HOME AS A PLACE FOR PROVIDING HEALTH CARE: ELDERLY CARE RECIPIENTS’ EXPERIENCE

by

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B.Sc., McGill University, 1994

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

May 2004

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Title of Thesis: Home as a place for providing health care: 
eldery care recipients' experience

Degree: Master of Science  Year: 2004
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Abstract

Home care is a relatively new field for rehabilitation professionals, including occupational therapists. Despite the “client-centered” practice guidelines, the focus of Occupational Therapy (OT) home care research has not been on the client’s experience. This study aimed to gain insight into the care recipients’ experiences of home care Occupational Therapy (OT) services particularly home modifications recommended by occupational therapists. In order to better understand the care recipients’ experience of home care OT, observation of the home modifications and of living and housing conditions of the care recipients was made.

A qualitative research approach was used to explore the individuals’ experiences from their standpoint. Semi-structured, in-depth interviews were conducted with long-term home care recipients in the Greater Vancouver area. Observations of home modifications were carried out with the care recipients or their family members present.

Two main themes emerged from the stories of the participants. The first theme ‘The Importance of Home, Neighborhood and Community Resources’ sets the context in which the participants of the study experienced home care OT services. Under this theme, socio-economic status, living and housing conditions, reliance on home care services and community resources and renegotiating the meaning of home and neighborhood are discussed. The second theme ‘The Experience of Home Care Occupational Therapy’ describes the impact of OT services on the participants’ daily lives, the role of occupational therapists as a source of knowledge, advocate and social support. The participants described their experiences of home care OT services as positive and enabling. However, their emphasis of OT services depended on their living, housing
Conditions and the level of community resources (formal and/or informal) available to them. Occupational therapists played multiple roles of expert, social support and advocate for those participants with low income and no family or limited social contact.

The conceptual bases of the study are drawn from occupational therapy's client-centered approach, feminist sociology and social geography. Individual-focused practice, the importance of everyday life experiences in generating knowledge and the importance of "the space" and "the place" in shaping the experience of disability are the central themes of these conceptual approaches. The findings of the study inform the above theoretical concepts. Issues related to client-centered practice and enabling environments are discussed in this paper. Limitations of the study and directions for future research are outlined.
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Acknowledgements

I thank all of the individuals who participated in this study for sharing their stories, wisdom and time with me. Their stories contributed to the understanding of home care services and the factors in shaping the experience of home care services including home care occupational therapy services. I am grateful to all of the study participants for receiving and accepting me in their homes with kindness. I have appreciated their effort and willingness to share their experiences, voice their concerns and feelings in order to improve the quality of home care services.

I thank those occupational therapists that assisted me in the process of recruitment and graciously answered my questions regarding the details of their involvement with the participants. Similar to the participants, they also showed desire to contribute to the improvement of the quality of home care.

I am grateful to all of my thesis committee members for their guidance and support throughout this project. I thank my supervisor, Dr. Lyn Jongbloed for her flexibility and approachability especially during difficult times that I have encountered throughout my graduate study. I thank Dr. Christine Carpenter and Dr. Alison Phinney for accepting to be part of my thesis committee and for providing me with valuable and timely feedback. I was able to complete this study with their support and commitment. I thank Dr. JoAnn Perry, for her time in providing external review of my thesis. I also thank Dr. Isabel Dyck for providing me with guidance and feedback during the initial stage of this study.
I thank my children, Azar and Meetra for their understanding and support throughout this project. They have shown patience and enthusiasm toward my goal of completing this study.
Chapter One: Introduction

Background of the Study

The purpose of this study was to explore elderly care recipients’ experience of home care Occupational Therapy (OT). The Canadian health-care system has undergone drastic changes in the last two decades. These changes focus mostly on economic strategies and policies designed to cut costs and create a “cost efficient” model of health care delivery. Expediency of inpatient care and subsequent early hospital discharge of acute and sub-acute patients has had a major impact on the growth of home care. The scope of home care programs has been broadened to include patients with chronic illnesses and conditions.

Advances in medical science and technology have resulted in increased life expectancy; the growing aging population with frailties and disabling conditions has become the major recipient of home care services. These factors have generated rapid growth of home health care. Community-based health care clinics and home care programs have expanded both in number and in the scope of services they deliver (Atchison, 1997). Older adults with chronic illnesses and disabling conditions require home care services on a long-term basis. In response to the needs of this population, a long-term care division of home health care has been created, resulting in the rapid expansion of Occupational Therapy (OT) services in this field (Atchison, 1997).

The philosophical basis of OT provides a strong foundation for theory and practice in the field of home health care. According to Opacich (1997), home care has provided a relevant context for the provision of OT since its inception. He argues that
because “OT addresses meaningfulness in living as it is expressed in the roles, habits, behaviors, and activities of each person, the importance of home cannot be understood, nor can the potential for home as a therapeutic setting be overlooked” (Opacich, 1997, p. 431).

A review of the Canadian Association of Occupational Therapists (CAOT) position statement on home care reveals that the CAOT strongly supports the essential role of occupational therapists in delivering health-care services in the field of home health care. In this position paper, Finlayson (2000) states the following:

Home care occupational therapy is firmly rooted in the historical and philosophical underpinnings of OT. Occupational therapists work with clients to enable meaningful occupation, including looking after themselves (self-care), enjoying life (leisure), and contributing to the social and economic fabric of their communities (productivity). The home environment has provided a natural and meaningful context to promote a person’s occupational roles. (p.351)

Finlayson (2000) asserts that occupational therapists value home-care programs and particularly home-care OT services because they occur in a setting where occupations that are personally meaningful and culturally relevant to the client can be addressed within the client’s home and community. However, research in the field of home care OT has focused mainly on efficacy studies (Moore, 1993; Gibertson & Langhorne, 2000; Walker, et al., 1999; Gitlin, et al., 2001; Day, Carreo & Stump, 2000; Lilja & Borell, 2001). Little attempt has been made to understand the care recipients’ experiences of home care.
Research Objectives

As noted earlier, home care is a relatively new field for rehabilitation professionals, including occupational therapists. Despite the “client-centered” practice guidelines, the focus of OT home care research has not been on the client’s experience. Based on the CAOT “client-centered” practice guidelines (Finlayson, 2000),

The essence of a healthy, functioning person is the balanced integration of physical, mental, socio-cultural and spiritual performance components to provide a sense of well being. Individuals integrate these components by engaging with social, cultural and physical aspects of the environment, which they affect and by which they are affected. (p. 352)

However, client-centered practice has not been reflected in the home-care research and the impact of home care on the individual’s home and environments has not been explored from the care recipients’ standpoint.

Many elderly people with chronic illnesses or disabilities are long-term recipients of OT home-care services; therefore, their homes function as their personal residences as well as settings for receiving health care. The consequences of providing health care in a home setting on the lives of the home-care recipients and their families has not been adequately studied; their experience of their homes as the site for receiving health care and particularly home OT services is not known.

The above issues based on the care recipients’ experiences of home care OT are addressed in this study. The main objectives of this project are to gain insight into the care recipients’ experiences of home care OT, particularly home modifications recommended by occupational therapists and the ways OT home care services have
impacted their lives. Therefore, the main questions which guided this study are: (a) what are the care recipients’ experiences of OT home-care services, particularly home modifications recommended by occupational therapists? (b) What are the meanings of the ‘home’ to the care recipients? (c) What are the physical layouts of the care recipients’ home, their household amenities, resources and social support? (d) What are the impacts of home-care OT services on the care recipients’ daily lives?

**Anticipated Significance**

The findings of this study will provide important information that could be used by all home care professionals to promote home care services that are meaningful to the care recipients. This study will enable home-care occupational therapists to reflect on the care recipients’ accounts of their experiences described in the study. Further it will enable occupational therapists to reflect on their own practices and to address issues surrounding home care in order to enhance compatibility between OT philosophy and their clients’ values and goals. Reflection on the accounts of care recipients’ experiences of home care might also enable therapists to advocate for their clients’ concerns regarding home care.

