CHANGE AND CONTINUITY: THE EXPERIENCE OF LIVING WITH A TERMINAL ILLNESS

by

PATTI O'BRIEN

B.Sc., Queen’s University, 1995

A THESIS SUBMITTED IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE DEGREE OF

MASTER OF SCIENCE

in

THE FACULTY OF GRADUATE STUDIES

(School of Rehabilitation Sciences)

We accept this thesis as conforming to the required standard

THE UNIVERSITY OF BRITISH COLUMBIA

August 2001

© Patti O'Brien, 2001
In presenting this thesis in partial fulfilment of the requirements for an advanced degree at the University of British Columbia, I agree that the Library shall make it freely available for reference and study. I further agree that permission for extensive copying of this thesis for scholarly purposes may be granted by the head of my department or by his or her representatives. It is understood that copying or publication of this thesis for financial gain shall not be allowed without my written permission.

School
Department of Rehabilitation Sciences

The University of British Columbia
Vancouver, Canada

Date Aug. 24/01.
Abstract

While participation in meaningful occupation has been shown to positively influence subjective health and well-being, there has been a neglect of the experience and meaning of occupation for palliative care clients to guide Occupational Therapists (O.T.s) in defining their role in this practice area. The intent of this study was to explore the experience and meaning of occupation for individuals with a terminal illness and to examine how different dimensions of their environment (social, physical, cultural or institutional) influenced their experience.

A qualitative research approach was implemented to explore the unique perspectives of the participants. In-depth, semi-structured interviews were completed with nine individuals diagnosed with a terminal illness, such as cancer or AIDS. Two main themes emerged from the stories of the study participants. The first theme 'The Impact of Illness on Daily Life' outlines the changes following diagnosis in the participants' approaches to life, relationships, changing ability to engage in meaningful occupation, and independent living. The second theme 'Shrinking Worlds: The Importance of Home, Neighbourhood and Community Resources' describes the increasing significance and changing meanings of various spaces making up the context of the participants' lives. The manner in which these individuals restructured and renegotiated their environment to accommodate their changing physical, social and financial needs are also discussed.

The participants described many losses as a result of decreased involvement in meaningful roles and occupations. Challenges related to living with a terminal illness (and specifically participating in occupation) were a result not only of their illness but
also dimensions of their environment which mediated their experience (for example, social policies, the meaning of spaces, attitudes of others and availability of supports). Participants used a multitude of strategies to remain engaged in meaningful occupations and roles, despite their changing abilities, and described many benefits of this continued involvement. Strategies included applying energy conservation techniques, residential relocation, utilizing equipment and services and discovering new activities in which to become engaged.

The findings from the research inform theoretical ideas around occupation and the environment as well as the role of O.T.s in working with individuals who are living with a terminal illness. Specifically, issues related to client-centred practice, loss and enabling occupation are discussed in this paper. Finally, limitations of the study and directions for future research are outlined.
Table of Contents

Abstract ii

Table of Contents iv

Acknowledgements vii

Chapter One: Introduction 1
  Background of Study 2
  Research Objectives 5
  Anticipated Significance 6
  Conceptual Framework 7
  Organization of Thesis 8

Chapter Two: Literature Review 11
  O.T. and Palliative Care 12
  Related Research 15
  Occupation 18
    The Influence of Occupation on Subjective Health and
    Well-being 19
    The Influence of the Environment on Occupation 22
  Conceptual Approach 27
    Concepts in Occupational Therapy 28
    Sociological and Geographical Perspectives 30
    Canadian Model of Occupational Performance 34

Chapter Three: Methodology 36
Increased Reliance on Support, Services and Resources 108

Chapter Six: Discussion 118

Change and Continuity 120

Theoretical Considerations 122

Occupation 122

Environment 126

Implications for Occupational Therapy Practice 133

Client-Centred Practice 133

Loss 135

Enabling Participation in Meaningful Occupation 135

Individual 136

Occupation 137

Environment 138

Limitations of Study 140

Directions for Future Research 142

References 144

Appendices 153

Appendix A: Letter of Introduction 154

Appendix B: Consent Form 156
Acknowledgements

This work is dedicated to all of those individuals who are faced with the immense challenge of living while dying. I am grateful to the nine individuals who shared their time, wisdom and stories with me. Their strength and courage is an inspiration.

I am deeply indebted to the members of my thesis committee. To my supervisor, Dr. Isabel Dyck, who gave generously of her time, expertise and patience and who helped me to appreciate the complexity of qualitative research. To Dr. Lyn Jongbloed for her constant encouragement and approachability. To Dr. David Kuhl who I consider my mentor and who taught me to trust my instincts. And finally to my external review, Dr. Barbara Paterson, for her time and insights.

On the Palliative Care Unit at St. Paul's Hospital I would like to thank Ms. Pamela Miller, Dr. Jacqueline Fraser and many of my other colleagues for providing me with the opportunity to do this study and being interested in this project. I would especially like to thank Mr. Harvey Bosma for his support, assistance with recruitment and sense of humour. Many thanks are extended to the home care nurses who helped with the recruitment process and to Mr. Mark Turis who made this possible. I would also like to acknowledge my colleagues and friends in the Occupational Therapy department at St. Paul's Hospital for their support, interest and patience. I would like to thank Ms. Jennifer Selman for her leadership and providing me with much needed time to complete this study and to Ms. Hang Le Lau for her technical support.

Thank you to Catherine Donnelly who has been both my good friend and sounding board throughout this process. I would like to thank my family for their support and encouragement and my dad who shared his "words of wisdom" from his experience.
And finally, thank you to Rob, for his incredible support and for the sacrifices that he also made for this goal to be achieved.
CHAPTER ONE

INTRODUCTION
Chapter One: Introduction

Background of the Study

The purpose of this study was to further explore the experience of living with a terminal illness from the perspectives of those who know. Using a qualitative research approach, the meaning and experience of occupation for these individuals was investigated to achieve a better understanding of its potential influence on subjective health and well-being, as well as the manner in which environmental influences may impact their participation. This information has then been used to inform the role of occupational therapy (O.T.) in this practice area (for example, what it means to enable occupation for these individuals). To date, the role of O.T. in palliative care has been poorly defined in the literature.

Occupational therapy seeks to enable individuals to achieve satisfactory performance in those everyday activities or occupations that they wish to or need to perform and which provide meaning in their lives. Occupation is everything that people do to occupy themselves, including looking after themselves (self-care), enjoying life (leisure) and contributing to the social and economic fabric of their communities (productivity) (Law, Polatajko, Baptiste & Townsend, 1997). Enabling occupation, means collaborating with clients to help them to do things rather than doing things for clients (Law et al.).

Occupational therapists work in a wide range of settings and with a variety of populations. One such practice area is palliative care. Palliative care is a program of active, compassionate care primarily directed towards improving the quality of life for the
dying (Health and Welfare Canada, 1989). It strives to meet the "physical, psychological and spiritual expectations and needs of the client, while remaining sensitive to personal, cultural and religious values, beliefs and practices" (Ferris & Flannery, 1995, p. 7). The philosophies of this approach include the belief that every individual has the right to make choices and participate in informed discussion regarding the selection of the best possible option(s) to optimize quality of life. Choices and decisions are respected and care is delivered in a person-focused, family-centred environment with the client and the family (as defined by the client) as the unit of care (Ferris & Flannery). The goal in palliative care is to provide care that reflects and treats the individual as a whole person with physical, psychosocial and spiritual needs (Health and Welfare Canada, 1989). It is provided by an interdisciplinary team because the needs of any individual, especially at the end of life, are too varied and too complex to be met by any one person or discipline (Kuhl, 1994). Occupational therapy is an integral component of this interdisciplinary team.

Qualitative research is often initiated in response to clinical 'dilemmas' or 'foreshadowed problems' (Hammell & Carpenter, 2000). The clinical 'dilemma' which triggered this study arose from my involvement as an O.T. on a palliative care unit. Previously, there had been a relatively high turnover of therapists in this position. Through conversations with other O.T.s in the department, it became evident that several of the previous therapists had been unclear of their role in working with individuals with a terminal illness. As a result, they had reported frustration and dissatisfaction in this position. This resulted in their eventual departure.
As I gained experience in working with this clientele, it became apparent to me that the focus of O.T. in this area was often inconsistent with traditional rehabilitation approaches. Because individuals with a terminal illness frequently experience deteriorating abilities, an emphasis on increasing functional capabilities and independence, and returning to lost roles and activities was not always realistic. Clients were frequently not identifying the expected goals of increasing their capabilities or independence, or striving for a balance among self-care, leisure and productivity. Modifying elements of clients' physical and social environments to optimize their performance became an increasing focus in my practice, as opposed to working with the clients to improve their abilities.

In an attempt to clarify my role and confirm that this change in focus was appropriate I reviewed the existing rehabilitation literature. Through this exploration I learned several things. In general, there is a paucity of information, especially recent publications, examining the role of O.T. in working with clients with a terminal illness. Contradictory statements are offered on the purposes of O.T. in palliative care. The literature offers principles for practice which are contradictory to the traditional rehabilitation focus of maximizing functional potential and independence and striving for a balance among self-care, leisure and productivity. Minimal O.T.-based research has been completed and information from the perspectives of clients has been presented mainly in the form of case studies, described from the viewpoint of therapists. Research located beyond the area of rehabilitation describing the experience of living while knowing one has a terminal illness is also limited. Much of the information that does exist is from secondary sources rather than from the individuals themselves. For these
reasons, therapists are frequently unsure of their role when working with individuals with life threatening illnesses (Bye, 1998; Gammage, McMahon & Shanahan, 1976; Lloyd, 1989).

Studies exploring the meaning and experience of occupation for individuals with life threatening illnesses are scarce. However, with other populations, empirical evidence does exist to support that participation in meaningful occupation influences subjective health and well-being and that dimensions of the environment impact occupational performance.

**Research Objectives**

The intent of this study is to explore issues related to living while dying, from the perspectives of those with first hand knowledge. Areas related to the primary role of O.T., which is to enable occupation, are examined. Specifically, the purpose is to explore the experience and meaning of occupation for individuals with a terminal illness (including what they hope to accomplish before dying and how they want to spend their time). Because a major focus of my intervention with clients is modifying their environment to better support their performance, and because of O.T.'s recent emphasis on the influence of the environment on disability experience, examining the impact of the individuals' different environments on their lives was identified as the second study goal.

Specifically, the central questions which guided this study are:

1. What is the meaning and experience of occupation for individuals at the end of life?
2. How has this changed with their illness?
3. How do various dimensions of the environment (social, physical, cultural and institutional) influence their illness experience?

4. What strategies have individuals used to cope with the many challenges related to their illness?

A qualitative research approach was used to explore these questions. This enabled participants to describe their unique experiences of living with a terminal illness, the personal meanings they attributed to this experience, and specifically their occupations, and to achieve a deeper understanding of environmental influences on their experience of disability.

**Anticipated Significance**

The information gained from this study will serve health care professionals who work with clients with a terminal illness in meeting their physical, psychological and spiritual needs. Specifically, the findings are relevant to both theoretical and practical issues in O.T. By obtaining insights about the experience and meaning of occupation for individuals at the end of life, as well as the manner in which elements of their environments may either limit or support them, the role of O.T. in this area of practice may be further defined and clarified.

The stories of the participants could also provide information valuable to the development of contemporary O.T. theory. This could include an increased understanding of how traditional rehabilitation principles may be modified to better suit this population. For instance, do clients wish to 'maximize their occupational performance'? Is their view of occupation consistent with traditional O.T. views of
occupation? Are there occupations which do not 'fit' into the categories of self-care, leisure and productivity? Do their experiences support O.T.'s increasing focus on the role of the environment in influencing occupational performance? Do clients perceive that their 'disabilities' are created because of changes in their abilities or as a result of inadequacies in their environment? Is it their preference to increase their abilities or to modify their environment to achieve their goals?

**Conceptual Framework**

Because of its focus on occupation and the environment, concepts from both O.T. theory and the areas of sociology and geography have served as a framework for this study. Concepts from theory in occupational therapy that have guided this research include the conceptualization of occupation and the recognition that participation in meaningful occupation can have a significant influence on the subjective health and well-being of individuals. Well-being has been defined as a "perceived state of harmony in all aspects of one's life, characterized by experiences of contentment and pleasure, by spiritual experiences and a sense of happiness" (Law et al., 1998, p. 83). Occupation is understood as occurring within the context of the person-environment-occupation relationship and changes in any of these elements may result in changes in participation. Consequently, the multiplicity of influences, many of which are environmental, which affect disability outcomes are recognized.

Sociological and geographical perspectives, most significantly ideas emerging from the Social Model of Disability and its development, have also been implemented because of their broad understanding of the environment and the manner in which its
different dimensions may influence an individual's experience of disability. The Social Model of Disability views disability as a result of restrictions imposed on individuals by unsupportive economic, political and social environments rather than as a consequence of an individual's functional limitations (Oliver, 1990). More recent literature has also emphasized the influence of impairment on creating disability experiences (Crow, 1996).

Physical and social spaces are viewed as socially constructed as they convey meanings (often determined by dominant groups in society) and may be designed to keep people 'in their place' (Kitchin, 1998). An individual may also attribute personal meanings to various places which affect their use of space and consequently shape their experience of disability. These meanings are malleable and may change over time. In medical geography there is an increased recognition of place and space as integral dimensions of the lived experience of health, illness and disability (Dyck, 1995; Wilton, 1996). The ideas from these disciplines have been used as a conceptual framework to inform this study. They will be discussed in more detail in chapter two.

**Organization of Thesis**

Chapter two consists of a review of the literature which is relevant to this study. Information examining the role of O.T. in palliative care will first be discussed. Studies which explore issues related to living with cancer and HIV/AIDS are also reviewed as these are common diagnoses for individuals in palliative care. Literature and studies exploring the influence of occupation on health and the environment on occupation will be outlined. The chapter will conclude with a discussion of the theoretical ideas which have informed this study.
Chapter three examines the choice of a qualitative research approach for exploring the experiences of the participants in this study, specifically the meaning and experience of occupation to them and the influencing elements of their environment. The specific methods used in the study are outlined, including the participant selection and recruitment, the data collection process and the analysis of the data. The demographics of the participants are also provided. Finally strategies used to increase the rigour of the research, and consequently the trustworthiness of the data, are examined.

Chapters four and five present the findings of the study, consisting of the themes which emerged from the stories and voices of the participants. In chapter four, the influence of terminal illness on the daily lives of the participants is explored, specifically the impact on their abilities and occupations, their relationships and their outlook in life. The skills and strategies that have been applied by individuals to manage their illness and remain involved in meaningful occupations and relationships are also described. In chapter five, the growing importance (and changing meanings) of homes, neighbourhoods and health care institutions are discussed. The manner in which participants have restructured and renegotiated their environment to accommodate their changing physical, social and financial needs are also explored.

In chapter six, the findings are integrated to provide a description of the participants' overall experiences of living with a terminal illness. The results of the study are related to existing literature and are used to inform various theoretical constructs, with a focus on occupation and the environment. As the study was initiated, in part, to clarify the role of O.T., the insights of the participants are then used to explore the scope of O.T.
practice in palliative care. Finally, implications of this study for future research and limitations of the study are considered.
CHAPTER TWO

LITERATURE REVIEW
Chapter Two: Literature Review

This chapter will first review the existing literature and research which addresses the role of O.T. in palliative care. Other studies, involving individuals with cancer, AIDS or other illnesses, which are considered to be relevant to the areas of interest in this study will also be discussed. This will be followed by an exploration of the literature related to occupation, a central construct in this study. This review has been divided into two separate sections; the influence of occupation on subjective health and well-being and the impact of the environment on participation in occupation. The gaps which exist in the information which is available will be discussed as well as how they will be addressed in this research. Finally, theoretical ideas that have guided this study will be examined. This will focus on concepts from sociology and geography, specifically relating to the Social Model of Disability and its development, as well as from current O.T. theory which address occupation, environment and disability.

O.T. and Palliative Care

A review of the O.T. literature revealed a paucity of material exploring the area of palliative care. A literature search was completed using the OT database, CINAHL and Medline databases with various keywords including occupational therapy, terminal illness, palliative care, cancer, AIDS and end of life. The majority of the O.T. literature was written in the 1980's with a limited number of more recent publications. Articles, for the most part, were descriptive in nature, shared therapists' perspectives and were not grounded in research.
The literature supported the notion that improving the quality of life for the individual who is dying was fundamental to practice. However, the articles offered contradictory statements of the role of O.T. in terminal care which might reflect the "patient's dual state of being, both living and dying" (Hasselkus, 1993, p. 721). Several authors focused on maximizing the individual's remaining abilities and maintaining their involvement in daily tasks and roles as the method of ensuring quality of life (AOTA, 1986; Lloyd, 1989; Picard & Magno, 1982; Pizzi, 1984). Others, however, emphasized the concurrent goal of helping individuals to prepare for death by 'downgrading' their activities to match their decreasing capabilities, by helping clients to relinquish roles, to cope with multiple losses and to achieve closure in their lives. This included recognizing and supporting approaching death and the emotions of grief and loss that accompany it (Bye, 1998; Flanigan, 1982; Gammage et al., 1976; Hasselkus, 1993; Holland, 1984).

Authors such as Frank, Nobbs and Stewart (1998) emphasized a rehabilitation approach while others, including Bennett (1991) and Holland and Tigges (1981), stated that improving or maintaining function was not an appropriate goal. Several articles identified the individual with the terminal illness as the client, while others included the family as a part of the unit of care.

Only two research-based articles were found in the O.T. literature which focused specifically on issues related to palliative care. Both of these studies explored the perspectives of therapists, not clients. In order to investigate the potential contradiction between O.T. principles and assumptions and the needs and experiences of people with a terminal illness, Bye (1998) explored the perspectives of 10 O.T.s practicing in palliative care. Based on the information provided by the therapists, Bye developed a conceptual
framework for practice with people who are terminally ill. She stated that O.T.s reframed their practice to be client-centred, to focus on short-term goals, to move away from traditional rehabilitation approaches and to re-evaluate traditional O.T. outcomes (i.e. away from maximizing independence and achieving a balance among self-care, leisure and productivity). The concept of 'Affirming Life: Preparing for Death' guided the practice of therapists involved in the study. This translated into helping clients to value their remaining lives while acknowledging and preparing for approaching death.

Assessment included identifying problems related to the deterioration of the client's activity level and role performance, to the caregiving process and social support systems, and to the caregiving environment. Intervention focused on building against loss (increasing internal resources by improving skills, knowledge, values and attitudes or external resources to compensate for decreasing internal resources), normality within a changed reality (participating in everyday activities), supported and safe care (ensuring effective supports, appropriate equipment) and assisting clients to achieve closure in some aspects of their lives in order to prepare for death (e.g. helping clients to go home for a final time). The focus was on the caregivers' abilities as well as the clients' functional status. Problems were examined within a broader context (i.e. looking at the caregiver and the caregiving environment as well as the client's functional status). Bye concluded that there was minimal O.T. literature that had dealt directly with the issues of closure for people with terminal illnesses, that had examined problems in a broader context and that had viewed the family as the unit of care.

In a sample of 44 O.T.s, Rose (1999) explored their attitudes towards addressing spirituality in their practice, stating that a terminal illness may precipitate spiritual
distress and a search for meaning and purpose. He defined spirituality as the experience of meaning in everyday life, with spirituality expressed through engagement with personally meaningful occupations. According to Rose, the spiritual domain in palliative care is less well-defined than the physical, emotional and social factors important in assisting people to die with dignity. Seventy-five percent of the study respondents agreed that therapists should incorporate activities into practice that would allow clients to express their spirituality. They identified ways in which spirituality could be addressed in palliative care including open-ended discussion, involvement in creative and meaningful activities, and active listening so that clients might be given time to explore their own feelings.

In summary, the available O.T. literature suggests that practice in palliative care may differ from the traditional rehabilitation focus of maximizing functional potential and independence, returning to lost roles, activities and relationships, and achieving a balance among self-care, leisure and productivity. However, minimal research has been completed and the existing literature provides contradictory ideas on the role of O.T.

Related Research

Medline and CINAHL database searches were completed using keywords such as terminal illness, palliative care and dying. In addition, a review of the Journal of Palliative Care, The Hospice Journal, the Palliative Care and Medicine Journal and several physiotherapy publications was completed. While many studies exploring various aspects of palliative care exist in the literature, three studies were located which were considered to be relevant to the proposed research. They were selected because of
their focus on the experience of living with a terminal illness or their emphasis on daily activities for individuals with a life threatening illness.

Mackey and Sparling (2000) conducted a qualitative study with three participants to increase the knowledge that could be used by physical therapists to more effectively assess and treat older people with cancer who were receiving hospice care. Four themes emerged as central to the experience of the participants, all of whom were older women living with cancer and receiving hospice care. The themes included the importance of social relationships, spirituality, outlook on mortality and meaningful physical activity. In the final category, participants acknowledged the longing for physical activities that had been important components of their lives and were closely linked to who they had been and the roles they had fulfilled. The authors concluded that, in addition to maintaining physical function, physiotherapists who attend to non-physical, as well as physical, aspects of care, may "foster social cohesion, help maximize life's meaning and support stabilizing strategies of older women with cancer who receive hospice care" (Mackey & Sparling, p.465).

