Transition: Understanding the Dynamics Of The In-Patient Rehabilitation Process For Older Persons With A Cancer Diagnosis

by

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A thesis submitted in conformity with the requirements for the Degree of Master of Science, Graduate Department of Nursing Science, University of Toronto

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Abstract

A qualitative study was conducted using grounded theory methodology to examine the process that older persons with a cancer diagnosis experienced in an in-patient rehabilitation program. Six individuals with a cancer diagnosis were interviewed twice, within a week of being transferred from acute care to in-patient rehabilitation and just prior to their discharge. Participants had a variety of functional deficits that resulted from cancer or its treatment. Content analysis of the tape-recorded interviews revealed that participants experienced a transition while in the rehabilitation program. The transition consisted of three phases which were (a) taking stock of the situation, (b) looking and moving forward, and (c) preparing for home. The three phases consisted of five major categories. The categories were (a) getting and staying motivated, (b) actively participating, (c) regaining function, (d) adopting adaptive behaviours, and (e) remaining hopeful. The three phases and the five categories derived from the data formed the substantive theory that described the transitional processes that occurred for older persons with cancer in an in-patient rehabilitation program. Implications for practice and suggestions for further research were examined.
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Chapter I: The Problem and Purpose

"An estimated 129,000 new incidents of cancer and 63,400 deaths from cancer will occur in Canada in 1999" (National Cancer Institute of Canada, 1999, p. 1). Cancer is primarily a disease of the elderly. "At age 25 the chances of developing a malignancy are 1:700 but by the age of 65 the chances increase dramatically to 1:14" (Byrne & Carney, 1993, p. 150). Twenty-five percent of new cancer diagnoses occur in Canadians, aged 60 - 69, while 45% of new cases occur in Canadians aged 70 and older (National Cancer Institute of Canada, 1999).

Approximately 50% of people with a diagnosis of cancer are expected to survive at least 5 years and many will have functional limitations that may negatively affect their quality of life (Kurtzman, Gardner & Kellner, 1988). As the population ages, persons over the age of 65 represent an important and significant cancer treatment group; not only from an oncology perspective, but also from a rehabilitative one. Historically, persons with cancer were often deemed incurable and doomed by some in the medical profession as well as by many in the public sector. Until recently, the rehabilitative needs of patients with cancer have received little attention.

Many cancer related and iatrogenic functional limitations are amenable to treatment. The impact that disease or treatment may have on mobility, nutrition, psychological attitudes, somatic comfort and the financial resources of the older person may be quite different from that of younger adults (Byrne & Carney, 1993). Currently, functional deficits experienced by older adults are being addressed in rehabilitation.
programs. The goals of these programs are to maintain or to improve the quality of life for patients with cancer and to help them return to their community.

The World Health Organization (World Health Organization, 1980) defines rehabilitation as a progressive, dynamic, goal-oriented and often time limited process that enables an individual with an impairment to identify and reach his/her optimal mental, physical, cognitive and/or social functional level. The goals of cancer rehabilitation are "to help the person to develop to his or her fullest physical, psychological, social, vocational, avocational and educational potential within the limits imposed by the disease and consistent with the treatment plan" (Kurtzman et al., 1988, p.791). Hence, the goals of rehabilitation are evaluated often through functional outcomes, such as the ability to carry out one's activities of daily living independently. Rehabilitation provides opportunities for the individual to improve function. Rehabilitation programs assist the persons, their family and the community to accommodate a limitation or loss of function and aim to facilitate social integration and independence. The purpose of this study was to have an increased understanding of the process that the older person with cancer goes through in an in-patient rehabilitation program.

**Literature Review**

The functional changes that constitute the dynamic process occurring in rehabilitation have been researched (Bunting, Baublik, Blevins, Dames, Ford & Levins, 1992; Mock, Burke, Sheehan, Creaton, Winningham, McKenny-Tedder, Schwager & Liebman, 1994). However, little is known about the dynamic process itself. A review of the literature revealed some studies that describe certain components of a dynamic
process, but no studies were found that describe the process that is experienced by the older person with cancer in an in-patient rehabilitation program.

Spencer, Hersch, Eschenfelder, Fournet and Murray-Gerzik (1998), used a longitudinal qualitative design to study 8 participants who were discharged to the community following admission to a transitional care unit. Participants ranged in age from 69 to 87 years of age and had multiple chronic illnesses. One objective of the study was to describe the adaptation trajectory of older persons who had physically deteriorated in acute care and had been transferred to transitional care. The study was done just prior to their discharge home to the community. Participants completed a Client Centred Evaluation that addressed: a) the older persons’ perceptions of why they were hospitalized; b) their expectations about life changes that this hospitalization might cause; and, c) their desires as to what things that they would like to be able to do when they returned home (Spencer et al, 1998). An assessment tool was used to provide structure for a collaborative discussion between the occupational therapist and patient. The discussion focused on how goal setting might influence the social and geographical or spatial context of each participant's place in the community. Occupational Therapists used the information to set adaptation-based goals and to problem solve with participants. Analysis of the data supported the use of adaptation-based goal setting in that goals were met in some fashion by 100% of the participants. This supports the practice of collaborative goal setting, which appears to be an important component of the process that enabled this group of older persons to return to the community.
Kaufman (1998) used a phenomenological approach to describe the relationship between illness and biography or the knowledge of self and the expression of a part of the self that needs attention following a major illness. This study involved a 65 year old woman following a stroke. Findings from this case study consisted of descriptions about the patient's concerns which focused on searching for the meaning of the illness, anchoring the illness in a predictable scheme of things and choosing among responsibilities. Kaufman pointed out that therapies, which focused on the accomplishments of discrete physical and visible tasks, did not address the patient's unresolved concerns. This study revealed a poignant description of some of the emotional difficulties and accompanying work that occurred following this person's major illness. This case study supports the need for increased understanding of the patient's concerns following a major illness, of which cancer is one. The study also demonstrated that a complete understanding of the rehabilitation process is necessary in order to address the concerns that patients may have following a major illness.

Spencer, Davidson and White (1997) studied the concept of helping clients to develop feelings of hopefullness about the future. The authors examined the cognitive, emotional and spiritual aspects of hope as reflected in the literature, described three clinical approaches to incorporate hope into clinical practice and addressed some of the concrete issues in implementing the approaches.

The health care and social science literature indicates that hope is interwoven in a complex process that evolves over time after a major loss (Spencer et al., 1997). The process is comprised of imagination, intention, and a sense of meaning and purpose.
Spencer et al, maintain that health care providers must engage clients in shaping their future by addressing the cognitive, emotional and spiritual aspects of hope with patients. Understanding more about the complex process following a loss related to cancer might help us to understand how patients achieve a state of recovery. This important work may be a forward step toward understanding the process assumed by patients in rehabilitation following a loss related to cancer.

A qualitative study conducted by Farrel and Hassey-Dow (1996) described the experience of cancer survivors. Three key themes were gleaned from the participants' stories: a) rendering the old life (i.e., giving up the life that preceded cancer diagnosis); b) transition to a different life; and c) living an altered life. The "transition to a different life" theme described elements of the cancer survivor's experience including "physical hardships, emotional loss, staring death in the face and learning to control the controllable" (Farrel & Hassey-Dow, 1996, p.77). This study provided meaningful descriptions of moments when nurses made a significant difference in the lives of patients. "Expressions of warmth and caring, such as being present during a diagnosis, holding a patient's hand, and providing referrals to support groups are ways in which health professionals humanize the experience of cancer" (Farrell & Hassey-Dow, 1996, p.80). These powerful moments of support should not be underestimated for their therapeutic value. The Farrel and Hassey-Dow study described the emotional transition that patients experienced following diagnosis and treatment for cancer. However, the
study did not address specifically the process that is experienced by the older persons with cancer in a rehabilitation program.

A review of the studies found in the literature has provided some understanding of the process or components of processes that occur following a major change or loss. Some studies focused on the emotional aspects and some on the functional aspects of the subsequent process that followed a major change. They used terminology such as adjustment, transition, goal attainment and adaptation. One study was specific to patients with a diagnosis of cancer and one study focused specifically on older persons. Two of the studies found were conducted by occupational therapists but may be applicable to nursing practice. Hence, there is some evidence to support that people with cancer, young or old, may benefit physically and psychologically from participating in rehabilitation programs (Yoshioka, 1994; Mock et al., 1994; Bunting et al., 1992).

Individuals in rehabilitation programs engage in a process where there appears to be movement through stages toward a recovery phase. The ability to describe the stages and phases that lead to recovery is fundamental to understanding how recovery is achieved. Interventions that are limited to the functional aspects of care do not adequately meet the needs of people who have gone through a life altering experience, such as a cancer diagnosis and treatment. An increased understanding of the stages that older persons with cancer go through toward the recovery process may enable nurses and other disciplines to intervene more effectively throughout that process.
There is a paucity of research that describes the stages in the transition process that older persons go through in an in-patient rehabilitation program. A gap exists in the nursing knowledge about the process that older persons with a cancer diagnosis go through in an in-patient rehabilitation program. Data from inductive research concerning the process that older persons with cancer go through in an in-patient rehabilitation program might enable nurses to intervene more effectively throughout this experience. The following question will guide this study: What is the process that the older person with a cancer diagnosis experiences in an in-patient rehabilitation program?
Chapter II: Methodology

Research Design

Grounded theory methodology (Glaser & Strauss, 1967; Strauss & Corbin, 1990), was utilized to inductively examine the process that older persons with a cancer diagnosis go through in an in-patient rehabilitation program. There is no inductive research describing this experience. Therefore, this investigator believed that this method enhanced our understanding of the experience and provided a richness of detail that assisted our understanding of the rehabilitation process (Strauss & Corbin, 1990).

Gaining Entrance to the Organization

Following formal approval for this study by the Office of Research Services at the University of Toronto, a letter seeking permission to conduct the study was sent to two rehabilitation hospitals. Both hospitals approved participation in the study. Unfortunately, one of the rehabilitation hospitals was unable to provide any participants that matched the inclusion criteria. Consequently, the study sample was obtained from one general rehabilitation unit that is part of a free-standing rehabilitation and long term care facility in Metropolitan Toronto. Letters explaining the purpose of the study and requesting permission to conduct the study was sent to the research committee and chief nursing administrator (see Appendix A) at the site, along with copies of the proposal.

Gaining Entrance to the Field

Once approval for the study was received, the nurse manager agreed to approach potential participants. The manager explained the study and requested permission for the
researcher to contact potential participants. The researcher then approached potential participants and gave a thorough explanation of the study. A detailed written explanation (see Appendix B) of the study was provided to each participant and two copies of the consent form were signed prior to the start of data collection (see Appendix E). One of the copies of the consent form remained with the participant.

Setting and Sample Procurement

The rehabilitation hospital used for the study is a combined rehabilitation and long term care facility that receives all referrals from a variety of acute care hospitals in the Greater Metro Toronto area. The unit consisted of 36 rehabilitation beds. Nursing care was delivered by a combined staff of registered nurses, registered practical nurses and health care aids. All nurses and aids worked rotating shifts. Participants were assigned an occupational therapist and a physiotherapist. The therapists remained consistent for the duration of participant’s stay in rehabilitation.