The findings of this study will also be beneficial to policy makers in health care, especially those in home-care administration, social services and housing sectors, to address issues related to the physical and social conditions and resources of their clients.

The accounts of experiences of care recipients will be also useful to advocacy groups and the education sector in promoting care recipients’ rights to quality health care services, and health-care decision-making.
Conceptual Approach

Concepts drawn from the ‘enabling occupation’ model of practice (CAOT, 1997), feminist sociology, and social geography have informed this study. The central concepts of these theories that are applicable to this study include the importance of an individual-focused approach in providing health care; the personal accounts of experience in generating knowledge; and the social, cultural, and symbolic meanings of home.

Occupational therapy is based on the belief that purposeful activity (occupation), including its interpersonal and environmental components, may be used to prevent and mediate dysfunction and to elicit maximum adaptation (Levine, 1988). Based on the CAOT (enabling occupation) model of practice, OT ethics of caring place each individual/client at the center of the health-care decision-making process. Despite the emphasis of the centrality of the individual/client, the ultimate role of the individual in health-care decision-making, particularly in the context of home care, has not been examined within OT literature. There is a lack of clients’ accounts of their experiences in generating knowledge in home care research. The concepts from these disciplines have been used as a framework informing this study. These concepts will be discussed in more detail in chapter two.

Organization of Thesis

Chapter two consists of a literature review relevant to this study. Current studies, which mainly examine efficacy of home care OT interventions, will be reviewed. Recent research from feminist sociology and social geography exploring issues related to the importance of individuals’ context and ‘space’ in shaping their experiences will be...
reviewed as well. The conceptual approaches for this study will also be discussed in chapter two.

Chapter three describes the specific qualitative research methods used in this study to explore the participants’ experience of home care OT, particularly the impact of home modifications on the participants’ daily life. The process of participant selection and recruitment, data collection and analysis are outlined. Specific strategies used to increase the rigor of the study and the trustworthiness of the data are also examined.

In chapter four and five, the two main findings of the study are discussed. The first theme, “the importance of home, neighborhood and community resources” sets the context in which the participants of the study experience home care services including OT services. Emergent related issues such as the socio-economic status, living and housing conditions of the participants, their reliance on home care services and community resources, and finally the increasing significance of their homes, neighborhoods and how they renegotiated the meanings of their homes and neighborhoods as their disability progressed are discussed. The second theme, “the experience of home care OT” describes the participants’ accounts of their experiences within their contexts. Related themes, the impact of OT services on the participants’ daily life and multiple roles of home care OTs are discussed in chapter five.

Chapter six presents an integrated description of the findings. The participants’ overall experiences of home care OT within their contexts are discussed. The findings are discussed in regard to related literature and the conceptual framework. The implications of the findings for home care occupational therapy practice and future research are discussed. Finally, the limitations of the study are examined.
Chapter Two: Literature Review

Rationale

Opacich (1997) argues that occupational therapists encounter philosophical and moral challenges in the field of home health care. The ‘medical’ model of practice in the field of home care imposes limitations on client-centered OT practice. In this regard, Peloquin (1996) argues that “occupational therapy practitioners must reiterate which philosophical beliefs and ethical commitments they hold dear or risk being defined by cost-controlling strategies that do not accommodate OT values” (Peloquin, 1996, p. 456).

A review of the literature reveals that research in home care has been mainly focused on efficacy studies with different patient populations. However, the concept of home as a place for providing health care has not been adequately explored in OT research literature. The central foci of occupational therapists in home care are physical environmental modification and prescription of assistive devices and equipment. Consequently, compliance with prescribed adaptive equipment has been the major focus of some of the efficacy studies (Adams, 1997; Baker et al., 2001). However, based on the occupational therapy client-centered model of practice, concentration on the frequency of use of adaptive equipment and the neglect of subjective issues of perceived benefit of equipment and its effectiveness has been critiqued (Wielanndt & Strong, 2000). Home-care practitioners have reported that the home environment does not always afford optimal space, personnel, and equipment for rehabilitation (Levine, 1988), and it is not always possible to carry out modifications in homes with limited space and resources (Levine & Gitlin, 1993). These studies reflect occupational therapists’ practical
challenges from their own standpoint, but care recipients' perspectives and experiences of OT home modifications, in-home adaptive equipment, and other aspects of home care have not yet been explored.

To better understand the physical, social and cultural environments in which care recipients live and receive services, subjective accounts of care recipients' experiences of home care need to be studied. This study may enable occupational therapists to better conceptualize their practice to encompass their clients' goals, values, environments, cultural life style and functional needs. The client-centered approach and cultural considerations (Levine & Gitlin, 1993) have been studied in regard to OT effectiveness in the home-care setting. However, the perspectives of home care recipients are essential to a client-centered home care OT practice. Furthermore, care recipients' accounts of their experiences are fundamental to a better understanding of the physical, social and cultural environments in which home-care recipients live and receive services. This understanding, in turn, will contribute to the improvement of the quality of home-care services.

As noted earlier, the concept of home as a place for providing health care, particularly from the care recipients' standpoint has not been studied in the OT research literature. A review of the occupational therapy literature reveals very few studies addressing issues related to home, environment, housing and resources. The following section describes these relevant studies. In addition, multidisciplinary studies related to the concept of home and the meanings of the home will be reviewed.
Related Research

The central focus of the literature concerning occupational therapists in home care is on physical environmental modifications and assistive devices and equipment in the home. Only a few researchers have critiqued the focus on home modification. For instance, Bachner (2000) has urged occupational therapists to consider and understand clients’ subjective feelings and learn about their clients’ relationships with their life spaces. She asserts that the socially constructed meaning of the home and symbolic value of personal objects should be considered before recommending home modifications. She argues that a narrow focus on the physical environmental modification based on the “medical model” of care delivery merely identifies physical dysfunction to establish treatment goals from the health professional stand point and too often neglects clients’ subjective accounts of their experiences and perceptions about their homes and recommended modifications.

Bachner (2000) also briefly discusses the emotional aspect of the home and how one’s home is an extension of one’s self-identity. She argued that, for example, “photos, antiques, and memorabilia can arouse within us past moments of great importance. Ego-supportive objects in a clients’ life-space are worthy of attention” (Bachner, 2000, p. 20). She concludes that, even though these objects may clutter a care recipient’s space and have an undesirable impact on her/his mobility, these props can bring physical and emotional comfort and can touch the human spirit, especially if carrying out daily tasks has become a source of frustration because of pain and discomfort.

In a similar study, Steward (2000) considers the home not as an architectural plan or neutral space, but as a space with a complex range of symbolic meanings. He argues
that providing health care services at home is not generally considered problematic by health care providers, even though, for many people, home space is small, over crowded and not designed for alternative functions. He explores the problems of defining and managing home space when new demands are placed upon it. According to the results of this study, home care recipients identified the loss of a right to have a boundary, defined and respected by outside authorities, as a considerable loss. Steward argues community occupational therapists often experience clients’ resistance to and non-usage of specialized equipment and adaptations or unexpected resistance from other members of the family. Occupational therapists usually interpret the rejection of their recommendations as “non-compliance”. However, the findings of this study revealed, “people are prepared to tolerate unexpected levels of inconvenience and discomfort rather than disrupt the function and meaning of household space” (Steward, 2000, p. 108).