Kagawa-Singer (1993) completed a study with 25 American-born Japanese and 25 Anglo-Americans who had cancer and were over the age of 45. The purpose of the study was to determine the effect of cultural beliefs on the experience of having cancer and the coping mechanisms used by members of the two groups. While participants in this study did not require the label of palliative care to be included in the study, they were all diagnosed with a life threatening illness and several participants died during the study time period.
The results of the study indicated that the degree of interference with daily activities or role responsibilities differed considerably for the two groups. Cancer threatened to invalidate the participants' social sense of self by interfering with their ability to fulfil their role responsibilities, such as spouse, breadwinner, parent, co-worker and friend. The participants appeared to measure their self-worth by the degree to which they were able to maintain their ability to satisfactorily fulfil their social roles despite their physical condition (Kagawa-Singer, 1993). Lifestyle modifications were a common reaction for all of the participants. When faced with their finite future, they often reassessed their daily activities and re-framed their priorities. Long term, abstract objectives were often replaced by very immediate and concrete goals with family and friends, such as being home for dinner every night instead of working late. Overall, 49 of the 50 participants perceived themselves as healthy, despite the fact that they were receiving treatments for cancer at the time of the study. Based on the results of the study, the author concluded that these participants considered themselves to be healthy because of their definition of health. Their definition was based upon their ability to "maintain a sense of integrity as productive, able, and valued individuals within their social spheres, despite their physical condition" (Kagawa-Singer, p.295).

Kuhl (1999) explored spiritual and psychological issues, experienced by persons who knew they had a terminal illness, by conducting a qualitative research study in which he interviewed 21 individuals diagnosed with a terminal illness. His specific research question was 'What is the lived experience of knowing one has a terminal illness?'. Themes which emerged from the interviews included communication, iatrogenic suffering, pain, touch, time, longing to belong, life review, truth, who am I? and
transcendence. Emotions which encompassed the experience of living with a terminal illness included guilt, grief, loss, doubt, despair, fear, anger and angst. The co-researchers focused on "their own experience of living, or remembering their lives, of seeking and longing to speak and hear the truth, to touch others as a means of being connected and contributing to a healing process, and to elicit from time, a quality of life that would bring them closer to understanding who they were, and who they might become" (Kuhl, p. 198).

Qualitative research methodology was used in each of these studies. This approach was appropriate to explore the unique perspectives of the participants as well as the meanings they had made of their experiences. Kuhl advocated for further research to develop or deepen our understanding of the experience of knowing one has a terminal illness. The purpose of his study was to contribute further to this understanding by asking questions pertaining to specific aspects of the experience of living with a terminal illness. Kagawa-Singer's study (1993) supported that subjective health and well-being for individuals with a life-threatening illness was influenced by their ability to participate in meaningful occupations and fulfil role responsibilities. As in Mackey and Sparling's study (2000), the findings of this research will improve the effectiveness of rehabilitation professionals' intervention with individuals with life-threatening illnesses.

**Occupation**

A preliminary review of the O.T. literature revealed a wealth of studies which explored the concept of occupation. However, research specifically related to occupation and individuals receiving palliative care is lacking. This section will examine several
studies which involve individuals with life threatening illnesses, which explore the experience or meaning of occupation, or the influence of the environment on occupation. These studies were selected because of their relevance to the areas of interest in this research project. They have been organized into two major categories which include occupation as a positive influence on subjective health and well-being and the influence of the environment on participation in desired occupations.

**The Influence of Occupation on Subjective Health and Well-being**

Unruh, Smith and Scammell (2000) completed a qualitative pilot study exploring the meaning of gardening for women who were living with cancer. The women in the study identified many positive attributes of gardening including meeting personal needs of challenge and creativity, bringing people together, providing fun and enjoyment, preserving memories, eliciting feelings of satisfaction in accomplishment, a vehicle to reflect about the meaning of life and a way to cope with the cancer experience through release, escape, control and relaxation. The authors concluded that gardening could enable spiritual expression and serve as a coping strategy for stressful experiences such as living with cancer. They summarized that engagement in personally meaningful leisure occupations may be important for subjective health and well-being.

Law and colleagues (1998) reviewed 23 studies in O.T. and other areas in health and social science to explore the effect of occupation on health and well-being. The findings indicated that withdrawal or changes in occupation can have a significant impact on a person's self-perceived health and well-being and that engagement in meaningful occupations may have a positive influence on these factors. The authors concluded that,
based on the findings of the 23 studies reviewed, there is empirical evidence to support the relationship between occupation, health and well-being.

Clark and colleagues (1997) examined the impact of meaningful occupation on self-perceived health and social and physical function in a randomized controlled trial with older adults. The central theme of the O.T. group was health through occupation. The focus of intervention was individualized, emphasized the importance of meaningful activity/occupation in their lives, and included specific instruction on how to overcome barriers to successful participation in desired occupations. Significant benefits were found across various health, function and quality of life domains only for members of the group which emphasized engaging in meaningful occupations (not simply generic activities) to improve health.

The results of the study conducted by Rudman, Cook and Polatajko (1997) also provided empirical evidence to support the claim that occupation exerts a positive influence on subjective well-being. This qualitative study explored the perspectives of 12 seniors on the importance and role of occupation. The positive contributions of occupation that were identified included a means to establish and maintain social connections, to express and manage identity, to achieve social recognition, a connector to the past, present and future and a means of organizing time. The findings also indicated that occupation may influence one's sense of well-being through the promotion of feelings of competence, improved mastery, being needed, belonging, doing something worthwhile, and escaping. An additional finding was that participants in the study did not spontaneously use the traditional categories of self-care, leisure and productivity. Instead they identified activities that involved social, mental and physical doing.
Fuhrer and colleagues (1992) examined life satisfaction, which they recognized as a component of subjective well-being for individuals with spinal cord injuries (S.C.I.). Life satisfaction was found to be significantly correlated with an individual's level of handicap, which included their ability to participate in occupations, maintain social relationships and move around in their community (mobility).

Similarly, Yerxa and Baum (1986) examined the relationship between engagement in daily occupations and life satisfaction among individuals with S.C.I. A significant relationship was found between satisfaction with performance in occupations such as home management and social/community problem solving skills and overall life satisfaction for individuals with and without spinal cord injuries. The quality of time use was also investigated in this study. Results would indicate that categories similar to those of self-care, leisure and productivity may not adequately represent the full spectrum of occupations. The findings also demonstrated that O.T.s agreed more strongly with each other than with the participants on agreement of categorization of the occupations. This may demonstrate that O.T.s have different perspectives on clients' occupations than the clients themselves do (Yerxa & Locker, 1989).

All of these studies have provided empirical evidence to support the relationship between occupation and subjective health and well-being. As well, two of the studies have suggested that the conventional categories of self-care, leisure and productivity may not always be relevant to clients or may not include the full range of occupations. This supports the exploration of the meaning and experience of occupation for individuals with a terminal illness in this research.
The Influence of the Environment on Occupation

An increasing number of studies in O.T. are examining the influence of the environment on an individual’s ability to engage in meaningful occupations. Because the influence of the environment on the occupations of individuals living with a terminal illness has not been specifically investigated, studies in other areas of disability research will be reviewed.

Bedell (2000) completed a qualitative study to gain an understanding of the daily life experiences of gay men with HIV/AIDS, who lived alone. Two themes emerged from the stories of the participants. The first was 'A Reasonably Stable Base' which represented the emotional, physical and environmental foundation that "pre-existed or was created as a consequence of living with HIV/AIDS" (Bedell, p. 197). This included the increasing importance of home as a safe place, as well as the influence of emotional and practical support from others. Formal and informal support networks were important to the participants in managing their daily routines. The second theme, 'Finding and Maintaining Balance', illustrated strategies used by the participants for managing and readjusting daily routines, goals and priorities. The findings of this study suggested that O.T.s have the potential to "assist urban gay men with HIV/AIDS with finding and maintaining stability and balance in their daily lives" (Bedell, p. 197).

The purpose of Levins' (2001) qualitative study was to explore factors which enable or discourage individuals with spinal cord injuries from becoming involved in physical activity or sport. The participants confirmed the potential importance of physical activity and sport in their lives following spinal cord injury. They found that these activities provided profound meaning in their lives and helped to create a positive
identity for themselves. They identified social factors (such as attitudes of others, limited access to resources and inaccessible environments) which played a significant role in facilitating or limiting their participation in sport and physical activity after spinal cord injury. The internal process of redefining self that occurs after injury was also found to have significant influence on involvement.

In Yerxa and Locker's study (1990), 11 of the 15 individuals with S.C.I. identified the following obstacles to community functioning: architectural barriers (5), lack of social resources, such as friends or social activities (3), lack of accessible transportation (2), lack of physical ability (2) and lack of financial resources (1). Physical limitations comprised only one of five factors which limited their participation in chosen occupations and were selected by only two of the 11 individuals. Three other categories which focused on elements of their environment (including physical, social and institutional components) were identified as frequently, or more frequently, as obstacles to community functioning.

Jongbloed (1994) conducted a two-year qualitative research study with 20 couples exploring adaptation at home following a stroke. Through the analysis of one case involving a woman who had experienced a stroke and her husband, it became evident that the consequences of a stroke are a result not only of physical changes, but of environmental influences as well. Following the participant's stroke, her ability to perform many of her previous occupations was disrupted. However, her husband's response to the changes resulting from the stroke influenced her experience of dependence, reduced physical function, and altered roles. This woman's limitations in
occupational performance were influenced more by the physical and social environment than by her residual skills.

Dyck (1992) explored the dynamics of person-environment interactions as they related to shaping mothering activities. Choices regarding paid work and mothering work for the 25 participants with young children were shaped by the "constraints and opportunities of the local conditions, themselves framed by broader social and economic processes" in addition to individual preferences (Dyck, p. 21). For the participants, specific methods of coping were influenced by social and physical aspects of their environment, such as their socioeconomic status, the provision of community resources, the demographics of a local area, and whether women had family members for support and assistance. This study demonstrated how the economic, social and cultural context, together with the women's own perspectives, influenced their definition and enactment of their chosen occupations, specifically related to mothering (Dyck).

Dyck and Jongbloed (2000) explored both the barriers to employment that women with multiple sclerosis (M.S.) experienced in the workplace as well as the resources, conditions and strategies that enabled them to continue working. Findings of their study indicated that although functional limitations affect employment status, non-medical factors, such as modification of work conditions, can enhance women's ability to work. The 23 women in the study who were not working were forced to live within the constraints imposed by disability income policies, which affected not only their income and their involvement in employment occupations, but also social and self-care activities. The results of this study emphasized that the choices the participants made regarding how
they spent their time and the occupations they engaged in were mediated by social and institutional elements of their environment (Jongbloed, 1998).

Dyck (1995) also reported that these women restructured the meaning and use of space (such as home and neighbourhood) as they responded to changes in "the physical and social capacity of their body" (p. 309). The social and geographical worlds of the women were shrinking with their illness as their home became their primary activity space. To continue to engage in everyday activities, the participants reorganized their physical space and social relationships within the constraints of their financial situation. There was an increased reliance on family and formal supports, decreased access to neighbourhood, increased isolation, increased health-related appointments and a reorganization of daily routines based on fluctuating abilities. For these women, their illness experience was given meaning within the constraints and opportunities experienced in home, neighbourhood and other spaces (Dyck).

Wilton (1996) completed a pilot study designed to explore the geographical dimensions of life with HIV/AIDS. The participants in the study were affected by the physical and psychological impact of their illness as well as social responses to their diagnosis. As a result of their illness, the men experienced diminished physical and social worlds. To cope with the challenges related to their illness, the participants made adjustments to their lives including modifying or relinquishing elements of their daily routines, finding new activities to replace old ones and drawing upon a variety of resources. The level of resources available to the participants varied (for example, financial resources) and affected their ability to respond to their illness. The study
demonstrated that a variety of dimensions combined to influence the individual experience of living with HIV/AIDS.

McClain, Cram, Wood and Taylor (1998) were interested in the impact of community accessibility on occupations or life tasks. They explored the perceptions of three individuals who used wheelchairs (an elderly person, a mid-life business owner and a child) regarding several elements of the environment. This included architectural accessibility issues in their communities and the impact of a policy (the Americans with Disabilities Act, ADA) which guarantees access to privately owned businesses. Each participant acknowledged that accessibility issues impacted on their ability to fulfil social roles as well as on their relationships. They reported accessibility problems which ranged from minor irritations to issues that made the physical environment inaccessible and therefore segregated them from the general public or limited them from being able to participate in desired occupations. Participants identified changes in the accessibility of their environment which had been influenced by the ADA policy. These subsequent changes had decreased the barriers to their participation in some chosen activities.

A few studies were selected from the literature on occupation to highlight several important issues. First, research provides empirical evidence that participation in meaningful occupation has an influence on an individual's subjective health and well-being. This supports O.T.s goal of 'enabling occupation' for clients. Second, the traditional categories of self-care, productivity and leisure may not adequately reflect the full spectrum of occupations for clients. Third, an individual's ability to participate in the occupations of his/her choice is influenced not only by his/her own capabilities but also by elements of his/her environment.
In summary, there is a paucity of literature regarding the role of O.T. in palliative care. The literature that does exist offers contradictory ideas around O.T.'s role and suggests principles which differ from traditional rehabilitation goals and practice. Minimal research has specifically addressed issues involving O.T. and palliative care and studies which have been completed have explored the perspectives of therapists not clients. Empirical evidence does exist to support the influence of meaningful occupation on subjective health and well-being as well as the manner in which the environment may facilitate or limit participation in these occupations. While these issues have been explored with individuals with cancer, HIV/AIDS, spinal cord injuries and other injuries/illnesses, they have not specifically been addressed with individuals who are terminally ill. Studies which have involved participants with terminal or life-threatening illnesses implemented qualitative research approaches which facilitated the exploration of the unique experiences of individuals within their specific context. It is evident that many gaps exist in the current literature and several of these have been addressed in this research project.

**Conceptual Approach**

In qualitative research, theoretical approaches influence the development of the research question, the areas that are explored and the manner in which the data are analyzed. Ideas from O.T. theory have been applied in this study which emphasize the importance of meaningful occupation and which have dealt with occupation in the context of an individual's environment. Concepts from sociology and geography, such as the meanings of places and spaces, have also been incorporated because of their value in
the environmental analysis of disability experience. These approaches are considered relevant because of the study's focus on meaningful occupation as well as the influence of the environment on the experiences of individuals with a terminal illness. For the purposes of this study the words environment and context will be used interchangeably.

**Concepts in Occupational Therapy**

The unique focus of O.T. is its emphasis on occupation as integral in promoting and maintaining health and well-being (Law et al., 1998). The importance of occupation has been recognized through the development of occupational science. There is no single definition of occupation, rather it has been conceptualized in a variety of ways. In the United States, occupation is defined as the ordinary and familiar things that people do each day (AOTA, 1995). In occupational science, it has also been defined by it's essential elements which include having a purpose or goal, having social and personal meanings and being "culturally, temporally and ecologically contextualized" (Hocking, 2000, p. 61).

In Canada, occupation has been defined as "groups of activities and tasks of everyday life, named, organized and given value and meaning by individuals and a culture" (Law et al., 1997, p. 34). They are considered to be meaningful when they fulfil a goal or purpose that is personally or culturally important (Egan & DeLaat, 1994). Meaning is therefore individually and culturally determined. In this study, occupation has been conceptualized in this manner. While occupation is viewed as much broader than activity, these two words have been used interchangeably in this paper.
In contemporary O.T. models, occupations are divided into three major categories. These include occupations which involve looking after one's self (self-care), enjoying life (leisure) and contributing to the social and economic fabric of one's community (productivity) (Law et al., 1997). Categorization is dependent on the purpose or the meaning of the occupation for each individual, not simply its inherent qualities. Examples of self-care occupations include functional mobility, dressing and grooming. Leisure occupations include socializing, creative expressions and sports. Examples of productive occupations include employment, homemaking and community volunteering (Law et al., 1997).

Occupational performance refers to the "ability to choose and satisfactorily perform occupations that are meaningful to the individual" (Law et al., 1997, p. 45). Occupation is performed within a context. Elements of the environment may either hinder or support an individual's participation in desired occupations. Over the past several years, O.T.'s view of the environment has continued to evolve. It's definition has broadened, as can be seen by the inclusion of cultural and institutional components of the environment (in addition to physical and social elements) and a move beyond clients' immediate surroundings (Law, 1991). The environment is no longer seen as an entity that is external to the individual and the relationships between the individual and the environment are no longer viewed as causal. The person and environment are no longer considered to exist independently of one another, but within a dynamic, transactional relationship. This evolving notion of the environment has been influenced by the inclusion of sociological and geographical perspectives into rehabilitation theory and practice.
Sociological and Geographical Perspectives

Social constructionism addresses the manner in which social phenomena, such as health and disability, are created and understood, in light of prevailing standards (Gillespie & Gerhardt, 1995). These social constructions are based on cultural norms and therefore vary from place to place and over time. They reflect the power relations of society as dominant groups in society hold the authority to define what is 'normal' or expected (for example, what behaviour is expected according to age and gender, and what is understood as normal function). These social constructions become taken for granted and, in turn, influence social perceptions and social policy and are played out in spatial relations.

The Social Model of Disability looks at how 'disability' is created or socially constructed (Oliver, 1990). What is defined as a 'disability' is determined by the social meanings that individuals attach to particular physical or mental impairments (Oliver). 'Disability' is viewed not as a consequence of an individual's functional limitations (or an intrinsic feature of impairment) but as a result of restrictions imposed on individuals by unsupportive economic, political and social environments (Oliver). External factors influencing the experience of disability include social attitudes, social policies and inaccessible and inadequately built environments. More recent literature has also stressed the importance of an individual's impairments in determining disability (Crow, 1996). While the notion that social factors generally dominate in determining quality of life for 'disabled' people continues to be emphasized, the role of impairment is also recognized. This means that for many individuals, restricted opportunities would still exist because of the subjective experience of their bodies even when disabling barriers in the environment
were removed. For many 'disabled' people, impairment is relevant, and impairment, as well as disability causes disadvantage (Crow).

Geographers have pointed out that social and physical spaces (such as home, neighbourhood and hospitals) are also socially constructed. Spaces are assigned spatial codes (often by groups in positions of power), which convey meanings, either explicitly or implicitly, about, for example, who 'belongs' in a particular space and what behaviour is expected. In this way they act "as a medium of the operation of social relations which shape people's experiences" (Dyck, 1995, p. 308). Spaces may be designed in ways that, intentionally or not, keep people 'in their place' by means of inaccessible environments or convey to people that they are 'out of place' because of non-normative behaviour (Kitchin, 1998). They may be socially constructed around ideas of normalcy and ablement and therefore create environments which are exclusionary for people with disabilities by restricting their physical access or social opportunities. Individuals may be constrained within and by the social space around them but may also challenge the accepted configurations of spaces of everyday life (Wilton, 1996).

As Kitchin (1998) has emphasized, an individual may also ascribe particular personal meanings to spaces, often based on the dominant social meanings they carry (e.g. their accessibility or prevalent social attitudes about acceptable behaviour), but which will be mediated by their own inscription as, for example, having a 'deviant' body or behaviour. Individuals may choose to avoid, or may be excluded from, certain spaces because of negative social reaction (e.g. stigmatization or discrimination) associated with particular medical diagnoses, such as HIV/AIDS or mental illness. In contrast, an individual may only be able to access certain places (such as a rehabilitation program)
because of their diagnosis or designation to a particular medical category (e.g. palliative care). Certain places may represent spaces where the individual may feel included or excluded, treated or mistreated. Individuals may choose to interact in spaces where they feel competent, confident, accepted or supported. Like all social constructions, these meanings are not fixed and may change over time.

In medical geography there is an increased emphasis on analyzing the influence of place and space on the lived experience of health, illness and disability. This includes examining how the use of space/place, and the meanings they are attributed, mediate or shape the experience of disability and how they are renegotiated by individuals (Dyck, 1995). For example, Wilton (1996) stated that space is a vital component in any attempt to understand changes that occur following diagnosis of an illness such as HIV/AIDS, as the particular places/spaces where an individual interacts affects the reaction from others and the resources that are available to them to cope with the challenges of their illness. As well, the physical and social consequences of illness affect the spaces surrounding the individual (for example, an individual's world may be diminished as they are unable to access the community and its resources).

Similarly, Rowles (1991), also a geographer, stated that there has been an underestimation of the role of a person's environment as a source of identity and well-being. He defined environment as more than the physical or social setting but as the "culturally defined spatiotemporal setting or horizon of everyday life" (Rowles, p. 266). This perspective includes physical, social, cultural and historical dimensions of an environment of lived experience. He advocated that O.T.s must focus not only on knowing and doing with clients, but also on being. Rowles suggested that O.T.s may
enhance their contribution to improving quality of life by more explicitly incorporating an increased concern with 'being' in place. An increased understanding of clients' being in place can be achieved through an exploration of the meanings, values, and intentionalities that underlie their experience of particular environments.

In summary, problems associated with disability are not considered to be solely the result of personal limitations in socio-political models of disability. They are primarily a consequence of a disabling environment and stem from the failure of the social environment to adjust to the needs and aspirations of people with disabilities (Jongbloed & Crichton, 1990a). This is contrary to the previous individualistic view which saw disability as a 'personal tragedy' with disabled people being unable to adapt to societal demands because of their functional limitations (Jongbloed & Crichton, 1990a). Disability is therefore regarded as a product of the interaction between the individual and the environment.