Sample procurement occurred over a one year period due to a limited number of potential participants who met the eligibility criteria for the study. Some of the potential participants did not speak fluent English, which made them ineligible. Ten potential participants met the criteria and were approached about taking part in the study. Three potential participants declined participation for unspecified reasons. Consequently, seven participants were recruited. One of the participants died from complications related to his illness prior to the second interview. As a result, data from this participant who died were not included in the study. The final number of participants in the study was six.
Ethical Considerations

Informed consent. Recruitment of participants, and any contact with potential participants was done through a neutral party. The nurse manager provided a brief explanation to the potential participants. When potential participants chose not to participate, no pressure was applied. The names of those willing to participate were forwarded to the investigator. Informed consent was obtained from each participant, following a detailed description of the study and a full advisement of the participant’s right to refuse without consequence.

Confidentiality. To ensure confidentiality and anonymity, initials identified participants only and only the investigator knew their full identity. All references to names were removed from any data collected. Other identifying information, such as a specified setting, was also removed from the findings. All data were kept in a file in the investigator's home.

Risks and benefits. Participants were asked to tell their stories and to reflect upon their experiences. The investigator was prepared to terminate the interview at any time and to refer participants to appropriate support personnel. Some of the information was of a very personal nature and emotions were evoked during the interview process. However, termination of the interview was not required.

Sample Selection Criteria

A convenience sample of seven participants was initially recruited to the study using the following criteria: a) age 60 or over; b) engaged in an in-patient rehabilitation
program because of a functional deficit acquired through the treatment of, or related to a

Diagnosis of cancer; and c) ability to speak English fluently. Both genders were

represented in the sample.

Demographic Data

Small amounts of demographic data were collected including the participant's age, type of cancer, medical history, gender and marital status. The purpose of collecting the demographic data was to describe the sample under study. A more detailed description of the sample can be found on page 20.

Data Collection

The primary mode of data collection in grounded theory is the interview (Strauss & Corbin, 1990). Recording observations in the form of memos is also an important component of the data collection process (Strauss & Corbin, 1990).

The data were collected over a twelve-month period, from April 1998 to March 1999. Participants were interviewed for about an hour on two separate occasions in a location chosen by the investigator. All participants were interviewed within a week of admission, with one exception. The exception was a participant who had been admitted 2 to 3 weeks prior to the Christmas holidays and had arranged for a holiday pass prior to starting rehabilitation. This participant was interviewed in early January. One exit interview took place in the community, three days following discharge, as the investigator was unintentionally misinformed about the discharge date. All interviews were audiotaped and were transcribed verbatim following each interview. Memos and
field notes were recorded immediately following each interview. These memos and field notes became a part of the data.

Participants were asked the following open-ended question at the beginning of the first interview: "What has it been like for you since you were admitted to the rehabilitation program?" The second interview began with "Since we last spoke, what has been happening with you?" Prompts were used to derive information from participants while further exploring various aspects of the participant's description of his or her experience.

Data Analysis

Coding procedures. The constant comparative method of data analysis has been the approach used for grounded theory (Strauss & Corbin, 1990). Open coding, axial coding and selective coding were utilized throughout the process of data analysis. Utilizing the constant comparative analysis method (Strauss & Corbin, 1990) categories emerged from the data. The investigator continually assessed the data by asking questions throughout the data collection process.

Open/substantive coding. Open coding has been defined as "the process of breaking down, examining, comparing, conceptualizing and categorizing data" (Strauss & Corbin, 1990, p. 6). In the initial phases of data analysis, data were coded in an unrestricted or open way using as many labels as possible. The purpose of the codes was to break down the data, line by line and to examine what was happening in the data. Codes that were similar were then grouped to form categories. Thirty-seven categories
emerged from the data (Appendix G). Transcripts were typed on one-half of an 8.5 by 11-inch page, double-spaced, so that there was room to identify the codes and write notes.

**Axial coding.** Strauss and Corbin (1990) have described axial coding as the process whereby the data are put back together by making connections between the categories. The paradigm model was used to examine the categories and to determine the relationships that existed between them. In doing so, categories and subcategories were linked and integrated through the constant comparative method. Then, categories were defined.

**Selective coding.** Strauss and Corbin (1990) described selective coding as the process of selecting the core category, systematically relating it to other categories, validating those relationships and filling in categories that require further refinement and development. Similarities and differences were noted between the themes, which led to the formation of larger categories. Categories naturally clustered into three major themes.

**Theoretical sampling.** Strauss and Corbin (1990) described theoretical sampling as the deliberate selection of participants on the basis of concepts that have proven theoretical relevance. Theoretical sampling in this study was not possible because of the small sample size.

**The paradigm model.** The paradigm model was used to assist the investigator in linking the related categories to the core category. The paradigm model is a model used in grounded theory to help the investigator determine the relationship that one category has to another and how the categories link to the key category. The paradigm model has five
components. The components of the model used to analyze the data are (a) the causal condition, (b) its relationship to the key phenomenon, (c) the context of that relationship, (d) the actions and interactions that impacted upon the phenomenon, and (e) consequences of the actions or the outcomes (Corbin & Strauss, 1990).

**Linking categories.** The categories were subsumed into three major themes. Using the paradigm model to further examine categories, links were sought between categories as well as an over arching theme that was common throughout categories. This over arching theme is known as the central phenomena. The central phenomenon or core category transcends all categories and has a relationship with all other categories.

**Process Analysis**

The linking of sequences of action / interaction as they pertain to management of control over or the response to a phenomenon is known as process analysis (Strauss & Corbin, 1990). The goal of process analysis is to give the reader a sense of the sequence of events as they occurred over time.

Through the use of process analysis, the investigator was able to conceptualize the data across phases. Throughout each phase, the same abstract categories were found that captured the experience of participants as they moved through the rehabilitation process.

**Memos.** Memoing is an important part of the grounded theory method (Strauss & Corbin, 1990). Memoing is the means by which abstract thinking and theoretical
development is derived from the data. As with sampling, the memoing process evolves with the various steps in the research process - open coding, axial coding and selective coding.

Code notes, theoretical notes, operational notes and field notes were kept as the data were collected. Memos were recorded and reviewed on a regular basis. Theoretical notes during open coding were used to guide the investigator in the development of the emerging themes. As common characteristics emerged, the investigator asked questions and actively looked for supporting data for the emerging themes. The purpose of the theoretical note has been to increase theoretical sensitivity and to give direction for further theoretical sampling. Operational notes were used as a reminder to the investigator to seek out, look for, and give direction to the next interview and/or observation. These memos included such tips as where to place the tape recorder or reminders to reinforce certain information with the participant. The field notes added contextual richness to the data.

Memos during axial coding reflected the investigator's attempts at integrating the concepts. The code notes reflected questions that were generated during the coding process such as "What is the relationship between these two concepts?" The theoretical notes reflected the data that supported the emerging theory as the core categories began to emerge. The code notes guided the direction of the field notes as the investigator probed the data and asked certain questions. The operational notes focused on suggestions for
further sampling or suggested categories or subcategories to focus on in the next interview.

**Trustworthiness of the Generated Data**

Lincoln and Guba (1985) have developed criteria, useful in determining the presence of rigor in qualitative research. Credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985) are the 4 criteria that were used to assess for rigor in this study.

**Credibility**

The term credibility is comparable to the term internal validity and is used as a measure of rigor in quantitative research. In qualitative research, the study is said to be credible when "the description and interpretation of the experience is so accurate that it would immediately be recognized by the people having the experience" (Sandelowski, 1986, p.30). As well, others reading the study are able to recognize the experience.

Tape-recorded interviews provided complete and accurate transcripts of participant responses. This eliminated any tendency toward selective recording of the data. Detailed field notes and memos were kept to add richness to data, promote accuracy of background information and record thoughts, feelings, and details of the analysis process. Participants were encouraged to tell their stories, uninhibited by hospital staff or family members. Participants were reminded that the investigator had no formal connection with the research setting so that participants felt free to share negative
comments if desired. Questions at the beginning of the interviews were open-ended. Additional questions were asked to clarify thoughts and to verify emerging themes.

Four transcripts were randomly chosen for independent coding and submitted to a committee member familiar with qualitative analysis. Independent coding ensured that the investigator was sensitive and accurate in the appraisal of the data. The identified themes were also given to this committee member. After some discussion, there was 100% agreement between the investigator and the thesis advisor.

Transferability

The transferability of findings is a term comparable to external validity in quantitative research. In quantitative research, the researcher must be confident that the findings are precise enough that they can be generalized beyond the sample used in the study. In qualitative research, the investigator's goal is to capture a specific situation, during a particular moment in time. The investigator's responsibility is to provide evidence, through thick description, that this goal has been achieved (Lincoln & Guba, 1985). Documentation that demonstrates the decision making process around the inclusion and exclusion of relevant descriptors must be provided (Lincoln & Guba, 1985). Transferability of the findings is therefore, not a judgement made by the investigator, but by the person who wishes to apply the findings. The person applying the findings must feel satisfied that sufficient data exist to support the conclusions drawn by the investigator.
**Dependability**

Dependability of the data is comparable to the term reliability. In quantitative research, reliability refers to the dependability of the data and is determined through study replication (Lincoln & Guba, 1985). In qualitative research, dependability is determined by another investigator’s ability to follow the "decision trail" (Lincoln & Guba, 1985). The study and its findings must be "auditable". In other words, another researcher would draw the same or similar conclusions from the data (Lincoln & Guba, 1985).

All data from taped interviews were transcribed verbatim to ensure accuracy. Some of the data collected in the study were coded independently by an experienced investigator (thesis committee member). Data, categories and concepts were compared and discussed with the thesis advisor.

Interviews were conducted in a consistent manner. All interviews began with the same open-ended question. Many interviews were arranged on the weekend so that the investigator and the participant were not rushed.

**Confirmability**

Confirmability of the study refers to objectivity. Confirmability is achieved when auditability, truth-value and applicability are established (Lincoln & Guba, 1985).

Prior to data collection, the investigator recorded personal values and preconceptions (see Appendix F). This process was designed to raise awareness about any bias that the investigator might possess. These preconceptions were revisited during the analysis process and reflected upon. The data were re-examined for evidence of bias.
that affected confirmability. As well, actual words and phrases used by participants were incorporated into the findings. This practice ensured that participant's experiences were represented.

**Limitations of the Study**

The findings that emerged from this study are only applicable to (a) the specific sample of participants in the in-patient rehabilitation setting and (b) the time frame within which the data were collected. The results of the study are not generalizable. As well, this study may be limited by the use of convenience sampling. Bias may exist in that participants were not randomly selected and may not be representative of the general population with regard to the experience that they described. Finally, the depth of the information that participants wished to share with the investigator may limit the results of the study.
Chapter III: Results

Description of the Sample

A total of six participants took part in the study. The sample consisted of 3 men and 3 women. Participants ranged in age from 60 years to 79 years. Three participants were married, one was single, one was divorced and one was widowed. One participant lived alone while others lived with a spouse or family member. Two participants spoke English as a second language, but were adequately able to articulate their experiences. Three participants had a primary diagnosis of breast cancer, one of lung cancer, one of multiple myeloma and one of soft tissue sarcoma. Three of the six participants had metastatic disease. The participant with multiple myeloma had diffuse disease and had prostate cancer about ten years prior to developing this current illness. The participants with lung cancer and sarcoma had no evidence of metastatic disease. One participant with breast cancer had had a prior mastectomy while in her twenties. Three of the six participants had previous experience with cancer. The three remaining participants had no knowledge of their cancer diagnosis prior to their emergency admission to acute care. Although, one person suspected that she might be ill.

All but one of the participants were significantly disabled due to their disease or the treatment. Five of the six participants were unable to ambulate at the time of admission to rehabilitation and required substantial assistance with activities of daily living and mobility. All participants had undergone surgery because of cancer and had received either chemotherapy or radiation treatments at a downtown hospital in Toronto.
When deemed medically stable, participants were transferred to rehabilitation. All but one of the six participants were in acute care facilities for several weeks prior to their arrival in in-patient rehabilitation. The participants’ length of stay in the in-patient rehabilitation unit ranged from 3 weeks to 6 months, with the average length of stay being around 11 weeks.

