are presented. To help orient the reader, the chapter begins with an explanation of family perspective in the context of this study. The findings are then organized within the identified central theme of Moving On. Three different components of Moving On are discussed within the categories of: (a) making sense of the experience, (b) managing the threat of recurrence and (c) rejoining the world of normal. In the final section, variations of how families experienced Moving On are explored and factors which appear to influence the quality and ease of the Moving On experience are discussed.

**Shared Perspective**

Given the definition of family as any group of two or more persons with the attributes of strong emotional ties, a sense of belonging and future obligation, each dyad that was interviewed was considered a family and will be referred to as such in the presentation and discussion of the findings. Because the interviews were conducted with the patient and another family member simultaneously there was opportunity for the individuals to hear and reflect upon each other's comments, continually shaping and modifying the description of the experience so that what emerged in each interview was a shared perspective on the first six months following completion of breast cancer treatment. However, it is important to recognize that the members of the dyad were not being interviewed as representatives of a larger family group, nor was the dyad alone considered the definitive family in any one case. In this sense the findings do not describe the total family experience. In reality, family can never be known in totality because of the complex and evolving nature of human experience (Hartrick & Lindsay, 1995). According to a systems theory a family is both a part and a
whole, a system made up of subsystems as well a subsystem of a larger system. The dyads were thus also a part and a whole. According to Hartrick and Lindsay, “family is a relational experience drawn forth through dialogical relationships between people” (p. 154). The findings in this study reflect the meanings, beliefs and experiences that are consensually shared by two individuals that consider themselves to be ‘family’.

Moving On

The findings show that the first six months after the completion of adjuvant treatment is a time of transition that can be summarized as Moving On, a phrase used by several families in describing this period. One participant summed it up this way:

I don’t think you can ever go back, I mean we went through the experience, I have breast cancer, we went through the experience, we went through the treatment, I don’t think you can ever forget about it but I think that you can and this is the other thing, this is the second chance to life for me so I’m going to build it all over again and I think we can move forward, I really think so...looking at the big picture I think that we can move on and resume our lives.

It is a time when the women and families in this study focused on the need and desire to move past the cancer experience, but also needed to acknowledge the changes that had resulted and incorporate them into their life. This experience has three components: (a) making sense of the experience, (b) managing the threat of recurrence and (c) rejoining the world of normal. This experience is not linear in that the components do not seem to be experienced in any particular order. Instead, the phenomena to be described occur concurrently, intertwining and overlapping each other.

Making Sense of the Experience

The first component of Moving On that will be discussed is Making Sense of the Experience. Wanting to understand why something happens seems to be inherent in human nature, and this was evident in the families in this study. Some families wondered what
caused the cancer, speculating on specific things that they believed could have triggered its
development. Participants also addressed the ‘why’ question by looking for reasons that the
cancer had come into their family – what was its purpose and how have they benefited or not
from the experience? These ideas are reflected in the sub-themes: (a) speculating on
reasons, and (b) identifying new attitudes and perspectives.

Speculating on reasons

Although they recognized that for the most part it was pure speculation and probably
would never really be known for sure, participants were curious about what might have
caused the cancer to develop. All speculated at least a little on possible reasons, and for a
couple of families it was a major topic of discussion. Perhaps because there really are no
definitive answers, there was little disagreement or dispute between the members of each
dyad regarding possible reasons behind the cancer. Some families suspected fairly concrete
causes for why the cancer might have developed, such as family history, environment, or
stress.

It’s a total stress related thing that your body cannot cope with a lot that gets thrown
at you. But, you know, then everything eventually sorts itself out and you would
have hoped that you’d come out of it but obviously sometimes you’ve taken one blow
too many and that may have been the cause.

Other families found less tangible reasons for the appearance of cancer in their life. In one
family, the woman diagnosed with the cancer had had several serious illnesses some years
earlier – she suspected that getting cancer was a way for them to test “the medical system and
the family, keep them all on their toes...”. Three of the diagnosed women talked about their
belief that the cancer occurred in order to give them “a second chance”. In no case were
these musings about reason a source of any significant frustration, nor were they fuelled by
frustration or anger with the diagnosis. Instead, they appeared to be a way for families to try to bring some order and logic to an otherwise chaotic event.

**Identifying new attitudes and perspectives**

Most families were able to identify specific outcomes of the diagnosis and treatment that helped them to make sense of the experience and give it meaning. The most common new perspective identified was an awareness of the preciousness of life. Some families talked about suddenly realizing that life was short, or could be shorter than they thought.

I never thought of my mortality before really, never really, I just assumed that I’m going to live till, you know, 75 or whatever but now...I mean S. was telling me one day about somebody’s father who passed away...that he was 63...well that’s another 16 years for me.

Everybody thinks they’re immortal and it actually makes you focus in on how short a time everybody has here really. And it may be twenty years, it may be thirty years but it’s still a short time and that’s something I’ve never really had in my vision before.

For most families this awareness of mortality translated into a resolve to take a more relaxed approach to life and “not sweat the small stuff”, a phrase used by both members of several family dyads. Some people said this attitude was already part of who they were but that the cancer experience had strengthened it. Consistent with being conscious of the preciousness of life, families expressed a new appreciation of each day and a desire not to waste it.

Make time or go away or do something or whatever, there’s never a better time than now because you don’t know what tomorrow is going to bring...

There was also a sense of uncertainty about the future, and therefore a need to act now was common.

Well now we don’t wait, if you want something, you do it, procrastination is gone...you don’t know what, where you’re gonna be in ten years time...

Not procrastinating meant not only living more in the moment, but also paying more attention to their own needs. One family bought a new car, others talked about speaking up
more readily in situations where they felt strongly about something. People had become less concerned about the small stuff, and more concerned about spending their energy (financial, emotional, physical) on the important things in their lives. Although this was mostly true of both dyad members, in a few cases it was a much more significant attitude shift for the diagnosed women. These women described coming to the understanding that they had ignored their own needs for years and now realized that they could do that no longer – that their own needs were as important as others. Situations where one dyad member’s priorities shifted considerably in comparison with the other’s sometimes resulted in discord or friction in the relationship which could make Moving On more difficult. This will be discussed further in a later section.

In addition to this attitude of putting themselves first, many families also talked about becoming more tolerant towards others. Families in general talked about increased compassion towards others who for whatever reason were less fortunate than themselves. One family indicated they thought they were “gentler people now”. One man took this a step further, indicating his intention to volunteer in the cancer centre in the future as a way of “giving back”. The significant other in the majority of dyads spoke about trying to be more loving or attentive towards their wife/mother/friend who had been diagnosed with the cancer.

I’m nicer to her, I think about the little things more.

...because I don’t want her to, you know, I don’t want to lose her so I’m giving her extra love, because I love her.

One family talked about how they were in touch more often with extended family members and had grown closer to them through the cancer experience.

All families believed that these new ideas or perspectives on life, the reinforcements of already held values, were in fact ‘good’ or positive outcomes that gave the experience
meaning. Even though changed perspectives sometimes contributed to tension or stress within a family, there was a still a sense from all dyad members that because they had learned and grown from it, the experience with cancer was not in vain. Finding meaning or reason in the experience helped to facilitate the Moving On process.

Managing the Threat of Recurrence

A second component of Moving On that emerged from the data is managing the threat of recurrence. During the post-treatment period, thinking about the possibility of the cancer coming back was inevitable to some degree and learning how to deal with those thoughts and the uncertainty they provoked was a major part of managing the threat of cancer returning and, ultimately, moving on. Families also took steps towards regaining and maintaining their health, hoping to influence the risk of recurrence or another cancer, by instituting a variety of lifestyle changes. Components of managing the threat of recurrence are: (a) thinking about it, (b) having a plan for follow-up, and (c) regaining and maintaining health.

Thinking about it

All families in the study thought about the cancer, however the degree to which these thoughts occupied their minds, and the specific nature of these thoughts, varied. For most families thoughts of the cancer were always there in some form or another.

It's like a drug, I guess, in a way. Once you’re, once you are an addict, they say you’re an addict for life, well once you’re introduced to the cancer, uh, that thought never goes out of my mind. I mean I have no idea whether it’s going to come back or reoccur or it may never...but it may, but that thought is always there, what if...

However, thinking about the cancer all the time did not mean that participants were actively or constantly dwelling on the subject. In fact, it was common for participants to describe the cancer as being “in the back of their minds”:
...it’s gone not totally out of my mind but right to the back of it and it’s not, is not forefront in my thinking, you know.

Even in a few families that indicated they thought about the cancer only occasionally, there was still a sense of the thoughts being there under the surface, so that it was inevitable that they would arise from time to time. In some cases, the diagnosed woman thought less about it than the other member of the dyad. A few denied worrying about the cancer coming back and claimed not to think about it at all. However, when the women were questioned further they admitted that it might cross their mind occasionally, often prompted by a comment or particular situation.

Families talked about how thinking of the cancer, bringing those thoughts into the front of the mind, was often triggered by a specific incident or interaction. One woman talked about when she first went back to the dentist post-treatment and how in filling out the health questionnaire she actually had to check off that she had had cancer. Another family was reminded of the cancer experience when they had their lawn sprayed for weeds and began to wonder about the effects of the pesticide.