In 1990, Jongbloed and Crichton discussed the implications of this shift from an individualistic to a socio-political definition for rehabilitation practice. The authors encouraged rehabilitation professionals to acknowledge the multiplicity of influences, many of which are environmental, which affect disability outcomes (Jongbloed & Crichton, 1990b). The need to pay attention to environmental contexts and focus on the interaction between the environment and individual factors was emphasized. Therapists were encouraged to expand their focus beyond the needs of individual clients and be less willing to accept individual explanations for problems which were, essentially, economic, social or political. They also advocated that the study of disability should be expanded to include environmental variables (Jongbloed & Crichton, 1990b).
Similarly, Mary Law addressed the environment in her 1991 Muriel Driver lecture. The influence of socio-political models of disability were evident in her lecture. She encouraged O.T.s to change their view about disability, understanding it as a problem caused by inadequacies in the environment that cannot always be remedied by changing the individual's capabilities (Law, 1991). She advocated for a focus beyond the client and their immediate environment and the development of new strategies for analyzing and modifying the environment. Finally, she encouraged the development of new O.T. theories that recognized the interdependence of the individual and the environment and the ways in which the environment may enable or constrain individuals and their performance.

**Canadian Model of Occupational Performance**

Many of the concepts discussed in this section have been incorporated into contemporary O.T. theory, literature and practice. One such practice model is the Canadian Model of Occupational Performance (CMOP) (CAOT, 1997). This model has incorporated the transactional nature of the environment, the person and the occupations they perform. The individual is viewed within their specific context and the influence of the environment on an individual's participation in society or ability to perform desired occupations is recognized. The model recognizes that changing any element of the person-environment-occupation relationship may result in a change in occupational performance. In this way, an individual's environment may either support or hinder their performance.
The environment moves beyond the client's immediate surroundings and is comprised of physical, social, cultural and institutional components. The institutional environment includes societal institutions and practices, including policies, economic components, such as services, funding arrangements and employment support, legal elements and political components such as government-funded services and legislation (Law et al., 1997). In intervention, there is an increased focus on removing environmental barriers and increasing supports in order to maximize an individual's occupational performance or participation (and consequently decrease their 'disability').

The concepts and ideas related to occupation and the environment which have been discussed in this section informed the development of this study. They influenced many of the study questions and informed the analysis and interpretation of the data that was gathered. Reciprocally, the findings of this research have also been used to inform these existing theoretical ideas. The next chapter will review methodological issues of this study.
CHAPTER THREE

METHODOLOGY
Chapter Three: Methodology

The choice of a research methodology is informed by the nature of the problem it seeks to address (Hammell & Carpenter, 2000). As stated by Kuhl (1994) in order to understand the experience of having a terminal illness one must hear from those who know. Qualitative approaches facilitate the exploration of individuals' unique perspectives as they enable people to describe their experiences, and the meaning of those experiences, in their own words. The purpose of this study was to examine the impact of having a terminal illness on the daily lives, and specifically the occupations, of individuals. A second goal of this study was to explore the manner in which elements of the environment may either limit or enable the participants. In qualitative research a deeper understanding of the interrelationship between individuals and their environments may be achieved as people are viewed as inseparable from their contexts. For these reasons, a qualitative approach was selected as most appropriate for this study.

This chapter will first review the main features of qualitative research. This will be followed by an outline of the specific methods used in this study, including participant selection and recruitment, the interview process and the analysis and interpretation of the data. The demographics of the participants will also be provided. Finally, the steps taken to increase the rigour of this study and enhance the trustworthiness of the data will be discussed.
Qualitative Research

Qualitative research is an umbrella term that encompasses a variety of different research approaches and traditions (Hasselkus, 1995). The central aim of this type of research is to attempt to "make sense of, or interpret, phenomena in terms of the meanings that people bring to them" (Denzin & Lincoln, 1994, p.2). Rather than testing existing theories it is concerned with producing descriptions and explanations of particular phenomena or experiences from the perspective of the individuals being studied (Hammersley & Atkinson, 1995).

Qualitative research involves an interpretive, naturalistic approach, with research occurring in natural, not artificial, settings. The "socially constructed nature of reality, the intimate relationship between the researcher and what is studied and the situational constraints which shape inquiry" are stressed (Lincoln & Denzin, 1994, p.4). Findings and knowledge are created or constructed as the research project proceeds through the interaction between the researcher and the participant as they create shared meanings. This is recognized as an active process with accounts being produced through selective observation and interviewing and theoretical interpretation of what is seen and heard. Therefore, there are many versions of reality that can be constructed, based on different emphases, different theories and different audiences, with no single best way to reconstruct and represent the social world (Hammersley & Atkinson, 1995). Because knowledge is co-created through this interaction, the 'positioning' or social locations of both the researcher and the participant influence the knowledge that is constructed.

'Positioning' is influenced not only by structural differences (such as gender and race) but also by personal experiences. All aspects of 'positioning' influence the type and
'quality' of data gathered as any 'gaze' is always filtered through lenses of gender, social class, race and so on. Because of these social locations, the researcher is always in a particular position of power in relation to the participants. This power and 'positioning' defines the parameters of the theoretical framework, the questions which are selected to be studied, the research design, the guiding questions in the interview and the way that the data is analyzed and written up (Bhavnani, 1993). Researchers must be reflexive about this 'positioning' to determine how it is informing the construction of knowledge and the accounts that are being produced.

In qualitative research purposive sampling may be utilized where the researcher selects a specific category of individuals to be interviewed rather than using a random process. An attempt to obtain statistical representativeness is not required, rather participants may be selected who are likely to increase the understanding of the research topic (Jongbloed, 2000). A small number of cases may be explored in detail in order to achieve an in-depth understanding of the phenomena being studied (Atkinson & Hammersley, 1994). The actual sample size is determined by the quality and completeness of the information obtained as data collection continues until the point of saturation is reached. According to Hammell and Carpenter (2000) saturation occurs when:

No new themes are emerging; when new stories confirm what is already understood while adding only slight individual variations; and when the researcher has exploited the opportunity to confirm or explicate these themes with as many people as it takes to feel confident in the plausibility and authenticity of subsequent analysis and interpretations (p. 6)
Qualitative research is pluralistic, with a wide range of interconnected methods being utilized (Lincoln & Denzin, 1994). The most common methods for data collection include interviews, participant observation and document review, although several other strategies are appropriate for specific research problems or situations. In all methods, the researcher is an active participant and is considered to be the primary instrument of data collection.

In-depth, semi-structured interviews are one of the most common forms of data collection in qualitative research. The objective in these interviews is to carry on a guided conversation and to elicit rich, detailed materials to be used in qualitative analysis (Mishler, 1986). This has also been referred to as a 'purposeful conversation' (Hammersley & Atkinson, 1995). The researcher has some knowledge of the topics he/she would like to explore but aims to facilitate the open expression of the participants' perspectives. Often the exact questions to be posed are not decided beforehand and all interviewees are not necessarily asked the same questions (Hammersley & Atkinson). A flexible approach is adopted that allows the discussion to flow in a natural way, without imposing any 'a priori' categorizations that may limit the field of inquiry (Fontana & Frey, 1994).

The influence of feminist critiques has resulted in a gradual change in the components of the 'proper' interview. Previously, the 'proper' interview valued objectivity, hierarchy and detachment and viewed science as a higher priority than the individual's concerns (Oakley, 1981). More contemporary interview styles attempt to avoid hierarchical relationships, instead establishing a collaborative approach to research which "engages both the interviewer and participant in a joint enterprise" (Oakley, p. 44).
The analysis of qualitative data is "inductive and concept gathering rather than deductive and hypothesis testing" (Dyck, 2000, p. 85). It does not occur at a distinctive stage but rather throughout the research process. This process works inductively moving from particulars to more general perspectives (Creswell, 1998). Data are examined for patterns, common themes and relationships between phenomena (Hammell & Carpenter, 2000). Interpretations are grounded in the data generated and conceptualizations rely heavily on the voices of the participants (Dyck). This process of conceptualizing the experiences of the participants, while grounded in the data, is also informed by the insights of the researchers, which are, in turn, influenced by existing interpretive concepts from the literature, as well as past experiences. Narratives are therefore not pure experiences of descriptions but joint constructions of both the researcher and the respondent (Dyck).

While the development of categories remains an essential step in qualitative research analysis, it is not a meaningful end in itself (Frank, 1997). According to Frank, the researcher should move beyond categories through analysis based on theoretical concerns, thereby 'recontextualizing the data'. Concepts from existing theories inform the interpretation in a way that allows them to confirm, refine or contextualize existing concepts (Dyck, 2000). In the analysis, the researcher is therefore not only describing and synthesizing the data but putting forth an interpretive position and examining the adequacy of existing conceptualizations (Dyck). Working with theory moves "beyond descriptions of experience to an increased understanding of the many dimensions of complex social phenomena" (Dyck, p. 86). Researchers do not need to limit themselves to
a single theory as a framework for analyzing data but may approach the data with multiple perspectives (Hammersley & Atkinson, 1995).

**Research Design**

The specific methods used in this study, including the participant selection and recruitment, the data collection and the analysis and interpretation of data, are outlined in this section. The demographics of the participants are also provided.

**Participant Selection**

Nine individuals participated in this study and were selected through purposive sampling. Participants were individuals who:

- were known to physicians working on the Palliative Care Unit (P.C.U.) at St. Paul's Hospital, Vancouver, B.C or belonged to the hospice program and known to a home care nurse in the community.

- had a terminal illness and were aware of their diagnosis and prognosis (so that they were open to discussing the experience of living with a terminal illness)

- were able to speak English fluently (so that the actual words of the participants could be heard and so that the use of a translator did not result in an additional layer of interpretation)

- had an anticipated life expectancy of four to 12 months (greater than four months to allow for follow-up interviews, to ensure that they were well enough to participate in the study and so that they were individuals who were
still participating in a range of daily activities, and less than 12 months as this is generally the limit for qualifying for palliative care services) had unimpaired cognitive function with an ability to understand the nature of the study and provide informed consent. Limitations around gender, age or ethnicity were not identified. Individuals were selected who met the inclusion criteria and whom their health care team believed would be able to lend insight to the research problem.

Recruitment of Participants

As the intent was to explore the experience of living with a terminal illness, regardless of where individuals were residing, the recruitment strategy reflected this interest. Participants were recruited from the P.C.U. at St. Paul's Hospital (where I am the staff O.T. and consequently was able to gain access) as well as from the larger hospice program, which includes individuals who are living in the community.

The P.C.U. at St. Paul's Hospital was opened in 1989 and provides service to individuals with life-threatening illnesses, most commonly individuals with cancer and AIDS. This is a 15-bed unit situated on the 10th floor of a tertiary care hospital in Vancouver, British Columbia. Thirteen of the beds are used for individuals requiring admission for symptom or pain management. Individuals are able to reserve the two others for periods of one week as necessary to provide an opportunity for respite for themselves and their caregivers. Members of the interdisciplinary team which service this unit include physicians, nurses, social work, music therapy, occupational and physical therapists, pastoral care, pharmacy, volunteers and the clients themselves.
The hospice program provides services to individuals residing in the community who have an anticipated prognosis of less than six months. In addition to resources, such as home care nurses, homemakers and rehabilitation professionals, which are available through their health units, individuals are able to access hospice physicians, clinical nurse specialists, social workers and hospice volunteers. The hospice team is available for consultation on pain and symptom management and end of life care.

In compliance with the Ethical Review Policy of the University of British Columbia, ethical approval was applied for through the UBC/Providence Health Care Office of Research Services. This is a joint committee that allows research to be conducted in Providence Health Care sites, which includes St. Paul's Hospital. Approval was received on September 28, 2000 (Number P0-0140). The University of British Columbia's required ethical procedures were followed which includes assuring the study participants of confidentiality.

The proposed study was presented to members of the P.C.U. interdisciplinary team including physicians, the social worker and nursing staff. This occurred both through one to one discussions as well as a written description in the team's communication book. Copies of the letter outlining the study were provided to interested team members and posted in a common area. Two presentations explaining the study were made to the Palliative Care Resource Group, which consists of home care nurses who provide service to palliative care patients in the community. After they had agreed to participate in recruiting participants for the study, they were provided with letters of introduction.
On the P.C.U., the appropriateness of a potential participant was often discussed amongst several team members prior to him/her being approached. As all potential participants met the majority of the inclusion criteria by virtue of their admission to the unit, the discussion revolved around issues such as clarification of prognosis as well as the receptiveness of an individual to discussing end of life issues. On occasion, team members also explored any potentially negative consequences of asking particular individuals. For example, for patients with relatively new diagnoses, concern was expressed about the (potential) emotional impact of some of the wording on the letter of information.

Either the social worker, a nurse or one of the physicians on the team contacted potential participants who were inpatients on the P.C.U. If they were residing in the community, their home care nurse approached them. The study was described to the individual with an explanation that involvement was entirely voluntary and a choice to not participate in the study would not affect their medical care. Individuals who were interested in the study were provided with a letter of information (see Appendix A). If interested, they were approached by myself and given the opportunity to discuss the project and sign a consent form (see Appendix B). Individuals in the community who were interested in the study either contacted myself or my thesis advisor directly or requested their home care nurse provide their names and were then telephoned by myself.

If a client in the community chose not to participate, neither the principal investigator nor myself were informed of their identity. Because I was a team member on the P.C.U. and was often involved in discussions regarding the appropriateness of potential participants, I was often aware of which patients were approached about the
study, however, they were not notified of this information. All individuals on the P.C.U. who were approached agreed to participate with the exception of one who requested time to consider the request and then subsequently became too ill. Those who chose to be involved were told that they could withdraw at any time without impact on their clinical care.

It was anticipated that if a participant were on the P.C.U. while involved in the study, he/she would be followed by an alternate staff O.T. throughout his/her participation in the study, if O.T. services were required. Eight of the nine participants were patients on the P.C.U. either at the time they were approached for the study or during their involvement. Of these, all participants except one were in the hospital for respite admissions. Potential participants were approached just prior to their discharge and attempts were made to complete the interview at home following their hospital stay. For participants who requested their initial interview be completed at the hospital during their admission, these interviews were conducted outside of work time and scheduled on the day of, or day before, discharge whenever possible. Several participants had respite admissions between their first and second interviews, however, minimal therapy was conducted given the nature of these admissions. Only information recorded during the formal research interviews was used in this study. Issues related to my role in the recruitment and interviewing process will be discussed in a later section.

The Participants

Nine individuals were involved in the study. A separate profile of each participant will not be included in order to protect confidentiality. All participants had a
terminal illness (six with cancer, one with leukemia, one with AIDS and cancer and one with another disease which she did not want identified). All were believed to have had a prognosis of approximately four to 12 months to live at the time they were initially contacted. The length of time since diagnosis was on average approximately two years. There were five men and four women and their ages ranged from 46 to 77 years old. No criteria were set regarding ethnicity. Seven of the nine participants were white. One participant was Trinidadian and one was Chilean. Both of these participants had lived in North America for over 30 years. All were able to speak and to understand English. Ethnicity was not seen to play a major role in this study.

There was considerable variation in the socio-economic status of the participants (from very affluent to being financially dependent on the Ministry of Social Development and Economic Security). All lived in Vancouver, however, homes were located in a variety of areas including Kerrisdale, U.B.C. endowment lands, Main St., the West End, Kitsilano and Yaletown. For the most part, these neighbourhoods are considered to be affluent areas in Vancouver. Two participants lived in houses and seven in apartments or condominiums (with two living in subsidized housing). Two participants were married, six divorced and one single. Four lived alone, three lived with family members (a spouse and/or children), one lived with a private caregiver and one lived with her son during the first interview and alone at the time of the second interview. The majority of individuals (eight of nine) had been working in some capacity at the time of their diagnosis. Examples of careers included businesspersons, a politician, service industry employees (restaurants and hotels), a teacher and a care aide.
Interviews

In-depth, semi-structured interviews were used to gather data in this study. All interviews were conducted by myself between the period of October 21, 2000 and March 23, 2001. Questions were generally open-ended and broad, designed to encourage participants to share their unique perspectives on how their illness had impacted their daily lives. Closed questions were used at times to either clarify meanings, elicit more detail or where participants appeared to have difficulty answering open-ended questions. During the interview, I probed more deeply on specific topics and issues and the participants were encouraged to supplement their answers to questions with any information that they felt was important.

Two pilot interviews were conducted initially in this project. Participants in these interviews met the inclusion criteria for the study and were selected through purposive sampling. The pilot interviews were completed with individuals (one man and one woman) who were willing to provide their insight into the concerns of the study, as well as the effectiveness of the interview questions. Their transcripts were used in the analysis of the data and they are included in the nine participants. Examples of interview questions, which guided these interviews, included:

1. Tell me about a typical day. How has this changed with your illness/since you learnt you had a life threatening illness?
2. How would you like to be spending your time?
3. What activities are important/meaningful to you? Has this changed with your illness?
4. What is important about them?
5. Are there things that you would like to be doing but can not? Are there things that you used to do but are no longer doing?

6. What is limiting you from being able to do these things?

7. Are there things or people around you that make things easier for you? Harder for you?

8. What would make it easier for you to do the things that you want to do?

9. If you could change things around you (i.e. your environment) what would you change? Why? How would this affect what you do/how you spend your time?

The two initial participants provided only minimal feedback regarding the interview process or questions. Both reported that the areas discussed were important and found the questions "okay" although one mentioned that she preferred questions which were specific and closed ended as this allowed her to focus her answers. Copies of the transcripts of these two interviews were provided to the three members of my thesis committee. Feedback regarding interview style, questions that 'worked' or 'didn't work' and other areas to explore beyond those initially identified were obtained from the committee members.

Based on feedback from both sources, as well as reviewing transcripts, modifications to the interview questions and process were made. It became apparent that several questions were not effective either because they were unclear or because they did not elicit meaningful responses. For example, a question regarding the blurring between the categories of self-care, leisure and productivity was dropped as the participants did
not seem to understand the question or did not appear interested in it (too theoretical). As another example, in response to direct questioning, participants had difficulty spontaneously identifying elements of their environment which limited them or that could be changed to support them. This was often the case even after specific examples were provided. However, when asked to describe a typical day, participants' answers would often reveal information regarding the formal and informal supports they used, examples of equipment they benefited from, the manner in which finances had enabled or limited them and the attitudes of others had influenced them. These were areas that I was interested in but specific questions were not required to initiate the discussion.

At times participants discussed issues at length that were not directly related to the research topic (for example, tensions between family members, past social history). They were provided the opportunity to do so as it was evident that this was important to them and because pieces of information were often gained from these conversations that related to items of interest (e.g. support, outlook). On occasion participants posed questions to me around issues such as the potential benefits of O.T., resources which existed in the community or details about the P.C.U.

Overall, a less structured approach which was more similar to a conversation (a 'guided' conversation) appeared more effective than a question and answer period. This meant that rather than following a pre-determined interview schedule, questions arose from the conversations of the participants, which focused more on the topics which they themselves identified as important. However, at the same time, many of the topics that were explored were also guided by the study's broad areas of interest (e.g. occupation, environment, how life had changed).
All interviews were recorded by audiotape. Only one participant commented on the audiotape. She requested taping be discontinued periodically, stating that she was self-conscious because English was not her first language. All audiotapes were transcribed by myself. This was a time consuming process, however, it provided another opportunity to hear the words of the participants, as well as the silences and inflections that accompanied them, and helped me to absorb more of the individuals' stories.

A field journal was also kept throughout the study. Immediately following each interview, I documented information regarding interview process, context and initial impressions in the journal. For example, I wrote about the art work that hung in one participant's apartment and after another interview I discussed the many strategies he had used to remain involved in previous leisure and work-related pursuits. Throughout the data collection process, as suggested by Hammersley and Atkinson (1995), 'analytic memos' were kept of ideas which were being developed and patterns which were emerging following interviews and reviews of transcripts. This analysis informed the subsequent data collection as changes were made to interview questions and focus based on themes which were emerging from participants' stories. Examples of areas that were not initially identified at the onset of the study but that emerged from the interviews included the importance/meaning of home and neighbourhood and the notion of fluctuating abilities.

Two interviews were conducted with all participants except one who died shortly after the first interview. The length of time that elapsed between the first and second interviews ranged from 18 to 121 days. This variation was due to scheduling difficulties, holidays, the amount of analysis occurring as the data collection process continued, and
multiple cancellations for a variety of reasons, mainly relating to the participants' illnesses. The second interviews that were completed with the first few participants mainly consisted of summarizing his/her initial interview and asking additional questions to clarify information. As well, areas of interest that had been generated (in the analytic memos) from reviews of the transcripts by the supervising committee and myself or which were emerging from interviews completed with subsequent participants were explored. Participants also provided additional information they felt was important and discussed changes that had occurred in their situation since their initial interview.

As the study progressed, the influence of ongoing analysis increased as commonalities and differences that were emerging between participants' stories were reviewed in second interviews. Participants were asked to provide feedback on this preliminary analysis in light of their own experiences and indicate/discuss if they related to the identified themes (if it "made sense" to them).

A total of 17 interviews were conducted. Interviews for all participants ranged from approximately 40 to 90 minutes and occurred in the locations of their choice. These included hospital rooms, an alternate room in the hospital (e.g. the lounge or the social worker's office) or his/her home. The goal was to conduct at least one interview for each person in his/her home, as the impact of an individual's environment was a focus of the study (to obtain an improved understanding of his/her context). This became increasingly important as the home/neighborhood emerged as a strong theme in the interviews. Five participants had one interview completed at home, two had both interviews at home, and two were interviewed in the hospital as they found this more convenient. Two
participants requested a list of questions prior to the initial interview as they wished to focus their answers/thoughts. They were provided with the original interview schedule.

**Data Analysis**

As discussed, analytic memos were made of any promising ideas that arose throughout the study following interviews and reviewing transcripts. As the data collection process proceeded, the data obtained were reviewed for emerging patterns. These ideas were then incorporated into future interviews.