The Three Phases of Transition

The core concept that emerged from the data and remained a dominant theme throughout the description provided by participants was transition. Beginning with their departure from acute care, participants were engaged in a dynamic process that would eventually result in them acquiring the necessary skills to go home. The transition process featured three distinct phases: (a) taking stock of the situation; (b) looking and moving forward; and (c) preparing for home. Five key categories continuously emerged from the data. The categories were: (a) getting / staying motivated; (b) actively participating; (c) regaining function; (d) adopting adaptive behaviors; and (e) remaining hopeful. The five categories subsumed in each phase will be explained in full detail. During each of the three phases of the transition process, the five major categories and their subcategories featured data that were unique to each particular phase.

The story told by participants entailed both negative and positive experiences. In some instances data represented competing forces that impacted upon the rehabilitation process.
In the first phase of rehabilitation, “taking stock of the situation”, the story featured reflections about the acute care experience and all that had happened to participants as a result of their disease and treatment. This phase bridged the acute care experience and represented the participant's arrival in the in-patient rehabilitation unit. The process involved participant's assessing where they had been and where they were now, both functionally and emotionally. In the taking stock phase, participants described both negative and positive aspects of their experience.

In the second phase, “looking and moving forward”, participants described the progress they had made, the changes that needed to occur before they could go home and the changes they had made to overcome barriers. In this phase, the data that represented the five categories (a) getting / keeping motivated, (b) actively participating, (c) regaining function, (d) adopting adaptive behaviors and (e) remaining hopeful, were different from the first phase. This distinct difference represented a forward progression. Participants in this phase were working hard toward achieving their goals (moving forward) and could look forward to a time when they could go home. Some participants experienced set backs that competed with their goal of going home.

In the third phase, “preparing for home”, participants were: a) cautiously optimistic about their illness and its long lasting effects; b) emotionally and physically preparing for the transition to home; and c) reflecting upon their rehabilitative experience. After spending weeks, or in some cases months in rehabilitation, participants incorporated having cancer into their new reality. Although they were heading home,
participants had to deal with the reality of permanent losses, changes to their quality of life and an ever-present uncertainty about how the cancer trajectory would play out.
Transition: An analytical diagram depicting the three phases and five categories of the experience of the older person with cancer in an in-patient rehabilitation unit.

<table>
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**Phase 1**

*Phase 1: Taking stock of the situation.* The first phase, “taking stock of the situation”, described the participant’s arrival and subsequent settling into the in-patient rehabilitation unit. As part of their admission process, participants were assigned to therapists and were given an explanation of the interdisciplinary setting. Participants now
had an opportunity to assess their personal situations. They reflected upon all that had happened to them and the reasons why they were unable to go home. Taking stock included describing the experience of: a) losing functional abilities; b) finding out about their cancer diagnosis; c) feeling pain and d) facing an uncertain future. The following statements highlighted the process of taking stock.

For some participants, their acute care experience was quite traumatic. Two participants were admitted to acute care with spinal cord compressions. In both cases, participants had no prior knowledge of their cancer; although, one participant suspected a problem. “They operated and they found a tumor on my spine and they also found a mass in my breast, which I have to admit that I knew was there” (P6, I1).

One participant, although diagnosed with cancer, was required to wait six months before having surgery. He described his physical status shortly after his arrival in rehabilitation. “The body was bankrupt. I can’t hold my hand up. I can’t move from left to right. I can’t stand up” (P4, I1). The same participant had a long and tumultuous post-operative course. He continues:

After 52 days they send me here. I come here and I am very weak. Before, I can’t stand up and I can’t walk. Now, after being at the rehabilitation centre, I can walk and I’m a tiny bit stronger, but not enough (P4, I1).

Another participant stated "I wasn't able to walk and still I'm unable to walk. I can't bear any weight on my right leg" (P1, I1).
Participants had a variety of experiences in acute care prior to their admission in rehabilitation. Yet all participants described a similar process of taking stock upon their arrival in rehabilitation. Taking stock of their experience was the first phase of the in-patient rehabilitation process. The five key categories that emerged from the data: (a) getting / keeping motivated; (b) actively participating; (c) regaining function; (d) adopting adaptive behaviors; and (e) feeling hopeful will be used to frame participant's stories.

**Getting and staying motivated in phase 1.** There were several subcategories linked to participants' descriptions of what motivated them in the first phase of their rehabilitation. Participants described their fears of becoming a burden to their families and to society. Fear of becoming a burden was a very strong motivator as all participants mentioned it. Separation from family, friends and from their familiar environments gave rise to determination and motivation. A desire to resume previously established roles as spouse, caregiver, father, mother, grandmother and so on, motivated participants.

Some participants described the support and encouragement that they received from their families and from the rehabilitation staff as key motivators. One participant stated: “My daughter takes me in. So, they take me home and that makes the week, you know. Gives you more encouragement when you come back because you want to get back to the family” (P6, I1).

Participants demonstrated their motivation by setting personal goals that they wished to or had to achieve before they could go home. One participant stated her
personal goal as "I want to be able to walk and then what ever comes, I can cope with" (P1, I1). Another participants stated:

With the physiotherapy I will strengthen these leg muscles and work at getting me back to being ambulatory and may be able to take some good forward steps in returning me to the state that I like being in and doing the things that I like to do (P1, I1).

One participant whose role prior to his illness involved helping a disabled spouse stated: "I'm concerned for her that I can't achieve enough progress while I'm here, to be able to get by in the household; to not create any more of a burden for her than I already am" (P1, I1).

One participant disliked the rehabilitation environment. She stated: "When I came here, as I told you, I was rather shocked. I thought it would be more like a holiday camp" (P5, I1). She felt that the rehabilitation environment was not at all what she expected. She found the environment stressful and felt she was misled about what rehabilitation would be like. However, this participant was still highly motivated. Her goal was to be with her daughter and granddaughter in their new home.

As participants took stock of their situation, they found many factors that helped them to get, and to keep motivated. Motivating factors were described by participants in both positive and negative terms. For example, a desire to regain adequate function and get back to a level of quality of life that was acceptable was voiced in a positive way. Participants also expressed negative motivating factors such as a fear of
institutionalization. Motivation was linked to other categories that predominated throughout the phase. Active participation, regaining function and hopefulness were interrelated categories that dominated the first phase, taking stock of the situation.

**Actively participating in phase 1.** In taking stock of the situation, participants soon realized that hard work in the way of active participation was needed to meet their goals. Therefore, active participation in the rehabilitation process was another category that featured prominently in the first phase of rehabilitation. Participants were given a schedule and were expected to attend therapy, 5 days per week. Therapy sessions were one hour in length but in phase 1, participants were often unable to complete an entire session. All participants went to physiotherapy and occupational therapy sessions.

Recreational activities were available, but optional. The increased activity was a change for participants. In acute care, the focus on activity was limited by the availability of resources and the participant's ability to engage in activity. Participants described their experience: "They got one therapist for 40 people and they can't do the same exercise 'cause they're very busy" (P7, I2).

"Just two times I make exercise with the therapist [in acute care] but I was very weak. It was not enough" (P4, I1). Participants were eager to engage in activities that would enable them to return home. A stabilization of symptoms, and controlled or reduced pain, enabled participants to actively participate. Two participants reported an improvement in appetite. Fatigue was a factor in the beginning, which was a challenge for most participants. As one participant described:
Everyday I have my therapist and she gives me exercises....And it is helping but I feel very tired after exercise. I have to stay one hour in the bed. Every time, like today, I'm in the bed to have a rest. I want to stay up but it's too much. I feel no good. My body needs a break. (P4, I2).

"When I walk with the walker in the corridor, I get short of breath. I walk with the wheelchair behind me and I said please, I need a break" (P4, I1). Participants were committed to staying active, even though it was very challenging to do so. Participants described the activities that they engaged in, in the beginning stages of their rehabilitation. "At the moment, I'm learning how to dress and wash, all the general things. And then every day I go to the gym for half an hour to an hour" (P5, I1).

Participants were eager to engage in activities that would enable them to return home. Participants were expected to be as independent as possible with activities of daily living, such as washing and dressing.

**Regaining function in phase 1.** In taking stock of the situation participants began to see changes in their abilities. Some changes were minor, while others were more substantial. Participants described minor changes such as increasing strength while more substantial changes included standing or taking a few steps with a walker. Regaining function was extremely encouraging and reassuring for participants. Participants were eager to share details of the progress that they had made thus far. As earlier described, most participants experienced a marked loss of function, including an inability to walk and complete their activities of daily living. Some participants had difficulty with bowel
and bladder control. When participants began to see a return in function, they expressed hopefulness about their future. Many participants set personal goals that involved getting back to their previous level of function. By starting to achieve those goals, participants were encouraged and motivated to do more. Taking stock involved looking for early signs that they might be able to return home. Therefore, regaining function served as a positive sign that participants were moving in the right direction. One participant described regaining function as: “My legs are coming wonderful. When I came here, my legs were very wobbly, very very wobbly and now I'm on the walker. I started on the walker the other day and I can feel the strength in them” (P6, I1).

Participant stated:

With the occupational therapist, I like to get up on a chair or a bench. It's not as difficult as it was. Before, I was like a dead weight. But the two of you got me up, and I can't get up by myself but I got up without too much difficulty. And I think that's the progress so far. And my appetite has been good (P3, I1).

"They really give you a good work out here. My legs are a lot stronger than they were” (P3, I1).

In phase 1, participants began to actively participate in therapy. Although the transition was gradual, participants reported some immediate improvements in their functional abilities. The major category, actively participating, was linked with the regaining of function.
Adopting adaptive behaviors in phase 1. Taking stock of participants’ situations involved thinking ahead about how certain tasks and roles would be handled in light of the participants’ loss of function. Participants were exhibiting adaptive behaviors in the first phase of rehabilitation. Adaptive behaviours are behaviours that individuals have changed because of the limitations experienced by them. Adaptive behaviours included activities such as planning household chores and accessing participant’s homes that were not barrier free. In phase 1, adaptive behaviours were at a cognitive level. Participants were planning their adaptive behaviours and thinking ahead to how they might cope with certain activities and situations. One participant, whose spouse was disabled, described how they had planned to manage some of the household chores:

The garbage has to be put out but she can't carry it and there is a risk to letting her do so. She really has to put it on a garden creeper cart and then pull it to where the garbage men can pick it up (P1, I1).

In taking stock of their situation, not only were participants thinking ahead, but were realistic in their self-appraisal about their future. It was clear that they expected changes in function to be long lasting, which they were, if not permanent. Some of the adaptive behaviors involved spouses and involved a role change for the spouse. One woman who lived in the Snow Belt described how her spouse had to adapt to her change in mobility. “He wants to buy a little snow blower because we've just got a little sidewalk that goes right up to the cottage and it's just the deck that you have to clean off” (P6, I1).
Taking stock, was a source of stress for some participants. Not all participants had significant others to help them to adapt. Some participants had significant others who were in no position to help. For some participants, adapting to new situations involved a role change for them and their spouse. There were varying levels of comfort with role changes that seemed dependent upon a variety of factors. Thinking ahead to how participants might adapt to certain situations created uncertainty and anxiety for some. One participant described:

My wife has some problems of her own. She has rheumatoid arthritis and it makes it very difficult for her to do certain things involving strength and the use of her joints; lifting and bending and things like that. So, from that point of view it's been very difficult. She has some misgivings about being able to care for me in my present state....which I think is probably correct because the house in which we live...we would have to switch to something that has a little more freedom for a wheelchair patient. I don't think I can get around in a wheelchair at home (P1, I1).