The specific content of the thoughts varied - sometimes people wondered about whether the cancer was gone, other times about whether it might recur, and sometimes they were just vague thoughts about the cancer in general. The ever present risk of recurrence was described with graphic metaphors:

I mean you know that it could happen. It’s like somebody is holding this thing about you and you don’t know whether they’re going to drop it or when or what...in the back of my mind I always think about that, or what if...

Well we’re always worrying about it...its like you’ve got somebody in the closet that you don’t know when he’s going to come out...in the back of your mind, you’re always thinking well, you know, you’re never a hundred percent sure you whipped it because...there are no guarantees.
Families found that the more they dwelt on thoughts of the cancer the more difficult this transition period was for them, and so in finding other ways to think about it they facilitated Moving On. Therefore, thinking about the cancer was often actually hoping, wishing or affirming that the cancer was gone and would not return. As one participant said, “I think it’s gone, it’s not coming back.” Many of the dyads also talked about the importance of “positive thinking”:

...another lady the other day, she came forward and said, “oh I had breast cancer seventeen years.” That’s what I try to keep in my mind, you know, 10 years, 17 years. To me that’s positive reinforcement.

These ‘positive’ thoughts tended to be deliberate, in contrast with the unbidden nature of more worrying thoughts about recurrence, and they facilitated Moving On.

In addition to replacing ‘negative’ thoughts with positive ones, participants also coped with the thoughts of cancer by keeping themselves busy or using techniques such as meditation in order to clear their minds, or avoid thinking about the cancer.

...families they can’t just sit in the house, that’s the one thing you don’t do, you have to get physical by a sport or walking or going to, you need more distractions and never sit at home alone...maybe later but right now to sit at home alone it’s, it’s very hard because then is when your mind starts playing tricks on you.

Having a plan for follow-up

Given the fear of recurrence evidenced in thinking about the cancer, families needed to know that a plan was in place to monitor the possible return of the cancer. The end of treatment was met with ambivalence; families were relieved not to be returning to the cancer centre too soon, yet they also felt vulnerable without some kind of monitoring. Families expected follow-up to include: regular check-ups with a doctor, regular mammography and/or other tests, and the opportunity/ability to contact someone with questions and concerns if necessary.
All families had some understanding of what their particular follow-up would involve, although not always in detail. Most knew when the next doctor’s appointment and the next mammogram would be but were sometimes not sure exactly what would happen after that. Many had questions about how follow-up “should” go. While most families denied having specific expectations for follow-up appointments, many were surprised that check-ups and tests were not more frequent. This surprise was more often directly expressed by the family member other than the patient. This may have been because the woman with the cancer diagnosis had often already determined a strategy to address any gaps. The main strategy women expressed was to take responsibility for themselves:

I think you have to take some responsibility for yourself, I mean you do have to say, okay, when, how many do I have, when do I have and make the appointments to start the ball rolling.

Many women said that if they felt they needed to see the doctor or have a mammogram at a time other than was scheduled then they would phone and request that. Women who were confident that they could contact the right person and get advice or an appointment if necessary were ultimately satisfied with the follow-up plan which, in turn, facilitated the other person’s acceptance of it, even if the frequency of appointments and tests was not quite what they expected.

Having a plan for follow-up then was not just about follow-up appointments. For all the families, the most important factor for satisfactory follow-up was having someone to ask questions of, someone who could be trusted, who understood and was familiar with the patient and family and what they had just experienced, and who could be readily contacted. Some people felt comfortable that their family doctor met this criteria, but others did not:
That’s very important just to have somebody that you can go and ask. I mean I know you have the family doctor but, hey, the one that was in charge of your treatment, let’s face it, was the cancer agency so...

Those who believed that a contact at the cancer centre was preferable were not always sure who they would call there. Some were confident that they could call their oncologist anytime, but others who had not always been happy with interactions with the oncologist during treatment were reluctant and felt left with little support in between appointments.

“It’s a period of time when people are left, you know, women are left with very, very little support and I know treatment is over but I think it should be a little bit more, more support, more, um, still keeping in touch other than, you know, come back and see me in four months.”

The families that felt this sense of abandonment were less confident about the follow-up and monitoring of recurrence, and thus had more difficulty in Moving On compared to those who felt more secure in the plan and their ability to get any answers or actions they might need.

All families found the research interview to be a useful follow-up, stating that they found it valuable to talk about their experience. Some of the partners felt they had not been as involved with the treatment experience as they might have been and so welcomed the opportunity to feel more a part of it. Both members of the dyad found it helpful to hear the other member’s thoughts as well as to voice their own. One man reflected that it was quite constructive to talk about it and in retrospect he wished he had had some counseling.

Regaining and maintaining health

The third way that families managed the threat of recurrence during the post-treatment period was to employ strategies that would help them regain and maintain health. These strategies considered health in a holistic manner, addressing psychosocial, emotional and physical issues. They were targeted to or affected not only the woman who had been diagnosed with the cancer, but also other family members and friends.
The most common and obvious strategy that families employed was to change lifestyle habits. People were eating more fruits and vegetables, trying to exercise more, and decreasing smoking. Families talked about becoming more aware of their bodies and how what they did to them could affect their health.

...now I’m taking all kinds of stuff, I’m buying organic fruits and vegetables where I can and I won’t be eating any meat either you know, well I shouldn’t say ever but very rarely will I eat anything that’s not organic. I don’t want to put any of those chemicals into my body...maybe one of those things are triggers for me and so I’m going to try and stay away from them and try and eat as healthy as I can and I’ve got to get myself back to the gym because that’s part of what I need to do.

I quit smoking the day after F. was diagnosed. Subconsciously I guess I was thinking it’s better health-wise.

Most of these changes were personal decisions made by the individual, as opposed to decisions made collaboratively by the family as a group. Food changes were a bit different however in that if the person who changed their food habits was the one in the family most responsible for meals then other family members often ended up changing their eating habits by default.

In keeping with a definition of health that is holistic, families also incorporated behaviours geared towards regaining and maintaining psychological, emotional and social health. As noted in the section on Thinking About It, families believed it was very important to think positively and not dwell on thoughts of the cancer. To this end, meditation, keeping busy, and avoiding negative people were cited as useful strategies.

You learn to screen people...you don’t need the negative ones and eventually you learn to do it yourself and be strong enough to say, jeez, I’ve got to go...

Opinions about support groups were mixed – some women found them helpful while others did not – but all families agreed that social contact and support were necessary for
health. This involved spending time with family, getting together with friends, going to church or social clubs.

[talking about a girl’s weekend]...Well I think its just nice to have the camaraderie around you afterwards and just keep busy, I guess...that’s helping me bounce back too, that I’m, that gives me something to think about...

Families also found that they had become more vigilant with regard to their health, and were acting or planning to act more quickly on any concerns. Family members expressed a heightened awareness of the need to monitor their own health – for example, women family members became more conscientious about performing breast self-exam. For some of the women diagnosed with the cancer, this hyper vigilance became extreme:

I kind of felt like a bit of a hypochondriac [going to have lymph nodes checked]...I feel like I’m a bit paranoid and every little thing, I pop in there...I’m running in there thinking you’ve got to find it, I know its in my body, you know, find it...I’m scared to death its going to come back.

This vigilance included being more aware of the potential for illness related to various situations that would not have been a concern prior to the cancer experience. One woman was concerned that what she initially thought was a mosquito bite might be something more serious. Family members sometimes compounded this hyper vigilance by “nagging” at their mother/friend/partner about health.

It was also common for families to feel the need to offer advice about monitoring health to others such as friends and co-workers. This advice was specific to cancer.

I absolutely emphasize to people that I know – if you haven’t been, you better go [for a mammogram]

Although all families employed strategies to regain and maintain health, those who indicated they were having some difficulty with this transition period tended to talk more
emphatically about these strategies or to use them more diligently in order to facilitate health. Paying attention to health assisted the Moving On process.

Rejoining the World of Normal

The third component of Moving On is rejoining the world of normal. Rejoining the world of normal combines what many families talked about as ‘getting back to normal’ – the resumption of previous ways of being – with new ways of being that take into account the cancer experience. It is, in fact, reconfiguring a new normal. To do this, families needed to acknowledge that the diagnosis and treatment phases were over by subjectively evaluating and appraising how well they felt they had done during the several previous months, as well as by deliberately choosing to consider the cancer experience in the past tense. Families also had to recognize the effects and impact of diagnosis and treatment, then work around those in order to achieve the normalcy they desired. Rejoining the world of normal involves: (a) putting it behind, and (b) working around the effects of diagnosis and treatment.

Putting it behind

Two strategies emerged from the data as ways that families put the experience behind them. Families used both of these strategies at varying times. One strategy was to summarize or evaluate the diagnostic and treatment period. Sometimes this was done through an overall assessment of how the family had dealt with and come through the experience thus far. Families often concluded that it was not as bad as they had expected:

It really wasn’t the major upheaval that I would have expected it to be, right? ...it didn’t have a major disruption in our life.