After the data collection process was completed, the summaries of each individual's story were reviewed with my thesis supervisor. Common patterns and differences between the experiences of those involved were discussed. For example, many described the creative strategies they utilized to remain engaged in activities they enjoyed. The data was then systematically organized through the process of 'physical sorting'. Quotes from each of the participants' transcripts were assigned to broad categories on the computer (for example outlook, relationships, and abilities). These were again reviewed with the principal investigator, followed by a discussion around conceptualization of the findings and further delineation of the categories.

Following this discussion, more specific codes were assigned to sentences and phrases throughout the transcripts. For example, originally there were 14 pages of quotes under a single heading entitled fluctuating abilities. This same data was then recoded into smaller units including fluctuating abilities, changing abilities, daily routines, impact on activity, pacing and so on. Codes that were used to organize the data were either spontaneously identified by the participants themselves (for example, one participant
talked about the importance of continuity in place for her) or were identified by myself
(for example, meaning of home).

The groups of data were then examined for relationships which existed between
them and the coded data were then collapsed into themes with subcategories. For
example, the data that were coded as timing, planning, organization, prioritizing and
adjusting daily routines were all grouped under the category of 'individual's strategies for
coping'. Once several themes were identified, those that seemed most central to the
analysis were identified and the focus moved to clarifying their meaning and exploring
their relationship with other categories (Hammersley & Atkinson, 1995). For example,
all of the strategies that individuals described for coping with their daily lives were
divided into three categories - those at the level of the individual, the environment and the
occupations in which they participate. This framework was influenced by the O.T.
literature which asserts that changes in any of these three areas may increase an
individual's participation in daily/meaningful activities. Common themes which emerged
were integrated to create an overall description of the participants' experiences, with a
focus on occupation and the environment. Pseudonyms have been used throughout this
study to ensure the confidentiality of participants. Verbatim quotes are presented
throughout the thesis with the grammar of the participants left unchanged.

Trustworthiness

A number of strategies have been identified that can be used by qualitative
researchers to enhance the rigour of their studies (Carpenter & Hammell, 2000). In this
study, many features of the research approach contributed to the trustworthiness of the
data. This includes, but is not limited to, peer review, presentation of quotes, member checking and reflexivity. Each of these will be discussed in this section.

Peer review occurred throughout the research process. All three members of my thesis committee reviewed the first three interview transcripts. All members had expertise in qualitative research and one individual was considered to be an expert in the field of palliative care. Feedback was provided by the committee members on the interview process as well as the areas that were explored with the participants. Throughout the analysis of the data, my thesis supervisor reviewed the interview summaries and the coding and categorization of the data. As well, discussions occurred around the similarities and differences across experiences as well as conceptualization of the categories and themes which were emerging. A second member also reviewed the preliminary analysis of the data.

Verbatim quotes have been presented throughout the findings section of the thesis to support the interpretations that have been made and to ensure that the voices of the participants are heard. Areas where there was inadequate data to support the emerging ideas or themes, were identified by my thesis supervisor. Subsequently additional excerpts from the stories of the participants were added, or if these did not exist, the statements were revised or discarded.

Member checking occurred in several ways in this study. This process provides participants with the opportunity to see how their accounts are being interpreted and used and to give feedback on this interpretation. A second interview was completed with eight of the nine participants. A summary of each participant's initial interview was reviewed and participants were provided with the opportunity to clarify meanings or supplement
any additional information. As well, the preliminary analysis of the data was reviewed with the participants and they were encouraged to provide feedback on the interpretations/themes that were emerging. Two participants requested copies of their first interview transcripts and both wrote several comments on their transcripts which ranged from grammatical corrections to clarification of meanings to insights they had gained. Four participants requested copies of all of their transcripts to review and one participant also requested copies of her interview tapes which were provided. Several of these individuals indicated that they intended to share their transcripts with their family members or leave them for their family after they had died. Participants were encouraged to provide any feedback they felt was relevant and validation of information was received from many of the participants. Any feedback received from the participants was then incorporated into the analysis and conceptualization of the data. Two participants also requested to review the final product with myself and this will be done following its completion.

It is evident that various aspects of my positioning influenced this study. I have attempted to be reflexive about how this positioning has influenced the research process, the data that was gathered and the manner in which the data was analyzed. As an O.T., I am influenced by the values and beliefs of my profession. These include that enabling meaningful occupation will influence health, that practice must be client-centred, that the emphasis is on working with clients in collaboration, that a holistic approach must be taken with clients viewed within their contexts and that clients' experience and knowledge must be recognized (Law et al., 1997).
My academic experience has also influenced my positioning through the theory and literature to which I was exposed. For example, throughout the Master's program I have gained a broader understanding of the environment and its impact on disability. I have also begun to incorporate an alternative viewpoint on the way that knowledge is created, the manner in which people make meaning of their lives and how this is influenced by the society around them. I have also been exposed to the advantages and disadvantages of different research methodologies. These professional and academic experiences influenced the values that I brought to the research as well as many of the concepts from theory and literature that I worked with in interpreting the data.

My experience working on the P.C.U. at St. Paul's Hospital resulted in a desire to contribute to the understanding of end of life issues in order to provide appropriate and supportive care to individuals who are dying. My history as an O.T. struggling with my role in this area further influenced my choice of study topic. The fact that the focus of my practice had been on facilitating participation in meaningful occupation with an emphasis on reducing environmental barriers and enhancing supports, again influenced the areas of inquiry during the interviews (e.g. occupation, environment). Based on this work experience I also had several assumptions regarding the findings that would emerge from the study. For example, that it was often simpler to modify elements of the environment rather than improve individual's abilities and that independence was not an important value to all individuals when living with a terminal illness.

To avoid dangers of misrepresentation as much as possible in this study, an emphasis was placed on dialogue and establishing conditions where participants could share their perspectives openly with me. I tried as much as possible to put aside my O.T.
'hat' instead assuming the role of researcher. This included asking questions that I may have felt that I already knew the answer to, or asking for clarification on comments whose meanings were not explicit although I may have felt that I understood them because of my professional background. These strategies were essential to ensure that I gained the participants' perspectives as opposed to simply confirming my own assumptions. The categories that were developed were grounded in the data from the interviews to ensure that the 'voices' of the participants were heard. While my own interest and experience informed some of the topic areas that were explored in the interview and analysis, the structure of the interviews encouraged participants to identify the issues that were important to them. As well, experts in the areas of palliative care (a physician) and qualitative research also reviewed transcripts and analysis and provided feedback.

I believe that my experience in working with individuals who were terminally ill had several other influences on the data that was gathered. Over the two and a half years I have worked on the P.C.U., I feel that I have developed a greater comfort level in discussing some of the issues in this study, such as loss and facing death. This likely made it easier for both the participant and myself to engage in this type of discussion. As well, my experience on the unit influenced the questions I did and did not ask because of previous knowledge of some of these issues (for example, respite programs and funding options).

In this study, eight of the nine participants were aware that I was the staff occupational therapist on the P.C.U. where they were inpatients (six were known to me prior to their first interview). Individuals with chronic or terminal illnesses have
experience of/with the health care system, a system which is filled with unequal power relationships, where the medical or health care professional is in a position of power and the patient in a subordinate or dependent position. In addition to this, individuals with a terminal illness are in a vulnerable position as they rely on the health care system for quality of life issues such as pain and symptom management. Because of my role as a health care professional, it was anticipated that potential participants might have perceived me to be in a position of power. Subsequently, they could have felt that they can not refuse to participate in the study, or, if they did participate that they could not share their honest perspectives for fear of the impact it may have had on their future medical care or their access to the P.C.U.

In an attempt to reduce the effects of this positioning, potential participants were not approached about the study by myself but by another member of their health care team who was not involved in the study. In both the letter of introduction and the U.B.C. consent form (see appendices A and B, respectively), it was clearly stated that an individual's refusal to participate in the study would not influence their future medical care. While my position on the P.C.U. team may have influenced some of the participants' willingness to participate in the study, often when I approached them after they had agreed to be involved they indicated that they had not realized that it was myself that was the co-investigator. During the interviews, it was reinforced to participants that their responses would not affect their future health care and that confidentiality laws prohibit the sharing of information to the members of their health care team.

With some of the participants, this previous relationship appeared to make them more comfortable in the interview, perhaps because a feeling of trust and familiarity had
already been established. All of the participants that had been inpatients on the P.C.U. discussed the unit and the services they had received there on many occasions throughout their interviews. This was likely influenced to some extent by my association with the unit. As well, because of previous interactions with me in my capacity as their O.T., this may have influenced some of the comments of the participants, for example emphasizing the benefits of scooters or bathroom equipment I had arranged for them.

Other aspects, which likely influenced the data that was gathered, were my young age, my gender and the fact that I do not have a terminal illness myself. It is evident that the specificities of my positioning as a researcher impacted the study in many ways. It influenced the questions I asked and the areas I was interested in exploring. It also influenced the data that was gathered as well as the way in which the data was analyzed. However, throughout the study I have attempted to be continuously reflexive, exploring and analyzing the ways that my positioning has informed the type and quality of data that was gathered. This process of reflexivity, in combination with member checking, peer review and the presentation of verbatim quotes, have enhanced the rigour of this study and consequently contributed to the trustworthiness of its results. The findings of the study, comprised of the themes which emerged from the stories of the participants, will be reviewed in the next two chapters.
CHAPTER FOUR

"IT WAS LIKE THEY CUT MY WINGS": THE IMPACT OF ILLNESS ON DAILY LIFE
Chapter Four: "It Was Like They Cut My Wings":

The Impact of Illness on Daily Life

"(Cancer) has changed my life upside down. Just that it's changed my life around, it's totally different now" (Samuel)

The purpose of this study was to contribute to the understanding of the experience of living with a terminal illness. Specifically one goal was to explore the experience and meaning of occupation for individuals who were approaching the end of life. This included how they wanted to be spending their time and what goals they hoped to accomplish before dying. As the participants recounted their stories, it became evident that it was impossible to explore the meaning of occupation in isolation but that it could only be understood in the broader context of their illness experience.

All of the participants in the study described how significantly their daily lives had changed as a result of their illness or disease. On average, participants had known of their diagnoses for approximately two years prior to their first interview. Collectively they had received a wide range of treatments including chemotherapy, radiation, surgery and drug therapy. They were now all considered to be appropriate for palliative care where the focus of treatment was no longer on cure but rather on improved quality of life and pain and symptom management.

As illustrated by the words of Samuel, being diagnosed with a terminal illness had a profound impact on the study participants' life experiences. Many described how their approach or outlook in life had shifted since their diagnosis and over the course of their illness. The majority of participants remained hopeful, focused on the present and
counted their blessing while acknowledging their own mortality and preparing for the possibility of death. They also described the manner in which their illness experience influenced their relationships with those around them. The dynamics of many of their relationships changed as family and friends became more of a priority, they became more dependent on others, were unable to connect with others in familiar ways and stigma towards their disease was felt.

All of the participants described deteriorating and fluctuating physical and cognitive capabilities which affected their ability to engage in a wide range of previous occupations. This included, but was by no means limited to, working, bathing, exercising and socializing with others. As a result, some of the participants described experiencing boredom and many struggled to maintain their independence. As well, new activities such as resting, following complex medication regimens and receiving and recovering from medical treatments, had to be incorporated into daily routines.

In addition to affecting their outlook, relationships, abilities and occupations, participants identified countless other losses they experienced as a result of their illness. These included a loss of financial security, feelings of contributing to society, being productive and being "normal". At the same time, participants described the many creative strategies they used to accommodate or compensate for deteriorating abilities in order to remain engaged in meaningful occupations and facilitate connections with others. This chapter will discuss many of these issues. While it has been divided into six sections it is important to emphasize that all of these facets of the individuals' experiences are interconnected.
Shifting Outlooks

Participants described in varying detail the history of their illness from the time of their diagnosis to their involvement in the study. They had responded to their diagnoses with various reactions. Joe said, "my whole world just stopped. You know, what am I going to do now? What am I going to do with my life? . . . Why me? You know, it didn't make any sense." He described himself as a "total wreck" and being a "living casualty ever since." He admitted "giving up hope" for the first several months after his cancer diagnosis but eventually incorporated his illness into his self-identity. He said, "It was just, after awhile it was just normal and that was it." Similarly, Cathabel also talked about the "devastating news" and her difficulty coping with her cancer diagnosis. In contrast, Anne said, "amazingly enough I feel really ready for this transition. I was actually relieved to hear the diagnosis."

Several participants, including Theresa and Gary, struggled with the uncertainty of their future. When talking about this facet of her experience, Theresa said, "I think (uncertainty) is probably the biggest problem people who have been deemed terminally ill have. . . . that end date is unknown, is unknown, completely unknown." Certainly Gary had many questions that reflected a similar sentiment, including "how long are you going to live, how long do you have, what about the things in life that you wanted to do and haven't done yet?"

Few participants talked more than just briefly about death itself and their ideas varied considerably. Several individuals such as Debra, Sandra, Warren and Anne claimed that they were not fearful of death itself. Anne had had a cancer diagnosis previously and had been in remission for 5 years prior to her current diagnosis. She was
grateful for this extra time and now felt ready to die. She said, "I feel complete. I feel like I've lived a very full, wonderful life. And even though I'm only 54, it feels fine that this is my time to go." Debra also indicated that she was not afraid of death itself but rather the deterioration in her abilities that would precede it. She said, "I'm not at all afraid of dying, it's a simple transition from life to death, but getting there through the disease I have that is so devastating..."

In contrast, when talking about the possibility of dying Samuel said, "still at other times, I'm frightened, who wouldn't be?" And although Gary was very open to sharing his experience of living with cancer, when questioned specifically about death his responses were short and he then promptly discontinued the interview. This may well have indicated his discomfort with the topic. Participants talked about steps they had taken to plan for the possibility of dying including preparing wills and signing 'do not resuscitate' orders. Cathabel had been paying a monthly fee for her funeral services so that her children would not be burdened with the cost and, at the time of her second interview, Theresa was preparing her memorial service.

While all of the participants identified death and deterioration as possibilities, the focus of all participants (with the exception of Anne) was on hope and a desire to live. They talked about hope for a cure, of getting better, of "returning to normal", of being able to accomplish their goals, of being able to be involved in activities and relationships and for time.

Many participants, including Gary, Cathabel and Joe talked about the hope of getting better or for time. Cathabel said:
I'm still determined I'm going to get to where I want yet. . . . It's not the
materialistic things in life anymore, it's survival. And that's what I want, just to
survive. And I'm going to. I know the odds are against me but . . . I'll make it.

Warren stated, "I don't find the prospect of death as fearsome as many people do. It's part
of life, no problem." However, he had traveled through Europe the year before to see
various specialists and receive treatment not approved in North America and remained in
contact with clinics involved with research focused on leukemia. Similarly, Gary also
talked about the hope of getting better and "returning to normal" when he said:

> It kind of bothers me when everybody started to talk about how sick you are. To
me, I don't want to think that way, you know. I want to feel well I'm going
through a phase in life where I'm going to improve and get better. . . . it's a thing
we look forward to, we like to be back to normal. . . . when I say back to normal, I
mean back to the type of living you used to live, the type of help that you used to
give to other people, things like that.

Theresa did not talk about hope for a cure but rather hoping for additional time. She said,
"You asked what goals I have and it's really to live from one birthday to another."

In addition to discussing hope, participants talked about counting their blessings
despite facing the end of their lives. They described redefining what happiness was, in
light of the illnesses that they faced. Warren and Joe both said, "I just feel lucky to be
alive". Debra and Anne reflected on how blessed they were to have the life that they had.
Anne said, "I feel like I'm really fortunate to have this life, to be well taken care of, to be
loved". Similarly, Debra appreciated her situation saying "I've led a full and busy life and
been called to so many different things that there is so much joy in simply being every
day... I just feel a sense of well-being in just being and doing." Joe's attitude had also shifted between the first and second interviews as he began to appreciate his current situation as opposed to ruminating on losses in the past. He said:

From the first time we talked that changed a bit... (Not working anymore) is still in the back of my mind... but it doesn't bother me as much as it did before because I realize I can't do it so why dwell on the past.

Debra had similar comments when talking about beginning to accept many of her losses when she said:

Oh you go through a mourning period of giving up hiking. And you look at the mountains and that overcomes you and you're playing the music and the need to get up and float across the room is so strong you think you can't contain it... but that passes.

She then proceeded to acknowledge positive aspects of her life that replaced the joy of these other activities, such as spending time with her grandchildren and knowing that her children were well grounded. Similarly, Anne talked about feeling satisfied with giving up many of her past activities and relationships when she said, "(Letting go) feels peaceful. And I feel at peace. I think that's why it feels good because I feel comfortable with who I am and where I'm going. So, it's a fine journey." Theresa was grateful for the gift of time, time to try different things and time to spend with her family.

Several of the participants, including Theresa, Gary, Warren, Sandra and Cathabel talked about shifting their focus from always planning for the future or waiting to do things to living in the present. They described how this was different from their previous approach in life. Sandra said, "I'm living day to day. I would like to do a lot things, yes,
but I know I can't do it, so I don't think about it. I think what can I do in the present."

Theresa described having always been a saver, putting money aside for her family's future. When she became ill, she and her husband decided to move to a larger home where she would be more comfortable. About her outlook, she said, "I'm just going to live every day and I think that's what we want. . . . For us to live normally, comfortably, every day, as much, as long as possible." Similarly, Warren described this change in focus by saying, "It's the first time in my life that I've just responded to the moment rather than planning the future all of the time." Gary also talked about shifting his approach when he said:

   Your outlook seems more for the present . . . you make the best out of it at present instead of like we used to when I was younger and didn't know that I was ill, always thought of I will do this when I retire.

   Interestingly, Cathabel's outlook appeared to shift over the course of the study period. In the initial interview, she talked about her future and activities, such as volunteering, that she was hoping to become involved with after she settled into Vancouver. However, when asked in her second interview if she had made any progress on these goals she responded, "I'm leaving all that and I'm not going to be worried about those things until such time as I get all these tests done and see the doctor and then see what happens from there."

   Impact on Relationships: Family and Friends As Priorities

   Not only did their illness influence their outlook and approach to life but participants also described the impact on their relationships with others. In this study,
only two of the participants were married or had partners, however, all of those involved, with the exception of Samuel, had children. Through telling their stories, it was evident that, for all participants, many of their relationships had changed since they had become ill.

All of the participants emphasized the importance of their connections with family and friends around them. These relationships were identified as foremost priorities for everyone except Joe and Samuel. Anne and Theresa were both married and had one child. They discussed how supportive their spouses had been throughout their cancer experience. Anne's son was in his middle 20's while Theresa's son was only 16 years old. Both of these women talked about using strategies throughout their day to enable them to conserve their energy for quality time with their families. Anne said, "I think I've changed what's meaningful. Pared back what's important and that's mainly my family. Seeing them is the most important part of my day." Theresa explained, "my son is my project now." Her goal was to build up his self-confidence and independence in order to help him to cope after she died. As well, once faced with her terminal diagnosis she decided that she would take her son to China to expose him to the Chinese culture that he had inherited from her side of the family.

Similarly, other participants talked about the importance of their relationships with their children. Gary explained, "I live for my son" and Sandra recognized that her illness had brought her closer to her two children. For Debra, her children and grandchildren were an important part of her life.

When asked if they had any 'unfinished business' they would like to accomplish before dying the majority of issues that were identified by participants were related to
relationships with family members. This included resolving conflict/tensions, helping others to come to terms with their illness or impending death, reconnecting with estranged family, saying goodbye and strengthening relationships. Joe and Cathabel both had a desire to reconnect with family members. For Joe this meant talking to his estranged daughter to see how she was doing, if she was married and if he was a grandfather. Cathabel wanted to hug her mother one last time. Gary wanted to go traveling with his son as he had promised him they would do this together when he retired. He was also taking the opportunity to talk to his son about issues such as marriage, careers and the future.

Debra described a desire to help her daughter face her dying. She said:

My daughter is not taking it well and doesn't want to face the fact that I'm losing the battle. . . . I feel it from her and I hope that she feels free to talk to me before I lose the ability to talk. That's one thing I want to accomplish.

Cathabel spent a significant portion of both of her interviews discussing her relationship with her children as well as the tensions between her three sons. She was concerned for her son who was also ill and for a son who had many personal problems. Her goal was to reduce some of the tensions that existed in the family. In her own words she said "I would like to see Joe, Greg, Fred, especially Fred, on amiable terms. . . . For Fred and them not to be disbanded (after I die)."

In addition to the increasing importance of family, Anne, Debra, Theresa, Joe and Warren talked about the significance of their relationships with friends. Anne said "I decided what was a high priority on my list and that was my relationships, my friendships. And so I've always maintained that. And I still feel that, that is what is
really important." She went on to say, "If anything (my friendships) might have gotten
better. Because I think when one has a terminal illness, others approach one with greater
respect and appreciation because they understand the time limit involved." Warren
admitted that Alice, his caregiver, had become his life over the past year and his family
joked about him marrying her. Debra talked about the peace of mind she experienced
from knowing that her friendships were solid and while Joe did not have a large social
network, he was grateful to friends in his building for supporting him.

Changing Dynamics and Shrinking Circles

Along with becoming more of a priority, participants discussed other ways that
their relationships with others had changed since their diagnosis. Debra described how
the joy of seeing her grandchildren was accompanied by questions such as "will I see
them graduate?" Many participants talked about an increased dependence on family for
practical and emotional support. Several participants, such as Gary, Debra, Anne and
Cathabel, expressed concern over this shift in their relationships with family members.
Gary's son had taken a leave of absence from work and Gary was concerned about his son
putting his life on hold to assist him. He said, "I don't want him, my son, to feel that he is
totally, that I have to be totally dependent on him. . . . I'm talking he neglected part of his
life, his enjoyment, he did these things for me." Anne and Debra also talked about a
desire to not be "too reliant on family" and Debra tried to spend time with her family
when she was at her "best". Cathabel had lived with two of her sons over the course of
her illness. She expressed concern saying, "I didn't want my son as a caregiver because I
figured it was not a good relationship." In contrast, neither Sandra nor Samuel expressed
concern over how heavily they relied upon family members for assistance. Joe continued to do all tasks for himself as he did not want to experience this dependence on others.