Taking stock of their situation prompted participants to think about how they might adapt their behaviour in their new and challenging circumstances. In phase 1, adaptation was primarily at the discussion phase as participants were not in a position to implement their plans. As well, uncertainty about the amount of functional gains that participants would achieve made it difficult to predict the scope of the adaptive behaviors that they would eventually adopt.
Remaining hopeful in phase 1. Although participants expressed feelings of uncertainty, these feelings were frequently offset by expressions of hopefulness. Participants had taken stock of their situation and were hopeful about a variety of things including being able to go home, to walk again and resume a quality of life that was acceptable to them.

Being transferred from acute care to rehabilitation was, in and of itself, a situation that promoted feelings of hopefulness. A participant reported: "If we make it, I hope to get back to a life that is enjoyable and fun. If we can't, well, I don't know what I'll do, deal with it then I guess" (P1, II). The same participant later stated:

I hope to gain some results from the methods of the rehabilitation. I've been admitted. I'm starting on Monday on the program that they've developed for me, depending on my leg, and what the doctors say about my leg (P1, II).

Another participant stated:

I'm a fighter, and as I said, my main priority when I heard about everything is my legs. I'll deal with the rest, whether it comes, but I want to have my independence to deal with it, you know what I mean? (P6, II).

In phase 1, taking stock of the situation entailed getting motivated to participate in the in-patient rehabilitation program. In doing so, participants began to actively participate, and see some positive changes in their functional ability. Although there were expressions of uncertainty, participants felt hopeful and encouraged by the signs of improvement that they were able to observe. The change process was apparent
throughout as participants settled in to the rehabilitation environment and began to lay the groundwork for achieving their goals. This experience represented the first phase of rehabilitation and gave rise to the next phase, looking and moving forward.

**Phase 2**

**Phase 2: Looking and moving forward.** In the second phase of rehabilitation, looking and moving forward, participants progressed to a level of physical and emotional well being that made the goal of going home appear more feasible. Adaptive behaviors were now more concrete and definite plans were under way to address problems related to going home. Symptoms such as pain and fatigue prevailed, but were becoming more tolerable. Participants were working hard, making gains and overcoming barriers to going home. For some participants, progress was interrupted by the progression of cancer. Many participants described a strain on themselves and their family created by transportation problems and the prospect of permanent role changes and losses. Although the future seemed more certain for participants, they still expressed feelings of vulnerability.

**Getting and staying motivated in phase 2.** The rehabilitation environment and the staff who worked there played a key role in helping participants to get and stay motivated. The rehabilitation environment placed different expectations on participants than that of acute care. Participants were expected to function at their highest possible level of activity. For example, participants who were now able to transfer to a commode would not be offered a bedpan. Participants were given a schedule and were expected to
attend therapy on weekdays. There was an understanding that even if participants were not able to participate for the full hour, they were still expected to attend a portion of their session. One participant described how she was motivated to participate:

They push you. If you did some leg exercises, that you did fairly well, they say try 40 or 50, or just a few more, you know. They give you a good push. They're excellent. And then if you do have your bad days, they don't push. Like sometimes the treatment bothers me and I'll say, I'm not feeling that good today. "Well, do the best you can", [they say] (P6, I1).

Another participant talked about how hard she worked in therapy:

I never missed out on anything. You can't think, well I have a headache today, or I'm sleepy or something, because it doesn't help your body. That doesn't reconstruct your body you know. You have to keep at it (P3, I2).

Another participant gave his impression of the rehabilitation setting. "The general atmosphere in the whole place is geared toward rehabilitation and gaining that physical stance" (P1, I1).

Participants described the relationship that developed with their therapist and how encouraging and supportive they were. Participants got a message, both implicitly and explicitly, that rehabilitation would benefit them. One participant expressed:

The therapists...I don't think they would be working on me if they didn't think I could walk, and I've shown a great deal of improvement and if I'm walking on the walker, then they seem to think I'm going to walk (p6, I1).
Families and significant others as well, played a key role in fostering motivation. Going home for weekend passes, and frequent contact at the hospital, were described by participants as being helpful and supportive. One participant described her feelings. “I can’t wait to get home and start exercising. They’ve got me in the pool and it’s really helped. I’m going home [for pass] and I think you can do better at home” (P6, II).

Two of the six participants had strained relationships with their families. For those individuals, motivation was still present. One participant was fearful that discharge home would be impossible. For him, the possibility of having to be placed in a nursing home was a significant driving force, which kept him motivated. He stated: “She [his wife] has some misgivings about being able to look after me in my present state” (P1, I).

Another participant had a court date pending to hear a property dispute involving his daughters and the ownership of, what was once his home. He had friends and an ex son-in-law who were supportive but he wanted to have his day in court and was working very hard to ensure that he got it.

Another factor that participants described as motivating was observing the progress of other patients in the in-patient unit. Being a part of the in-patient rehabilitation unit exposed participants to people with a variety of medical conditions that lead to their admission to rehabilitation. Hence, participants did not feel alone or isolated because of their limitations. The cancer was not a focus of their admission. The focus was on changing the functional limitations so participants could return home. One participant described her experience:
I was down there [in therapy] for about three days, seeing this ninety-year-old Chinese woman, sitting in a chair. She had an artificial limb from her knee down to her foot. And he [another patient] kept telling her to get up and she kept shaking her head "no". So about the fourth day, this man got up on the bars and he was in the same situation. She was watching and they told her to get up and she walked right across the floor in a walker. I couldn't believe it, ninety years old. I clapped my hands. I think I was the only one, but I clapped my hands. She had to see if it could be done before she got up; and she smiled, quite pleased with herself (P6, I1).

Getting and staying motivated in the second phase of their rehabilitation was multifactorial. There were both internal and external forces that gave participants the encouragement and support that they required. Although there were similar motivating factors in the first and second phase, there was also a notable shift. Participants seemed less focused on their fears, such as becoming a burden or being placed in a nursing home. The focus shifted to moving forward with their rehabilitation goals and looking forward to going home.

Active participation in phase 2. Active participation in phase 2 featured hard work on the part of the participants. Diminished symptoms were an indicator that the disease process was under control. Participants began to feel well enough to participate in the rehabilitation program, which allowed them to look forward to the future. One example from the data is as follows: "Since I been here, for the pain that I used to have, I
don't have much pain now, like before, so I would say that everything is improving” (P2, II). A reduction in symptoms such as pain, nausea and fatigue allowed most participants to engage fully and actively in the program. As well, two participants reported improved appetites and improved sleep patterns. Although most participants felt a substantial improvement in their ability to participate, there were still some symptoms that remained problematic. Two participants experienced fatigue and shortness of breath. One participant was unable to complete a full session of therapy without stopping to rest. Activity tolerance remained poor, even at the time of discharge. For this participant, age and a low haemoglobin played a role.

Some participants had interrupted stays in rehabilitation. Re-admissions to acute care for symptom management or cancer related problems were an unwelcome reality for two participants. One participant was admitted for reinforcement of a lytic lesion on the femur. He had more than 50% bone loss on his femur and the possibility of a pathological fracture was very real. For this participant to learn to walk again, the lesion had to be re-enforced. This same participant had to have emergency radiation for a tumour affecting his vision. Another participant was admitted for drainage of her arm, which became swollen due to obstructed lymph nodes. Length of stay, as well as morale was affected by interruption in rehabilitation. One participant stated:

When one can't walk, that's bad enough, but then with my vision was affected, it certainly didn't make it any better to see two objects every time I came into my room. I guess I'll find out through the application of the treatments where we go
from there but anyhow, the feeling is a sinking feeling naturally when one feels that possibly ones life has taken a turn for the worse, which I'm sure it has and I wonder what to do (P1, I1).

As well, frequent appointments and follow-up visits for bone scans, CT scans, appointments with oncologists and radiation specialists took time away from their rehabilitation programs.

The structure of participants’ homes resulted in most of them being confined to the hospital until they were able to climb stairs. Physical barriers delayed participant’s ability to apply his/her newly acquired skills in the home environment. One participant was able to go home for weekend passes prior to her discharge. One participant was physically well enough to go for weekend passes but had no where to go at the time because of property dispute with his family.

During the second phase of their rehabilitation, active participation was a key category that emerged from the data. Participants were able to participate due to a reduction in their symptoms, which lead to a general feeling of well being. However, for one participant, length of stay and moral were substantially impacted by all of the problems that he encountered. Active participation in phase 2, looking and moving forward, was naturally linked with regaining function. As participants felt better and were able to actively participate in their program, they began to make functional gains and achieve their goals.
Regaining function in phase 2. With few exceptions, participants began to regain function in leaps and bounds in phase 2. As previously mentioned, only one participant was able to walk upon arrival to the in-patient rehabilitation unit. In the second phase of their rehabilitation, participants began to walk with assistance and even return to their baseline with some activities. Regaining function signaled an ability to overcome barriers such as stairs. One participant, who lived in a barrier free apartment, was still eager to be able to navigate stairs because her bridge club was in a church basement. One participant expressed his satisfaction. “After 40 days, I can go six stairs up and six stairs down. Yes, it was great for me. That was only [a] dream” (P4, I2).

Another participant explained how she worked and achieved a previous level of function:

They made you work your legs, you know, and arms and all of this. So, when I came here, it took two people to get me up from a chair from a sitting position.

But now, I can get up from the chair myself, you see (P3 I2).

Regaining function also meant that participants could be less dependent on their families, friends and significant others. Participants were seeking and accepting support from families and friends, which resulted in time and effort for most of the significant others. Even though the support was willingly provided, participants expressed concern about the toll their illness was taking on the rest of the family. Families spent time commuting across the city or from towns outside the city to visit their family members. Only one participant was able to go out for weekends. Her family spent time providing personal care, gathering equipment and organizing changes that were needed at home.
One participant described her situation. "He's [her husband] doing fine. I think he feels better that I'm coming home. It's a long drive for him to come here and he doesn't very often miss a day" (P6, I2).

Participants were grateful for the help of others. However, the help that they received served as a constant reminder that they were unable, perhaps permanently, to resume their previous roles:

Prior to coming down with this cancer, which hit me overnight by the way, I used to help her [his wife] around the house. I used to do the cleaning, the vacuuming and things like that....putting out the garbage. All those things that I suppose men do around the house when they’re married and now she finds herself unable to perform any of those tasks. (P1, I1).

This participant had particular tasks around the house that he was responsible for. He was unable to regain his baseline level of function. In his second interview he states:

I'm not much more capable of contributing to things in the household than I was. I can look after myself better, but my wife, for instance, who needs help because of rheumatoid arthritis....I'm afraid I really can't be of help to her (P1 I2).

This same participant did feel he had regained enough function to be able to drive a car. He stated:

I don't think my eyesight will have any bearing on my driving at the present time.

The only thing is my leg is a little sore. Whether I'd have difficulty jamming on
the breaks in an emergency, I don't know, but I'll also take that as it comes...maybe wait a little until I feel my leg is stronger with use (P1, I2).

Participants had mixed results with regard to the successes that they hoped to achieve. In phase 2, it became clear how much function would be regained. As they moved through the phases, participants began to work through the fact that all aspects of their function had not been regained. It was unclear whether functional gains would be made after discharge. Hence, participants progressed to the next step of looking and moving forward, adopting adaptive behaviours.