Families sometimes described the diagnosed woman as being very sick with treatment yet followed with a statement that they had all gone through it very well. Whether the experience was ‘bad’ or ‘good’ was not based on physical illness itself. For one woman the
passage of time was a factor which allowed her to distance herself from the awful details of her treatment experience.

And I forget all of the details, horrible things that I went through and I think, oh well, you know, it wasn’t that bad.

Families also evaluated their situation by comparing it to other people or other significant events. This often brought them to the conclusion that the cancer experience was not the worst thing that had happened to them, or if it was the most significant event in their lives thus far, there were other things that could be worse.

I think it was actually worse with my brother. It was worse, that was worse than what I’ve gone through but then its different.

One dyad talked about how there are “a lot of worse illnesses than cancer”. For one couple dealing with their daughter’s ongoing drug addiction was far more trying than dealing with the cancer. For all families this evaluation was about not how they had done from a medical point of view – how sick they had been or what problems had occurred – but whether from their own point of view they believed they had handled the treatment period successfully and could consider it finished.

The second strategy that families used to “put it behind” was to make a conscious choice and effort to consider the cancer experience in the past tense. Participants talked about considering that they or their significant other was cured, about going on as if the cancer had been eradicated (despite their knowledge that it could recur). One woman stated “I like to say I have had, H-A-D, I had breast cancer.” Another family said “We’re finished that page, turn the page and we’re moving on now.” All dyads consistently expressed a need and desire to put the experience behind them:
...its time that we got going with things here and I think that at some point you have to put some of this stuff behind you, I think you’ll always live with it and you can’t forget it but you don’t want to live with it everyday.

Cancer is the topic...but it’s like everyday, I mean you get to a point where you get really tired of always talking about that, you know, you want to just...be normal.

At the same time many acknowledged that it was not an easy thing to do.

I knew it was going to be tough but it’s harder than you think, you know, it’s when you start living it day by day, it is a lot harder than you would have ever realized before you went into this time frame after treatment.

Lingering effects of the treatment such as weight gain, fatigue, hair loss, were reminders of what they had been through, and made them aware that putting it behind them, rejoining the world of normal, and ultimately moving on, was a process that would take time. In some families, both dyad members recognized this but in others, perhaps not surprisingly, it was more difficult for the woman who had been diagnosed with the cancer to put it behind them than it was for the other family member.

I just feel this sort of disappointment where all of a sudden he thinks that its come and gone and this is all past but he doesn’t see, realize that I do have these sort of thoughts [about having cancer]...then all of a sudden its done now and its sort of like you think your life should be back to normal but you know it doesn’t happen overnight.

**Working around the effects of diagnosis and treatment**

In addition to “putting it behind”, rejoining the world of normal required families to acknowledge that some things had changed as a result of the cancer diagnosis and treatment. These changes, whether temporary or permanent, affected the families’ abilities to do what they had done prior to the cancer diagnosis, effectively acting as barriers to rejoining the world of normal. In order to facilitate the moving on process, alternative or ‘new’ normal behaviours and activities had to be sought where previously normal ones were no longer always possible or appropriate.
Many of the treatment effects that families had to work around were physical. Fatigue in the diagnosed woman was the single most common side effect preventing them and their families from resuming usual activities. It was also the most distressing for women and family members alike, partly because it was unpredictable:

My energy goes in spurts, like one day I can just whiz through the house and some days I get tired half way through whatever I’m doing.

Other physical effects mentioned included sore arms (from chemotherapy or surgery), and menopausal symptoms such as hot flashes. These effects limited or changed the activities the diagnosed woman could do personally as well as requiring adjustment from the family. One way of adjusting was to do different activities:

We don’t do as much actively as we used to...we have to wait a little while...you kind of, you know make do with other activities.

It was also very common to do doing things more gradually, to a lesser degree, or in stages. One woman talked about reinvolving herself in a community group that she had previously been very active in. She chose to take a “light position” and indicated she would not be at every meeting as a way of slowly easing herself into what had been a normal part of life for her. Another dyad had to find ‘new’ vacation plans:

Well we were supposed to be going away for a couple, two or three weeks which is what we normally do...so [now it’s] a week and a bit we’re going away, just pulling a week off.

Body changes related to breast surgery required women to redefine their image of themselves – they had to get to know themselves all over again and learn to feel comfortable with the loss of a breast or the scars from lumpectomy.

Right now in order to touch my skin where the scars are I have to use gloves or I can’t touch. I don’t know if it’s just me or if it’s a mental thing but I cannot touch those scars.
The loss of a breast as well as menopausal symptoms also significantly affected intimacy between partners. Women were generally more self-conscious about their appearance - some had started wearing t-shirts to bed when they had not done so previously. One couple could not cuddle as they had done before because with the hot flashes she became too uncomfortable.

We’ve changed, we’ve lost a lot of intimacy because we’re not used to my body and I think that’s a big loss.

There was no sense from any of the male partners in this study that they were repelled by their wife’s body changes, instead there was matter-of-fact acknowledgement that something was different and that as a couple they were trying to make whatever adjustments were necessary to maintain an intimate relationship.

Hair loss, applicable only to those families in which the diagnosed woman had received chemotherapy, had a significant effect. Hair symbolized being normal, and until there was a reasonable amount of hair growth there was a sense that the diagnosed woman was still a cancer patient. One couple identified that the first time they went out after the woman’s hair had grown so it looked like she “just had a real short cut” was a significant turning point towards life feeling normal again. Women did continue to wear their wigs as a way of working around the hair loss but it was not a particularly satisfactory solution.

Certainly the diagnosed women in each family expressed more concern about alterations in their appearance, whether through hair loss, weight gain, or breast changes, than did the other family member. Conversely, other family members expressed more concern about functional changes in their partner/mother/friend, such as fatigue, that prevented activities.

Families also had to work around or learn to work with some of the attitudinal and perspective changes described in Making Sense of the Experience. For example, did the ways
families previously spent money or took vacation ‘fit’ with their new recognition of the preciousness of life, or did they need to readjust their desires, expectations, plans? Two different partners talked about being unsure how to act in response to their spouses’ new expression of needing independence.

I know her, I’ve known her for all these years, now she’s not the same person, now she’s got different ideas, different little thoughts here and there and I was just trying to understand that.

An extreme example of the difference in priorities that occurred within a few families is seen in a couple where the woman had had a mastectomy and was on the waiting list for breast reconstruction. Her priority was the reconstructive surgery, even if it interfered with a trip they had been planning for over a year, because having two breasts was one of her symbols of being normal. The spouse was just glad she was alive, even with one breast, and therefore his priority was the trip. Normal for him had to do with their activities; reconstructive surgery would interfere with the trip thereby postponing rejoining the world of normal as he defined it.

As noted elsewhere, all families were “tired of having cancer on the plate everyday” and expressed a desire to rejoin the world of normal, but the degree to which they had to work around the effects of treatment influenced the rate and ease of the process. Those families that experienced less disruption and limited side effects during treatment had less to ‘work around’, and therefore could rejoin the world of normal more easily. Different expectations with regard to how long it should or would take to be normal were apparent among the families, between the members of the family dyad, as well as within individuals. Families and individuals would alternate between impatience, wanting to be normal right away, and acceptance that full healing and recovery would take time and was a gradual
process. There was recognition that many of the changes that had to be worked around were in fact temporary, and participants tended to be more impatient in dealing with these than with changes that were more long-term or permanent. Male partners in particular were more likely to express frustration with having to work around changes and to wish that things could get back to normal more quickly.

In this section the post-treatment experience has been described through the metaphor of Moving On – women and their families work to ‘move on’ past the diagnosis and treatment into a new normal by Making Sense of the Experience, Managing the Threat of Recurrence and Rejoining the World of Normal. In this next section some specific variations within this experience will be explored.

**Variations in Moving On**

Throughout the descriptions of Moving On and its subcategories there have been references to the idea that some families ‘moved on’ with apparent ease, but others experienced various challenges during this transition period. Specifically, six of the eleven family dyads experienced more difficulty than the other five family dyads. Some of these difficulties have been described briefly within the various components of the Moving On process yet this gives the impression that the difficulties were isolated and individual. In fact, some of the difficulties the six families experienced were remarkably similar and manifested in a common response. Words used by the women or family members to describe this response to the completion of treatment included: in limbo, a relapse, a funk, distress, in bad shape, a depression.

I kind of bounced back in January but I’m kind of having a relapse or something. I don’t know what it is, no energy and I don’t know what it is.
While it was always the diagnosed woman who expressed feeling this way, other family members recognized and were affected by it.

And then when I noticed there was, she was, she was in bad shape, she was really bad for the first week or two after, um, noticeably, and then I guess it started wearing on me and I didn't notice it you know, I started getting quite stressed out, I didn't notice because it kind of crept on me slowly right?