Participants also talked about the changing dynamics of some of their friendships. Anne and Sandra talked about no longer being able to participate in the reciprocity of these relationships. Anne said, "I still have as many friends... but it's more one-sided now. It isn't the give and take of friendship. It's them helping me, or them coming to visit me... so the dynamic has changed." Similarly, Sandra described finding it difficult to be the person receiving assistance from others when previously she had always been the caregiver, in both her career as a nurse and care aide and in her personal life.

Several participants discussed friendships they had lost or that had been weakened as a result of the attitudes of others towards their disease, or because of their own inability to participate in activities or spend time with others. Gary described a social network that had been shrinking as he lost contact with many friends, colleagues and acquaintances. As his disease progressed, he was no longer able to participate in many of the activities that provided a social connection between himself and others. He had retired from work as a teacher after 35 years, was no longer able to tutor the children of friends or continue with his bridge group. He felt that many friends no longer considered calling him to play bridge or to go out because he had declined their offers in the past. In addition he felt that the attitudes of others contributed to his shrinking social network. He stated, "just because you have or you are laid up with this disease, it's like a stigma and they don't want to have too much to do with you." Similarly, Sandra described losing friendships as a result of her illness. She said, "some people don't want to see me because
they want to remember Sandra the way she was before. . . . even my friends I found out they don't want to see me for that reason."

Debra also shared similar experiences with prejudice in both professional and personal relationships. She described how this stigma had impacted on her friendships when she said, "and couples I did things with, as I shake more and use a cane, I had to stop seeing people where the pity got in the way of them being able to be friends." After her retirement Debra began to speak at an entrepreneurial club for women. As a successful businesswoman herself, Debra served as an invaluable resource. However, she eventually had to relinquish this role because she felt that the perspectives of the women in the club were "if she's shaking that badly there must be something wrong with her mind too." Finally, Debra had also lost friendships as she was no longer able to participate in many of the activities she did with friends. She said:

Then you lose a lot of things you can no longer do, like going out with your friends at the drop of a hat. . . . so I have lost touch with several groups of active friends and that was a loss.

Warren and Samuel also described an inability to participate in many of the activities (such as going to restaurants, coffee shops and concerts) they used to do with friends and family. Cathabel had also lost many connections with others when she moved to British Columbia. In contrast, Joe had always been a "loner" and Anne described purposefully "letting go" of many acquaintances as she prioritized who she wanted to spend her time with. She said:

I've let go of a lot of people. I had a big social group that I was part of and I don't care to . . . like I got phone calls from people who we were never really close to . . .
and I don't really feel the need to connect with those people anymore, but some of
them have asked to see me. And some I've said no to.

Participants described the many implications their illness had on their
relationships. For most of those involved, relationships with family and friends became,
or continued to be, their priority. For many, the dynamics of their relationships changed
as they depended more on those around them for support or were unable to engage in the
reciprocity of friendships. As well, many of the participants felt their social networks
were shrinking as they were unable to spend time with others in shared activities such as
work and leisure occupations. Several participants also described the manner in which
stigma towards their illness had resulted in lost relationships and limited their
involvement in meaningful occupations.

Changing Abilities

Since the onset of their disease, all of the participants had experienced a decline in
their physical abilities. While many recounted that these changes had occurred gradually,
their abilities were now significantly different when compared to those prior to diagnosis.
Symptoms included pain, shortness of breath and falls as well as decreased strength,
balance and mobility. For example, Sandra said, "I don't have the strength and I can't lift
nothing, I can't bend, I can't do it." Without exception, participants described the
dramatic change in their physical energy levels. This was emphasized by all participants
and was the most significant limiting factor across the experiences. As Anne explained,
"cancer just eats away at your energy." She described that prior to her illness, she had led
a very active lifestyle with her days filled by work, yoga, swimming, walking and
socializing. Her low energy levels had now limited her to spending the majority of her
days resting and sleeping. Similarly, Samuel described "a lack of energy" and becoming
"more and more tired". And Sandra related, "I'm doing nothing and I want to be doing
everything... sometimes I can barely open my eyes." These reduced energy levels
significantly impacted on the participants' ability to engage in many occupations as will
be discussed throughout this chapter.

In addition to changes in their physical capabilities several participants, including
Gary and Warren, described how their attention and concentration had been affected.
Prior to his illness Warren was a successful international businessman. He reported that
he was no longer able to remain involved in these pursuits in part because of decreased
energy but also as a result of an inability to concentrate for extended periods of time. He
explained, "I don't want to stay out more than an hour because my attention flags and my
capabilities wander." Similarly Gary, a retired teacher, described how he was no longer
able to assist with tutoring children or playing bridge with friends because of decreased
attention and concentration. He recounted a recent experience where he had been unable
to remember the answer to a simple math problem in a newspaper crossword puzzle
despite his history of teaching high school math for 35 years.

As well as a gradual deterioration in their abilities over the course of their illness
the majority of participants described fluctuations in their function throughout the day.
For example, Samuel explained, "sometimes I feel really good and other times, I crash."
Debra and Theresa experienced similar fluctuations as both found their "best" times of the
day to be in the morning or early afternoon. Debra related, "my days are very short, on
even good days I'm usually finished by 3 or 4 in the afternoon... I can't do anymore
physical activities." Theresa described a similar experience saying, "I'm usually much better in the daytime. At night I seem to get worn down."

For all participants their abilities also fluctuated from day to day and over time. They described days when they experienced increased pain and other symptoms as well as times when their abilities improved. These variations were often influenced by treatment they received or when they were able to achieve more effective pain and symptom control. As an example, Theresa's description of her abilities differed markedly between her first and second interviews for this study. During this time period she had undergone a course of radiation treatment. She described these changes:

I was becoming more and more disabled at the time. And (radiation) certainly helped a lot . . . my pain subsided. My mobility has not continued to decline and in fact I have regained some strength so when I have to go up the stairs I used to have to hang on with all my strength and now it is not as difficult. . . . Life is back to some normalcy again.

Cathabel's abilities also varied throughout her involvement in the study. At the time of her initial interview, she described a lifestyle that continued to be relatively active as she spent the majority of her days out in the community, walking, riding the bus and window-shopping. However, she canceled her second interview several times because of feeling unwell, complaining of significant pain and shortness of breath as well as decreased energy, strength and mobility. As her medication regimen was modified, her pain was better controlled and she was able to complete the second interview at which time she said that she "felt stronger in the last couple of days then (she had) in a long time". Anne recounted a similar experience of feeling improvement following a change
in her medications after an admission to the hospital. Because of this she stated, "I haven't had much nausea and that has been wonderful, much more freeing. It's very freeing and it gives me more energy because I'm not expending it getting sick." Several participants described how these daily fluctuations in abilities made planning for the future difficult as they were unable to anticipate what they would be capable of doing from day to day. Theresa said, as a result, "it's daily adjustment."

Over the course of the study several of the participants were taking steps to maintain or improve their functional abilities. Samuel was working with the physiotherapist to increase his mobility and strength so that he would be able to climb stairs and ladders, prerequisites for discharge home. Debra was also attending therapy sessions to improve her left arm function. Gary and Theresa both described a regular exercise program and Theresa and Cathabel Anne discussed the importance of daily walks. In contrast, trying to improve their physical abilities did not appear to be a focus for participants such as Warren, Anne and Sandra. In summary, individuals disclosed that their illnesses had resulted in abilities which had deteriorated since their diagnosis and which often fluctuated over time. The most significant limiting factor for all participants was decreased energy.

**Occupations Lost and Gained**

Participants described the multitude of ways that these deteriorating and fluctuating abilities impacted on their day to day lives, including their involvement in daily routines and occupations. When diagnosed, eight of the nine participants were engaged in work-related activities in some capacity. By the time of their involvement in
this study, all of these individuals had had to discontinue work as a result of their illness. All participants except Anne identified this as a major loss as they described the significant impact having to relinquish work had had on them. Losses associated with no longer participating in the work force included changes in self-identity, loss of financial security, independence, sense of challenge, daily structure, connection with others, as well as feelings of contributing, being productive, helping others and "being normal".

Joe described working seven days a week, 16 hours per day prior to his diagnosis. He was employed as a cook in two different restaurants, working from 6:30 a.m. to 1 p.m. at one restaurant and from 4 p.m. until 2 a.m. at the other. As he explained "work was it, that was my whole day and I enjoyed doing it." He was instructed to discontinue work immediately after his diagnosis of lung cancer as the shortness of breath, decreased energy level and poor standing tolerance he experienced limited him from performing his job demands safely. He described the experience of giving up work as "Oh I felt bad. . . . really because that's all I'm used to doing and all of a sudden I can't do it anymore? I was going nuts, I was so used to working."

Similarly, work was a major occupation for Cathabel. She was diagnosed with lung cancer shortly after retiring from her position as a bookkeeper. She described retirement as one of her most challenging experiences. She had planned to continue with bookkeeping work on a part-time basis, to fill her days and supplement her pension income, however, she explained, "that didn't materialize because all this came up." She did continue to work selling flowers on the weekends. She talked about how much she enjoyed this job because of the companionship of her colleagues, the interactions with customers, the additional income she earned and because she was seen as a leader in the
group and her co-workers described her as a positive influence on others. However, she relinquished this role as well only months before her initial interview when she "went to work one weekend and (she) had to come back home because (she) knew (she) couldn't handle it anymore."

The sense of loss associated with discontinuing work was a similar finding across the experiences of the participants. Gary said, "You work your whole life, I worked in a job helping people for 35 years and all of a sudden it came to an end. I can't do what I want anymore." In contrast to the other participants, Anne was surprised at how easy she found selling her private business. She described a sense of relief hearing her diagnosis as this explained to her why her business had been failing. She had not had the energy to continue to recruit business and her diagnosis provided a rationalization for this. While she acknowledged missing work, she felt that she had been ready for the transition.

Not only were participants required to relinquish their roles as workers but their ability to remain involved in other occupations also became more limited as their disease progressed. Many of the participants, including Cathabel, Warren, Sandra and Samuel, experienced increasing difficulties with managing their own personal care. For example, Sandra said:

In my shower, I can't go by myself. I fell twice already plus I don't have the energy now to stand up in the shower so I have to be sitting and somebody helps me with my hair and I can only wash half my body.

Using the shower/bathtub was identified as the most common struggle with personal care amongst the participants. Other activities such as dressing and managing medications
were also identified as challenging. Participants described these activities as difficult because of the amount of energy, strength and mobility they required.

Anne, Samuel, Cathabel, Gary, Sandra, Debra, Joe and Warren all reported having difficulty with, or being completely unable to perform, homemaking tasks such as shopping, cooking, cleaning and laundry. Samuel, who lived alone, said, "I can't shop, I can't cook... I can't keep my apartment clean." Anne's story of attempting to clean her condominium illustrates similar challenges. She explained, "I tried to sweep and I had to go sit down three times to rest and it is just a tiny place. It was just too much for me to do it." Many of these participants received assistance with these tasks.

Finally, participants described the many ways in which their illness had impacted on their ability to pursue their leisure interests. They described limitations with activities such as exercise, craftwork, visiting, socializing, going to restaurants and movies and travelling. For Anne, exercise had always played a significant role in her life. She described exercise as "one of the hardest things to give up" and identified this as a major loss. Although she was forced to give up many of her more strenuous pursuits, such as biking and swimming, she attempted to continue with walking and yoga after her diagnosis. However, as her energy and mobility continued to deteriorate she eventually had to stop doing yoga and was now "wiped out" following short walks. Overall she said:

(Cancer) is pretty encompassing - it's taken my energy so everything has changed from my activities, my focus and interests are all affected. . . . Like sometimes I'll lie in bed and think okay I could do so and so and so and so and then I'll stand up and I
can barely walk into the living room and I'll think, no, I'll scratch that plan. . . . (Cancer) is very debilitating, very slowing down.

In her second interview, Anne also admitted that as her cancer progressed she was becoming less interested in participating in activities outside of her home. She said, "I used to be interested in many more things and was social and outgoing. I'm not anymore. I'm much more introspective. I'm just in my own quiet, family world." Therefore, for her, participation was limited not only by her deteriorating abilities but also as her interests and priorities changed as her illness progressed.

Debra was also no longer able to engage in many activities, such as travelling, horseback riding, dancing, hiking and going out with friends. She described all of these as significant losses. For example, she said, "You know letting go of riding, I thought for awhile that I was just going to expire from the loss. And same with dancing." The opportunity for Debra to participate in many of her interests varied greatly depending on her abilities at the time. The impact of these fluctuating abilities was evident in her description of her daily routine. When asked to describe a typical day she responded, "Everything from total disability where there are days when I can't get up and walk to even the kitchen to days when I have some mobility to days where I have enough mobility to go out for lunch."

Similarly, Sandra described many activities that she was no longer able to engage in:

I can't (travel) anymore because I have to go with somebody in the wheelchair and they have to push me. . . . and my computer I can't use it anymore because my fingers won't work. . . . you can't work, they cut everything from you. I used to be
a good reader, I can't read anymore, I can't focus. I tried to do some sewing and it's so hard, then I tried to knit and I couldn't.

Warren was unable to frequent restaurants, plays, dance recitals and the theatre as his mobility was becoming more restricted. When reviewing the transcript of his first interview, he revealed that he was surprised at how "considerably" he had "cut back" in his activities, however, he viewed this as "inevitable" in light of his leukemia. Samuel also described the impact of his decreased energy and mobility on his leisure activities when he said, "I can't do the same things I did beforehand. I can't walk too far. I can't see my friends as often. I can't just get up and go to a movie, you know, things like that you used to do everyday." Finally, many of the participants including Warren, Gary, Theresa, Sandra and Joe had been required to discontinue driving as their illness had progressed and they identified this as a loss as well.

As a result of their inability to remain involved in many of the activities they found meaningful, Joe, Samuel and Anne talked about the boredom they experienced as a result of their inability to participate in previous interests, occupations and roles. Samuel said, "now I have so much time on my hands." Similarly, in their first interviews, Joe said "I'm bored and I've got nothing to do" and admitted to smoking more to fill his time and Anne described her days as a "pretty boring experience".

Along with affecting occupations that individuals had been involved with prior to this diagnosis, the illness or disease of each participant brought several new activities into their lives. When recounting their typical days, it became apparent that for many of the participants a large portion of their daily routines consisted of medical appointments, treatments, hospitalizations and medication regimens. For example, Sandra had spent the
majority of the past year having, or recovering from, over 10 surgeries, in addition to being in the hospital for respite or symptom management admissions. Samuel had also spent the past several months living in the hospital. When discussing her daily routine Theresa explained that she had "quite a tough schedule of medications" which consumed a large portion of each morning. As well, when asked if she had become involved in any new hobbies or activities she responded, "but a lot of my leisure time, not leisure time . . . making these medications takes a lot of time, so I don't really have that much time." Her afternoons were often spent attending various appointments as she was involved with Western, Chinese and Tibetan medicine. Similarly, large segments of Cathabel's days were consumed by medical appointments and visits by home care nurses. Scheduling a second interview had been challenging as her calendar was filled with these types of commitments.

Finally, all participants talked about their need to rest. They acknowledged that rest had become a significant activity in their day. Several participants, such as Warren and Theresa, scheduled regular rest periods into their daily routines while others described requiring rests after specific activities such as walking or bathing. For Samuel resting helped him to re-energize and get his "second wind again". Anne and Warren both revealed that the amount of time they spent resting was increasing as their disease progressed. Warren said, "I seem to be spending a lot more time just dreaming and sleeping." Anne also admitted using rest not only to replenish her energy but also to fill time. She said, "it has been where I can just sleep anytime for as long as I want. Which is kind of nice because there isn't all that much to do. . . . Definitely I use it to fill time."
The changes that participants experienced in their functional capabilities had a profound effect on their ability to participate in many of the activities and occupations which were important to them, which they needed to do or which they enjoyed. Most significantly participants described the many losses associated with being unable to continue working and engaging in personal care and leisure pursuits. Several participants also described a sense of boredom as a result. Finally, new activities such as rest and following medication regimens were incorporated into the daily routines of all of those in the study.

Creative Strategies To Facilitate Continued Involvement

While participants identified a multitude of occupations in which they were no longer able to be involved, there were also many activities that they continued to enjoy. This included preparing meals, doing their own cleaning, entertaining and spending time with others, writing articles, traveling, corresponding with friends, reading, preparing lunches for family, visiting summer cabins, doing research, sitting in on university classes, watching television, enjoying the arts and going for walks. For example, Debra said:

I enjoy cooking. I enjoy having a meal by myself. . . . I light the candles, I put on my music and I read and I make myself three course meals and things that I've never been able to do for myself in my life. And I always use china and crystal and enjoy setting the table and putting out my meal.

Anne attempted to incorporate one social activity into each day and, similarly, Cathabel related the necessity to leave her apartment each day, despite her declining mobility.
Participants acknowledged the many benefits they experienced as a result of being involved in meaningful occupations. These included, but were not limited to, occupying the mind, taking their focus away from their illness, providing challenge, something different to do, filling time, making them feel that they were contributing, were improving or were "normal", helping or connecting with others and for social recognition and pure enjoyment. For example, Joe discussed the benefits of participating on the tenants' advisory committee for his building:

(Participating on the committee) keeps me on track. I don't think much of anything else but what I'm doing so my mind is not worried about the cancer or anything like that, I'm just busy with something else so I don't bother thinking about it.

Gary talked about the importance of remaining involved in activities he enjoyed saying, "I think (being involved in activities/programs) does make a difference for your outlook and they way you see and do things."

Participants used a variety of strategies to enable themselves to remain involved in many of the activities and occupations in which they were interested, despite their changing abilities. Debra explicitly identified applying skills she had previously used in work and day to day living to her current situation. She said:

Again it all comes down to economy of energy. If you've had that in your regular life, you know before you've taken ill, when you've got a terminal illness, you can't help but apply all of the rules that allowed you to bring up a family, and work in your community and work out and travel and do all those things you know. So, I'm applying all of that stuff to maintaining an independent lifestyle.
When asked specifically, Theresa confirmed that she also used work-related skills such as planning and organizing to manage her functional limitations.

Many of the participants adjusted their daily schedules to accommodate their fluctuating needs. Anne said, "I never go out in the morning. I try to schedule everything later in the day." Debra also explained, "I try to put (appointments) in the mornings on the days I'm feeling well." Debra and Joe modified their routines based on how they were feeling on particular days. Joe said, "depending on how I feel, like I said, if I don't feel like talking to anybody, if I had a bad night, I'll just get my coffee and go back upstairs and spend the day there." Similarly Debra described that a "bad day" for her was "just truncated" as she eliminated social activities from her schedule and focused on maintaining herself at home.

The majority of strategies that were applied, such as prioritizing, planning and pacing, were related to conserving energy. Many of the participants talked about prioritizing how they wanted to spend both their time and energy. For Theresa and Anne, this meant spending time with their husbands and children. Cathabel said, "I just do the things that I have to do. Which the main things in my mind at the moment are eating, taking medication and being able to get out of bed." Debra had also prioritized what was important to her and how she wanted to be spending her time. She said:

(Taking care of my things) gives me joy . . . so as long as I can I will do that. The things I would rather give up, going out to the movies, then I would give up having my music and nice dinners.

Participants also talked about carefully planning out their activities to discover ways to make tasks simpler and to conserve their energy. Theresa combined her errands
with her daily walks and planned what she would need over the course of the day so that she could limit the number of times she had to use the stairs in her home. Debra talked about the planning that enabled her to continue to prepare elaborate meals for herself. She said:

So, I find I plan my meals ahead of time, carefully, and I prepare those things in the morning and if I can't lift them out of the fridge, I make those complicated meals on days when I have somebody coming in and before they leave, they put it in the oven and I just have to turn it off.

Several participants, such as Joe, Cathabel and Debra, also described pacing themselves when they were performing activities. Joe refused to accept assistance from homemakers as he felt that if he was no longer able to make his own meals and do his own cleaning he would have nothing to do and would then "really feel useless". Although he found many of these homemaking tasks challenging, he paced himself and divided activities into smaller, more manageable segments. As an example he said:

Like I'll vacuum the carpet in the living room, then I'll sit down, have half a cigarette. Then I'll get up and vacuum the carpet in the hallway, and the small one in the bathroom and then I'll go sit down and finish the cigarette. Then I'll haul the carpet into the living room. I drag my cart outside first, then I get the stuff ready to wash the floor. Then I sit down for another half hour and then I get up and wash one section of the floor and I sit down. . . . I pace myself.

Cathabel described a similar approach with dressing when she said, "I have to get everything laid out, what I'm going to be wearing, and I just sit down and do it step by step." Warren attempted to simplify tasks when possible. For example, instead of getting
dressed to go down to get the mail he would simply put a sweater or jacket over his pajamas. Instead of bathing and shaving daily he would do these tasks every second or third day.

Participants also modified the manner in which particular activities were performed/done in order to remain involved. For example, Anne explained that instead of socializing at restaurants she would invite friends to her home, as this required less energy as she did not have to get dressed, walk to the restaurant and wait for her meal. Instead of preparing all of the food for guests at a dinner party, Theresa would order food for delivery or request each guest bring a dish. Instead of visiting with others face to face participants such as Warren and Theresa corresponded with friends and family by e-mail or by telephone.