The concept of home and the experience of a place and its impact on people’s health and well being have been studied by other disciplines such as social and medical geographers and environmental researchers. For instance, Rowles (1991) criticizes occupational therapy’s central emphasis of performance from a geographical perspective and emphasizes the experience of the place. Rowles states:

My argument is that widely accepted and internalized tenets of contemporary occupational therapy philosophy may be compromising and limiting the potential of the field. Emphasis on performance, as manifested by knowing and doing, has tended to relegate the notion of being (as a component of well being and a fulfilling life) to an ancillary role. One outcome of this has been inadequate consideration, at least until recently, of the role of the person’s experienced
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spatiotemporal environment in conditioning his or her response to dysfunction
and to the intervention strategies designed to remedy them. (P.270)

Rowles (1991) advocates for more understanding of the clients’ being:

In place- that is, their immersion within a life world that provides the culturally
defined spatiotemporal setting or horizon of their everyday lives. This
phenomenological perspective embraces physical, social, cultural, and historical
dimensions of an environment of lived experience. Thus, the life world not only
includes the person’s current setting but also has a space-time depth that is
uniquely experienced within the framework of personal history. Being in place
expresses immersion within such a lifeworld. Increased understanding of client’s
being in place can be achieved by exploration of the meanings, values, and
intentionalities that underlie their experience of particular environments. (p.266)

He particularly emphasizes the importance of understanding the environments of those
elderly who have lived in the same setting for many years, as this may have become a
repository of meanings, and a part of the self that is linked to their identity (Rowles,
1991). In a study related to the home as a place for health care, Gardner (2000)
emphasizes the impact of home-based acute care on the environment of the home and
neighborhood. He argues that:

While our modern sensibility recognizes the bureaucratic power of hospitals, this
also renders us sensitive to a view of home as a private space, a haven from the
demands of the world. The very word home evokes feelings of familiarity,
comfort, security, nurturance and peace, but recent domestication of health care
could be morally questionable in that illnesses and treatments can make familiar
domestic setting alien and confuse family roles. The juxtaposition of the accoutrements of pathology and illness with the non-pathological setting of home has the potential to create an environment that is as alienating and culturally strange as the hospital setting itself. (p.14)

Gardner (2000) advocates for health care providers to develop more sensitivity to the space of home as one of sanctuary with multiple social and emotional functions that contribute greatly to the well being of people in health and illness. Furthermore, he emphasizes the negative impact of the invasion of the acute care technology into the home. He argues that this technology, if needed, should not dominate the home and transfers the hospital environment into the home. Gardner (2000) concludes the following:

The challenge for nursing is to change our understanding of home from a place where people go when medical science is finished, to a concept of home as a therapeutic environment. A further challenge is to resist compliance with the relocation of acute care into the home as an imperative of funding schemes to achieve economies. Home (acute) care should not just be a means for freeing up hospital beds, but needs to be viewed as an opportunity to care for people in a preferred, therapeutic environment. (p. 15)

In another related study, Teeland (1998) critiques the lack of research related to the role of the dwelling in home care. He argues that the phenomenon of being discharged from the hospital for convalescence and treatment in the home and how this may affect the way members of the household value and use the dwelling are not usually considered. He discusses various meanings of the home and emphasizes those meanings
having to do with privacy, identity, familiarity and their inter-relatedness. Moreover, he asserts that it is quite common that residents as well as researchers make a strong association between the home and ideas of freedom and independence. However, although some dwellings allow people a good deal of freedom even while they are sick, other dwellings do not. Although stairways, high thresholds, noise, and great distance from shops and taxis might be easy to tolerate when one is entirely healthy, these circumstances might create an environment that is much less safe than a well-designed hospital. In such cases, the home becomes less of a “castle” than a “cage”. For some people, returning home might simply mean returning to the bedroom; for others, the once so proper living room may now be turned into a permanent bedroom.

Teeland (1998) reminds the reader that various machines and aids, from special beds to advanced medical equipment, may dominate the dwelling upon returning home, and the home can in some cases be radically transformed. It may become less and less like the original home and more and more like a mini-hospital. This phenomenon may affect the other members of the household as well. The day may have to be scheduled in new ways, and former routines, such as eating at a certain time and place, may have to be abandoned. Space in the dwelling once differentiated into zones including different rules for different members of the households might have to be re-negotiated and the other household members might lose their privacy. The healthy person may find that their home has come to resemble a hospital and it is not the ideal place for social gathering.

Teeland (1998) discusses the concept of the home as a work place for the visiting health care professional. He poses the basic question as to whether the dwelling is the home of the resident/patient or the place of work for the health care professionals. He
argues that professionals naturally demand working conditions that are safe and easy to use. Although this might be what the sick person desires it should not be assumed that this is the case. He also discusses power relations in home care. In this regard Teeland (1998) states:

Even though the authority of the health care professionals may be reduced in some cases, their presence in the home accentuated by the various items of medical technology can nevertheless be quite strong. Any readjustment of power depends on the sickness in question and the negotiating position of the residents. Usually, the smaller the dwelling, the greater is the chance that the professionals will dominate. (p.279)

In regard to the issue of power relations, Teeland (1998) discusses the notion of the knowledge of the whole person that can lead to control and domination by professionals. He asserts that, in home health care, the professionals get to know about the patient’s physical and psychological status and also they know what is going on inside his/her home, perhaps including intimate aspects of the individual’s personal and social lives. He explains that the knowledge about the care recipients gives the health worker a more complete picture of the sick person. Teeland asserts that:

This knowledge is clearly asymmetrical; the patient knows little of the health care worker’s personal life. It remains to be seen whether home health care enables a more two-sided exchange by facilitating interpersonal dialogues that would otherwise have been constrained in the hospital environment. (p. 280)

In a similar study, Tamm (1999) provides the reader with concepts associated with the meaning of the home. She argues that having the home as a personal territory
helps people organize their lives by creating order, predictability and stability in their lives. The demanding aspects of the surrounding environment are reduced in the home; there is protection from stress and over stimulation and from the crowding of strangers. She emphasizes the individual and cultural differences of the meaning of “home”. Moreover, she identifies the concepts of privacy and the right to solitude and personal space to be very central in western cultures. She states that, “The home is a strong hold of people’s basic needs and feelings of security, safety and identity” (Tamm, 1999, p. 50).

Tamm (1999) further asserts that:

The daily activities carried on in the home, structure one’s life and create a healthy balance between activity and rest, work and leisure, waking and sleep. This organizes one’s life and counteracts impairment, stress and chaos. The other aspect to be considered by the home health care providers is the importance of things in people’s homes; the things surrounding a person at home are emotionally charged. They harbor memories of experiences and relations with others, in this light, the objects surrounding us become a sort of extra skin; an integral part of the image that one has for oneself and shows to others. The older a person is, the more meaningful the things in the home are perceived to be. It is these things that help the aging person to remember his/her life, to re-live the feelings of the past, to create a feeling of belonging, stability and continuity.

(p.51)

Tamm (1999) criticizes home-care professionals for their lack of consideration of the emotional impact of home modifications on many of the care recipients and their families. She argues that home adaptation by occupational therapists can mean that the
home must be adapted to the impairment, including widening door openings for wheelchair access, moving furniture, replacing a bath tub with a shower etc, at the same time, a home adaptation involves other family members and has an impact on family members’ relationships. Often families feel that the home no longer has the personal atmosphere that they used to associate with, and the sanctity of their home has been encroached upon (p. 54). Based on her findings, she suggests that having to re-arrange furniture in one’s home according to others’ wishes, or introducing technological or assistive aids, is perceived as a significant intrusion in the home, as home furnishings are part of family identity. Tamm (1999) further argues that:

When rehabilitation takes place in the home, the family is forced to open its door to a considerable number of unfamiliar persons (nurse, occupational therapist, physiotherapist, and nursing assistant) who come and go at different times. Privacy in the home is thereby disturbed, the different members of the family must adjust to the working hours of the professionals, and that which was private, but is exposed to the gaze of many. (p. 52)

Tamm (1999) argues that when rehabilitation takes place in a home setting the home has to function as a private place for the patient and the patient’s family as well as a public workplace for the rehabilitation staff. This combined functionality makes conflicting demands on the home, demands that are practically impossible to meet. In regard to the medicalization of the home, Tamm poses these questions:

How does one want the home and old age to be? Whether to receive care and rehabilitation in the home, even if one is denied autonomy, dignity and privacy, and allow one’s home to be changed into semi-public institutions, where
unfamiliar people come and go? Or to consider well-designed institutions, where one has more privacy and better rehabilitation than in the home, to be preferable? A third alternative is through different training schemes to change rehabilitation in a home setting into a more positive experience than it is today. (p. 54)