Families who experienced this state of being thought about recurrence more, were generally less satisfied with their plan for follow-up, were more deliberate in their use of strategies to maintain and regain health, indicated they found it harder to put the experience behind them, and had more treatment effects to work around. In addition, in some of these families the relationship between the diagnosed woman and her partner appeared to be under more stress – differences in opinions and priorities resulted in tension that required more direct attention to resolve. The two key issues that seemed to be at the root of the difficulties were: a sudden decrease in contact with health care professionals (which meant less support, no 'active' monitoring or treating of the cancer, and an empty time schedule) and physical effects of the cancer (particularly fatigue) which impeded the resumption of previously normal activities. The diagnosed women felt caught in a circle - to feel better they needed to do more, but to do more they had to feel better.

The length of time these feelings of being in limbo lasted varied between families. One women indicated it only lasted a few days because she recognized the negative feelings and made a point to put them out of her mind. Another woman was still feeling somewhat abandoned and unsure even after five months. Yet all the families who experienced this difficulty also believed they were making progress, and employed many of the same strategies used by those families that appeared to experience this transition period with more ease. All eleven family dyads made efforts to Make Sense of the Experience, Manage the
Threat of Recurrence, and Rejoin the World of Normal but as has been mentioned, there were tasks or experiences within the process of Moving On which themselves acted as barriers or facilitators and thus influenced the transition process. For example, dwelling on thoughts of the cancer made it more difficult to move on but finding ways to manage those thoughts, such as with positive thinking, facilitated Moving On. Next, a variety of factors related to either the family itself, to the type of treatment, or to interactions with health care professionals that appeared to influence one or more of the Moving On subcategories and/or the overall rate and ease of the Moving On process will be explored.

Family Factors

Family factors are the age/stage of the family, family beliefs, and previous life events. Many of the participants identified personal and/or family beliefs or philosophies as a way of explaining how they were coping in the post-treatment period. These were broad statements indicating how the family generally approached life, and were often illustrated with specific examples. One dyad in talking about how they were coping with some of the difficulties they had encountered post-treatment said they were “not quitters”, and illustrated that by recounting a previous experience with job loss. Several families talked about having an upbeat and positive outlook on life and how their belief that it was important to approach things optimistically helped them cope with the cancer experience.

The age of the diagnosed woman may have influenced the experience of Moving On to some degree. Families where the woman was older were also families that no longer had children at home. These families tended to experience Moving On more easily than those in which the diagnosed woman was younger and/or there were still children at home. The older
families thought less about recurrence and needed to make less adjustments to rejoin the world of normal; these were also the families that had received radiation alone.

Families that talked about at least one significant life event, previous to the cancer, that they believed was worse or more difficult than the cancer, also appeared to Move On more easily. They more easily found positive meaning to attach to the cancer experience. Because they had a previous event to compare to the cancer, they tended to appraise their own cancer experience more favourably and could put it behind them. It is also possible that in coping with a significant event previously they had learned behaviours or strategies that facilitated their management of the cancer experience, although this was not explored in the interviews.

Type of Treatment

Of the 11 participating family dyads, five had experienced radiation treatment alone following lumpectomy, three had experienced chemotherapy and radiation following lumpectomy, two had had mastectomy followed by chemotherapy and radiation and one had had a mastectomy followed by chemotherapy alone. In general, the five families who had experienced radiation alone experienced less difficulty in the post-treatment period compared to the six whose treatment included chemotherapy; they thought less about the cancer returning, felt more in control of their follow-up and health, talked more in terms of having put the cancer experience behind them, and experienced less treatment side effects that required adjustments. Why this was so cannot be determined from this study but a few reasons can be speculated on. It may be related to the overall length of the treatment period – a course of radiation alone is considerably shorter than when it is combined with chemotherapy, or even than chemotherapy alone. It may be related to an actual physiological
effect of chemotherapy, or it may be due to the fact that a more complex and lengthy
treatment regime causes more changes and disruption to family life so that it is more difficult
to Move On. Also women who have chemotherapy do so because they have a higher risk of
recurrence; this could result in a greater fear of recurrence and therefore a greater need to
manage that threat, or more difficulty in putting the experience behind them. The type of
surgery also had an influence. Families in which the diagnosed woman underwent a
mastectomy were in the group which experienced more difficulties post-treatment; the loss of
a breast created a significant change which both the diagnosed woman and her partner
needed to 'work around'.

Interactions with Health Care Professionals

Interviews with families included questions about their experiences with health care
professionals in the cancer care system throughout their diagnosis and treatment phases,
postulating that these might influence their experience post-treatment. Generally, families
believed they were well taken care of and were often pleasantly surprised to find that the
cancer care system did not seem to be in as dire a condition as they believed the general
health care system to be. Despite this, families experienced both positive and negative
contacts with health care professionals which revealed that the most important qualities in
any interaction were to be treated as a human being, and to be offered hope and reassurance.
Families who had experienced these qualities in their interactions with health care
professionals during the treatment phase seemed to have an easier time Moving On whereas
problems in communication during treatment appeared to negatively influence relationships
between the family and health care professionals and contribute to difficulties in the post-
treatment phase.
Being treated as a human being

Families identified a number of scenarios in which they felt the professionals they encountered treated them with the respect deserving of fellow human beings. One of the most important ways that health care professionals showed respect was related to time. Families felt respected when people took time – to listen, to phone, to inform.

When we sat down with Dr. and he says his thing and talks to you about the situation and then sits back as though he had all the time in the world, which I’m sure he doesn’t have and, you know, to be able to talk to him and ask questions and want to make sure that, are you sure that’s everything, there’s nothing else you want to ask…

In contrast, people felt pushed aside when the doctor was rushed and did not take time to listen to them.

I know he’s overworked but he’s always in a rush, he comes in the room and he’s already, he comes in and you’re going to talk to him and he’s already going to the door…in the end I used to write my questions before I went in so I wouldn’t waste his time and he wouldn’t run away on me either.

In addition to being given time, being treated as a human being included having one’s own time respected. Several families talked about their distress at being kept waiting for long periods of time without even being informed.

Another way that families believed indicated they were being treated as human beings was when health care professionals provided them with accurate and necessary information in a respectful and appropriate manner. Negative experiences described by families involved miscommunication – information was incorrect or incomplete, or not communicated in a clear fashion. Positive interactions included having information written down for them, being listened to, being phoned at home by the physician.

Families also felt like they were being treated as human beings when health care professionals made the effort to ask or talk about things other than the cancer. People felt
strongly that they were more than their cancer and when others recognized this they felt validated and respected. Participants also appreciated knowing a bit about the health care professional as a person to some degree. In addition, when talking about the cancer they didn’t always want to hear just facts or statistics or studies but appreciated personal anecdotes or opinions. Contrary to what many health care professionals believe, that by offering personal opinions they may ‘sway’ their patients decisions or actions, the participants in this study believed that hearing opinions and thoughts of the health care professional just added a human dimension to the interaction.

Finally, just being recognized and remembered helped participants feel important and respected – that they were not just a number. Several participants commented on times when a nurse or radiation therapist recognized them in the hallway and said hello; this type of interaction validated them as someone other than just another cancer patient.

**Hope and reassurance**

The offering of hope and reassurance was a quality that families consistently looked for in their interactions with health care professionals. Many of the diagnosed women in particular believed this to be vital and necessary in getting them through the treatment. Negative experiences involved physicians who could or would not communicate positivity during visits.

Now before you go tell me something that I can hang onto, you know, that’s going to carry me through this because it was just all the [worst-case scenarios], I mean I understand that they have to do it, you know, they are afraid of lawsuits and everything but hey, at the end there is a patient who is sitting in front of me, let’s leave them with a positive little something to take with them.

He just didn’t seem to make me feel positive as my friend’s doctor did...I wanted some reassurance that, you know, things can be okay...but he was reluctant to give that kind of reassurance.
Families were not expecting their physicians to offer false hope, yet they did feel strongly that there was always something reassuring that could be pointed out.

Overall, families that identified negative interactions with health care professionals during the treatment phase, specifically if they felt not listened to by their physician or that the physician did not offer the hope and reassurance they sought, had more difficulty in the post-treatment phase. In particular, as was described in a previous section, Having a Plan for Follow Up was more of a concern for them as they had trouble identifying a satisfactory contact person.

In this section variations in the Moving On Process were discussed, highlighting the fact that the initial post-treatment period was more difficult for some families than for others. Several common factors related to the family such as beliefs, age and stage, and previous significant events, as well as factors related to the treatment such as chemotherapy/radiation and interactions with health care professionals provide possible explanations for the variations.