**Adopting adaptive behaviours in phase 2.** In phase 1, participants began thinking about how they would adapt their behaviour, should it be required. In phase 2, participants had made more concrete plans about how adaptation would be achieved. Participants had to consider many aspects of life, including recreational activities, mobility, accessing their homes and doing other household chores. For some participants there would be minor changes required, while for others, adaptive changes were much more substantial. Adaptive changes involved families as well as participants.

One participant who lived with her family provided funding toward the purchase of an accessible house. She explained:

Before, it was terrible really. I had to go out 28 steps to get into. And then 28 after you went through the door to the upper floors of the apartment, so every time I went, L. had to lug the wheelchair up and down all those stairs. It was pretty bad, whereas now, we've got the wheelchair in the garage and 4 steps to get to the
garage and 4 steps to get from here up to the ground level, which I can do with
leaning on the handrails (P5, I2).

This was a major adaptive change but a necessary one.

Another participant adapted by accessing privately purchased support for him and
his wife. He states: “My wife hired a lady who was with the home care program. She
hired her privately to do the house cleaning” (P1, I2). This participant was the primary
caregiver for his spouse and realized that he no longer could manage in the same way.

Of benefit to one participant was the fact that she was able to go out for weekend
passes. She was able to try some of the adaptive behaviors in the home. Her family
installed a ramp at her daughter’s home so that she would be able to go home for
weekends. “It’s been three months for me. [My daughter] has my own bedroom for me
and my own little room…and I can get up the stairs. I bum up the stairs” (P6, I2).

Another participant describes his adaptive behaviors:

In my case with a mobility problem, I had to learn to climb the stairs and there’s a
way to do it. If one follows the methods that they teach, it’s much easier to climb
and descend the stairs than if one tries to do it naturally (P1, I2).

Participants gave consideration to recreational activities that they had previously
been engaged in. Prior to their illness participants had engaged in activities such as
gardening, playing bridge and cooking. Along with other adaptive behaviors they had to
rethink how they might have fun when they leave hospital. Participants concerned
themselves with the quality of life that they would have once at home. One participant
described how she had made some changes due to a permanent change in mobility:

I belonged to the 55 plus club at ____ but there, I can't go back down there because there are stairs and I can't do stairs. And I was told not to because I could tumble and bring everyone else along with me. But at the K.B. club, there are no steps (P 3, I2).

In phase 2 of their journey through rehabilitation, participants became aware of functional limitations that would require them to adopt adaptive behaviors. Adaptive behaviors spanned such activities as role changes, moving to accessible housing and planning recreational activities. Adopting adaptive behaviors represented a compromise for participants. Activities would have to be modified but not entirely given up. In spite of the gains not achieved, most participants expressed hope about the future.

**Remaining hopeful in phase 2.** Phase 2, looking and moving forward, was a phase that represented progress toward the ultimate goal of going home. As participants progressed through the looking and moving forward phase of their rehabilitation, they began to appraise the losses and gains, affecting many aspects of their lives. Throughout this phase, many expressions of hopefulness were present in the data. Expressions of hopefulness ranged from statements of cautious optimism about the future to extreme gratitude for the progress made thus far in their rehabilitation. For some participants, the experience in acute care was quite traumatic. Engaging in the rehabilitation process afforded them an opportunity to put the experience behind them and to start looking
forward. One participant expressed: “I hope I can forget everything. This is my vision. To forget everything and to think about what I was [like] before” (P4, I2).

Another participant stated how she couldn't envision getting better until she had spent some time in rehabilitation:

Since January, I've been a bit of a nightmare. And I could just visualize me...I could see me lying in bed with all of this but I couldn't take that picture away from me for a few days. And now that I can see that it's not that way now...that's not it! And so now, this picture is fading away of all this bad stuff, you know, that happened there. Because you know, it was a nightmare. What else could you call it (P3, I2).

Going through the rehabilitation process gave participants hope about their prognosis and possible outcome as well:

I tried to put on a happy face, so to speak. In other words, I tried to have a little faith in the outcome. I told myself that if one lives or dies, it is sometimes a matter of luck. I would hope that things would turn out favourably, and I tried not to dwell on the possibility that things would not turn out favourably. So, I may be deceiving myself a little, but at the same time, one has to have faith in the ultimate outcome or there's not much point in going through treatments and physiotherapy and so on if one does not believe there is going to be some improvement (P1, I2).

Another participants stated:

Well, I lived with the possibility [of having cancer recur] for quite a few years.
There was hope in me that I would get it all, and immediately this is when the urge to change my life around "survive" (P3, I1).

For some participant, the hope that was expressed centred on a hope for more functional improvements: “Hopefully it won't be too long and I can go home without the walker” (P3, I1).

The expression of hope during the looking and moving forward phase of the rehabilitation process indicated that participants were able to put some of the trauma related to their diagnosis and treatment in acute care behind them. They hoped to reap the benefits of rehabilitation so that they could move through to the next phase of their journey, preparing for home. The category, feeling hopeful, was linked to motivation and participation.

Again, during phase 2 the categories were interrelated and together, representing a dynamic change process. For some participants it took several weeks to achieve and for others, it took several months. All participants were working through physical and psychological processes that constituted a transitional phase.

Phase 3

Phase 3: Preparing for home. All but one of the participants stayed in the hospital for the duration of their rehabilitation. One participant who did go out for weekend passes went to her daughter's home and not to her own home. One participant had not been home for more than six months. One participant was unable to go to his home because of a legal issue involving his daughters and his family home. Upon
discharge, he would go to live with his former son-in-law. One participant was interviewed post discharge at her daughter's home in Scarborough. She had been home about three days at the time of the interview. Participants were facing a variety of discharge situations in phase 3. Regardless of their situations, all participants were making plans about the things that they would do when they reached home. Some plans were specific and some were more general. Although discharge situations were different for participants, there were similarities that emerged from the data. The data clustered into the five major categories: (a) getting and staying motivated; (b) actively participating; (c) regaining function; (d) adopting adaptive behaviors; and (e) feeling hopeful.

In the third phase, "preparing for home", participants were able to look back upon their rehabilitation experience and see how far they had come. They began to envision themselves at home, coping with their limitations, adapting to situations and trying to adjust to the changes. Preparing for home meant participants were giving thought to how their time at home would be spent. Participants had clearly moved beyond the daily routine of attending their therapy sessions and were now making plans for getting and being at home.

Getting and staying motivated in phase 3. In phases 1 and 2, participants were setting personal goals and were motivated to work hard at achieving their goals. One of the key motivating factors for participants was to overcome the barriers that would prevent them from being discharged home from hospital. By phase 3, participants had
overcome many barriers and were ready to leave the in-patient rehabilitation setting. In the category, getting and staying motivated, participants changed their focus from issues related to ambulation and activities of daily living and centered more on quality of life issues. The quality of life issues that participants concerned themselves with focused on needs, such as recreational activities. Now, they were motivated to resume certain other familiar aspects of their life, such as travel.

One participant described his plans:

We'd like to spend our remaining, or declining years without too much physical difficulty...go places, do things, nothing terribly physically demanding, but a little travel, a cruise, a trip abroad or something like that would be nice (P1, I2).

This participant had multiple myeloma and had quite a severe disability upon admission. After 6 months of complications, set backs and uncertainties this participant was starting to think about future recreational plans.

Another participant described her plans. “Well, my husband says when I'm mobile, we're going on a cruise, a Mediterranean cruise. I don't know. We'll have to wait and see” (P, I2). This participant as well had quite severe physical limitations upon admission. She did not sound as confident about travelling at this time. Cautious optimism was again evident in her approach.

Other participants had less elaborate plans:

I'm going to try not to stay too much in the bed. The front of the house, it's got a
big window. You can see the people walking and the neighbours coming and going. I'm going to enjoy it like that, to pass the time. I've got a yard. I can't go outside yet but I'm going to watch the pigeons and the birds eat (P4, I2).

The simple pleasures represented in this participant's statement exemplify the activities that he hopes to engage in once he is at home.

"And then I may pick up bridge again. I would like to play with some that are not just out for points, but for the pleasure of the game" (P3, I2).

Another participant was unable to think about any recreational plans until she had secured landed immigrant status. She stated:

No, I can't think about it [making plans] until I know if I'm going to be staying. You can't plan if you've not heard after all these months whether you're going to be allowed to stay in the country (P5, I2).

Her situation was unique because of her social circumstances. She experienced added stress due to her uncertain future with regard to her immigration status.

Participants were discharged when they were able to ambulate adequately enough to overcome barriers to going home. Some participants were not at the activity level that they aspired to at the time of their discharge. They were motivated to improve their present situation and to reach a higher level of functional ability. One participant intended to achieve her goals by continuing her therapy at an outpatient rehabilitation program after her discharge:
I really wanted to be walking on the cane before I left, but then when they said that where I'm going [for] the therapy I'm going to get, that they can do that for me, then I'm fine with it (P6, I2).

Family support and the support of significant others continued to be a motivating factor for participants. Participants, who had experienced the support of family and friends throughout their illness and recovery, continued to be motivated to improve their function. One participant expressed: “Oh ya, I'm going to get better. You can't let it get you. You live with it and you do the best you can with it. Especially, if you have your family behind you” (P6, I2).

For a variety of reasons, there were varying levels of family support for participants. All, however, did identify some degree of support from family or significant others.

One participant was single and had no children. This participant had made plans that included the help of friends, but she did not wish to have to depend on them too much. Motivation that was fuelled by the fear of becoming a burden to others was a common thread throughout all phases of the transition process:

I don't have that many friends, but I have a few good friends. I hope I get a scooter. I don't know whether I will or not...to be able to go out on my own without depending on people to come and get me. They've got their lives to live. They have their things to do, you know, their obligations and what not (P3, I2).

In phase 3, getting and staying motivated was still a prominent theme in the data.
However, the focus of the motivation was on getting back to some degree of normalcy after having cancer and experiencing function deficits.

**Actively participating in phase 3.** In phases 1 and 2 of the rehabilitation process, participants were working through their symptoms and moving toward a level of active participation in hopes of achieving some functional return. By Phase 3, many symptoms, such as pain and nausea had improved substantially. Symptoms no longer interfered with day to day participation in activities of daily living. They were still present but for most participants symptoms had diminished substantially.

One participant described how his pain and other symptoms had improved:

I'm still taking some morphine, but it's been reduced to one quarter of the original amount. It doesn't seem to effect me too much mentally anymore, as it did originally. Initially too, I had hypercalcemia, which I understand occurs when the cancer eats away at the bones, it releases calcium into the blood stream. And excessive calcium in the blood also makes one dizzy and definitely confused. And of course, cutting down on that is a big help; I'm sure (P1, I2).

Exercise tolerance and fatigue levels also improved for most participants: although, two participants did continue to complain of fatigue. For one participant this problem was expected to improve over time, while for the other participant, fatigue would likely get substantially worse due to his illness and prognosis. Another participant who experienced edema in her arm and had to have it drained, was now controlled on diuretics and had improved mobility in her arm. Hence, in phase 3, participants had
progressed to a much more tolerable level of symptoms, signifying a readiness to go home and a feeling of wellness that they had hoped to gain by the time of discharge.

Participants were very actively involved in the discharge planning process in phase 3. They were aware of what services and equipment would be required at home. Transportation was arranged and plans were made. One participant had planned what she would eat for her first meal at home. Directions were given to families about how to prepare and get the necessary equipment. There was a sense of excitement and anticipation on the part of participants. One participant described the flurry of activity at her home:

My husband and son-in-law built me my own door. They worked it out for me... and then my other daughter; she's going to build a ramp for her door because it's awful hard when you go visiting. You have to take your ramp [and] your commode, you know. All of these things (P6, I2).