Participants also remained involved in previous activities or interests in different capacities. Because of her pain and decreased energy, Theresa had to discontinue work as the curator of a museum. However, she continued to remain involved in work-related interests by doing her own reading and research about archaeology and going to China to "feed (her) own personal interest of Chinese archeology." Samuel had been unable to work full-time because of decreased energy but instead began a position which did not require heavy physical labour and which provided him with the opportunity to work for a few hours, two to three days per week. Debra was no longer able to manage her own company, however, she continued to have regular lunch meetings with a group of business women, became a speaker at an entrepreneurial group, and followed business news in the paper. She was also unable to participate to such a large extent in the world
of arts and ballet, however, she continued to attend concerts, read books on art and dance and audit art history lectures at the university.

Similarly, Warren had found several ways to remain involved in many of his interests. He was no longer able to participate in the world of international business on a full-time basis but continued to be involved through setting up educational scholarships and foundations and consulting on problems related to business and education with friends through meetings and over the telephone. He was no longer able to attend concerts and theatre but instead watched music programs on television, listened to BBC and admired his art collection. He was no longer able to travel but instead chose to live in the highest building in the city which offered him a view of both the ocean and the mountains, talked on the telephone to friends all over the world, covered the walls of his apartment with artwork he had purchased in different countries, looked through pictures of places he had been, watched travel shows and reminisced about his time in other countries. Debra also acknowledged that reminiscing helped her to remain involved in activities that had been enjoyable but that she was no longer physically capable of doing. She said, "One day I realized that I was still doing all of those things literally, not literally in the sense still riding but I was still riding, the joy of all those things is very much there still to replay."

Although this did not appear as common, participants also discovered new interests and activities which they found meaningful, which matched their abilities and, in some instances, replaced roles they had lost. Joe's story provides a clear example of this. As he was no longer able to participate in the work activities which had previously consumed his days Joe described a lengthy period following his diagnosis where he did
nothing but stay in his apartment. He described eventually "snapping out of it" as he realized he was not going to simply give up and die but wanted to continue living. He gradually became involved in activities such as helping others in his building, going for walks and frequenting bars. Eventually he assumed duties related to making coffee for his entire apartment complex, he served on his apartment's tenants' committee and helped to organize functions for his building such as communal meals and outings. During his first interview, Joe complained that nothing he did provided him with the sense of challenge that work had. However, in the second interview he admitted this was no longer accurate as his responsibilities and involvement on the tenants' committee were expanding.

Cathabel and Gary discussed seeking out activities to replace work, such as volunteering and attending programs at community centres, however they did not initiate this involvement over the course of the study. Debra also described now being able to enjoy simple tasks such as preparing and serving meals that she had been unable to do when she was working.

**Independence**

All of the participants except Anne and Warren talked about the importance of remaining independent despite the changes in their abilities as a result of their illness. For example, Debra said, "I'd like to maintain my independence as long as I can." Joe stated, "I do my own thing and I want it to stay that way until I can't anymore. And I hope to God that's going to be a long time from now. I'd like to be independent. I'm happy that way. It's not going to change." In contrast, Anne explained that at this time in
her life she felt that it was acceptable for her to receive assistance from others and she did not identify independence as a major goal. While independence was paramount for most of the participants, their definitions of this construct varied considerably.

For participants such as Samuel, Joe, Debra and Theresa, being able to do things for themselves was an important indicator of their independence. Samuel and Debra both claimed that it was important to them to be able to continue to do their own personal care. Samuel said, "I won't ask for help until I absolutely have to have someone in the bathroom there with me when I shower. I want to do that on my own as long as I possibly can." Similarly Debra said, "I cut out the social things so that I can just maintain myself independently you know so I can bathe and put things in order." Joe, Sandra and Theresa talked about being able to engage in activities such as going out into the community, shopping and doing housework. Joe said, "so it takes me an hour to wash my floor. Big deal, at least I'm doing it myself. I don't have to rely on somebody else doing it for me." Sandra said:

Now I have the scooter. . . . you can go out by yourself and shopping a little bit and you are secure, you have a scooter, you don't have to rely on nobody or wait for a friend to take me here, take me there you know. I feel more independent. . . . It gives me a little bit of independence and freedom.

Joe, Debra, Cathabel and Sandra all identified living alone as an important component of remaining independent. According to Debra, despite her illness "the independent drive remains and I think for me, that's in my life that's very important to live alone." When talking about the option of moving from his apartment into a hospice Joe said, "there is someone to look after you 24 hours a day, which is nice. . . . but you're
not living on your own." Theresa and Warren also talked about a desire to live at home as long as possible, and were grateful that they had the financial resources to do so, although they did not specifically link this to independence.

For some participants it was not the ability to do things for themselves that was central to being independent but rather being able to exercise control over their lives. Certainly this was true for Cathabel who, after moving into her own apartment, said, "I'm in charge of myself now. I'm looking after me. And I make my own decisions about myself. I will need help maybe somewhere, in some areas, but I will make my own decisions." Similarly Joe also talked about the importance of control:

I'm free, I can do what I want. If I want to go out, I go out, if I don't to hell with it, I just stay home. But at least I have the option to be able to do it. If I didn't have the option then I would be in pretty bad shape. I'd deteriorate a lot faster.

Debra recognized that as her disease progressed she would no longer be able to do many of the things that were vital to her independence. Although she was willing to accept assistance she talked about the importance of remaining in control:

You don't realize what an essential thing (control) is in your life until you start losing it. . . . that is what independence is all about and I know when I lose it, it will be somebody else's routine, when they come in, when I have my bath, whether I read during the night or not, when I eat, and that, that's going to be a real test of how much courage I really have.

Over the course of their involvement in the study, it was evident that Gary, Debra and Cathabel were making attempts to regain some of the independence that they had lost. Gary was becoming more self-sufficient with activities such as administering his
medications and cooking meals and said, "I've been improving in the sense of doing things... I had to depend on (my son) to do a lot of things and now gradually I don't."

Cathabel wanted to, and did, move from her son's apartment into her own home. Following a stroke, Debra was attending therapy sessions to regain some of her arm function to enable her to continue to do her own personal care and prepare her meals.

As the study progressed it became clear that illness and disease had had a significant impact on every aspect of the lives of those involved in the research. Changes in their outlook, relationships, physical and cognitive capabilities as well as their ability to remain involved in meaningful occupations were evident. Participants recounted innumerable losses related to, and as a consequence of, these changes. However, at the same time participants had found many creative ways to accommodate their changing needs through applying strategies to conserve energy and modifying their activities. By doing this they were able to continue to be actively involved in many aspects of their lives despite their functional limitations. Participants also described many ways that they had restructured their environment to facilitate their participation and to meet their changing needs. This will be the focus of the next chapter.
CHAPTER FIVE

SHRINKING WORLDS: THE IMPORTANCE OF
HOME, NEIGHBOURHOOD AND COMMUNITY RESOURCES
"the world is shrinking very rapidly now . . . I know it's going to shrink a lot more"  
(Debra)

From its conception, one goal of this study was to explore the influence of individuals' contexts on their experiences of living with a terminal illness. Initially the focus was on identifying enabling and limiting elements of individuals' physical, social, cultural and institutional environments. Several examples of these barriers have already been discussed, such as the negative role that stigma played in limiting Debra's and Gary's involvement in meaningful occupations. However, when listening to the stories of the participants, it became evident that, while important, the influence of the environment moved beyond these concrete issues. Participants talked not only about their deteriorating abilities, the relationships they had lost and the activities and occupations in which they were no longer able to participate, but also the changes in the everyday worlds they inhabited.

For all those involved in the study, it was clear that their worlds were shrinking (socially and spatially) as their disease progressed. This was evidenced by their decreased social contact with others, reduced participation in occupations and limited ability to access their community. The growing importance of their homes and neighbourhoods was evident as was the increasing significance of health care institutions. Participants renegotiated the meanings attributed to the various places they accessed as their illness progressed. At the same time they restructured their environment to accommodate their changing physical, social and financial needs. Participants not only
made changes to their physical surroundings but also organized their social environments to maximize their involvement in activity and achieve goals. This included accessing both formal and informal services and resources.

Restructuring Home

At least one interview was completed in the homes of seven of the nine participants. Their homes ranged from subsidized bachelor apartments to large houses with many rooms in affluent areas. Individuals described venturing out into their neighbourhood less frequently as their energy and mobility decreased and symptoms such as pain, shortness of breath and nausea increased. Consequently, they began to spend more and more time within their homes.

Participants described the various features of their homes that they enjoyed. Warren and Sandra both talked at length about the view from their apartments and how meaningful this was to their lives. Warren had specifically moved to his apartment because of the view which allowed him to "see the mountains and the ocean and the snow and the peaks." Having a "wide open spaces view of things" while still remaining in the city had always been important to him. About her view, Sandra said, "sometimes when I can't sleep at nighttime I'm going to the window in the living room and I can see Vancouver with all the lights on... it's just beautiful."

Warren, Debra and Theresa all discussed the artwork that hung on the walls of their apartments. Warren talked about the sentimental value of his art, as he had collected it from excursions around the world, while Debra had selected pieces of art that she simply enjoyed admiring and Theresa had prints of work-related interests. When
discussing their homes, both Warren and Joe acknowledged how helpful the other tenants in their buildings had been. Warren described his apartment as "a wonderful place to live. People here in the building are very kind and very thoughtful and helpful." This was especially important for Joe, as these people formed his main support network. This will be discussed more fully in a later section.

All of the participants discussed features of their homes which enabled them to continue to participate in activities and that made things easier for them. For example, Theresa talked about being able to manage her home because there were no stairs in the main living area. Samuel was able to continue to do his own laundry because of the laundry room's proximity to his apartment. Sandra and Joe were both able to store their scooters in their apartments as the entrances to their buildings were accessible and there was sufficient room for the scooters both in the elevators and within their apartments. Joe said:

I drive the cart right into my room because we have a handicapped entrance outside in the back lane. So, I just drive around there, unlock the door, go right into the elevator, get off on the first floor and just drive to my door.

Several participants, such as Cathabel, Debra and Joe discussed the benefits of having a small living space so that they were able to continue to maintain their homes despite their decreasing energy levels. Because of its small dimensions, Debra was also able to move around her apartment without assistance, using the furniture for support. Because of his balcony Warren was able to go outside without leaving his apartment and Gary's house had a basement suite which enabled his son to live with him and provide assistance.
In addition to aspects of their homes which they enjoyed or which enabled them, participants described elements which limited their participation. Most commonly this was the presence of stairs or ladders, but also included the lighting and having to go outside to smoke. Samuel lived in a building where he had to climb several flights of stairs to access his apartment. He talked about how this limited his involvement in activities outside of the home. As an example he said, "I wouldn't be out enjoying a coffee at one of the coffee shops. . . . because I think, ugh, all those stairs I have to get up to get to my apartment." As well his bed was located in a loft that had ladder access only and this made simple tasks, such as using the bathroom during the night more challenging. Theresa anticipated increasing difficulties with spending time at her cottage because she had to use a ladder to access her bedroom. Similarly Debra said, "I can't go over to our place on Salt Spring Island anymore because it's too hard for me you know to climb over the rocks and to get to the cabin and I don't want to be carried."

Many participants described the ways they had restructured their homes to meet their needs and to enable them to continue with some of their interests. For example, Theresa's husband had a fireplace installed in the living room as he anticipated that she would be spending the majority of her time there. Debra, Theresa and Anne had each arranged a 'resting' area in their main living room, with pillows and blankets so that they were able to rest comfortably. Several participants described installing equipment to increase their safety, independence and ease with day to day activities. This included grab bars, bathseats and appliances such as dishwashers. Gary, Sandra and Samuel described the bathtub equipment they used to facilitate their independence in personal care. Gary said, "I was using (a bathboard and grab bars) over at the hospital and all of a
sudden I came home and my son had them done here and it was a great, great help."

Theresa's occupational therapist was also arranging for similar equipment, such as a raised toilet seat, a stool and "a handle bar that would help (her) to get in and out of bed easily" so that she could conserve her energy.

Four of the nine participants had even moved homes to accommodate their changing physical, social or financial needs. Debra "gave up" the house where she raised her children because she "could no longer climb the stairs" and was unable to manage her large estate. Similarly, Cathabel was also unable to negotiate the stairs to access her apartment and also required more support then was available to her where she lived. Theresa moved with her family from their small townhouse to a larger, more comfortable house that would accommodate her changing needs. She said:

My husband anticipated that as my disease progressed I might have problems negotiating stairs so about 10 months ago we moved, we moved here. . . . So I can essentially exist on one floor without having to go downstairs, and I don't, I can't. And this place is very wide, you know very easy to accommodate a wheelchair if I ever need one.

Anne also described moving homes following a first cancer diagnosis five years ago. She said, "we moved into a very small place that's easy maintenance. . . . went to a quieter place." Sandra's move differed in that she relocated to a subsidized apartment as her income had been significantly reduced when she was no longer able to work. She stated that her apartment was not only more affordable but she loved its layout, location by the beach and the view from her balcony.
Participants described elements of their home which enabled them and also limited them. They described how they had restructured their environments to reduce physical barriers and facilitate their participation and ease with activities. This included installing equipment and moving to homes which were more suitable to their changing needs.

Renegotiating the Meaning of Home

As participants' energy and mobility decreased, they were unable to remain involved in many of their previous community-based occupations such as working, socializing and engaging in leisure pursuits. Consequently, their homes became more of a focal point as they spent an increasing amount of time there. As an example, Anne said, "before I was much more external and out in the world, using the parks and public pools and going to theatres and restaurants more and being home is (now) more important."

Homes became much more than simply places to sleep and eat, but where many individuals followed their leisure interests, socialized, took care of themselves, were productive and received medical treatment. By listening to their stories, it was evident that the homes of the participants had many meanings attributed to them which were renegotiated as their disease progressed. These included a place of independence, control, comfort, peace, safety, privacy, lack of privacy, ease, risk, tensions, stress, a place to be with family, to socialize and to participate in meaningful activity.

Anne described spending the majority of her days resting in the condominium which she shared with her husband. Her apartment was invaluable to her for many reasons. She described this feeling by saying, "I feel panicky when I think of not having
it. It's very important that I have this place, this serene retreat. It doesn't have to be great or fancy, it's really comfortable. It feels like mine." In addition to providing a sense of security and belonging, Anne's home represented a place where less effort was required. Staying home was much simpler than venturing out into the community and she therefore often invited people over to visit instead of going out. She provided an example:

Like I'll often opt out and have people bring food here, rather than go to a restaurant to eat. . . . Because it's quiet and peaceful here. I'm very happy here, very comfortable. And to go to a restaurant and have to shower and put on clothes, that is really exhausting.

Warren had lived alone in a one-bedroom apartment prior to his illness. As his disease progressed and he required more assistance, he hired a live-in caregiver who slept on the futon in his living room. His home no longer represented a place of privacy. Warren reported significant changes in his ability to participate in various activities outside of the home. He talked about these changes:

We used to, when I was more mobile, I'm not mobile anymore, used to go out to dance recitals or theatre or music but I haven't been able to do that for about six months now. Just walk with a walker. Go down and get the mail. Sometimes I go outdoors. Once in a while we go out and get a meal.

He spent time with Alice, watching movies and working with her to improve her English. Instead of going to theatres and concerts for entertainment, he watched T.V. and listened to the radio in his home. Instead of going to art shows, he admired his art collection in his apartment. Instead of travelling to see friends and family, he spoke to them on the phone. As he said:
I have four daughters who live in Minneapolis and I telephone them once or twice a week so I'm busy on the phone and I have lots of friends all over the world I talk to on the phone also.

He followed business ventures on the television and in newspapers and consulted on business and education matters from home. For example, a friend had come from Minneapolis the day before to discuss a business venture. Therefore, his home became a place to socialize and to participate in leisure and productive pursuits.

Similar to Sandra, Joe had lived in a subsidized apartment for the past several years. As he no longer spent his days working at various restaurants his productivity was now linked to his apartment complex. He served on the tenants' advisory committee, and helped to organize group social events. He was responsible for making the coffee for all of the tenants and spent each morning down in the lounge socializing with others. He said:

I'm the guy in charge of making coffee for the past four years. So, I make coffee every night and go down there in the morning and have a couple of cups of coffee and talk to the guys . . . I'd say about 50 percent of the people go down there in the morning so you always have somebody to talk to.

He also invited several tenants to his apartment for supper on occasion or visited others when he desired companionship. On days when he was feeling unwell, he simply remained in his apartment reading, watching television and doing chores. Therefore, Joe's apartment was his place of refuge and support as well as where he worked and socialized. About his apartment he said, "I'm glad I moved in here. Like I said I've got
something to do." Finally, Joe associated his home with feelings of independence and control.

Similarly, living alone was a symbol of independence for Cathabel. As she began to feel better following treatment, she moved from her son's home to her own apartment as she felt that she was still able to live independently. In her first interview she stated, "I still feel that I could live on my own, but at my own pace, doing my own thing." This desire to live independently was compounded by the tensions associated with living with her son. Her first interview was completed on the day after discharge from the hospital and she said, "even yesterday coming home I could feel stress building up." Cathabel moved to her own apartment prior to her second interview. During our second visit she described the difference in her outlook her move had made as she felt much more at peace and in control. She explained, "it's more relaxing because I can do what I want, when I want." Along with the positive meanings associated with her home, however, Cathabel felt isolated and driven to leave her apartment at least once a day. As well, being responsible for all of the homemaking activities was a struggle as was paying for her elevated rent on her limited income. Therefore, for Cathabel her home appeared to represent a place of mixed meanings.

Debra, Gary, Sandra and Theresa described engaging in more and more of their activities within their homes. Debra said she was unable to leave her apartment in the afternoons because of decreased energy and other symptoms and spent her time reading, watching television and listening to music. Theresa described entertaining at home when she said, "now I see a lot of friends and I like gatherings because this house is a very sociable house, it's good for groups to come." Similarly, Sandra described socializing in
her apartment by saying, "I watch a lot of T.V., and then I have some friends or ladies, my mom's age, you know they are 80 years and up and they come to my house and they make tea and we play cards." Gary described doing exercise in his apartment when he said, "I try to move around the house and try to be a little more active, like try and touch your toes, swing your arms, or do a little aerobic exercise . . . it's a start just to be active."

Joe, Sandra and Samuel all compared the meaning of their homes to other places such as hospice or the hospital. Sandra went to view a hospice as she was having difficulty managing living alone in her apartment. After the visit she agreed that having someone to care for her 24 hours a day would be helpful but compared hospice to her home by saying:

The (hospice) is beautiful, the people are nice, but I guess I'm not ready to go there yet. It made me feel more sick. It makes me feel like I still have something that belongs to me. I have my apartment, I have my privacy. If I go there I can't put anything in those little rooms that belongs to me.

Joe's home care nurse had also been encouraging him to move into a hospice. However, to Joe being able to live alone and having control over when and how he did things was paramount to his sense of independence. It was his opinion that "to be in a place like that, you might as well give up and die . . . It's sort of like, to me, it would be like being in jail." He felt that he would have nothing to do because everything would be done for him and also that people there would be too old to provide good companionship.

It was evident that for all participants, the meaning of their homes were renegotiated as their illness progressed and they spent an increasing amount of time there. The meanings attributed to their homes and other places were as significant as their
physical or social features as these meanings shaped the participants use of space (for example, where they chose to live).

The Increasing Significance of Neighbourhood

As the participants' worlds became smaller, not only did the importance of their homes increase but so did that of their neighbourhoods. Individuals in this study lived in a variety of areas throughout Vancouver, although all were either located close to downtown or in relatively affluent areas. The attributes of the neighbourhoods in which they lived were highlighted by many of those involved in the project. Specifically, participants described the benefits of the locations of their homes in terms of access to resources, continuity of place, the beauty of the area and its physical accessibility. This was especially apparent for those individuals who had relocated following their diagnosis.

Eight of the nine participants discussed the importance of the location of their homes. To some, like Sandra and Warren, this was because the area itself was attractive. Sandra said, "I would love to go for a walk, where I live it is beautiful." For others, it was because of the availability of services and resources. This included access to a variety of stores or the proximity of a bus route, the institutions where they received treatment or other resources such as community centres. Anne enjoyed her neighbourhood immensely because of it's trendy shopping area. She said, "I do a little walking I like to go to the theatre that's two block away so I can still walk up there. . . . I still walk to several restaurants." However, the area itself was relatively hilly which she found challenging as her mobility decreased. Gary enjoyed his neighbourhood because it was quite, safe and there was a community centre located nearby. About his
neighbourhood Warren said, "I like Jervis, I like Davie Street. It's full of surprises, everytime I go out there, full of interesting characters."

The influence of location was especially evident for the four individuals who had moved since their diagnosis. When exploring potential new homes, participants considered not only the features of the houses/apartments themselves but also the neighbourhoods in which they were located. Continuity of place was an important factor for both Theresa and Debra as both women chose to stay in the same general area when they moved homes. Debra said:

As our world shrinks from traveling to literally every place in the world to traveling down to the beach and 10th Avenue and everything, once your world is shrinking, I think it's very difficult for someone to be moved out of your essential environment... 33 years of shopping there, I know everyone. They know me... and there's a continuity that's important to me to maintain now... just the university, I know every building and the stores on 10th and everything. Those are vital sort of benchmarks for you when you get out in now what has become a very small world... But it's part of what I see as my independence and my being is to be where I have these benchmarks around me.

Theresa also selected her particular house for many reasons related to its location. It was within the catchment area for her son's school, the neighbourhood was quiet and it was close to many shopping areas so that she was able to combine her daily walks with continuing to do her own errands. She described the location of her house as:

I'm so thankful that (a major shopping mall) is so close by because I can do so much there... it's a very nice 15-minute walk. There's no traffic, I can walk
through a park if I want to, I can chose a number of routes to get there. . . . This is a very central place.