**Summary**

This chapter has presented the findings from interviews with 11 family dyads. The major theme identified to describe the experience of women and their families in the first six months following completion of adjuvant treatment for breast cancer is Moving On. Moving on is a process of transition when families begin to move past the cancer experience into normal life – a new normal that must take into account the cancer experience. It is comprised of three distinct but overlapping elements. The first element is Making Sense of the Experience where families speculate about the reasons cancer came into their life and identify new perspectives and attitudes. The second element is Managing the Threat of
Recurrence. Families struggle with thoughts of the cancer returning, wonder about appropriate monitoring, and take action to maintain and regain health. The third element is Rejoining the World of Normal where families make decisions about putting the cancer behind them and adjust to the effects of the treatment. For some families Moving On was more challenging than for others, and feelings of depression, being in limbo or a funk arose. Relationships between partners were sometimes tested. Variations in the Moving On experience may be influenced by factors such as family beliefs, age, stage of family, previous significant life events, and the type of treatment. The quality of interactions with health care professionals also may affect the ease of Moving On – to be treated as human beings and to be offered hope and reassurance throughout the cancer experience were key features for women and their families.
CHAPTER 5: DISCUSSION OF FINDINGS

This study provides an investigation into the challenges faced by women and their families in the first six months after completion of breast cancer treatment. The purpose of this chapter is to discuss the findings of the current study in relation to the current body of knowledge: how are the findings similar or different to what is already known?; how do they extend or enhance previous research? In the findings, the idea of Moving On emerged as the main metaphor to describe what families experienced in the first six months post-treatment for breast cancer. In striving to move on women and families used a variety of strategies to make sense of the experience, manage the threat of recurrence, and recover normalcy. These findings have perhaps shed some light on how the experience of finishing treatment manifests itself in daily life. Although nothing within these findings is startlingly new, the information may serve to extend or enhance findings in the bodies of literature related to cancer survivorship and families with cancer. Two specific areas have been chosen for further discussion.

In keeping with the researcher’s belief in the importance of the family perspective the first issue is chosen because it is what seemed to be the most important to the families. Without exception, every family participating in the study made some reference to wanting to be normal. Yet, it became clear that “rejoining the world of normal” was not necessarily the same as going back to normal – these families were not returning to a life that was exactly the same as before the diagnosis of breast cancer. However, it was also very clear that something called normal was important – it was a place that all the families in this study wanted to get to. Why? What is appealing about ‘normal’? How is ‘normal’ defined? Do different family members define it differently? Is there a ‘family normal’? How do people
determine when they are 'normal'? If the 'normal' after cancer is a 'new normal' how is it different or the same as the 'old normal' – what makes them both 'normal'? How do people know when they are back to, or have regained normalcy? In this chapter the researcher will explore possible answers to some of these questions in light of the findings of this study and other current literature.

The choice of the second issue was influenced by the researcher’s background as an oncology nurse in the cancer care system – it reflects her own bias as to what is of importance or interest in this context. Although somewhat of a secondary finding, the importance of the healthcare relationship and the family’s need for hope and positivity within it stood out as significant. In particular, those families who believed these qualities were lacking in the relationship with their oncologist felt unsupported in the post-treatment period and were more likely to feel ‘in limbo’. How does the relationship between patient and health care professional influence the illness experience? When families say they want to be given hope, what is it hope for? As a health care professional, how does one facilitate hope? How does one convey positivity and hope yet be truthful in offering information about cancer and it’s risks? The family-health care provider relationship, and specifically the role of hope within it will be discussed in the second half of this chapter.

**Recovering Normalcy**

In the current study Rejoining the World of Normal was identified as one component of the process of Moving On after treatment for breast cancer. Before exploring the process of getting to normal, it is perhaps appropriate to first examine what defines ‘normal’ versus ‘not normal’.
The dictionary defines normal as “conforming to or consisting of a pattern, process, or standard regarded as usual or typical” (Reader’s Digest Association, 1977, p. 921). Similarly, normal was defined by participants in a study by Hilton as “a desirable state that was safe, stable, and free of health problems and vulnerability and consisted of their usual behaviour patterns and routines” (1996, p. 607). In the current study participants identified two components of normal: appearance, and the ability to function. With regards to appearance, it was clear that families considered that having hair and having two breasts was normal for women. Certainly these aspects of appearance conform to the usual or typical for women in North American society, and the families tacit acceptance of these features as symbols of normalcy highlights what Thorne calls ‘the power of the norm’, the assumption that being normal is good. In our society, normal is often equated with ‘normative” although, as pointed out by Anderson, Elfert & Lai (1989), the latter is ‘intended to have statistical rather than moral connotations’ (p. 258). This leads to the notion of normal “as a social judgment that values averageness over individuality” (Thorne, 1993, p. 59). Normal then is based on what society has dictated it to be. One family illustrated this point when describing how much more normal it felt to be out in public once the woman had a reasonable amount of hair growth. It is interesting to note that the diagnosed women in each family expressed more concern about alterations in their appearance, whether through hair loss, weight gain, or breast changes, than did the other family member. According to Thorne (1993), visible differences in the form of altered appearance announce a departure from the normal, triggering certain social responses and influencing social interaction. As with the participants in her study, changes in physical appearance of the women in this study affected how they felt about themselves in addition to forcing them to confront the reactions of others.
And even though, unlike the chronically ill individuals in Thorne’s study, the women in this study could expect to overcome their most obvious visible changes (hair and weight gain), as long as the changes were apparent they were still a barrier to achieving normacy.

The second component of normal according to the families in this study was the ability to function. This meant being able to do everyday things that had been fairly routine or typical for their family, such as working around the house, volunteering in a social organization, going on vacation, participating in sports or other recreational activities. That “normal” can be equated with ability to function has been identified by a variety of authors. The Reintegration to Normal Living (RNL) Index developed by Wood-Dauphinee and Williams (1987) contains eleven items, of which eight relate to the subscale of Daily Functioning: indoor mobility, community mobility, taking trips, self-care, work activity, participation in recreation, social activity, and assuming family roles. For the participants in Thorne’s study normal was “strongly linked to the capacity to engage in the activities of everyday living” (1993, p. 56). Robinson (1993), in her research into the process of normalization for families with chronic illness, found that ‘doing normal things’ included working inside or outside the home, going to school, taking vacations, going on field trips, or going shopping. In this current study, although the diagnosed women were more concerned with alterations in appearance, family members expressed more concern about changes in their partner/mother/friend, such as fatigue, that interfered with the family’s functioning and ability to engage in specific activities. Thorne (1993) identified fatigue as an invisible difference, with a set of specific social reactions. Fatigue, as it is experienced by patients undergoing cancer treatment, is usually described as profound and, as identified by the women in this study, often continues for months after treatment. As Thorne points out,
intense fatigue such as this is difficult if not impossible for others to appreciate. This may be one reason that family members found it to be more distressing – it clearly affected activities that the family could do and yet it was not easily understood by them. In addition, inherent in normal family activity are normal family roles. During the cancer experience, roles often shift and family members assume responsibilities that previously (i.e. normally) did not belong to them. It makes sense, then, that the family members would be more focused on normalcy in relation to functioning because it is their own functioning that is directly affected.

There are two other criteria that may help define a function or activity as normal for a family. First, Robinson (1993) identified that the ability of all family members, regardless of health or age, to do normal things is important. This illustrates that all family members’ lives are affected by the illness and that it is only when all members, individually and as a group, are able to function in expected ways that things are normal. For example, one male partner in the current study talked about his work schedule and how he had needed to alter it during the treatment period. His schedule slowly returning to its’ pre-cancer routine was one measure of life getting back to normal. Secondly, for something to be normal it has to have significance for the individuals and family, therefore families define normal in ways unique to their own family (Robinson; Thorne, 1985). The same things are not necessarily normal for all families. In this current study, for example, vacations were meaningful to one family, whereas sports and recreational activities were more meaningful to another. It appears that families value normalcy with respect to two perspectives – that of society as pointed out earlier, and that of themselves as unique entities.
Normal may be described not only by the presence of certain features or qualities but also by an absence – in this case the absence of health problems (Hilton, 1996; Thorne, 1993). Participants in this study indicated that their lives were normal before the cancer experience began, and that they were expecting their lives to be normal again once the cancer experience was behind them – this implies that having cancer was not normal, that the absence of cancer is normal. This is problematic however in that the threat of recurrence is ever present - once could have cancer again at any time – and since some of the effects of the diagnosis and treatment are permanent, normal can never again be as before the cancer diagnosis. As with people with chronic illness (Thorne, 1993) participants in this study were required to alter their idea of what was normal, in order to facilitate the regaining of normalcy.

Normalization, getting back to normal, and reintegration to normal living are similar concepts/ideas that have been identified in the literature in a variety of contexts. The concept of normalization was originally used in the context of deinstitutionalizing disabled children and adults but has evolved to describe an individual’s or family’s response to a member’s illness or disability, in a variety of contexts including chronic illness and cancer (Anderson, Elfert & Lai, 1989; Hilton, 1996; Knafl & Deatrick, 1986; Robinson, 1993). The process of “rejoining the world of normal” undertaken by the participants in this study parallels these similar concepts as the women and families redefined and redesigned normal family life. Several strategies were employed by the families as they attempted to regain normalcy in the post-treatment period. “Putting it behind” was accomplished by subjectively appraising the cancer experience – in some respects, a final evaluation of the diagnosis and treatment phases. Families often evaluated their situation by comparing it to other people or other
significant events. This strategy has been identified by other researchers (Cowley, Heyman, Stanton & Milner, 2000; Hilton, 1996; Robinson, 1993; Thorne, 1993) as a way to minimize the personal and social significance of the illness experience, thus reinforcing one’s own normalcy. In this current study, families also chose to deliberately consider the experience behind them, which could also serve to minimize the significance of the experience. According to Robinson, people look for ways to put the chronic illness experience into the background so that it becomes a backdrop for life rather than life itself. They choose to focus on the events or information that support coming toward normal. As was discussed previously, one definition of normal for the participants in this study meant not having cancer, and therefore using the past tense when talking about the cancer, for example, may reflect a deliberate strategy to regain a sense of normalcy.