According to the findings of Tamm’s study (1999), the goal of rehabilitation in the home has not been established with complete inclusion of care recipients and their family’s goals and views of quality of life. She asserts that:

The goal of rehabilitation in the home setting is to help the patient to become as independent as possible so that he/she can enjoy as high a quality of life as possible. At the same time the professionals’ view of what quality of life means to the functionally impaired elderly person is fairly vague. When care-receivers, relatives and occupational therapists were asked what the goal of rehabilitation was, they had differing opinions on it, and it was the occupational therapists’ goals that steered rehabilitation. (p. 53)

Tamm (1999) asserts that in connection with chronic illness and functional impairment, the elderly individuals will lose the home as a private territory, a place to be in solitude and decide over his/her own life. Instead the home becomes a place filled with worry, insecurity and helplessness. She further asserts that:

Neither is the home now an existential center for the family, but a place where many unfamiliar people come and go, and interfere in their lives in different ways. Of course, there are lonely people who can see the rehabilitation sessions of the caregivers as positive social events, but for the families that have been studied
they mean disruptive factors in their lives, despite being necessary for the care-receiver’s fragile health. (P.53)

As noted earlier, in home-care OT, not enough attention has been given to the care recipient’s dynamic relations to the social, emotional and physical aspects of their environments. However, studies in the fields of social and medical geography address these important concepts by emphasizing the dynamic relations of the individuals with their environments. The concepts of home space, disabling environments, and the meanings of home have been addressed in the sociology and social geography literature. These studies provide insight and knowledge, which can greatly contribute to the OT base of knowledge and improvement of the quality of care in home care. For instance, Gant’s study (1997) emphasizes the impact of environmental and social barriers on health and personal mobility of elderly individuals. He argues, “It is now acknowledged that many of the daily difficulties encountered by elderly people with disabilities are not wholly caused by health impairment, but rather by prevailing attitudes in society, insensitive planning and local environmental circumstances” (Gant, 1997, p.207).

Gant (1997) views age and disability as social constructions, which are configured differently in space. He emphasizes the creation of an enabling environment, stating:

Since the 1980s, changes have occurred in the philosophy and practice of urban design. The concerns of less mobile people have been taken into account in urban re-design. The elderly have benefited from pedestrianisation of shopping and resource areas such as retail outlets, food and grocery stores and financial services. (p. 208)
Gant (1997) also stresses the importance of access to alternative public transportation and elimination of environmental barriers such as stepped entrances, heavy doors, lack of ramps and wheelchair accessible spaces in creation of an enabling environment. He argues that the enabling environment and opportunity for equal access to social and health services would improve the quality of life for elderly people. This in turn will reduce the risk of elderly individuals becoming frail and housebound and ultimately less dependent on home health care professionals. Gant (1997) also discusses the suitability of the home for providing health services. He argues that this is not generally considered to be problematic by most health care providers, even though for many people home space is small, over crowded and not designed for alternative functions such as health care services.

The physical condition of the home and its impact on people’s health has also been the emphasis of some epidemiological studies. For instance, Evans, Hyndman, Stewart-Brown, Smith and Peterson (2000) show the correlation of poor housing with health outcomes in low socioeconomic populations. In this study, Evans et al. show that physical characteristics such as cold and damp housing are closely related to poor health and conditions such as asthma and chronic respiratory symptoms. However, they emphasize that the relation between cold and damp housing and ill health is complex because many other social and economic factors associated with poor housing also affect health.

Evans et al. (2000) argue that certain subgroups are even at higher risk within low socioeconomic populations. For example, the elderly with no social network and support are at extremely high risk. They assert that, considering the association of poor housing
and ill health, it could be argued that those who stay at home are more likely to notice and be affected by poor housing conditions. The majority of those providing care at home are women caring for children or sick family members, or women working as formal caregivers at home. According to epidemiological studies reviewed in Evans et al.'s study, these women experienced more symptoms of illness and health problems than others; therefore, housing conditions and particularly the conditions of poor and marginalized groups should be considered more seriously in home care.

In a study related to community resources, living condition and nutritional status of poor and elderly populations, Lyon and Colquhoun (1999) argue that poor community resources and low incomes of the elderly greatly contribute to poor nutrition and health. Lyon and Colquhoun (1999) assert that:

Local shopping environments are made less viable by in-store and retail park diversification, which result in the relocation of important services for the elderly such as pharmacies and post offices. The situation can be acute in rural areas. In some circumstances there may be neighborhood support networks, but these will not be a feature of all housing areas. (p.64)

Lyon and Colquhoun (1999) emphasize poor home condition of many elderly people and the impact of poverty, particularly nutritional poverty and limited resources in remote areas. Furthermore, they criticize the home care system for not considering the elderly’s poor nutritional status, home conditions and the impact of all these on their health. The major emphasis of this study is on poor housing and the social and community resources available to the elderly, particularly in remote and rural areas.
In another similar study, geographers Nemet and Bailey (2000) also emphasize poor living conditions of the elderly in rural areas. They state, "Increased demographic demands coupled with impoverishment is making elder health care delivery fragile in many rural areas. Increased distance between parents and children implies greater separation between the elderly and potential in-family sources of care (Nemet & Bailey, 2000, p.1198). Based on the findings of this study, they report higher rates of poverty among older populations in non-metropolitan areas.

In regard to the relationship between distance and utilization of health care by elderly populations living in rural areas, Nemet and Bailey (2000) frame the decision to visit a physician or seek health care services in the context of the experience of place. Nemet and Bailey (2000) assert that:

Activities such as commuting to work, purchasing food, and visiting friends and relatives are important elements of an individual's activity space. Among the elderly, trips for grocery and to community institutions are particularly important. Therefore, the nodes (origins and destinations) and paths (routes) of activity space thus provide a powerful, and observable, way of describing the experience of place in daily life. (p.1200)

Nemet and Bailey (2000) emphasize 'activity space' and 'experience of place'. With regard to the utilization of health services, they state:

Activity space can be interpreted as direct awareness of space with individuals experiencing places within their activity spaces qualitatively differently than places outside it. In short, the elderly may be experiencing places within their activity spaces as familiar and those outside as unfamiliar, thus experience of
place also contributes to variation in utilization rates across the rural elderly.

(p.1205)

According to the results of this study, Namet and Bailey (2000) suggest that educational programs that emphasize health promotion could efficiently improve the situation of the rural elderly. Moreover, they assert that interventions such as screenings and blood testing if bundled with grocery shopping or other routine activities in the community can most effectively improve health conditions of the rural elderly. One can conclude that this will enable the elderly to function more independently at home with less need for home care interventions. Therefore, housing and living conditions of homes within communities and also amenities available to the residents of our communities should be considered as important factors in home care. The improvement of housing and community living conditions should be the central focus of home care intervention and strategy. With regard to the improvement of housing condition of the care recipients, The Romanow Commission (2002) has also identified the need to expand coverage of home care under the Canada Health Act to integrate home care with the overall continuum of care. The commission supports collaboration between home and community care and housing providers to develop supportive living arrangements for the care recipients.

Medical geographers have emphasized the importance of physical and psychological characteristics of the home and environment. For example, Sooman and Macintyre (1995), in a study related to public health, argue that the environment in which people live and work can have both favorable and adverse effects on their health and well being. They assert that strategies for improving health need to take local environmental circumstances into account. In this study they demonstrate that in two socially contrasting
areas, the opportunity structures in the poorer area were less conducive to health or health-promoting activities than in the wealthier area. Some of the examples of the opportunity structures include access to healthy recreation, food, and transportation.

Sooman and Macintyre (1995) examined six broad domains consisting of amenities, social problems, fear of crime, area reputation, neighborliness and satisfaction with neighborhood in two contrasting neighborhoods. They found that, in general, the residents of the most socially advantaged neighborhoods had the most positive perceptions of their health and those in the least advantaged areas the most negative. It should be noted that psychological and emotional aspects of living in poor and disadvantaged neighborhoods experienced by the residents have not been explored in home care research.