She then continued to describe several other shopping areas which were located nearby. Along with the continuity of location that was important to Debra, she also chose to remain in the same area when she moved because it was close to the university where she occasionally attended art history lectures, concerts and other performances.

The impact of location on an individual's experience was especially evident during Cathabel's interviews. Cathabel had moved to Vancouver to receive support from her family, however, because she had moved from another province she did not qualify for subsidized housing. As well, by moving she had lost many of her friends and contacts and consequently described a "lonely existence". She described both positive and negative aspects of the neighbourhood where she had lived with her son. Their apartment was located at a busy intersection in downtown Vancouver. While there were several seniors' centres in close proximity, she found the area itself crowded, busy and expensive. She found that her ability to frequent coffee shops and restaurants, a significant pastime for her, was restricted "because everytime you went out there was always people, people, people and if you went out in the street you got shoved."

When deciding to move to her own apartment, there were several factors that Cathabel considered when choosing its location. She wanted to be in a quieter neighbourhood but one that was still relatively close to downtown because her son and the seniors' centres were located there. As well, she hoped to live near the cancer clinic where she received treatment or "on a bus route, where there are no hills and that to climb." She also wanted to be in a specific area of Vancouver where there were a high
density and wide variety of stores where she could window shop. At the time of her second interview Cathabel had moved into her own apartment. She emphasized the benefits of her new neighbourhood, in particular, the less dense population and the small cluster of stores and coffee shops she was able to access. She said, "I make a point of going out for a walk just even to the corner store or the flower store or to the bread and butter there each day."

The features of neighbourhoods were clearly important as participants spent more time in their immediate communities. For many of those involved, the location of their homes was critical to their ability to access services and remain involved in valued activities. The importance of specific qualities of neighbourhood was especially evident in the stories of those participants who had moved following their diagnosis.

Increased Reliance on Support, Services and Resources

The impact of the broader social environment on the experiences of the participants was also evident when listening to their stories. As their illness progressed many relied more heavily on the services and resources available to them from both formal and informal sources. Without exception, all of the participants discussed the emotional, practical or financial support they received from informal or formal networks. Many talked about how grateful they were to those who supported them and acknowledged that without this assistance they would be unable to remain at home or do many of the things they wanted to do. However, the amount and type of assistance that participants were willing to accept varied. Some participants, such as Gary and Cathabel,
relied heavily on informal support networks while others, including Sandra and Samuel were more dependent on formal services.

Participants discussed the emotional support they received from both formal and informal caregivers, including friends, family, pets and professionals. Types of support that were identified included companionship, someone to talk to, encouragement, shared experience, laughter, a feeling of safety and being treated like a "normal person". Many of those involved including Theresa, Debra, Anne and Gary talked about the support they received from their family members. Theresa described her husband as being "phenomenally supportive" and said that her son was "always propping up (her) spirits."

Joe talked about friends in his apartment building saying, "if I want to go talk to them for awhile I just knock on the door and walk in and sit down and talk to them if I feel lonely or whatever." He felt that it was because of their support and encouragement that he had become reinvolved in life after his cancer diagnosis. He admitted, "I think if it hadn't been for them I'd still be in the same hole. . . . I'm thankful to them for that because now I have a better outlook." Similarly, Debra acknowledged the support she received from those around her when she said, "different people have different things that help through phases and you know just knowing they are there and that's solid helps you in a way that is too large to even find words for."

Cathabel acknowledged the emotional support she received from a number of women at the cancer clinic explaining, "the group of us just meet and we each talk about our own thing. . . . you know you have to have other people." Gary emphasized how beneficial it was when others treated him like a "normal person". He explained, "nobody
wants to be treated or reminded about being sick and I think they do a good job (at St. Paul's) of treating you as if you are normal."

Participants appreciated the wide range of practical assistance they received from those around them. Examples of practical tasks included assistance with personal care, homemaking (vacuuming, cleaning, laundry, grocery shopping, taking heavy items out of the oven and so on), dispensing/organizing medications, running a bath, preparing or delivering food, picking up supplies, providing transportation, liaising with physicians and running errands. This assistance enabled participants to remain at home, to conserve energy and to spend their time involved in activities which they found valuable. Warren said, "(assistance from Alice) gives me free time to do nothing and that's important for me because most of my life I've been doing something."

Many of the participants relied on family members and friends to provide this assistance. Certainly this was the case for Gary. He said, "my son basically when I found out I had prostate problems he took care of me, basically did all the cooking and cleaning and so on. . . . I don't know what I would have done without him." Similarly, Samuel's mother had come to stay with him when he was unwell and he described her as "instrumental" in helping him. One of Cathabel's sons came to help her after she received treatment while living in Ottawa. Since she had been living in Vancouver, all three of her sons provided assistance to her in many ways. For example she said, "on a Friday Fred he'll come down and if I need anything for shopping . . . we'll go up to Safeway. . . . He came last week and did the bathroom."

Samuel, Sandra, Anne and Gary all received support with practical tasks from homemaking services funded by the Ministry of Health through their health units.
Samuel explained, "(Homemakers) would clean the bathroom, do the dishes, vacuum, dust, you know they would take care of my house and make sure it's clean and tidy."

Previously, Gary's son had been providing the majority of care for him, however, once he was able to access homemaking support, he was able to encourage his son to return to work. He said, "homemakers do basically anything to make you comfortable." And Sandra described that in addition to providing assistance with practical tasks "now that I'm going to have (the homemaker) everyday we'll be visiting, going out for walks together."

Theresa, Warren and Debra all paid privately for assistance. Warren employed a live-in caregiver who did all of his cooking and cleaning and assisted him with personal care, as well as providing companionship. His statement that "as long as Alice can take care of me I'll stay here. And if not then I'll go more actively into the search for assisted care" demonstrates that this assistance enabled him to remain at home. Debra and Theresa had also hired outside help and both acknowledged that they had the financial means to pay for 24-hour support in the future if this was necessary. Debra acknowledged how beneficial this assistance was when she said, "I have help Monday, Wednesday and Friday so I literally don't have to do any work until my arm is perfectly healed."

In addition to homemaking services, participants identified a wide range of programs that they accessed in order to manage their daily lives. This included meal delivery services, volunteer visitors and drivers, physicians, hospitals and respite programs. Home care nurses provided assistance with medication management, monitored symptoms, liaised with physicians and served a connection to other resources
such as homemakers and rehabilitation professionals. Gary described his experience with his home care nurses when he said, "they helped me a quite a bit in the sense of medicine and like they knew when I wasn't well. . . . so that's when we came up to P.C.U.". Rehabilitation professionals assisted participants such as Debra and Samuel to improve their functional abilities and provided equipment, education and strategies to manage day to day activities with greater ease and/or independence.

Anne, Gary, Debra, Sandra, Joe, Theresa and Samuel all emphasized the increasing importance of the health care system for them. Theresa explained, "the health system . . . is to help people reckon with daily adjustments that we must make as a result of complications or symptoms or, as you say, limitations of their disease." Having moved from the United States, Warren was very appreciative of the Canadian health care system. These same individuals also described the important role that the P.C.U. at St. Paul's Hospital played in helping them to manage their illness. To some extent these remarks were likely influenced by my association with the unit, however, participants repeatedly identified the P.C.U. as a source of support even after I had reinforced to them that this was not the focus of the study.

Samuel had been in the hospital for several months and was the only participant who did not live at home at some time during the study. He described an increasing dependence on the hospital as he said:

I feel like it would be so nice to go home but I feel very safe here. And it would probably only take me one day at home to go, oh I'm so glad to be home, it wouldn't take long you know if everything was arranged . . . but like I say once I
get home, it might take me awhile to feel that I'm safe. Anything could happen, anything could happen at any time.

Similarly, Joe described a feeling of security knowing that he was able to access the P.C.U. if he encountered any difficulties while at home. He said, "now I know if anything happens, I just call the ambulance and they drive me right up here to the 10th floor." Sandra had spent a large portion of the past year in the hospital. She admitted, "I shouldn't say it but I feel great (when I come to S.P.H.), it's one of my favourite hospitals. I want to die here." She claimed that she felt safe on the P.C.U., that staff were like family who treated her well, were experts in care and provided her with assistance in many of her daily activities.

Gary and Anne had both had several respite admissions over the past many months. Gary was grateful that he was able to continue to access the unit as these admissions provided an opportunity for his son to take a break and do his "own thing". Gary also appreciated the treatment he received from staff who treated him as "normal". He benefited from having medical problems investigated and treated, as well as education to increase his independence. He described his experience:

I would say the things that help me to get better is what treatment I get say from the nurses at S.P.H. and the health unit. . . . I know if there is anything that bothers me, I will tell the doctor there and they will get someone from the hospital and they will look after it. . . . And I think that after I leave the hospital and go back home I seem to feel better.
Overall, he relied on these admissions to help him "get back on track". While Debra had only had one admission to the unit for respite, she described this as a positive experience when she said:

> It gives you a sense of peace for a week that you don't have to be so aware of all of your surroundings. . . . that there are back up systems there and that there is always people around. And all you have to do is sort of heal and rest and get yourself ready.

Another aspect of the environment which participants discussed was the financial resources which they accessed. The socioeconomic status of the participants in this study varied greatly. While financial constraints were not identified as a concern for several individuals others identified this as a significant stress in their lives. For many, their current income was significantly reduced as compared to prior to their illness. Sources of income were not discussed in all of the interviews, however several participants discussed the financial support they received. Financial assistance was provided for some of the participants through disability pensions from the Ministry of Economic Development and Social Security (Joe, Sandra, Samuel) as well as other sources such as retirement and disability pensions through employers (Cathabel, Theresa, Gary). While Joe found this difficult and demeaning he recognized that he did not have any other options. He explained, "I'm a very proud person and I don't like taking handouts and to me (disability insurance) is a handout. It took me awhile to get used to it but now like I said I've got no other choice." Similarly Sandra said, "at first it was really embarrassing to get the money from welfare." Joe and Sandra also received rent subsidies through B.C. Housing.
While income from these various sources enabled the participants in many ways, several described financial struggles which affected their ability to participate in desired occupations and achieve goals. For example, in order to live in her own apartment, Cathabel was forced to accept assistance from her sons, who were also struggling financially. Although she received a limited income she did not qualify for subsidized housing as she had moved from out of province. She complained of costly medical expenses and was unable to afford to visit her mother in Scotland for a final time (a goal she hoped to achieve before dying). Sandra described similar hardships such as having to grocery shop in a different neighbourhood where costs were more affordable and finding it difficult to save money on her reduced income. Joe admitted that he had sold his car as he was unable to afford to maintain it and talked about trying to save money for a rain cover so that he could continue to use his scooter in inclement weather. About his financial situation he said, "towards the end of the month . . . (I'm) pretty damn close to being broke."

In contrast, Debra, Theresa and Warren were all able to afford 24-hour support if required. Warren was able to travel to Europe in search of treatment and/or cure and Theresa was able to take her son on a trip to China and felt very fortunate to have financial security. As well, while Samuel also received disability benefits he felt his income was sufficient because of his low cost of living.

Participants also received financial assistance through funding for specific pieces of equipment such as mobility aids and personal care devices. Sandra, Samuel and Joe had all accessed funding for equipment through the Ministry of Economic Development and Social Security. For example, Joe and Sandra had recently acquired electric scooters
to compensate for their decreased mobility. They both emphasized the tremendous
difference the scooters had made in their lives. Sandra referred to her scooter as a "piece
of freedom" which enabled her to access her community independently. Joe initially
found using the scooter "demeaning" and preferred to use his cane because he said, "at
least you don't look so bad with the cane, but when you go out with the cart everybody is
looking at you . . . and to me it makes me feel weird." As he began to use the scooter
more frequently, his appreciation towards it increased. He said:

   The scooter makes a whole lot of difference. I do my own shopping, I go
   wherever I want to go. . . . I don't have to worry about taking the damn bus and I
do not have to worry about my leg being sore. . . . but it's fun, it gets me around
   nice and easy and I don't have any problems.

He experienced an improved quality of life as he was able to become re-involved in many
activities such as shopping, visiting friends and going to the beach. Without government
funding neither Joe nor Sandra would have been able to afford the cost of their scooters.

Some of the participants purchased equipment privately or through their employee
extended health benefits, however, for the majority of other participants these options
were not available. Participants also accessed equipment on a short-term loan basis
through programs such as the Aids to Independent Living Program and the Red Cross
Loan Cupboard. For the most part, equipment was arranged by O.T.s and P.T.s (mobility
aids) based in the hospital or within the community. Theresa explained that her O.T. was
"working through the system to get some of that stuff" to help her to conserve her energy
with daily activities.
Participants discussed the many ways they had increased supports and reduced barriers in their environment in order to facilitate their continued involvement in activities and achieve desired goals. This included restructuring their physical environment by installing equipment, making changes to their homes and moving. They also began to access the formal resources and services that were available as well as accepting assistance from informal caregivers. By doing so, participants were able to compensate for (some of their) deteriorating abilities and enable themselves to continue to do some of those things that were important to them, such as continuing to live at home, spend time with others or to be independent with various tasks. As well, the homes and neighbourhoods of the participants became increasingly important as their ability to access the community decreased. Participants renegotiated the meanings attributed to their homes and other places, such as hospitals, as their illness progressed.
CHAPTER SIX

DISCUSSION
Chapter Six: Discussion

The impetus for this study came from my experience as an O.T. working with individuals who were living with a terminal illness. I frequently felt unsure of my role in this area of practice as my approach often appeared to conflict with traditional rehabilitation goals. A review of the limited amount of existing literature which has explored issues related to rehabilitation and palliative care did little to clarify this situation for me. Minimal research exists and the majority of articles share therapists' perspectives. They offer contradictory statements regarding the purpose of O.T. in palliative care which, in many instances, conflict with traditional rehabilitation practice. The perspectives of those who know what it is like to have a terminal illness have been inadequately explored.

In an attempt to clarify the role of O.T.s in palliative care, this study was initiated. The purpose of the research was to contribute further to the understanding of the experience of living with a terminal illness. Specifically the study explored the experience and meaning of occupation for individuals who have a terminal illness, as well as the influence of their environment on their illness experience. A qualitative research approach was used to examine the study questions. This proved to be an effective strategy as it enabled participants to recount their unique experiences, and specifically the personal meanings of occupation and the influence of various dimensions of environment on their experiences. As well, they were able to describe important facets of their experiences which were not initially identified as a focus for the study.
All of the participants described the significant impact their illness had on their lives. As a result of pain, fluctuating cognitive and physical abilities and environmental constraints participants were required to relinquish many of their roles and occupations. Most significantly, the eight participants who were employed at the time of their diagnosis were unable to continue working. As well, participants described an inability to perform personal care activities and a wide range of leisure pursuits including exercise, travel, reading and going to the theatre. Several individuals admitted feeling bored as a result of this decreased participation and many described struggling to maintain their independence despite their changing abilities. Daily routines had to be further modified to incorporate illness-related activities such as resting and following complex medication regimens.

Participants described relationships which had been strengthened as friends and families became, or remained, priorities and provided emotional and practical support. At the same time, friendships were lost and dynamics of relationships changed as a result of stigma, an increased dependence on others and an inability to participate in shared activities. Participants also talked about facing their own mortality and how this had changed their outlook or approach to life. Homes, neighbourhoods and health care institutions became more significant in the lives of the participants as their needs changed and their ability to access their communities decreased. Participants described the many meanings that they associated with their homes and other places and explained how these were renegotiated as their illness progressed.
As a result of these many changes (including their decreased participation in meaningful activities and occupations) participants recounted many of the significant losses they experienced. These included a loss of health, hope, future, sense of immortality, independence, identity, financial security, connection with others, companionship, a daily structure/routine, a sense of challenge and feelings of contributing, being productive, helping others and being "normal".

Participants restructured their lives to manage their illness and its effects, maintain some continuity, achieve goals and remain involved in valued occupations and relationships. They described shifting their focus to concentrate on the present, acknowledge their blessings, redefine what was important and focus on hope. At the same time, participants acknowledged their own mortality and attempted to prepare for the possibility of death by relinquishing roles, achieving closure in some aspects of their lives and resolving unfinished business.

Individuals found creative ways to remain involved in valued occupations and they described many benefits of this continued participation. For some, this meant engaging in previous activities in a different capacity while others discovered, or were searching for, new activities to enjoy, provide structure and meaning to their days and, in some instances, replace lost roles and occupations. Participants also applied skills such as planning, pacing and prioritizing to conserve energy and adjusted their daily routines to meet their fluctuating abilities. Some of the participants worked to improve or maintain their capabilities, however, more commonly, elements of the environment were restructured to facilitate their engagement in activities. This included accepting assistance from others, accessing resources, moving homes and using adaptive equipment.
to accommodate functional limitations. In summary, while participants experienced many changes as a result of their illness, they attempted to restructure and renegotiate their environment, shift their outlook, modify activities and apply skills to maintain their involvement in meaningful occupations, manage their illness and achieve some continuity in their lives.

Theoretical Considerations

As stated by Dyck (2000) analysis in qualitative research is a recursive process with data informing theory and theory informing the interpretation of data. In this section, the insights gained from the participants will be used to inform theoretical ideas around occupation and the environment.

Occupation

The primary role of O.T. is that of enabling individuals to achieve satisfactory performance in those everyday activities or occupations that they wish to or need to perform and which provide meaning in their lives (CAOT, 1997). Empirical evidence has demonstrated that participation in these pursuits positively influences subjective health and well-being (Law et al., 1998). However, the experience and meaning of occupation for individuals living with a terminal illness has been inadequately explored in the literature. One of the primary goals of this study was to improve the understanding of what it means to enable occupation for these individuals and, consequently, how their subjective health and well-being may be positively influenced despite the challenges of their illness.
Participants acknowledged the significant impact their illness had on their ability to remain engaged in many meaningful occupations. As described, they experienced a multitude of losses as their involvement in valued roles and occupations diminished. Similarly, other studies have demonstrated that cancer and HIV/AIDS have resulted in a disturbance in daily activities and the fulfillment of role responsibilities such as spouse, parent and worker for individuals (Bedell, 2000; Kagawa-Singer, 1993; Mackey & Sparling, 2000; Wilton, 1996).

Although participants were unable to continue with many previous occupations they remained engaged in a wide range of valued activities and roles. This was accomplished by restructuring their environments, applying a variety of strategies, seeking new activities or modifying the manner in which they were involved in previous occupations. Some of the benefits of this continued involvement included occupying the mind, providing challenge, taking their focus away from their illness, something different to do, social recognition, filling time, making them feel that they were improving or were "normal", spending time with others and for pure enjoyment. These positive qualities are similar to those identified by participants in other studies (for example, Rudman et al., 1997; Unruh et al., 2000). They are also consistent with the properties of occupation outlined in the O.T. literature. Here occupation is defined as a source of meaning, purpose, choice, control, balance, satisfaction and a means to organize time and generate income (Law et al., 1997).

While the majority of participants expressed a desire to remain involved in meaningful activities, Anne described a process of becoming much more "internal" and accepting "letting go" of roles and activities over the course of the study. She died
shortly after this interview (84 days had elapsed between her first and second interviews). Warren also described spending much more time just sleeping and dreaming as his illness progressed. This may demonstrate that an individual's need or desire to remain involved in meaningful occupations may diminish as they are closer to dying. This would need to be explored further in future studies.

Overall, the findings of this study support Law et al.'s conclusion that withdrawal or changes in occupation can have a significant impact on a person's self-perceived health and well-being and that engagement in meaningful occupations may have a positive influence on these factors (1998). Therefore, enabling meaningful occupation for individuals with a life-threatening illness can be a valuable contribution of occupational therapists working in this area. However, it must also be recognized that the experience and meaning of occupation, and the desire to remain involved, may change over time and as an individual's illness progresses.

In O.T., increasing an individual's independence with various activities is a common goal for intervention (for example, Trombly, 1995). Many of the participants in this study were attempting to maintain or increase their independence in some areas, despite changes related to their illness. For others, this was not a goal. The participants' definitions of what constituted independence also varied. For some it meant being able to do things for themselves or being able to live alone. However, for others it was not the ability to do things themselves that was the most critical factor but rather having the freedom and the ability to exercise control over their lives (for example, making decisions about when to have a bath or how much assistance they received). These findings
demonstrate that independence is not always defined as the ability to perform occupations independently and that achieving independence is not a goal for all clients.

It was anticipated that this study would explore whether the three theoretical categories of occupations (self-care, leisure and productivity) were appropriate and encompassed all of those identified by individuals with a terminal illness. Through discussing the experience of occupation with the participants, it became evident that it was difficult to assign many of their occupations to mutually exclusive categories. For example, the occupation of preparing a meal meant vastly different things to several individuals (often based not only on the purpose of the occupation but also on their abilities at the time). Cathabel considered cooking to be necessary for survival while Samuel considered cooking to be one of his most significant leisure activities. Debra described preparing her own meals as one of her foremost priorities despite the availability of assistance. This occupation appeared to represent both productivity and leisure for her, as she described many of the challenges that she encountered with the tasks yet she considered it to be a significant source of pleasure and enjoyment.

The purpose of many occupations (which would subsequently affect their categorization) changed for participants over time. For example, Warren had been involved in the business world as his profession. Although he had to retire from working, he continued to contribute by consulting on business/education matters and spent time following business ventures in the paper. Similarly he followed financial developments strictly out of interest as he had relinquished the management of his assets to his daughter. Theresa had been required to discontinue work as the curator of a museum but
had continued to pursue some of her work-related interests, such as researching Chinese archaeology, purely for pleasure.