Other strategies that families in this study used to achieve the desired normalcy had to do with their various attempts at working around the effects of both the diagnosis and the treatment. Before they could make adjustments to compensate, however, the women and their families first had to recognize the effects and impact of the diagnosis and treatment. Knafl and Deatrick (1986) identify a number of criteria for defining and recognizing the concept of normalization, one of which is acknowledging the existence of the impairment. Families in this current study were very clear about the ways their cancer experience had affected them, identifying physical symptoms such as fatigue or sore arm related to breast surgery as well as related consequences such as not being able to participate in certain activities, or loss of intimacy between partners. As profound and/or lasting effects were recognized, they made adjustments for the impairments that then allowed them to behave in ways they considered normal. An example of this from the current study is the woman who
decided to take a minor position in a social organization that she had previously been very active in, but not attend every meeting – she adjusted her activities because of fatigue but still maintained them to a degree that supported normalcy in the eyes of her and her family. This is somewhat reflective of another criterion of normalization suggested by Knafl and Deatrick: “engaging in behaviours to demonstrate the essential normalcy of the family to others” (p.219). Robinson (1993) identified something similar in the strategy of ‘pacing’, a strategy chosen by ill adults and children when lack of energy was a problem, whereby energy is budgeted and activities planned accordingly. There is a key difference, however, between this strategy of engaging in normal behaviours as portrayed by the participants in this current study and as described by both Robinson and Knafl and Deatrick. The latter suggest that in finding ways to engage in normal behaviours families intend to cover up differences and convince others outside of the family that they are normal. In this current study the findings suggest that women and families were motivated not by the opinions of others so much as the need to convince themselves that they were on the road to normal.

The desire to be normal, the recognition of effects of diagnosis and treatment that impede normal, and the process of finding new or altering old ways of being and doing in order to regain normalcy, have been discussed by other researchers in relation to the concept of normalization (Knafl & Deatrick, 1986; Anderson, Elfert & Lai, 1989; Wood-Dauphinee & Williams, 1987), in chronic illness (Robinson, 1993; Thorne, 1993), and in the experience of breast cancer (Samms, 1999; Nelson, 1996; Hilton, 1996). Clearly, women and families in this current study demonstrated similar or related concepts.
Hope in the Context of the Family-Health Care Provider Relationship

Another finding of this study was that various factors appeared to influence how women and their families experienced the post-treatment period. One of these factors was the relationship between women and families and the health care providers in the cancer care system. Specifically, supportive communications, especially the attitudes of hope and respect, seem to be key features desired by women and families within the context of their interactions with health care professionals during the diagnosis and treatment of breast cancer. In fact, those families that identified what they perceived as unsupportive relationships struggled more in the post-treatment period than those families who were pleased with their interactions. A number of researchers have identified the importance of the health care relationship in the illness experience of patients and families, and that the nature of the encounters can be a factor determining transition to wellness (LeShan, 1989; Like & Zyzanski, 1987; Nelson, 1996; Robinson, 1993, 1996; Thorne, 1986, 1988, 1993; Thorne & Robinson, 1988a, 1988b, 1989). Some specific attributes of the health care provider that have been recognized by patients and family as helpful and contributing to a positive relationship include: honesty, respect, empathy, accessibility and optimism (Nelson, 1996; Robinson, 1993; Thorne, 1986). It is this last quality, what Robinson (1996) calls a positive orientation, and the participants in this study talked about as hope or being positive, that is of interest here.

In order to discuss hope in the context of the healthcare relationship, it is necessary to understand what hope is. Participants in this study specifically used the term “hope” in describing what they wished for from healthcare professionals, but never specified that they wanted hope for something in particular – no one ever indicated that they wanted the
physician to provide them hope for a cure, for example. Instead, the hope they were wishing for seemed to be a sense of optimism and encouragement. One woman called it "something to hang onto". Another participant talked about wanting some reassurance that things can be okay - that the possibility exists for things to improve. Inherent in the hope they talked about is a sense of future orientation - hope is equated with possibility. Dufault and Martocchio (1985) describe two spheres of hope - generalized and particularized. Generalized hope is broad, and protects against despair by imparting an overall motivation to carry on, implying a sense of movement forward. Nekolaichuk and Bruera (1998) define hope as a "multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving a future good" (p. 36). One aspect of the hope that the participants wished for in this study, then, was encouragement for the future.

Participants made it clear, however, that in requesting this hope for the future they were not expecting to hear only good things nor did they want superficial cheerfulness. Families recognized that they might need to be told things that were difficult to hear but wondered if there could not be more of an attempt to balance these things with other positive messages. Hope, says Nelson (1996), can be fragile in the face of uncertainty and this fragility is easily fostered or shattered by words and information. For participants in her study (women between two and six years post treatment for breast cancer), "balancing both positive and negative information flow was an integral part of hope" (p.64). She found that health care professionals can nourish hope through optimism, by including both positive and negative possibilities in their discussions with patients and families. In addition, she found that the women in her study needed a certain outward confidence from others to foster hope in the face of their uncertainty. There is no question that uncertainty, and thus a feeling of
loss of control, is inherent in the cancer experience. Hope and optimism might offer some illusion of control and predictability (Fife, 1994). Similarly, one dimension of hope proposed by Nekolaichuk, Jevne and Maguire (1999) – situational hope – integrates predictability and boldness. Boldness is equated with confidence. Because cancer facilitates neither of these things, and actually contributes to the opposite, it makes sense that confidence and positivity on the part of health care professionals, demonstrated through balanced information-giving, might shore up hope in the patient and family.

Several authors recognize an interpersonal aspect of hope – that affiliations with others influence one’s hope or ability to hope through affirmations, encouragement and willingness to listen (Dufault & Martocchio, 1985; Nekolaichuk et al., 1999). It was clear in this study that the listening abilities of the physicians and nurses that the families encountered was key to the perception of a supportive relationship. According to Thorne (1993) families judge the credibility or trustworthiness of health care professionals not just by their competence but also by their ability to communicate, particularly their active listening skills.

Relationships that are considered credible and comfortable are thought to facilitate hope (Nekolaichuk et al., 1999). In this study, the willingness to listen was only one aspect by which the families judged the credibility of the health care relationship. Being listened to indicated to them that they were being treated with respect, as human beings. Health care professionals’ respect for the patient as a unique individual has been identified as a key value for patients and families (Robinson, 1993; Thorne, 1993). This implies that to some extent health care providers must make an attempt to know their patients and families as the unique people that they are. LeShan (1989) states that “…statistical tendencies often exist, but every
person is unique and can be understood only in the context of his or her particular genetic endowment and life experience, and how they have interacted…” (p. 103). Robinson found that deep interest in a family’s situation was key to a positive relationship. Families in this current study felt strongly that they were more than their cancer and when others recognized this they felt validated and respected. Relationships between an individual and the world, and an individual’s perception of their unique place in the world are referred to as meaning.

The concept of meaning gives a sense of coherence to life, and several authors propose a connection between meaning and hope (Fife, 1994; LeShan, 1989; Nekolaichuk et al., 1999; O’Connor, Wicker & Germino, 1990). If, as Fife suggests, meaning is “derived partly from the individual’s perception of the ability s/he has to accomplish future goals…” (p.310) then there is a parallel to the sense of possibility that is also a dimension of hope. In turn, hope is connected to feeling one’s life has meaning – people hope for, or derive hope from, that which has personal significance to them (LeShan; Nekolaichuk et al). It is possible that seeing the patient in the context of their whole life (respect as a human being), supports that there is meaning to their life, that it is not just about the cancer. This in turn contributes to an overall feeling of hope.

Most health care professionals agree that hope is important for health and wellness (Dufault & Martocchio, 1985; Nekolaichuk et al., 1999). However, many health care professionals view hope from a disease-focused orientation – hope equals cure (Kodish & Post, 1995; Nekolaichuk & Bruera, 1998; Thorne & Robinson, 1988a). This contrasts significantly with the multi-dimensional concept described above, in which hope stems from encouragement, confidence, balanced information, and respect for the individual within supportive relationships. In addition, health care professionals’ approach to relationships with
patients and families has traditionally been that the relationship is the background to the care, that the real ‘care’ is in the treating of the disease (Robinson, 1996). Yet the families in this study, and in others (Robinson, 1996; Thorne & Robinson, 1988a, 1988b) considered the relationship between them and their health care provider to be a part of the care. It has been noted that there is often a discrepancy in values, interests, and expectations between health care providers and recipients (LeShan, 1989; Robinson 1996; Thorne & Robinson, 1988a, 1988b). Similarly, for several of the families in this current study the relationship between them and their health care provider was not what they expected or wanted it to be. Although a minor finding within the overall results of the current study, the importance of the family - health care provider relationship to the family is underlined, particularly in regards to the fostering of hope.