Active participation on the part of families, significant others and participants themselves was apparent during the preparing for home phase. Although families and friends were involved throughout the entire process, participation was intensified at this time.

Regaining function in phase 3. In phase 3, as participants began preparing for home, they looked at changes in function in a different way. In phase 2, participants looked at regaining function in terms of the barriers that needed to be overcome before they could go home. They talked about mastering the stairs and walking with a walker.
Participants with obstacles at home were focused on these barriers, because going home was a primary goal. Now that these goals were achieved and it became clear that participants were able to go home, regaining lost function was viewed more as a continuum. Participants could now ambulate and go up and down stairs. However, they wanted to be stronger, faster and more confident in their abilities. One participant stated: “I'm going to be all right. Then when all the strength comes back...it's not all back...I'm still a little shaky” (P6, I2). Another participant spoke about her approach to her therapy. She felt that the harder she worked, the more she would be able to achieve. She stated:

I think when I worked, I worked very hard you know. I worked long hours and I did work too hard. I think the same thing applied to the physio...that I was going to get everything I could out of it to get better, you know (P3, I2).

Participants believed that they would continue to improve following their discharge and that home was the best place for them to be. Whether or not participants did continue to improve and to what extent, is beyond the scope of this study.

**Adopting adaptive behaviours in phase 3.** In phase 3, those participants who had not regained the degree of function that they had hoped for planned how they would alter their activities to suit their current level of function. In preparing for home, participants were anticipating the changes in behaviour that would be necessary. Some participants had very specific ideas about activities while others seemed to want to get home before making any definite plans.
Participants shared their ideas:

I can't conceive of myself doing too much that's physically demanding at the present time because I still have a limp and I still have leg and back pains. I've thought about acquiring a computer and spending some time with that. I find that very interesting so that's one thing that I may do (P1, I2).

Just one time per day, I'm going downstairs to the basement to change a little bit...you know... from upstairs. I go one time downstairs to stay for two hours and I stay on the sofa. I'm going to stay on sofa and watch T.V. and watch a little bit, the back yard. We need it time to be stronger. You can't be stronger at home in one week or two weeks (P4, I2).

The adaptive behaviors that participants engaged in seemed to be realistic. Their approach to what it would be like for them at home was based on the reality of the situation. Although participants were still hopeful that they would get stronger, participants were preparing themselves for a changed approach to their behaviour at home. One participant described having to "bum" up and down the stairs until she was able to manage in a different way. This method is commonly taught to people who have some mobility but who are limited by weakness. Adaptive behaviors were a theme that prevailed throughout the data but as with other categories, evolved to reflect the current situation. Now those participants were about to go home, adaptive behaviors reflected their plans in their home environment.
**Remaining hopeful in phase 3.** In phase 3, participants continued to express feelings of hopefulness. As with the other categories in phase 3, participants’ expressions of hope focused on the future. In earlier phases, expressions of hopefulness were focused more on the physical tasks that would allow them to go home. Now that those tasks were achieved, participants were hoping for some quality of life as well as some length of life. Some participants were still awaiting follow-up test results to determine if they had responded to treatments. Although they maintained fairly optimistic attitudes, they were also realistic in their appraisal of the situation. Several participants had metastatic disease and knew that their prognosis was guarded.

Expressions of cautious optimism continued to dominate this category in phase 3. One participant stated:

> I don't know what the future holds for me. None of us do I suppose? But when you've been through an illness like this, you can't possibly know what the future holds. So, I'll just try to take things as they come and try to remain retired

(P1, I2).

Another participant stated: “I've got a few years yet. I've got too much to see. I'm just starting to retire, you know what I mean?” (P6, I2). Both participants mentioned retirement. Clearly, participants felt that cancer hit them at a time in their lives when they should be able to enjoy their grandchildren, their freedom and so on.

Participants were hopeful about their potential for physical improvements. As stated earlier, participants were discharged when they were able to successfully overcome
barriers to going home. Most participants were hopeful about achieving a level of function that exceeded the level that they had upon discharge. "I hope I continue to improve and be more capable physically. At the moment though, I do have restrictions and climbing and descending stairs is a big problem" (P1, I2).

Throughout the phases participants remained hopeful about the future. In the third phase, however, there were differences in the statements that participants expressed. The statements reflected thoughts about the future and a sense that every moment of life would be cherished in a different way.

In summary, participants were engaged in a dynamic process that occurred over time and involved a transition. There were several themes that emerged during the analysis process. The data were clustered into three phases and five major categories. The three phases were: (a) taking stock of the situation; (b) looking and moving forward; and (c) preparing for home. The five major categories were: (a) getting and staying motivated; (b) actively participating; (c) regaining function; (d) adopting adaptive behaviours; and (e) remaining hopeful. Although the transition was an iterative process for participants the phases were reported in a linear fashion for the purposes of clarity.
Chapter IV: Discussion: Integration of Findings with Prior Literature

As part of the grounded theory methodology, it is important to integrate the findings with the existing literature (Glaser, 1978). A review of the literature, after data are collected and findings are written, may validate study findings or may be used to point out how findings differ from a body of research (Strauss & Corbin, 1990). The findings should fit with and build upon the prior work of others in the area of interest (Strauss, 1987).

In this present study, grounded theory methodology was used to examine the process that older persons with cancer experienced in an in-patient rehabilitation program. The process that participant’s experienced was an iterative and non-linear one; but for the purpose of clarity in describing the findings the results were reported as such.

Participants were engaged in a dynamic process that occurred over time and involved a transition. The time frame under consideration began with participants’ arrival in the in-patient rehabilitation unit and evolved to the point where participants were departing for home. The data naturally clustered into three phases: (a) taking stock of the situation; (b) looking and moving forward; and (c) preparing for home. The phases consisted of five major categories: (a) getting and staying motivated; (b) actively participating; (c) regaining function; (d) adopting adaptive behaviours; and (e) remaining hopeful.

In grounded theory methodology inductive and deductive methods of data analysis are used to assist in the identification of themes. As participants told their stories,
it became clear that their lives and circumstances held little similarity. However, despite these differences, participant accounts of their thoughts, feelings and actions were similar. These similarities constituted the description of the transition process that participant’s experienced.

Cancer is primarily a disease of older persons. Improved methods for early detection of disease and advances in treatment are changing illness trajectories for many individuals with cancer. As the population ages and advances in cancer treatment prolong lives, the quality of those lives will become paramount. There will be an increased demand for the services that help promote quality of life as well as the prolongation of life. Understanding the process that older persons with a cancer diagnosis go through to achieve an improved quality of life is critical for health care providers. The story that emerged formed the basis for the description of the transition process that has added to our understanding of the experience of older persons with cancer in rehabilitation.

A search of empirical and theoretical studies existing in the literature was conducted to examine the relationship of the current findings to the existing body of knowledge. Literature in the areas of transition, motivation, adaptation and the use of hope as a coping strategy were revealed. As well, the results of this present study bear similarities to the literature reviewed prior to the collection and analysis of the data. These similarities are also highlighted in the discussion.
Transition was the key phenomenon that emerged in the findings of this present study. Although the area of oncology rehabilitation is relatively new, the concept of transition is one that has been of interest to a variety of disciplines spanning a period of more than two decades. Several studies were found in the area of transition as it pertains to phases of human behaviour following a major life-altering event such as experiencing a loss of function due to cancer. Authors have described transition in a number of different ways. Schlossberg (1981) defined transition as "an event or non-event that results in a change in assumptions about oneself and the world and thus requires a corresponding change in one's behaviour and relationships" (p. 5). Schlossberg included non-events, as well as events, in the definition. She explains that the failure of expected events to occur may also result in changes in assumptions and behaviours. Levinson, Darrow, Klein, Levinson, and Mckee. (1977) defined transition as "a turning point or boundary between two periods of greater stability" (p. 208). Transition has also been defined as "any change that has important consequences for human behaviour." (Spierer, 1977, p. 385). Chick and Meleis (1986) defined transition as "a passage or movement from one state, condition or place to another" (p. 238).

Weiss' (1976) work on transition included the concept crisis as a component of the definition. Crisis is described as "a severely upsetting situation of limited duration during which the individual's resources must be hastily summoned" (Weiss, 1976, p.143). Weiss goes on to say that if change occurs, "the individual moves into a transition state; a period marked by relational and personal changes, including attempts to deal with
upset, tension or fatigue and attempts to find new sources of support" (p.144).

Participants in this current study also described a crisis situation that occurred when they received a cancer diagnosis prior to their admission to rehabilitation.

The many descriptions of transition found in the literature bear similarities to the study findings. All definitions include the key component, change. Transition is precipitated by a major event. It results in alterations in the ways one thinks, feels and behaves. Most authors agree that transition may result in positive and negative outcomes (Weiss, 1976; Moos & Tsu, 1976; Lieberman, 1975; Chick & Meleis, 1986).

For the participants in this present study, becoming ill with cancer and losing substantial functional ability constituted a major event. For most participants the cancer diagnosis and the associated disability came rapidly and unexpectedly. Receiving a cancer diagnosis and spending weeks and months recovering from the cancer and its treatment constituted a life event of dramatic proportions for participants. Even following their admission to the rehabilitation unit, participants remained focused on the crisis of finding out about their cancer diagnosis and experiencing the loss of functional ability associated with it.

Weiss' (1976) work in the area of transition further supports the findings in this current study. In Weiss' study crisis marks the first of three stages in the transition process, which he described as a severally upsetting situation of limited duration, or crisis. Weiss described the second phase of transition as "a period marked by relational
and personal changes, including attempts to deal with upset, tension, or fatigue, and attempts to find new sources of support" (p.145)

In the second phase of the transition process in this present study, participants were engaged in a change process. Participants were engaged in a variety of activities that fit well with both authors' descriptions of the second phase of transition. Participants' descriptions included a great deal of upset, tension and fatigue. Participants expressed worries about their ability to go home and to have a satisfying quality of life. They worked through symptoms of fatigue and pain. Rehabilitation staff provided a source of support, as did their families.

Levinson's et al. (1977) description of transition included a movement toward a point of greater stability. The data representing the third phase of the transition process in this present study is comparable to Levinson's description. Although participants were not completely back to their baseline level of function, descriptive data in the third phase did support a condition of greater stability compared to the time of admission.

Weiss' (1976) description of "a stable new life organization and a stable new identity" (p. 147), in the third phase of transition, differs from the reality described by participants in this present study. Although the third phase, preparing for home, marked a point of greater stability for participants: the concept of a stable new life organization and a stable identity are not consistent with the findings in this present study. This investigator believes that participants may eventually reach the state of stability described by Weiss provided that their disease does not progress. The investigator believes that
results similar to Weiss’ study may have unfolded if data were collected over a longer time period.

There are also similarities between the findings in this present study and the qualitative study by Farrel and Hassey – Dow (1996) that examined the experience of the cancer survivor. Three phases of transition were described in Farrel and Hassey-Dow’s study: (a) rendering the old life (b) transition to a different life and, (c) living with an altered life. Rendering the old life entailed going from being an active, productive individual to facing a life threatening illness. Participants in this present study gave similar accounts of how they had suddenly become ill with cancer and the emotional trauma that accompanied the experience. In phase 1, taking stock of the situation, participants reported in detail, their experience in acute care. The second phase and third phases in this present study were similar to the “transition to a different life” phase described by Farrel and Hassey-Dow. Farrel and Hassey-Dow reported the physical and emotional hardship that cancer survivors experienced but eventually reached a state of feeling victorious about successfully coping with a life threatening illness. Participants in this present study reported similar feelings as they prepared for home following a challenging experience in rehabilitation.