In summary, it was difficult to assign many of the occupations identified by the participants to distinct categories. A single occupation often had a different purpose for each person and this could change as their illness progressed. Categorization appeared to be influenced not only by the purpose or intent of the occupation but also by the individual's abilities at the time. As well, the categorization of some of the occupations which were identified by participants as meaningful or which took up their time was unclear. Some examples include resting, following complicated medical regimens, receiving and recovering from treatment, attempting to resolve tensions and achieve closure, reminiscing, life review and "simply being".

Environment

In contemporary O.T. theory, the environment is no longer viewed as an entity that is external to, or independent of, the individual, but rather within a dynamic, transactional relationship with the individual (Law et al., 1997). Occupation is performed within this context and, consequently, elements of an individual's environment may either hinder or support his/her participation in desired occupations. Disability research in O.T. involving other populations, such as those who have experienced strokes, multiple sclerosis, HIV/AIDS or spinal cord injuries, have provided empirical evidence to support this relationship (for example, Bedell, 2000; Dyck & Jongbloed, 2000; Jongbloed, 1998; Jongbloed, 1994; Levins, 2001; McClain et al.; Yerxa & Locker, 1990). However, the impact of the environment on the experiences of individuals living with a terminal illness
has not been examined within the rehabilitation literature. The types of environmental barriers and enablers that exist and the manner in which they impact the lives of these individuals have not been previously investigated.

In this study it was evident that factors beyond deteriorating function affected the participants' ability to engage in meaningful occupations and achieve desired goals. Participants described many elements of their physical environments which enabled or limited them. This included the presence or absence of stairs, the proximity of services and resources (such as stores, bus routes, family and community centres) and the terrain of their neighbourhoods. To increase their participation and to conserve energy, participants restructured their environments to remove barriers and increase supports to accommodate their changing physical, social and financial needs. This included moving into new homes and neighbourhoods, installing equipment to increase ease and independence with daily activities and using mobility aids, such as scooters, to improve their access to the community. These strategies paralleled those identified by women who were coping with M.S. (Dyck, 1995).

This finding that elements of the participants' physical environments served as either supports or barriers to their participation in meaningful activity is consistent with the results of other studies. The majority of studies in the rehabilitation literature which address physical barriers have involved individuals with spinal cord injuries. Architectural barriers were identified by individuals with spinal cord injuries as obstacles to community functioning (Yerxa & Locker, 1990) and participation in sports-related activities (Levins, 2001). Similarly, participants in McClain, Cram, Wood and Taylor's (1998) and Dyck and Jongbloed's (2000) studies acknowledged that accessibility issues
impacted on their ability to fulfil social roles as well as their relationships. The men with HIV/AIDS in Bedell's study found that where they lived had an effect on services they received and the amount of effort required to access and obtain these services (2000).

The influence of the social environment on the daily routines of the participants was evident. They emphasized the increasing significance of relationships with family and friends as their illness progressed. This finding was similar to the experiences of men living with HIV/AIDS who reported that they were closer to their families and had fewer, but closer, friends (Bedell, 2000). The women with cancer in Mackey and Sparling's study also stressed the importance of social relationships, particularly with family members (2000).

The emotional and practical support of other individuals was a significant feature across all of the experiences. This included the provision of encouragement and companionship and assistance with daily activities such as homemaking and personal care, as well as with managing symptoms. Many participants acknowledged that the support they received from both formal and informal caregivers was integral in their ability to remain at home, to spend time with others and to remain involved in occupations. Similarly, Wilton (1996) and Bedell (2000) found that social networks and service agencies played a vital role for men coping with the challenges of HIV/AIDS. Participants in this study also described how their experiences were affected by stigma and unsupportive/negative attitudes of those around them. Findings from several other studies (including Bedell, 2000; Dyck & Jongbloed, 2000; Jongbloed, 1994; Levins, 2001; McCuaig & Frank, 1991; Wilton, 1996) have also demonstrated that an individual's
experience of disability, including their opportunity to participate in meaningful occupations and roles, is shaped by the attitudes of those around them.

It was evident that the experiences of the participants were affected not only by aspects of their immediate physical and social environments but also by their broader context. This includes social policies which influence access to, and availability, of programs and resources. Without exception, all of the participants described the importance of being able to utilize formal support services such as homemakers, home care nurses, and rehabilitation professionals. Participants involved in this study either had the financial resources to afford 24-hour private care or had access to an increased amount of community services because of their palliative care designation. None of the participants complained of being unable to access sufficient resources.

Many of the participants also relied on various sources for income assistance and for funding for much needed equipment. While participants admitted that they benefit from this assistance, many reported that because of this restricted income they were unable to achieve certain goals, save money, purchase equipment or supplies or engage in meaningful activities such as traveling or going to restaurants. Participants in other studies also reported similar limitations as a result of the limited incomes associated with disability pensions. Jongbloed (1998) found that the activities of women with multiple sclerosis who accessed disability benefits were severely curtailed by lack of income. The men with HIV/AIDS in Wilton's study also found that the (U.S.) government benefits they received were barely enough to manage/survive on (1996).

It is evident that the experiences of the individuals in this study would be very different if they were unable to access these services and resources. Many would be
unable to remain at home, access equipment and supplies and would not receive assistance with daily activities such as bathing, preparing meals, cleaning and shopping. Because participants were able to access this assistance they were able to save their energy for more meaningful activities and interactions and the stress and demands placed on informal caregivers was often significantly reduced.

Without question, the stories of those involved in this study highlighted the significant impact of the society in which they interacted on their experiences of living with a terminal illness. The descriptions of the participants' experiences provide empirical evidence to support socio-political models of disability, such as the Social Model of Disability. As described, this model views disability as a consequence of the restrictions imposed on individuals by unsupportive economic, political and social environments (Oliver, 1990). While this has been a useful framework for understanding the experiences of the participants, the results of the study have also demonstrated that an inability to participate in the full range of activities is not solely a result of unsupportive (or inaccessible) environments. Many of the participants described the physical and cognitive changes they had experienced as their diseases progressed. These included decreasing mobility and concentration as well as changing interests, priorities and attitudes. Similar to the experiences of men with HIV/AIDS in Bedell's study (2000), diminished energy levels were the most common symptom which influenced the daily lives of the participants. Based on the reports of the participants, it does not appear that changes to their environment could eliminate their experience of disability entirely. These findings support some of the more recent literature which has stressed the influence of an individual's impairments on determining disability (Crow, 1996). For
many 'disabled' people, including the majority of the participants in this study, impairment is relevant, and impairment, as well as disability causes disadvantage (Crow).

It is evident that many dimensions of the participants' surroundings had significant enabling or limiting effects on their illness experiences. At the same time, participants actively restructured their environment to manage the physical, social and economic consequences of their illness. In many cases, this occurred with the encouragement of friends, family and/or health care professionals. Many discussed the equipment they used to increase their safety, independence and ease with daily activities, such as bathing and mobilizing. For example, while the worlds of Sandra and Joe appeared to be shrinking as their mobility decreased, the acquisition of electric scooters facilitated their access to their communities and enabled them to participate independently in activities such as shopping and socializing. In addition to utilizing equipment, participants also increased the amount of assistance they received, accessed resources and moved to more accessible homes and neighbourhoods. By creating more enabling environments, the participants were able to facilitate their involvement in meaningful occupations, connect with others and achieve goals such as remaining at home and being independent, despite the progression of their illness.

In addition to restructuring their physical and social environment, participants renegotiated the meanings they associated with various places as their illness progressed. They talked about the many meanings, such as safety, privacy, ease and tension which they associated with their homes. Similarly, the men in Bedell's study had ascribed meanings to their homes such as safety, control and a place of escape, in light of their experience with HIV/AIDS (2000). Places outside of the home, such as the hospital or
hospice also came to embody a variety of meanings for individuals in this study. These associated meanings were often influenced by the physical and social attributes of the various places (such as the way they were treated, the amount of support they received and the ease with which they were able to do things). The meanings that were attributed to particular places, such as home, hospital and hospice also served to enable or limit the individuals in this study as they shaped their use of space and physical geography.

The findings of this study support O.T.'s evolving notion of the environment, including its influence on the experience of disability. Rehabilitation professionals have been encouraged to acknowledge the multiplicity of influences, many of which are environmental, which affect disability outcomes (Jongbloed & Crichton, 1990b). The environment is conceptualized as including physical, social, cultural and institutional elements. These ideas are supported by the results of this study which demonstrate that challenges related to participation in meaningful occupations were a result not only of the individuals' deteriorating abilities but also the unsupportive or inaccessible environments in which they interacted. This moved beyond the physical and social elements of the individual's immediate environment to include broader issues such as social policies and the values of others. Many participants had discovered ways to maintain their involvement in a variety of occupations despite their changing function. While in some instances this occurred by improving their functional abilities, more commonly this was accomplished by modifying elements of their surroundings to remove barriers and increase supports. Participation was maximized when elements of the environment were able to accommodate or compensate for the changing needs of the individual.
In addition to issues such as accessibility, proximity and availability of resources, attitudes of others and the impact of social policies on experiences, the meanings that are attributed to various places and spaces must also be examined to achieve a comprehensive understanding of individual-environment interactions. Rowles (1991) has suggested that there has been an underestimation of the role of a person's environment as a source of identity and well-being. This contention is supported by the stories of the participants in this study.

Implications for Occupational Therapy Practice

The ultimate goal of this study was to gather information to clarify the scope of O.T. practice in the area of palliative care. In this section, the insights of the participants will be used to inform the practice of O.T.s working with individuals who are living with a terminal illness. Specifically, the discussion will focus on client-centred practice, loss and enabling occupation.

Client-Centred Practice

The findings of this study support the importance of being client-centred when working with individuals who are living with a terminal illness. The concept of client-centredness is fundamental to O.T. practice and theory. In O.T., client-centred practice means demonstrating respect for clients, involving them in decision making, advocating with and for clients in meeting their needs and otherwise recognizing their experience and knowledge (Law et al., 1997). While the themes in this study emerged from common elements of the participants' stories it is important to emphasize that the experiences of
each of the individuals was unique. For example, although independence was a common issue identified by many of the participants, ideas around this concept were highly variable and it was not identified as a goal by all of those involved. While many participants discussed their outlook towards their illness and mortality, some of those involved appeared to be accepting of their approaching death, while the majority chose to focus on hope/cure/survival. While the majority of participants talked about a desire to maintain or increase their participation in meaningful occupations, one participant did not.

The themes which emerged from the stories of the participants represent common principles which may be used to inform practice. For example, by knowing that decreased energy was a common experience for the individuals in this study and that strategies to conserve energy were effective, these issues may be explored when working with clients to determine the impact on their lives. However, it is important to gain an understanding of the unique experiences and perspectives of each individual instead of making generalizations (for example, that all individuals want to maximize the use of resources and services, such as homemakers and hospice) or relying on theoretical assumptions (for example, that increasing independence in occupation is a goal for all individuals). Client-centred practice means supporting clients where they are (for example, focusing on hope versus death) and exploring their unique goals and priorities (for example, how they want to be spending their time and energy).
Loss

It was evident that the experience of living with a terminal illness involved innumerable losses for all of the participants. These included, but were not limited to, loss of ability, meaningful occupations and roles, relationships, future, hope and independence. The experience of loss was similar in other studies involving individuals with cancer and HIV/AIDS (for example Bedell; 2000, Kuhl; 2000; Mackey & Sparling, 2000). In practice, it is important to support clients through loss and grief and provide opportunity for the expression of these emotions. This was also identified as a role for O.T.s in palliative care by other authors (Bye, 1998; Flanigan 1982; Gammage et al., 1976; Hasselkus, 1993; Holland, 1994; Mackey & Sparling, 2000; Rose 1999).

Strategies which could be used include open-ended questions and providing time and opportunity for discussion so that clients can explore their feelings and experiences, being present in interactions and providing clients with the opportunity for spiritual expression by facilitating their involvement in meaningful and creative activities (Rose).

Enabling Participation in Meaningful Occupation

Research has supported the positive influence of meaningful occupation on subjective health and well-being. In this study, all participants described the losses they experienced as a result of decreased participation in many valued activities and roles. However, despite changes in physical, social and financial resources, participants attempted to remain involved in several of their previous occupations or roles and acknowledged the many benefits of doing so. Enabling participation in personally and culturally meaningful occupation is the fundamental goal of O.T. and can therefore be a
valuable contribution for O.T.s working with individuals living with a terminal illness. This has also been highlighted by other authors. (AOTA, 1986; Bye, 1998; Lloyd, 1989; Picard & Magno, 1982; Pizzi, 1984). It is important to note however that one individual described a diminishing need to continue to engage in occupation shortly before she died. Therefore, the desire to remain involved in occupation may be less for individuals who are closer to dying and this should be considered when working with clients at this stage. As well, several participants described a shift from spending time 'doing things' to reminiscing and engaging in life review. Although these have not traditionally been considered occupations, they are appropriate for individuals who are dying and O.T.s must consider their role in facilitating these processes. Participation in meaningful occupations may be optimized by changing any element of the person-environment-occupation relationship (CAOT, 1997).

Individual.

All of the participants in this study described abilities which had deteriorated since their diagnosis and which fluctuated over time. Several participants had benefited from intervention aimed to increase their functional abilities at some time during their illness. For others, this was no longer an appropriate or effective strategy. Assessment and intervention of physical, cognitive and functional abilities may be appropriate within the limits of clients' level of impairment and within the context of their goals and the demands of their environment. For example, if a client's goal is to live alone, his/her ability to access the bathroom, manage medications or cook safely may need to be assessed.
Many participants in both this study and Bedell's research (2000) had applied skills such as planning, prioritizing, pacing and modifying daily routines in order to remain involved in activities despite fluctuating abilities. As Bedell concluded these strategies are similar to O.T. interventions such as work simplification, energy conservation, time management and goal setting (2000). Therefore, O.T.s can serve as valuable resources in providing education and opportunities for the development of these skills as well as cultivating transferable skills clients had previously used in work and daily living. These strategies of assessing clients' abilities and function and building against loss by increasing internal resources such as skills and knowledge are similar to those identified by other authors (AOTA, 1986; Bye, 1998; Lloyd, 1989; Picard & Magno, 1982; Pizzi, 1984).

**Occupation.**

In some cases, participants discovered new activities to replace lost roles or occupations. However, more commonly participants implemented strategies (such as modifying the manner in which an activity was performed) to continue their involvement in previous occupations and interests. The findings of this study indicate that, where possible, a focus on enabling continued participation in current or past activities, occupations and roles is more appropriate than discovering new ones.

Occupational therapists are well suited to help clients with this process because of their skills related to analyzing and grading activities. Assessment and intervention may include analyzing the physical and cognitive demands of previous occupations which are now challenging and problem solving strategies to increase ease and independence with
these activities. It may also include working with clients to identify the elements of activities which are meaningful (such as providing challenge or an opportunity to help others) and exploring other activities which have similar properties but are more suitable considering their functional abilities and social and physical resources. Helping clients to relinquish roles and activities, reminisce, engage in life review, achieve closure, attain goals and resolve unfinished business are also appropriate roles for O.T. based on the stories of the participants and have been identified by other authors (Bye, 1998; Flanigan, 1982; Gammage et al., 1976; Hasselkus, 1983; Holland, 1984; Mackey & Sparling, 2000; Rose, 1999).

Environment.

As evidenced by the findings of this study, it is crucial to understand the experiences of each individual within his/her broader context. This means acknowledging that an individual's experience of living with a terminal illness is affected by elements of their physical, social, cultural and institutional environment (which includes social policies which influence the availability of, and access to, services and resources).

Intervention may focus on restructuring physical and social environments to reduce barriers and increase supports in order to facilitate participation in occupation and connection with others by accommodating the individuals' changing needs. Barriers identified by participants in this study included inaccessible physical environments, unsupportive attitudes of others and decreased financial resources. Elements of the environment which supported participants included accessible homes and
neighbourhoods, emotional and practical support from informal caregivers and formal services and resources. The meanings that were attributed to various places such as home, hospital and hospice also enabled or limited individuals as they influenced their use of space. All of these issues should be explored with clients to determine how they are influencing their experience.

Family and friends should be included as part of the unit of care and intervention may include providing emotional support, education (e.g. transfer techniques, resources) and facilitating access to services and resources (e.g. meal delivery, funding programs). These strategies are similar to those identified in Bye's framework for practice (ensuring supported and safe care).

Jongbloed (1998) and Bedell (2000) have also suggested a role for O.T. in addressing broader environmental issues through involvement with disability advocacy organizations who are attempting to bring about change in disability income policies. Therapists may also be involved in other policy issues such as advocating for the provision of adaptive equipment, accessible housing, and other resources. Based on the experiences of these participants this appears to be another valuable role for O.T.s.

The literature indicates that therapists are frequently unsure of their role in working with individuals with a terminal illness, in part because of the contradictory ideas presented regarding the purpose of practice in this area. This had also been my personal experience in working on a palliative care unit and was the clinical dilemma which initiated this research. The results of this study support many of the approaches which have been identified in the rehabilitation literature as potential roles for O.T.s working in palliative care. They also support the overall concept of 'Affirming Life and
Preparing for Death' which has been incorporated into Bye's framework for practice. It is crucial to understand the unique situation of each individual, including what their goals and priorities are and what is possible in light of their impairment and the social and physical resources which exist. Considering these factors, the therapist must then work with the client to determine which approach is most appropriate and will be most effective in supporting and enabling the client.

While this study supports many of the descriptive accounts, or studies which explored the perspectives of therapists, the findings are unique as they are grounded in research which has focused on the experiences and perspectives of individuals with first hand knowledge of living with a terminal illness. In summary, it is evident that O.T.s may play a valuable role in helping clients to manage their illness, maintain their involvement in meaningful occupations and achieve continuity in their lives despite the many challenges related to their illness. Perhaps Theresa put it most eloquently when she explained that the role of O.T. is to help people who are living with a terminal illness to learn "how to deal with the day to day, the present, the fact that you are still here".

Limitations of Study

As with any study there were a number of limitations to this research. The first issue is the number of participants which were involved. The findings from this study are based on data gathered from nine individuals. This is a small sample compared to the number of individuals who are living with a terminal illness and the full range of experiences have not been explored. For example, individuals who had recently been diagnosed or whose ethnicity or culture played a larger role in their illness experience
were not involved in this study. However, while the experiences of all individuals will not be the same as those in the study, the themes which emerged may serve as principles which may be common across experiences and may guide clinical practice in this area.

Another aspect which may limit the transferability of the findings is that all of the participants in this study lived in a major urban centre which is relatively physically accessible and has many resources (such as palliative care units, hospice programs, community centres and equipment loan programs). By virtue of the recruitment process all of the participants were connected with resources in the community, at a minimum either a palliative care unit or a home care nurse. These often serve as access points to other services such as homemakers and rehabilitation professionals. As well, because of the palliative care designation of the participants they were able to access an increased amount of services and resources. The experiences of these individuals may be different from those of others, such as individuals in rural settings, as they have been provided with access to equipment, medical support and assistance with daily activities, at minimal or no expense. This is especially important to note because the influence of environmental factors was a focus in this study. The experiences of individuals who do not have the benefit of these many resources or of a similar type of health care system (e.g. where they are required to pay for services) could be very different from those described in this study. The effect of socioeconomic status may then vary according to where people live. However, insights into the types of barriers and supports in the environment which may affect the experience of individuals living with a terminal illness can still be beneficial.
As noted, I had contact with eight of the participants prior to, or during, their involvement in the study in my role as an O.T. This previous relationship may have influenced their willingness to participate in the study as well as some of the data that was gathered. For example, participants may have emphasized the benefits they received from the P.C.U. or from equipment I had arranged for them. As well, my previous knowledge of the participants' situations may have influenced the questions I asked and the areas I explored during the interviews. Finally, the participants in this study had an estimated life expectancy of four to 12 months (only one participant died before this time), therefore, the results may not be generalizable to individuals with a prognosis of less than four months.

**Directions for Future Research**

In this study, one of the two participants who died shortly after their interviews appeared to have a limited desire or need to be involved in meaningful occupations. This may indicate that issues related to participation in meaningful occupation may change as individuals are closer to dying. In this study participants were selected who had an estimated prognosis of four to 12 months. The experience and meaning of occupation could be explored with individuals with a shorter prognosis.

The majority of the participants in this study had been aware of their diagnoses for an average of two years and had been considered to be appropriate for palliative care for at least several months. The issues involved in this study could be explored with individuals who have been diagnosed more recently. This could provide additional information regarding issues such as the impact of diagnosis, the process of relinquishing
roles such as the worker role, or the steps individuals take to achieve closure or resolve unfinished business.

Because of the participants who were involved, ethnicity did not appear to play a large role in this study. Further research could explore the role of culture and ethnicity on the experience of living with a terminal illness. Finally, the effectiveness of O.T. interventions, such as providing education regarding energy conservation and managing daily routines, modifying activities, assisting with life review, adapting the physical environment and providing equipment such as scooters, for individuals living with a terminal illness could be explored in a future study.
References


APPENDICES
The information you provide will be used in conjunction with information given to me by others with a terminal illness to further develop the palliative care that is provided through St. Paul's Hospital and within the community. Specifically, this information will help to develop the role of Occupational Therapy in palliative care.

If you require further information please feel free to call me at 806-8114. I would be pleased to discuss this with you. If you have any questions about your rights as a participant in research you may contact Dr. Richard Spratley, Director of Research Services, University of British Columbia at 822-8598 or Dr. James Kennedy, Chair - UBC/Providence Health Care Research Ethics Board at 806-8164.

Sincerely,

Patti O'Brien, O.T.(c)