**Summary**

The findings from this study illustrate the experiences of women and their families in the transition period following treatment for breast cancer. In this chapter, two specific findings have been highlighted – one major, in accordance with its obvious significance to the women and families in the study, and one minor, because of its interest to the researcher.

First, the allure of ‘normal’, the concept of normalization and the process of regaining normalcy were examined in light of the finding that reestablishing a normal life was an important focus for the participants of this study. Definitions of normal incorporate societal, familial and individual perspectives as well as aspects of appearance, functioning and health. The process of rejoining the world of normal involves recognition of any impairment or change as well as the employment of a variety of strategies designed to overcome or work around those changes.
Secondly, the concept of hope within the context of relationships between family and health care provider was explored, given the researcher's interest in the impact these relationships can have on the overall cancer experience, as well as the intriguing finding that some families expected their health care provider to give them hope. Hope is best defined as a multi-dimensional concept related to a variety of aspects such as possibility for the future, interpersonal relationships, and personal meaning. Health care providers may facilitate hope in patients and families through encouragement, respect, confidence, and the provision of balanced information. This encourages a view of the family-health care provider relationship as an integral part of the care being provided, rather than as secondary to the treatment of disease.
CHAPTER 6: SUMMARY AND IMPLICATIONS

Summary of the Study

Because most women today do not die after a diagnosis of breast cancer but go on to live for many years, an understanding of how they experience the completion of treatment is particularly relevant for both diagnosed women and their health care providers. As well, with the increasing recognition that cancer is a family affair it follows that the completion of treatment may be significant for not only the diagnosed woman, but also her family. Although there is research describing overall survivorship issues for women with breast cancer, there was very little found that specifically investigates the initial post-treatment period and even less that does so from a family perspective. Therefore, the purpose of this study was to describe the experience of women and their families in the first six months following completion of adjuvant treatment for breast cancer.

Interpretive description was the qualitative method chosen for this study. Arising within the philosophy and theory of nursing, this method facilitates an in-depth description and interpretation of the phenomenon that is relevant and applicable to the practice of nursing. Potential participants were initially identified and approached by either the primary nurse or oncologist at a cancer centre visit.

The sample was comprised of eleven family dyads consisting of a woman diagnosed with breast cancer and a family member of her choosing. Family was purposely defined very broadly; one family member was a best friend, two were daughters, and the others were male partners. Each family was interviewed once in a face to face, unstructured interview at either their home or the cancer centre. Analysis occurred concurrently with data collection.
From the analysis, the metaphor of Moving On emerged as an appropriate overall descriptor of the post-treatment experience from the perspective of the diagnosed women and their families. Three major non-linear components of Moving On were identified: making sense of the experience, managing the threat of recurrence, and rejoining the world of normal. Families were trying to make sense of the experience by speculating on reasons for the development of the cancer and by identifying new attitudes and perspectives resulting from the experience. The most common new perspective identified was an awareness of the preciousness of life which resulted in families resolving to take a more relaxed approach to life and “not sweat the small stuff”. Managing the threat of recurrence meant dealing with the often present thoughts about whether the cancer was gone or might return as well as having a plan for follow-up. It was extremely important for all families to have a person who knew them and whom they trusted available to them for support and questions. Families incorporated lifestyle changes and became more vigilant about their health in order to regain and maintain physical, psychosocial, and emotional health. All families were anxious to rejoin the world of normal. They made conscious efforts to put the experience behind them and work around the effects of the diagnosis and treatment – reconfiguring a new normal by combining previous ways of being with new ways that take into account the cancer experience.

The findings also revealed that six of the eleven families had a different experience post-treatment than the other five families. These six families described feelings of being in limbo, distress, or a funk. They thought about recurrence more, were generally less satisfied with their follow-up, were more deliberate in their use of strategies to regain and maintain health, indicated they found it harder to put the experience behind them, and had more
treatment effects to work around. There were two key issues that appeared to be at the root of these difficulties; physical effects of the cancer and treatment, particularly fatigue, impeded the resumption of normal activities, and the sudden decrease in contact with health care professionals left them feeling unsupported. In contrast, the other five families experienced greater ease in Moving On.

A variety of factors appeared to contribute to these variations in Moving On. These factors were either related to the family (age/ stage of development, beliefs, and previous significant events), or to the cancer care that they received (type of treatment and interactions with health care professionals). Common family factors amongst the families who had more problems post-treatment were being in a stage of development that included children at home or where the diagnosed woman was younger, and having limited prior exposure to serious or significant events. With regard to treatment, families in which the woman had undergone radiation therapy alone had fewer treatment effects to overcome and therefore an easier time Moving On. All families described being treated with respect and offered hope and reassurance as very important aspects of their interactions with health care professionals; those that experienced a more difficult time after treatment believed that these qualities were lacking in their interactions with health care professionals during treatment.

This study reinforces the ideas that the illness experience does not necessarily end with the completion of treatment, and that cancer is indeed a family affair. Women and families continue to experience emotional, psychosocial, and physical effects of the diagnosis and treatment in the first six months after treatment ends. In order to make the transition to life after cancer, they undertake specific tasks and face common experiences. This study has a variety of implications for clinicians, educators and researchers.
Conclusions

The following conclusions may be drawn from this study:

- Women with breast cancer and their families continue to experience the effects of diagnosis and treatment beyond the actual completion of treatment.

- The initial 6 months following completion of treatment seems to be a period of transition for women and families. This period involves a need and desire to move past the cancer experience, but also a need to acknowledge and incorporate changes resulting from the diagnosis and treatment into their lives.

- Women and families face a number of common tasks and may employ a variety of similar strategies during the transition period following treatment for breast cancer.

- Women and their families try to find reason or meaning in the breast cancer experience, often by identifying changed perspectives on life.

- During this transition, women and their families struggle with thoughts of recurrence, wonder about appropriate monitoring, and take action to maintain and regain health.

- An important outcome of the transition beyond active treatment seems to be regaining normalcy, in which families make decisions about putting the cancer behind them and adjust to the effects of the treatment.

- Despite the commonalities, variations exist amongst family experiences. These variations may be influenced by a range of factors such as treatment modality, age, family stage and type, previous experiences, family beliefs, and interactions with health care professionals.
Supportive communications, especially the attitudes of hope and respect, seem to be key features desired by women and families within the context of their interactions with health care professionals during the diagnosis and treatment of breast cancer.

**Implications**

Following the completion of any type of research, the researcher must ask – what is the point? Given the conclusions drawn above from this small study, various implications for clinical practice, research and education are suggested.

**Clinical Practice**

There are three general implications for clinical practice that arise from the findings of this study. First, health care professionals involved in the care of women and families with breast cancer would do well to recognize that the illness experience extends beyond the completion of treatment. Clinicians often tend to think about the "end of treatment" as if it were a unitary phenomenon, because it signals an important aspect of involvement with the patient in a particular way. Conceptually, then, it may have been made into a stage that is assumed to have unitary proportions, and yet it may not be experienced quite that way by individuals. It is clear from the findings of this study that women and their families continue to experience effects of the diagnosis and treatment after the treatment is completed. The end of treatment does not equal the end of the experience with breast cancer, as it is often considered by health care professionals in the cancer care arena. Given this, health care professionals must take into account the process by which people reintegrate into their lives. They might consider ways to prepare women and families for a period of transition post-treatment, facilitate normalization, and provide support through the post-treatment period. Strategies such as discharge planning interviews, completion of treatment information
packages, or support groups, or education evenings with a specific focus on the post-treatment transition period might offer women and families an opportunity to discuss fears and ask questions ahead of time, learn what they might expect when treatment ends, and prepare ways to cope with the transition. The findings also suggest that not all women and families experience the post-treatment period in the same way, and that for some it can be quite challenging. This suggests the need to develop a comprehensive plan for follow-up (including information about who to contact for various concerns) that is specific to the needs and situation of each individual woman and family. Health care professionals must learn to recognize when a woman and her family are struggling post-treatment and be prepared to offer the necessary care and support.

Secondly, the findings of this study support the idea that cancer is a family affair – both the diagnosed woman and the people she considers to be family are affected by the diagnosis and treatment of breast cancer. In the post-treatment period, issues related to the breast cancer diagnosis and treatment arise for the individual woman, for individual family members and for the family as a group. In clinical practice, care is usually concentrated on the diagnosed woman, particularly in the follow-up period, as it is often only the woman who attends appointments. However, the findings of this study suggest that truly comprehensive care would include family of the diagnosed woman – not just seeing the woman in the context of her family, but considering the family as the unit of care with respect to the breast cancer diagnosis and treatment. While it is well and good to understand this theoretically, in practice there are many barriers to this approach, including lack of time, lack of expertise and lack of appropriate environment. Nevertheless, the first step is to consider including families as a way to enrich and extend rather than complicate the care provided. Individual
physicians and nurses can cultivate a family-focused environment by requesting and welcoming the presence of families, asking specifically about family issues, and speaking directly with family members. Because all family members feel the effects of diagnosis and treatment in some way or another, it follows that talking about ways that cancer can affect family dynamics and roles is an important intervention. Those health care professionals whose role includes administration might look into ways to design health care delivery that facilitates family care such as offering support services for families or providing larger rooms and longer appointment times to accommodate family discussions.