In summary, the reviewed literature reveals a lack of consideration of ‘home’ as an important aspect of the individual’s sense of being in home care OT. This is contradictory to OT client-centered practice. Occupational therapy’s emphasis on environment and its social, cultural, and emotional aspects has been neglected in home care. Home care occupational therapy’s main focus on home modification is mostly driven from the borrowed medical model of practice. In the Bachner (2000), Steward (2000), and Tamm (1999) studies, the approach of home care occupational therapists with regard to home modification has been criticized. Tamm (1999) argues that home modification by occupational therapists could transform the home into an unfamiliar and alien place, with the loss of its personal atmosphere. She further argues that, for example, having to re-arrange furniture in one’s home according to others’ wishes, or introducing
assistive devices such as grab bars in one’s bathroom, is perceived as an intrusion in the home, because home furnishing are considered part of the self and the family identity.

However, when occupational therapists identify the client’s physical dysfunction (for example, the client’s difficulty with toilet transfer) they recommend assistive devices such as grab bars and raised toilet seats. This is the common practice of home care occupational therapists and is considered to be the logical intervention. Steward (2000) argues that occupational therapists often perceive clients’ resistance to and non-usage of the recommended equipment and home modification as non-compliance on their clients’ part. They interpret this as the rejection of their recommendations. A better understanding of the client’s position can be achieved with implementation of a true client-centered approach through consideration of the emotional and psychological aspect of the home. The ‘logical approach’ of prescribing medical equipment and home modification may not be a client-centered approach to home care. As Steward (2000) expresses in his study, it is evident that people are prepared to tolerate unexpected levels of inconvenience and discomfort rather than disrupt the function and meaning of their homes.

Little has been done in home care occupational therapy research with regard to the consideration of the home in the context of community and neighborhood. However, Rowles’s study (1991) has provided occupational therapists with a fundamental analysis of the tenets of the profession’s philosophy. He challenges occupational therapists to consider the individual’s experience of place and lifeworld to achieve a comprehensive understanding of the client. He suggests that the individual’s experience of place could be understood by exploring the meanings, values, and intentionalities that underlie the client’s experience of particular environments. This exploration includes the
consideration of concepts such as privacy, identity, control, comfort, familiarity, security, family relations, nurturance and peace, all of which are associated with the meaning of ‘home’.

The issue of power relations between professional care givers and care recipients and its impact on the home are explored in Teeland’s study (1998). The concepts of medicalization of the home and the home as a work place for health care providers are discussed in Tamm’s study (1999). These are very important and relevant issues to occupational therapy practice, particularly in home care. However, little attention has been paid to these concepts in occupational therapy home care research. There are a considerable number of materials related to the concept of enabling environments in the occupational therapy literature; in practice, this has been interpreted and limited to the elimination of physical environmental barriers. In occupational therapy, this concept has not been explored with regard to the limitations of the social and community resources available to the client.

The Gant (1997), Evans et al. (2000), Lyon and Colquhoun (1999), Nemet and Bailey (2000), and Sooman and Macintyre (1995) studies reviewed in this paper emphasize the importance of enabling environments from physical, economical, emotional and social stand points. The importance of social resources in enabling the individual and communities is discussed in these studies. Occupational therapists can benefit from this multidisciplinary literature. They need to achieve a better understanding of their client’s experience of place and ‘home’ in order to be able to provide quality care based on their clients’ needs and goals as expressed by them.
Home as a Place for Providing Health Care

Conceptual Approach

Client-centered philosophy

As noted before, the philosophical basis of OT provides strong foundations for theory and practice in the field of home health care. Law, Baptiste and Mills (1995) provide the following definition of “client-centered” practice in OT:

An approach to providing occupational therapy, which embraces a philosophy of respect for and partnership with people receiving services. Client-centered practice recognizes the autonomy of individuals, the need for client choice in making decisions about occupational needs, the strengths clients bring to a therapy encounter, the benefits of client-therapist partnership and the need to ensure that services are accessible and fit the context in which a client lives.

(p.253)

The Canadian Association of Occupational Therapists (CAOT, 1997) defines client-centered practice as a collaborative approach in which occupational therapists demonstrate respect for clients, involve them in decision making, advocate with and for clients in meeting their needs and otherwise recognize clients’ experience and knowledge. However, according to Gage and Polatajko (1995), the term ‘client-centered’ means different things to different practitioners. In this study, they found that the description clinicians gave of client-centered practice ranged from consideration of the client’s need to having the client direct the process.

Based on the CAOT (1997) definition, Sumsion (2000) provides a revised definition of client-centered practice in occupational therapy. She asserts that “there are many factors that influence the successful implementation of client-centered practice,
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including a clear determination of who the client is and the recognition of the impact of resources" (Sumson, 2000, p. 308). She provides the following definition:

Client-centered occupational therapy is a partnership between the client and the therapist that empowers the client to engage in functional performance and fulfill his or her roles in a variety of environments. The client participates actively in negotiating goals, which are given priority and are at the center of assessments, intervention and evaluation. (p. 308)

The conceptual models of occupational therapy practice such as the Canadian Model of Occupational Performance (CMOP) (CAOT, 1997) and the Model of Human Occupation (MOHO) (Kielhofner, 1995, Kielhofner & Forsyth, 1997) place the client at the center of health care provision. However, despite the fact that the OT ethic of caring emphasizes the centrality of the individual, the ultimate role of the individual in health care decision-making has not been examined within OT literature. In occupational therapy practice, these models have been applied to understand the dynamic relationship of human to its immediate physical and social environments.

Consideration of the discussed concepts and their interconnections (from other disciplines such as feminist sociology and social geography) will allow for a more comprehensive understanding of the individual’s experience of disability and his or her involvement with the health care provision system. In this regard, O’Brien, Dyck, Caron and Mortenson (2002) emphasize the limited application of the Canadian Model of Occupational Performance (CMOP) in occupational therapy practice. In comparison to a large number of feminist informed studies in Nursing and Social Work literature, there are only a very few references available within OT.
Miller (1992) asserts that OT has more in common philosophically with feminism than with medicine. She further argues that the core concepts of OT such as the environment, meaningful activity and autonomy of the individual are based on OT models of practice such as the CMOP and the MOHO, which encourage the consideration of dynamic processes of environment as it relates to human being. In a similar study, Hamlin, Loukas, Froehlich and MacRae (1992) emphasize the compatibility of feminism with the OT’s philosophical base and the applicability of feminism as an inclusive model of personal empowerment and social justice for all. However, only a small number of researchers in occupational therapy have examined OT principles from a feminist standpoint (Pierce & Frank, 1992, O’Brien et al., 2002). For instance, Pierce and Frank (1992) provide a feminist analysis of motherhood and family-centered care. They explore the work of a mother from her perspective. Using a feminist socio-cultural analysis, they offered a new understanding of women’s care-giving work in OT.

Despite the emphasis of an individual-focused approach, in general, there is a lack of exploration of the individuals’ accounts of experiences in generating knowledge in occupational therapy. Feminist sociology emphasizes the importance of the women’s accounts of their experiences in generating knowledge.

Feminist sociology

Concepts drawn from feminist sociology have informed disability research in the past two decades. In disability research and particularly, in home care, issues related to physical, emotional, social, cultural environments, socioeconomic status, public and institutional factors are overlapping at many levels. Therefore, the exploration of personal
experience of the care recipient from a broader perspective (feminist sociology) will allow for a better understanding of the disability experience in the society. The Dyck (1995) and O’Brien et al. (2002) studies addressed issues related to the experience of disability and how interconnected social, economic, cultural and political factors shape the individual’s experience of disability in our society.

Among the critique of mainstream disability and home care research, Thorne and colleagues (1997) argue that providing health care at home, regardless of its advantages, imposes considerable consequences on the family and the home. Therefore, they suggest that clinicians become aware of the complexities of how aging, illness, and disability are lived in our society by exploring and understanding individual’s daily experiences. In this regard Morris (1992) emphasizes old age and disability as important aspects of one’s identity, and the importance of the incorporation of the subjective reality of older women in disability research.