Motivation was another important concept that emerged from the data. Getting and staying motivated, was a category that continued throughout the three transitional phases. Participants engaged in activities that precipitated the necessary changes for transition to occur. Without the motivation to engage in the activities transition was
unlikely to happen. Therefore, the concept of motivation shared an important link with the key concept, transition. Another strong motivator was the rehabilitation environment itself. There was an expectation of participation by virtue of participant's presence in rehabilitation. Participants were expected to participate even when they did not feel 100% well. Participants were pushed to do as much as they could instead of withdrawing from the session entirely. Participants spoke positively about his approach and were encouraged to work harder and to do more, which they reportedly perceived as beneficial.

In reviewing the literature, the work done by Ajzen (1991) on the Theory of Planned Behaviour, shares certain similarities with the findings from this present study. Ajzen's work proposed that the central determinant of behaviour is the person's intention to perform the behaviour. Intention is composed of three independent variables that are attitude, subjective norm and perceived behavioural control. The Theory of Planned Behaviour proposes that individuals will perform behaviours that they: a) evaluate to be positive; b) believe to be important by others whose opinions are valued; and c) perceive to be under their own control (Ajzen, 1991).

In this current study the findings support the notion that participants performed behaviours that they perceived to be of benefit. These perceptions, or attitudes developed through participants: a) experiences around improved levels of function; reduced symptoms such as fatigue and pain; and c) achieved personal goals. Participants reported that the activities that they were engaged in appeared to be helping. They reported
feeling the strength return and being able to do things that they could not do when they first arrived in rehabilitation.

The subjective norm variable described by Ajzen (1991) proposed that others opinions have a bearing on one's motivation to participate. In terms of the findings in this present study, it is clear that participants valued the opinions of the therapists, nurses, social workers, doctors and others directing their care. It appears that participants in this current study were motivated to participate by what they observed and the social pressure that they felt to participate.

Perceived behavioural control is said to be linked to control beliefs that are based upon the opportunities and resources available for performing the behaviour (Ajzen, 1991). The intent to participate is linked to the ease or difficulty that the individual perceives to be involved in performing the behaviour (Ajzen, 1991).

Participants in the current study were exposed to the appropriate resources and opportunities by virtue of their presence in the rehabilitation setting. Participants were provided with the structure and the support that they needed to promote their intention to participate. The rehabilitation environment provided them with the structure, the support and the security required by participants to fully engage in the process. For example, most participants had to learn to navigate stairs before they could return home. Learning to do this activity safely and effectively required the appropriate resources and the controlled environment to enable participants to try this activity.
Another study found in the literature examined the process of goal setting, using a goal attainment scale, in the community (Lloyd, 1986). The approach was used to demonstrate progress to clients in the community with mental illness. The tool is said to be useful in a number of ways, including motivational enhancement (Lloyd, 1986). Although there was no formalized approach to goal setting and the demonstration of goal attainment with participants in the rehabilitation setting, many reported that achieving personal goals was motivating for them.

The study by Spencer, Hersch, Eschenfelder, Fournet and Murry-Gerzik (1998) supported a strong link between collaborative goal setting and adaptive behaviours in older persons with a chronic illness. Participant’s articulation of their personal goals was a category component that was present in all three phases of the transition process. Participant’s description of the goal setting process in this present study did not appear to be a collaborative process but there was evidence in the patient record that discussions about goals setting had taken place. As well, the study by Spencer et al, focused specifically on adaptive behaviours whereas goals described by the participants were much broader. Participant goals included a range of activities from improved motor function to recreational activities.

The concept of hope was another prominent theme that emerged from the data in this present study. Remaining hopeful was a theme that emerged throughout all phases of the transition process. Examples of expressions of hope ranged from hoping that the rehabilitation would be effective to hoping to be able to go home and maintain a
satisfying quality of life. Expressions of hope were a form of coping used by participants. Participants reportedly used hope to alleviate stress created by the possibility that things may not turn out the way that they would like.

In a study by Halstead and Fernsler (1994), on coping strategies of long-term cancer survivors, the researchers stated that "effective coping is viewed by participants as strategies that increase hope, do something about the problem, restore equilibrium and use available support systems" (p.98). The researchers used a quantitative approach to measure effective coping in this population. Halstead and Fernsler's (1994) study supported the finding in this current study that suggested that expressions of hope were effective ways of coping with problems experienced because of cancer or its treatment. Cancer patients in the Halstead and Fernsler study (1994) had survived cancer for greater than five years but the investigators found that survival rates did not result in different choices of strategies for subjects. Also, the researchers found age-related differences in the coping styles of subjects in the study. In this present study the sample of participants was from an older age group. The experience may differ for the person who is in the young or middle adult years. Although the participants in this current study could not be described as long-term survivors, remaining hopeful was a major category in the findings. Participants seem to have used hope as an important coping strategy in a variety of situations during their rehabilitation process.

Spencer, Davidson and White (1997) describe hope as "a complex process made up of imagination, intention and a sense of meaning and purpose" (p. 197). Promoting
the use of hope as a therapeutic intervention for clients in rehabilitation may be dependent upon many factors including the characteristics of the client, the problem that brought the client to therapy, the service delivery setting and the therapists capabilities and strengths (Spencer et al, 1997). Participants in this present study did not report the deliberate use of strategies by therapists to promote hope as a coping strategy, yet it was a prominent category throughout their experience. In light of the difference in findings, it appears that hope may be promoted both formally and informally through the rehabilitation process.

The biographical study by Kaufman (1988), described the experience of a person following a stroke who had unmet emotional needs following her stay in rehabilitation. Participants in this present study did not report unmet emotional needs. However, the person in the case report was nine months post stroke at the time of the interview. Similar results may have been found if data collection continued for an extended period with participants in this present study. There was no mention of unmet emotional needs from the participants in this present study.

In reviewing the literature that exists about transition and the other major categories there were some findings that were similar to those reported in the present study. However, the description provided in this study was not found in any other describing the process that the older person with cancer experiences in an in-patient rehabilitation process.
Chapter V: Summary, Recommendations and Concluding Statement

Summary

Understanding the dynamics of the transition process for older persons with cancer in an in-patient rehabilitation program has provided some unique insights into the transition process that occurs. A qualitative approach using grounded theory methodology was used to examine the process that older persons with a cancer diagnosis experienced in an in-patient rehabilitation program. Six individuals with a cancer diagnosis were interviewed twice, within a week of being transferred from acute care to in-patient rehabilitation and just prior to their discharge. Participants had a variety of functional deficits that resulted from cancer or its treatment. Content analysis of the tape-recorded interviews revealed that participants experienced a transition while in the rehabilitation program. The transition consisted of three phases which were (a) taking stock of the situation, (b) looking and moving forward, and (c) preparing for home. The three phases consisted of five major categories. The categories were (a) getting and staying motivated, (b) actively participating, (c) regaining function, (d) adopting adaptive behaviours, and (e) remaining hopeful. The three phases and the five categories derived from the data formed the description of the transitional process that occurred for older persons with cancer in an in-patient rehabilitation program. The body of empirical and theoretical
knowledge that exists in the area of transition, motivation and hope supported the findings of this present study. However, conceptual and methodological differences may account for some of the variations in findings.

**Recommendations for Further Research and Practice Considerations**

The results of this present study illustrate the usefulness of grounded theory methodology in understanding the dynamics of the in-patient rehabilitation process experienced by older persons with a cancer diagnosis. The data from this study identified three phases and five major categories. A larger sample of participants in a variety of rehabilitation settings would help to further develop a more comprehensive description of the process. Research in the area of transition shared similar findings to those generated in this present study. However, most of the studies found in the literature were from the 1970's. Society has changed substantially since most of this research conducted. The reason for the decline in the number of publications in this area is unknown. However, there is still a great deal to learn about transition from both a conceptual and an empirical perspective. For example, more longitudinal studies would aid in the description of the stabilization period following a major transition. More testing of existing theories is necessary in order to enrich our knowledge base and our practice.
The chronicity of cancer as an illness has been widely recognized. With the aging population, issues related to living with cancer will be on the rise. Recurrence of the illness is not only a threat, but also a reality for many individuals who have had a cancer diagnosis. Another area for further research may be to examine the experience of individuals who have had a cancer recurrence and are undergoing a course of rehabilitation. An examination of the similarities and differences in the transition process are of interest as there may be practice implications that warrant a different approach for a population experiencing cancer for the second time.

The examination of possible age and gender related differences in the transition process for individuals with cancer diagnoses in a rehabilitation program is another recommended area for research. The study by Halstead and Femsl (1994) found age related and gender differences in their examination of coping strategies among subjects with a cancer diagnosis. In this present study the sample of participants were from an older age group. The experience may differ for the person who is in the young or middle adult years. It is important to know if differences exist so that practice can be tailored accordingly.

Oncology rehabilitation is a relatively new and growing practice area that will require continued development as our population ages. It is important to understand the
process that individuals with cancer go through in rehabilitation. By increasing our understanding, therapeutic interventions and outcome driven approaches to care can be further developed. For example, Spencer et al (1996) utilized certain strategies to promote hope in cancer patients as a deliberate strategy to assist coping. A more complete understanding of the transition process will allow nurses to engage participants in activities known to be beneficial to the process.

Currently, in Canada, there are no known rehabilitation units that specifically serve individuals with a cancer diagnosis. Persons with cancer may benefit from an integrated program that meets their rehabilitative needs while still undergoing treatment. A unit such as this may enable individuals to get home quicker. Interruptions in the transition process due to re-admissions to acute care for further treatment or follow-up tests was a reality for some participants. A closer integration of rehabilitation and acute care services, may reduce the interruptions to the transition process.

**Concluding Statement**

This present study captured the experience of the older person with cancer in an in-patient rehabilitation process. Participants engaged in a transition process that presented in different stages of activity. This study was a preliminary step toward increasing the understanding of this process for health care providers. A beginning
theory of understanding the dynamics of transition for the older person with cancer in a rehabilitation process has been generated using a grounded theory methodology.
References


Appendix A

Letter to the Chair of the Nursing Research Committee at the Participating Hospital

Dear ___________.

My name is Chris Zettler and I am a registered nurse currently studying as a graduate student in the Master of Science program at the University of Toronto. As part of the completion of this program I am planning a research study under the supervision of Natalie Bubela from the Faculty of Nursing. I am writing to you to ask your permission to conduct this study in the rehabilitation unit at your facility. I am also requesting the use of a designated nurse’s time to contact potential participants utilizing a standardized, introductory letter. If these identified patients agree to participate in the study, their written consent will be obtained and a copy of the consent form and a detailed explanation of the study will be left with them.

The purpose of the study is to gain insight into the experience of the older person with cancer who is participating in an in-patient rehabilitation program. It is hoped that the information gained from this study will assist rehabilitation nurses to understand the process of rehabilitation for this population. The first interview will take place 3 to 5 days following transfer to the rehabilitation unit. A subsequent interviews will take place after 4 weeks or just prior to discharge. The up to 1-hour interviews will take place on the unit and with the patient’s permission, will be tape-recorded. Prospective participants will be assured of their right to refuse participation in the study without any affect to the care they receive.
I am enclosing a copy of my thesis proposal and the letter of approval from the office of Research Services, University of Toronto, for review by your ethics committee. If you have any questions, please feel free contact me at any time.