Finally, the findings of this study direct health care professionals to strive to build a relationship with families that is based on mutual respect and offers hope and reassurance. Rather than the one-dimensional view of hope as cure, health care professionals would do well to consider hope as a multi-dimensional concept and learn how to facilitate it within the individual patient and family’s experience and meaning. This means recognizing the uniqueness in each patient and family and taking an interest in who they are as people, separate from the cancer. As families struggle to rejoin the world of normal, health care professionals can provide encouragement and support based on the individual’s definition of normal, rather than the dominant cultural view or that of the health care professional. The importance of being available and willing to listen cannot be underestimated. Health care professionals might want to establish a way of providing information that balances the positives and the negatives. The nature of cancer is such that delivering bad news, or at the very least, communicating uncertainty, is an inevitable part of oncology practice. Yet it is likely that there is also something positive that can be imparted. A certain amount of confidence and optimism on the part of the health care professional can go a long way in
supporting hope in the face of uncertainty. While it is clear that health care professionals need to be aware of what and how they communicate with their patients and families, building a relationship is more than communication skills. It is important for health care professionals to understand that their relationship with patients and families is not merely a background, but part of the overall cancer care and as such requires as much time, care and commitment as the treatment.

Research

In this study, some families found the post-treatment experience to be more challenging than other families. A number of factors were identified which may have influenced these variations in the post-treatment experience: treatment modality, age, family stage and type, previous experiences, family beliefs, and interactions with health care professionals. Further research isolating these factors, large population surveys for example, may shed light on the nature of their influence and lead to ways to identify those women and families that may be at risk for having more difficulty “moving on” after treatment.

The majority of family dyads in this study were women with male partners, therefore it was not possible to explore the notion of how the illness experience is influenced by gender of the family member. Further research with individuals and family members of different genders – for example, men with cancer and female family members, or women and female partners – would be useful to explore the relationship between gender and the illness experience.

Clearly, the relationship between health care professionals and patients and families, and the communication within that relationship, are important and influential aspects of the illness experience as indicated by many of the families in this study. How can health care
professionals best foster hope and positivity within the individual patient and family's experience and meaning? What other qualities do patients and families look for or hope to avoid in relationships with health care professionals and how do they help or hinder the therapeutic relationship or various health outcomes? What is the role of the health care professional in facilitating normalcy, or supporting meaning-making for patients and family recovering from a diagnosis and treatment of cancer, and how might interventions related to these two concepts influence health outcomes? These are just some of the questions that could be explored with a variety of studies, particularly those designed to evaluate health outcomes or compare interventions.

Professional Education

Although direct implications for the education of health care professionals are limited, the findings of this study do highlight the importance of effective and appropriate communication skills within the context of a therapeutic relationship. Further, there is some evidence of the critical significance of the relationship itself as a factor in how the patient and family experience the post-treatment period. It follows that if health care professionals are to be able to communicate effectively and be with patients and families in relationships that are truly therapeutic, then the necessary skills must be taught and the appropriate attitudes fostered within basic healthcare education programs. For example, instruction in communication could focus not just on how to deliver bad news, but on how to provide balanced information and foster optimism and confidence. Examination of hope as a multidimensional concept, much more than just hope for a cure, might encourage health professionals to explore the unique hopes of their patients and families. Rather than simply teaching about the disease and treatment, educators might focus on the illness experience to
foster compassion and interest in the individual patient and family experience. The relationship between patient/family and health care professional must be acknowledged, not as mere background in the treatment of the cancer, but as a key piece in caring for the whole person.

Other ideas for subject matter within educational curricula for health care professional education arise from the general findings of this study, and from the reasons that this study was undertaken in the first place— that women and their families continue to experience the effects of diagnosis and treatment of breast cancer after the treatment is completed. It is imperative that health care professionals learn early on in their education of the ongoing effects of diagnosis and treatment, in order to better appreciate the cancer experience from the view of the patient and family. This would include then, not just the physical aspects of the illness but also the psychosocial and existential ramifications. Furthermore, an emphasis on the family as the focus of care and the skills of family assessment in all aspects of health care, not just the traditional areas of pediatrics and maternal/child care, would prepare health care professionals to care for people in the contexts of their lives with an appreciation of not just the commonalities but also of the uniquenesses inherent in each situation.

Conclusion

This qualitative study explored the experience of women with breast cancer and their families in the first six months following the completion of treatment. In striving to move on past diagnosis and treatment, families seek meaning, struggle with the possibility of recurrence, redefine and slowly regain normalcy. For some families the process is relatively easy, for others it is a challenge, for all it is a time of change and transition. Although the
nature of this small study precludes generalizations, the findings may enhance our understanding of the experience that women and families face in the immediate aftermath of treatment for breast cancer, and perhaps encourage us toward exploring these issues in future research. In the words of songwriter Jimmy Cliff:

“Sittin here in limbo, but I know it won’t be long.
Sittin here in limbo, and I feel like a bird ain’t got no song.
...and I’m waitin for the dice to roll...
and I still gotta little time to search my soul.
I can’t see where life will lead me,
but I know where I have been.
I can’t see what life will show me,
but I know what I have seen.
...it’s time to be movin on.”
REFERENCES


**Information and Consent Form**

**Study Title:** The Experience of Women and Families in the First 6 Months Following the Completion of Adjuvant Treatment for Breast Cancer.

**Investigator:** Chris Emery, RN, BSN,
Masters Student, UBC School of Nursing (943-0203)

**Faculty Advisors:** Sally Thorne, RN, PhD,
UBC School of Nursing (822-7482)
France Bouthillette, RN, PhD,
B.C. Cancer Agency (877-6000 local 2620)

**Purpose:**
I have been asked to participate in a Masters thesis research study. The purpose of the study is to better understand what it is like for women and their families after adjuvant treatment for breast cancer has finished. I understand that I am being asked to participate in this study because I or someone in my family has recently completed adjuvant breast cancer therapy and so I have personal knowledge of this experience.

**Procedures:**
I understand that if I decide to participate in this study, I and other family members who have consented will be interviewed together, once or twice by the investigator. The first interview will last approximately 1 hour and will take place in a mutually agreeable location in the cancer agency or at my home. If possible, one follow-up interview of approximately 30 minutes will be done to clarify points discussed in the first interview. The interviews will be audio-taped and transcribed into written form by the investigator. At any time during the interviews, I can request that the tape or any portion of it be erased.

**Risks and Potential Benefits:**
Participating in this study presents no risks to my health. I will be contributing to new knowledge about the impact of completing adjuvant treatment for breast cancer which will assist nurses and other health care professionals to provide optimal care for future patients and families. Additionally, I may find it beneficial to discuss my family’s experience when treatment for breast cancer finishes, and to learn about other family members’ thoughts and feelings. If I would like to continue to discuss issues or concerns beyond the research interviews, a cancer agency patient and family counsellor can meet with me.

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APPENDIX B

Sample Trigger Questions for Initial Interview

1. Tell me what it has been like for each of you since you (your mother/wife etc.) finished treatment for breast cancer?

2. How is this different than the time during treatment?

3. What, if any, were your expectations for this time following the end of treatment?

4. Did you as a family ever discuss these expectations?

5. How is this time different from or similar to what was expected?

6. What are some of the issues, concerns or questions that have come up for you individually and as a family since you (your mother/wife etc.) finished treatment?

7. What things have you done individually or as a family to address these issues, concerns, or questions?

8. How have your nurses or other health care providers been helpful or not since treatment finished?

9. What kinds of things would you like nurses or other health care providers to understand about what it’s like for families after treatment for breast cancer is finished?
APPENDIX C

Revised Trigger Questions

1. Although I'm most interested in hearing about the time since you completed treatment, as an introduction it would be helpful if you briefly recount your treatment experience.

2. And so your last day of treatment was when? What is it like for each of you now that the treatment is over? What is the best thing? What is the worst?

3. Tell me about some of the issues/concerns/questions that you have now? (for self, each other, other family/friends). What is your biggest concern? How are you addressing these issues? (individually or as a family)

4. Have you dealt with other significant events in similar ways?

5. Sometimes people are concerned about the cancer coming back... is that in either of your minds at all?

6. What were your expectations for this time following the end of treatment? How has this time been different from or similar to what you expected?

7. What has changed for you with this whole cancer experience – either in the way you think about things, or how you live on a day to day basis? Tell me about the gains. Tell me about some of the losses.

8. When was your last appointment with the oncologist? Do you see him/her again? What plans did he/she discuss for following up in the future? How is that for you? Some studies have suggested that people may feel abandoned when treatment is over... does that describe at all how you are feeling?
9. Thinking of the interactions you’ve had with health care professionals throughout your entire experience from diagnosis to now, can you describe something that was very helpful or positive? Something that was negative or not helpful at all?