Regarding the relevance of feminist theory to home care research, Peter (2000) emphasizes that feminist ethics can be effective in addressing issues such as interdependency and communitarian approach; care giver and receiver choice; and the importance of care recipients’ everyday life experiences in generating knowledge that offers a social and political critique and proposes progressive social changes.

As noted in the previous sections, the majority of home care recipients are elderly people with chronic illnesses and disabilities. Therefore, concepts related to impairment and disability also need to be addressed in home care research. Oliver (1992, 1990) argues that disability is culturally produced. He emphasizes that social class is an important factor of the cause of disability, and similar to poverty, impairment is also not
randomly distributed in societies. Therefore, it occurs in a structured way and this in turn challenges the notion underpinning the medical model and personal tragedy theory of impairments and disability. He argues that the differences among people with disabilities in different societies can not be explained by chance or cultural relativism, but are culturally produced through the relationship between the mode of production and the central values of the societies concerned. Therefore, in our industrial society with its emphasis on the able body and ability to produce commodities, people with disability are considered ‘different’. This is a socially constructed difference in our industrial societies.

Since the conceptualization of disability as a form of “social oppression” (Oliver, 1990), the theoretical analysis has shifted from individual and impairment to disabling environments and discrimination. However, a number of academics working from within a predominantly feminist perspective have critiqued the materialist approaches of Oliver for his neglect of the diversity of the individual experiences of disability (Morris, 1991; Stuart, 1992; Crow, 1996; Morris, 1992). These writers have argued that the social model undervalues the role of the dynamic relationship between physical, socio-cultural and political factors in shaping the experience of disable people (Barnes & Mercer, 1996).

In this regard, Crow (1996) argues that, by focusing primarily on external disabling barriers, the social model of disability implies that impairment has no part in determining the experiences of individuals with disability. Furthermore, this approach fails to acknowledge the subjective reality of many disabled people who experience pain, illness, and loss of function and dignity. She suggests that a renewed feminist approach is vital to include self-expression, total understanding of subjective experiences and identities of people with disability. Crow (1996) emphasizes the individual’s different life
circumstances and the importance of subjective experiences of disability expressed by the individual.

Social geography

In attempts to address the multi-layered dimensions of disability experience, social and medical geographers have been analyzing the relationship between space, illness and disability from a more comprehensive social and political standpoint. For example, Dyck (1995) analyzes the changing meaning of home, neighborhood and city spaces for women with Multiple Sclerosis. Kitchen (1998) emphasizes space as an active constituent of social relations. He asserts that space is socially constructed and plays an important role in producing and maintaining the processes of exclusion of disabled people.

As noted, very few studies have addressed the concept and meanings of the home in relation to health and health care provision. Among these Bachner (2000) emphasizes the emotional aspect of the home and how one’s home is an extension of one’s self-identity. Steward (2000) asserts that home is not a neutral space, but it is a space with a complex range of symbolic meanings. Rowles (1991) advocates the consideration of the place as experienced spatio-temporal environments by individuals. The symbolic meanings and the emotional aspect of the home have not been addressed in home care occupational therapy.

This study has drawn from the concepts of feminist sociology and social geography in exploring home care recipients’ experiences of OT services.
While occupational therapy client-centered philosophy is compatible with these concepts, they have not been adequately integrated in occupational therapy practice. Using care recipients' voices, this study may enable home care occupational therapists to better understand their clients' experiences so they can ensure a client-centered practice in home care. Moreover, a comprehensive view of 'home' as expressed by home care recipients could shape and influence the opinions of health care providers and ultimately influence the policy decision making process. This would also provide occupational therapists with the knowledge they need to be able to provide quality care and advocate for their home care clients. The following chapter will review the methodology of the study.
Chapter three: Methodology

As stated by Hammell and Carpenter (2000) fundamental to qualitative methodology is a concern to describe and understand how people make sense of their lives through exploration of their perspectives and everyday realities. In this study, the choice of qualitative methodology is informed by the nature of the problem it seeks to address (Hammell & Carpenter, 2000). As noted earlier, this study aims to gain insight into the elderly care recipients’ experiences of home care OT. Therefore, qualitative approach is used to explore the care recipients’ experiences from their standpoint.

Qualitative methods are appropriate when seeking a deep understanding of the study participants’ point of views; and when context is integral to the main concern of the study. In this study, context is addressed as an integral part of the study question. As emphasized by Hammell and Carpenter (2000), qualitative research is pluralistic, comprising a variety of approaches that reflect both the philosophical positions and the demands of the specific research context. In response to address the specific concerns of this study, in-depth semi-structured and interactive interview and observation of the participants’ homes and overall living conditions were carried out.

In this chapter the rational for the choice of qualitative methods will be reviewed. The process of participant selection and recruitment will be outlined. The interview process, data analysis and interpretation will also be outlined. The participant profiles will be provided and finally, the strategies taken to increase the rigor of the study and consequently the trustworthiness of the data will be discussed.
Qualitative Research

In this study, a qualitative approach and particularly a thematic analysis were used to address the proposed research questions. Qualitative research is concerned with the meaning of social phenomena and the individual’s experience. Due to its approach to the human experience, qualitative inquiry is being used more frequently within health research. Creswell (1998) asserts that qualitative research is an inquiry process that aims to explore and understand a social or human problem. Denzin and Lincoln (2000) also assert that qualitative researchers study phenomena in their natural settings, attempting to make sense of or interpret phenomena in terms of the meanings people bring to them. It has been suggested that qualitative methods should be used when little is known about a phenomenon, when the research question pertains to understanding or describing a particular phenomenon or event about which little is known. Qualitative methods are particularly useful when describing a phenomenon from the research subject’s point of view (Morse & Field, 1995). Morse and Field (1995) assert that:

In clinical and health care research, the “native point of view” may be the perspective of the patient, caregiver, or carereciever. Qualitative research is usually conducted in a naturalistic setting so that the context in which the phenomenon occurs is considered a part of the phenomenon itself. (p.10)

Silverman (2002) asserts that qualitative research methods can provide a deeper understanding of social phenomena than would be obtained from purely quantitative data. Qualitative research inquiries are concerned with the complexity of social interactions as expressed in daily life and with the meanings the research participants themselves
attribute to these interactions (Marshall & Rossman, 1999). They assert that qualitative research is pragmatic, interpretive, and grounded in the lived experiences of people.

Because qualitative research emphasizes the meaning of a social phenomenon, the value of context and individual’s experience, it was selected as a suitable methodology for this study. This research project is an exploratory and descriptive study emphasizing the value of context and setting (the home) and seeking an understanding of the research participants’ experiences of home care OT.

Hammell and Carpenter (2000) argue that qualitative methods provide rehabilitation researchers with the tools to explore their clients’ experiences, beliefs and the meanings with which they make sense of their lives. Furthermore, in regard to the appropriateness of qualitative research in occupational therapy, Hammell (2001) argues that “while qualitative research is not, by definition, client-centered, it holds the potential for a client-centered research process” (p. 231). She emphasizes that qualitative research places emphasis upon understanding the client’s perspectives and values, as does the client-centered philosophy.

In regard to the popular trend of evidence-based practice, Hammell (2001) argues that, because in reality clients usually have not been involved in defining the nature of evidence, “the evidence is likely to be biased towards the perspectives of occupational therapists. This provides a poor foundation on which to be based subsequent evidence for practice” (p. 229). She suggests that qualitative methods enable researchers to identify their clients’ need from the clients’ standpoint, thus the qualitative method may be the most appropriate strategy in developing the client-centered, evidence-based practice of occupational therapy.
Research design

In-depth semi-structured interactive interviews and observation of the participants’ homes were chosen to explore the participants’ experiences of home care OT. In attempt to gain insight and deep understanding of the participants’ experiences, semi-structured interviewing method was used to allow the participants free expression and to elicit detailed answers rather than short answers and simple ‘yes’ or ‘no’ responses. Open-ended questions were developed to address the study questions and related issues. A few follow-up/probing questions were asked to clarify issues discussed by the participants and/or to encourage more in-depth responses throughout the interview sessions. Questions concerned the participants’ daily experiences, points of view, and feelings regarding their homes and home care services, particularly home care OT. The interviews were audiotaped and transcribed verbatim. Additional data were collected in the form of field notes, including observation of the participants’ homes, overall living conditions and any conversations made during the tour of their homes. Following each interview, I summarized my impression and perception of what issues were the most important to that participant. In addition, field notes included other relevant information and conversations not captured on audiotape. The field notes were incorporated in data analysis and interpretation of the data.