Sincerely;

Christina Zettler, R.N.
M.Sc. Candidate
Appendix B

Explanatory Introductory Letter given to the Nurse Manager or Nurse Designate

Dear __________

My name is Chris Zettler and I am a graduate student in the Master of Science Program at the University of Toronto. As part of the requirements for this program, I am conducting a research study under the supervision of Natalie Bubela, member of the Nursing Faculty at the University of Toronto.

The purpose of the study is to gain insight into the experience of the older person with cancer who is participating in an in-patient rehabilitation program. It is hoped that the information gained from this study will assist rehabilitation nurses in understanding the process of rehabilitation for this population. The Office of Research Services has approved this study at the University of Toronto.

I would like to request your assistance in the recruitment of up to eight prospective participants for the study. Enclosed you will find a copy of the sample criteria for potential participants as well as a standardized introductory information sheet for you to read to each potential participant. If the potential participant is willing to speak to me regarding participation, I will approach him/her to explain the study in more detail.

The inclusion criteria is as follows: 65 or older, admitted to rehabilitation because of a functional deficit that is related to cancer or its treatment, English speaking and has no evidence of cognitive impairment.

I will then obtain written consent before proceeding with the first interview. I will notify you of my readiness to accept another participant into the study as it is essential to
complete the transcription and analysis of each interview before proceeding with the next.

Once my readiness to continue the interviews is communicated to you, I will ask you to contact another potential participant. Following this request, I will contact you on a daily basis until I obtain the name of the next participant who has agreed to be in the study.

When I meet with the potential participants, I will inform them that they have a right to refuse participation in the study and have the right to withdraw from the study at any time. Refusal to participate in the study will not affect their care in any way.

The study will involve interviews that will be tape-recorded. If the participant does not wish to be audiotaped, I will not include them in the study. It is critical to the study that the first interview takes place within 3 to 5 days of the participant's arrival in the rehabilitation unit. The purpose of this frame is to obtain data about their initial impression of their experience in the program. There will be a subsequent interview 4 weeks following admission or just prior to the patient's discharge. Again, I will keep in daily contact with you or your designate in order to keep informed about each participant's progress toward discharge.

Thank you very much for your co-operation with the recruitment of potential participants. If you have any questions or concerns about this project, please feel free to contact me at the phone number below. Would you please let me know if you would be willing to assist me in the recruitment of my sample?

Sincerely,

MSc Candidate

Christina Zettler, R.N.

Enclosure(s): Appendix C
Appendix C

Standardized Introduction to the Study to be Used by the Unit Manager or Nurse Designate in Approaching Patients

There is a nursing study being conducted on this unit about understanding the process for older persons with cancer who are undergoing rehabilitation. The purpose of the study is to gain a greater understanding of this experience from the patient's point of view.

The nurse conducting the study is Chris Zettler, a registered nurse who has worked in the area of rehabilitation for many years. She is currently a graduate student in the Master of Science Program at the University of Toronto. Chris is conducting a research study under the supervision of Natalie Bubela, from the Faculty of Nursing at the University of Toronto.

Chris would like to meet with you to tell you more about the study. Agreeing to meet with her does not mean that you have agreed to participate in the study. Whether or not you agree to participate in the study will in no way affect the care that you receive in our unit. Do you agree to my giving Chris Zettler your name so that she could come to talk to you about the study?

If yes: Thank you, I will notify Chris and she will contact you.

If no: Thank you for listening to my explanation.
Appendix D

Clinical Information Form

Research Project: Understanding the Dynamics of the In-Patient Rehabilitation Process for Older Persons with A Cancer Diagnosis

Investigator: Christina Zettler
under the supervision of Natalie Bubela

Mr/Mrs ______________, Thank you for agreeing to meet with me in order for me to further explain the purpose of my study. As you learned earlier, I am a registered nurse who has worked in the area of rehabilitation for more than 10 years and I am presently a graduate student at the University of Toronto. As part of the requirement for the Master of Science Program, I am conducting a research study under the supervision of Natalie Bubela, Faculty of Nursing, University of Toronto.

The purpose of this study is to begin to develop a theory that will aid in the understanding of the rehabilitation process of the older person with cancer. The ultimate purpose of the study is to provide information that will assist the caregiver in supporting the older person with cancer through the development of effective interventions. If you agree to participate in the study, I would like to arrange a convenient time to meet and talk with you about your experience. The study will involve a maximum of two, 1 hour interviews, both of which I would like to tape record so that I can accurately record what
you have told me. The first interview will take place 3 to 5 days after your admission on the Rehabilitation Unit. A subsequent interview will take place 4 weeks later or just prior to your discharge. I would also like to share my study findings with you following your discharge to clarify any information that you, and others like you have given me.

I will be interested in hearing about your experience since you were admitted to the rehabilitation unit. The interviews will be confidential and no individual responses will be shared with staff members. Only myself and my thesis committee members will access the typewritten transcripts of the interviews. However, they would not have access to your identity as the transcripts will be identified with code numbers only. No names will be revealed in the reporting of the study results and all tapes and transcriptions will be destroyed upon completion of the study and following the seven year waiting period. I would like to use some of your exact words to describe your experience to enrich the material in the study's report. Although you may be able to recognize a quote as being yours it is unlikely that anyone else will be able to identify it as yours. I will be providing you with a summary of all findings, once data analysis is complete. To do so, I will send you a letter summarizing the study findings and after a few days, telephone you to ask you whether or not the summary adequately reflects your experience.

It is not expected that you will benefit directly from participating in the study, however, it is hoped that the information gained in the study will benefit other people that require rehabilitation because of cancer or its treatment. Although there is the possibility that sharing your experiences with me may arouse some unpleasant feelings, you may find it helpful to share your feelings with a receptive listener. Should you become distressed, a referral can be made so that supportive counseling can be made available to you.
It is important for you to understand that should you decide not to participate in the study, the care that you receive will not be affected. Also, if you agree to participate in the study, you are free to stop any interview and to withdraw from the study at any time without any affect to your care.

If you have any questions about the study or your participation in it, you are free to contact me at any time. Your interest in my study is greatly appreciated and I thank you for taking the time to listen to my explanation.

Would you be interested in participating in my study?
If yes: I would like to review a consent form with you and ask you to sign it.
If no: Thank you for taking the time to listen to my explanation.
Appendix E

Consent Form

Consent For Research Project: Understanding the Dynamics of the In-Patient Rehabilitation Process for Older Persons with A Cancer Diagnosis

Investigator:
Chris Zettler
under the supervision of
Natalie Bubela

I ________________ have been asked to participate in a nursing study exploring the experience of the older person with cancer who is an in-patient in a rehabilitation program. The study is being conducted by Chris Zettler, a registered nurse and Master of Science student at the University of Toronto, under the supervision of Natalie Bubela, Faculty of Nursing.

I understand that the purpose of the study is to gain insight into the experience of the older person with cancer in an in-patient rehabilitation program. I understand that while I may not benefit directly from taking part in the study, the information that is gained may help others with similar experiences in the future and the nurses involved in their care.

As well, I realize that, although unlikely, it is possible that I could become upset during the interviews. Should I become upset and wish to seek help, I understand that emotional support is available and can be arranged, with my permission by contacting Chris. I do become upset, I understand that I can stop until I am ready to continue or stop altogether.
I know that taking part in the study is my own decision. I can withdraw from the study without affecting the care that I receive in the rehabilitation program.

I understand that participation in the study involves a maximum of two interviews and a review of a mailed summary of the study findings after discharge. I understand that with my permission, the interviews will be tape recorded and then later transcribed on to paper.

I further understand that all tapes and transcriptions will be destroyed upon completion of the study, after the seven year waiting period, and that all information will be kept confidential. I also understand that no information will be released that would disclose my personal identity. I understand the possible risks and benefits involved in the participation in the study.

I understand that by agreeing to take part in the study, I am also permitting Chris Zettler to review my hospital chart for information required for the study. I will also be given an signed copy of the consent form. If I have any questions about the study, I know that I can call Chris.

I acknowledge that the study has been explained to me and that any questions that I have asked have been answered to my satisfaction. I understand the information on the consent form and agree to take part in the study.

__________________________
Print Name

__________________________
Signature                      Date

The person to contact about the research is Christina Zettler.
Appendix F

Beliefs, Assumptions, and Preconceptions of the Researcher

The following are the beliefs, assumptions and preconceptions held by the researcher about the experience of the older person with cancer in a rehabilitation setting.

1. The participant will report a more optimistic outlook about the future because of his/her experience in the rehabilitation program.
2. The participant will express that s/he is less fearful than when first diagnosed.
3. A positive change in attitude about their circumstances will be reported by the participant during the course of his/her stay in rehabilitation.
4. Some participants will identify a "turning point" when s/he began to feel better.
5. The physiotherapist will be highly praised for his/her role in the person's recovery.
6. Nurses will receive some recognition for their role in the person's recovery.
7. The participant will report that s/he feels more prepared to go home because of having been in the program.
8. Participants with perceived strong family support will report more motivation to participate in rehabilitation.
9. The participant will articulate that the nurses have a different approach to caring in rehabilitation. i.e. promotion of independence.
10. Some participants will express anger about the approach of the nursing staff re: encouragement to be more independent.
11. Fear about a recurrence of the disease will be articulated by the participant.
12. Some participants will express feelings of depression associated with their diagnosis.
### Appendix G

**Data Chart By Theme Frequency**

<table>
<thead>
<tr>
<th>Theme</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interrupted rehab course</td>
<td>4</td>
</tr>
<tr>
<td>Helpful dedicated staff</td>
<td>13</td>
</tr>
<tr>
<td>Getting back to baseline</td>
<td>11</td>
</tr>
<tr>
<td>Acute care experience</td>
<td>17</td>
</tr>
<tr>
<td>Seriousness of having cancer</td>
<td>8</td>
</tr>
<tr>
<td>Cancer progression</td>
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</tr>
<tr>
<td>Loss of functionability</td>
<td>15</td>
</tr>
<tr>
<td>Living a useful life</td>
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</tr>
<tr>
<td>Barriers to going home</td>
<td>7</td>
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<tr>
<td>Traumatic experience</td>
<td>11</td>
</tr>
<tr>
<td>Symptom manifestation</td>
<td>22</td>
</tr>
<tr>
<td>Functional status at start of program</td>
<td>8</td>
</tr>
<tr>
<td>Loss</td>
<td>16</td>
</tr>
<tr>
<td>Sense of hopelessness</td>
<td>7</td>
</tr>
<tr>
<td>Self reassurance</td>
<td>6</td>
</tr>
<tr>
<td>Loss of spirituality</td>
<td>20</td>
</tr>
<tr>
<td>Loss of independence</td>
<td>10</td>
</tr>
<tr>
<td>Cancer as chronic illness</td>
<td>3</td>
</tr>
<tr>
<td>Learning about cancer</td>
<td>4</td>
</tr>
<tr>
<td>Uncertain future</td>
<td>14</td>
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<tr>
<td>Pinning hope on rehabilitation</td>
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<tr>
<td>Valuing rehabilitation</td>
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<tr>
<td>Adaptation</td>
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<tr>
<td>Fear of becoming a burden</td>
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<tr>
<td>Comparing/reflecting upon the experience of others</td>
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<tr>
<td>Effect on the family</td>
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<tr>
<td>Supports</td>
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<tr>
<td>--------------------------</td>
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<tr>
<td>Improvement in symptoms</td>
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<tr>
<td>Remaining positive</td>
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<tr>
<td>Regaining function</td>
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<tr>
<td>Lack of support</td>
<td>6</td>
</tr>
<tr>
<td>Feeling challenged</td>
<td>14</td>
</tr>
<tr>
<td>Self-blame</td>
<td>4</td>
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</tbody>
</table>