The following sections outline specific elements of the research design, including the participant selection, recruitment, data collection, analysis and trustworthiness of the data. The participant profiles will be provided as well.
Pilot Interview

A pilot interview was conducted with one elderly participant who met the participant selection criteria. The purpose of this interview was to evaluate the appropriateness of the interview questions and the interview process and to ensure that the questions were relevant to the participants. The pilot interview was effective in providing useful information. The participant expressed that the questions made sense to her. This participant shared her experience of homecare services and particularly home care OT services with enthusiasm and provided detailed responses to the interview questions as well as the effectiveness of the interview questions. Therefore, in consultation with my thesis supervisor, it was decided to include the transcript of this interview as data in the data analysis of the study. I used the participant’s feedback in developing follow-up questions to probe more detailed responses whenever appropriate during the rest of interviews. This participant was involved in the same process as the rest of the study participants.

Participant Selection

Nine individuals participated in this study. They were older adults 65 years of age or older who live in their homes alone or with their family. The participants have required Long Term Care (LTC) services that were provided to them by one of the Community Health Centers (CHC) in the Greater Vancouver area. All of these participants have received home care OT services particularly home modification within the last twelve months. The participants had to be cognitively competent to understand the purpose of the study and comprehend the research questions and voluntarily consent to participate in
the study. To determine competency the participants had to understand and describe back
to the researcher all the following three points: (1) the purpose of the study; (2) the
procedures involved; and (3) the fact that they are free to refuse to participate at any time.
All the participants had to have received at least two home visits from a home care
occupational therapist. They had to be able to speak English fluently.

Recruitment

To recruit elderly LTC recipients who had received home care OT services, three
letters were developed: one letter was addressed to CHC care coordinators, one addressed
to the occupational therapists working with CHC, and one for the prospective
participants. During the period of recruitment, I contacted several occupational therapists
who work with CHC throughout the Lower Mainland. As an occupational therapist
working with elderly clients in acute settings in a geriatric hospital, I had referred many
of my clients to home care OT upon their discharge from hospital. Through this process, I
had built rapport with many home care occupational therapists. With their help I was able
to identify and recruit volunteer participants who met the participant selection criteria.
Throughout the time of recruitment, I attended four meetings at different CHC to
present the proposed study and its potential benefit to OT practice in the field of
community/home health care. At these meetings, I provided the older adult managers and
occupational therapists with the introductory letter explaining the purpose of the study
and its potential benefit to the CHC (Appendix A) and to professional development of OT
practice (Appendix B).
Upon agreement with the CHC administration, staff occupational therapists at the CHC provided the letter of recruitment/invitation (Appendix C), explaining the purpose of the study to potential participants. Due to reported high case/work loads and low priority of research studies for some of the CHC managers, it was found that some of the home care occupational therapists were unable to assist with the recruitment and as the result, the process of distribution of the recruitment letter to the prospective participant was very slow. Therefore, follow-up telephone calls were required. As the participants were known to the CHC occupational therapists, to minimize their potential influence in obtaining consent and to ensure the participants’ voluntarily consent, it was preferable for the researcher to explain and review the purpose and procedure of the study with the participants and obtain signed consent forms before the start of the interview session. Interested participants were asked to contact the researcher directly. Contact information was included in the letter of invitation. Some of the interested participants preferred to be contacted by the researcher to arrange the interview. This was communicated to me through the CHC occupational therapists that have known these participants well.

Before the initiation of the interview and upon the participants’ agreement, I obtained a signed consent form from all the participants who agreed to participate in the study (Appendix D) and I provided all the participants with a copy of the consent form for their reference. Effort was made to ensure that the voluntary sample of the research participants represented the variety of circumstances in which home care is provided; for example, participation from different socioeconomic backgrounds and demographics within the Greater Vancouver area was encouraged. The duration of recruitment and data collection phase was approximately seven months.
Data collection

The eligible participants were interviewed using the interview guide (Appendix E). I conducted all the interviews with the nine participants, between the period of September 25, 2003 and January 20, 2004 in the participants’ homes. The interview guide consisted of open-ended questions using jargon-free language to facilitate the interview session. The research questions focused on the participant’s experiences of OT home care services, particularly home modifications. However, during the interviews, probing questions were asked to elicit more in-depth responses in an attempt to better understand the issues discussed by the participants. At times participants focused on issues that appeared most important to them (e.g. recent cut in homemaking services, social support of home care providers). These participants were given the opportunity to discuss the issues important to them, as they were relevant to the concerns of this study and the participants’ experience. With the participants’ permission, interviews were recorded using an audiotape to allow the participants free style of expression and ensure accuracy of data collection. I transcribed verbatim all the audiotapes. The participants were offered the opportunity to complete the interviews over shorter sessions if they required or preferred shorter sessions. However, all the participants completed their interviews in one session. The average time of the interviews was forty five minutes to one hour.

Observations of home modifications, adaptive equipment, and other OT recommended in-home changes were completed (Appendix E). The tour of the care recipients’ homes took place with the participant or a family member present. I carried the tape recorder during the tour to record any spontaneous feedback from the
participants. I also took detailed field notes to record these observations, my overall impressions, information regarding the participants’ context and their major concerns.

Following each interview, I wrote a summary on the participant’s main concerns and perspectives expressed throughout the interview session and my entire encounter with each of them. For example any body language or gestures indicative of specific emotions or emphasis were recorded as field notes and were used in data analysis of the study. The interview and observation took between one to two hours.

Participant Profiles

The participants of this study included five women and four men over the age of 65. They lived throughout different areas of Vancouver and the Lower Mainland. Pseudonyms are used within the study to protect the participants’ and therapists’ identities and to ensure confidentiality. Seven of nine participants were from European background. One participant was Slovenian who had lived in Canada for over 35 years and one was an aboriginal woman.

The participants were from varying socio-economic backgrounds. They all lived in rented dwellings except one participant who lived in her own house in an affluent area of Vancouver. Two of the participants lived with their spouses, one of the participants was married but his wife lives in a nursing home and he lives alone in a private home (assisted living facility) and the rest were single or widowed who lived alone. The following section highlights the individual profile of the study participants.

- Mike is a 65 year old man with Multiple Sclerosis who lives alone in a BC housing project in a wheelchair accessible bachelor suite in Burnaby. His suite is modern and it is equipped with all of his required equipment.
including ceiling to floor transfer poles, electric bed, manual and power wheelchair. Large elevator and ramps are in place outside of his suite. His source of income is old age and disability pension. He is divorced and has no family or other social support. His only source of social support and contact are his homemakers and other home care providers.

- Andrea is a 68 year old woman with Cerebral Palsy who lives alone in a Co-op housing in a large and bright one bedroom wheelchair accessible town house on the east side of Vancouver. Her home is equipped with two ceiling lifts, electric bed and bathroom safety equipment. Elevator and ramps are also in place outside of her suite. Her only source of income is old age and disability pension. She is single and has no family in Vancouver. Home care providers and homemakers are her only source of social contact and support.

- Patti is a 66 year old woman with osteoarthritis, diabetes and severe chronic obstructive pulmonary disease. She lives alone in a BC housing project in a small one-bedroom apartment on the east side of Vancouver. Her suite is not wheelchair accessible and most of her living space is used for her oxygen tank, scooter, wheeled walker and footstools. Her bathroom is equipped with all of her needed safety devices. There are elevator and ramps in place outside of her suite. Her only source of income is old age pension. She is single and estranged from her son who lives outside of BC. She has few friends in her building and these friends, homemakers and
other home care providers are her only source of social contact and support.

- Rose is an 87 year old woman with arthritis and chronic joint pain who lives in a small bachelor suite in a BC housing project in Burnaby. Her suite is semi wheelchair accessible. She has most of her needed equipment in place including a manual wheelchair and hospital bed. There are elevator and ramps outside of her apartment. Her sources of income include old age and long-term disability (through Nursing) pensions. She is divorced and estranged from her two daughters and has limited contact with some of her grand children. Her main social contacts are through some neighbors and her homemakers.

- Michelle is a 79 year old woman with diabetes, poor mobility, weakness and the condition of failure to thrive. She lives with her husband and mentally disabled adult son in a small two-storey town house with two bedrooms in a BC housing project in downtown Vancouver east side. Their home is not wheelchair accessible and there is no elevator or ramps outside of their residence. They moved from a Northern Reserve long time ago and consequently they are not receiving any financial support from their band. Their only source of income is old age pension and some funding through the Department of Indian Affairs for some medical coverage.

- Ken is a 78 year old man with one-sided severe muscle weakness due to multiple strokes. He is widowed and lives alone in a one-bedroom semi
Ron is a 78-year-old man with heart condition, arthritis, diabetes, and chronic back pain who lives with his wife in a large one-bedroom apartment in Co-op housing. Their home is not wheelchair accessible but they have access to an elevator outside of their suite and safety equipment in their bathroom. He is a veteran and DVA client who is eligible for full coverage of his equipment needs and some homemaking services. Their source of income is their old age pension. He has a daughter who lives close to them and assists them as needed.

Cameron is a 76-year-old married man who lives alone in a private home (assisted living facility) in New Westminster. His wife has been living in a nursing home close to the facility where he’s living for several years. He has a chronic heart condition, prostate cancer, and arthritis in his hips. His suite is small but equipped with modern furniture, safety devices including a call bell for 24 hours emergency management and grab bars in his bathroom. Meals and cleaning services are also provided to him in this facility. He is a DVA client but he does not rely on the funding from
DVA. He reports to having financial means and support from his children to cover his medical and equipment needs.

- Melissa is an 87 year old widowed woman who lives with private live-in care giver and homemakers in her own big house in affluent area of Vancouver west side (point Grey). She has Parkinson’s disease and experiences poor mobility and recurrent falls. She receives all of her needed medical attention at home including doctor visits and blood work. She has all of her needed equipment including a chair lift, wheelchair and walker and grab bars and other safety equipment in her bathroom. Her house is very spacious and bright with a beautiful view of the mountains and the city. She has received some funding for her needed equipment but she is financially able to cover the cost of any equipment that would not be covered and the cost of any other needed medical and homemaking services. Her private homemakers/companions and other home care providers are her only source of social contacts and support.

Data analysis

Recorded data were transcribed verbatim and were organized according to specific emerging themes or ‘meaning units’ (Creswell, 1998). Thematic analysis and interpretation of the data was conducted thorough readings of the transcripts and field notes. Manual methods such as color-coding (using highlighters) and reorganizing of the transcript into categories of emerging themes (using colored post-it notes) were used to manage the data. As noted earlier, a summary of the participant’s context of experiences,
their main concerns and issues was made following each interview. Issues emerged from these analytic notes (e.g. recent cut of homemaking services) were incorporated into the rest of the interviews as appropriate to the individual’s situation. Throughout the period of data collection/interviews and transcription, the data and analytic field notes were reviewed for further emerging themes.

During the period of data analysis, the summaries of the participants’ transcripts, analytic notes, common themes, similarity and differences between their experiences were discussed with my thesis supervisor. Upon approval of the process of analysis, sorting of the data into categories of broad themes and sub-categories of more specific and related themes continued until no further themes emerged. For example, many of the study participants described the home care providers as playing an important role in enabling them to remain in their homes. Some emphasized the role of social support and advocacy of home care professionals in their life. All of the participants discussed their homes, neighborhoods, financial means, social support or lack of social support. Therefore, quotes from each of the transcripts were assigned to broad categories and more specific codes were assigned to statements and phrases related to the categories throughout the transcripts. Following discussion regarding the conceptualization of the findings with my thesis supervisor, the elements of the contexts (their home, neighborhood and community resources including financial means, family/informal or formal support) in which each of the participants experienced home care services were identified and coded. Codes were listed and then were collapsed into sub-categories by grouping similar codes. Larger themes emerged and were organized as a result of this process. Common themes were integrated to reach an overall understanding and
description of the participants’ experiences based on their environmental (physical, social) and economic contexts.

Two main themes and five related themes emerged, which represent the findings of this study, and codes were grouped under each of these themes. The participants’ verbatim quotes were used to illustrate these themes. Those themes that were discussed by the majority of the participants and also the issues that were emphasized more were identified as the central themes of the study. Final changes to the themes were developed during the process of writing the findings and as a result of some of the participants’ feedback.

**Trustworthiness**

To ensure accuracy and credibility, the participants were provided with the opportunity to provide feedback during the analysis phase of the study. The strategies used to ensure the transparency, the merit and the rigor of this study included, but not limited to, researcher reflexivity, peer review, and member checking (Denzin & Lincoln, 2000).

Throughout the research process, peer review was carried out by the members of my thesis committee. They reviewed the first four interview transcripts. All members had expertise in qualitative research and they provided feedback on the content of the interviews. During the period of data analysis, my thesis supervisor and other members of my thesis committee reviewed the preliminary analysis of the data. Similarities and differences of experiences between the study participants as well as emerging themes central to the concerns of the study were discussed with the members of my thesis
committee. Verbatim quotes have been presented throughout the findings section to support the interpretations that have been made. Following discussion of the findings with the members of my thesis committee, additional quotes were added to support the emerging themes that were further developed throughout the period of data collection and analysis.

Member checking was ensured by providing opportunity to all the participants to review and give feedback on how their accounts of their experiences were reflected and interpreted in the study. These participants were encouraged to read copies of their interview transcripts and my preliminary analysis of the data before follow-up telephone calls. Three of the participants agreed to a follow-up telephone call so they could review the draft analysis of the data (their accounts) with me. With their permission, I delivered to them these copies. Their feedback regarding emerging themes and the ways their responses were interpreted were positive and they agreed with the drafted emergent themes. However, they provided more clarification and they further emphasized some of the topics or issues within specific topics. Consequently, I was able to reflect on the participants’ views expressed at this stage and incorporate their feedback into the data analysis. These three participants and the occupational therapists that provided home care services to these individuals asked to receive the final product of this research study. This will be done upon completion of the thesis.

Throughout the research process I was aware of my social position as a middle-class professional woman and how my social position/identity could influence the research process and interpretation of the data. I attempted to maintain this awareness through a continued reflection on my social location and relationship with the
participants. As stated by Mason (1996) “Reflexivity is ensured through the process of turning one’s analytical lens on oneself” (p.151).

As an occupational therapist, I hold certain professional values including the belief that services provided to the individuals must be based on their stated needs according to their values and goals and environmental contexts. These values are congruent with the concept of ‘client-centered’ practice as described in occupational therapy literature. As a woman who values the personal experiences of everyday life as a valuable source of generating knowledge, I was aware of the potential influence of these values on the research process and data analysis. I have worked in an acute hospital with a geriatric population for many years and I have referred many older adults to home care OT. However, much of the feedback that I have received from elderly care recipients and occupational therapists were indicative of the challenges facing the care recipients as well as the therapists. This elicited a desire to further understand the experiences of home care recipients from their standpoint. As I have acquired more academic knowledge about qualitative methodologies, I have not claimed neutrality and instead have reflected on my various positionalities and how these may have influenced or guided data collection, interpretations and my behavior throughout the study. As an occupational therapist with professional experience in the field of home care, I had several assumptions regarding the research findings. For example, that the elderly care recipients view independence as functioning on their own without any help and that environmental, social and economic contexts have significant impact on the elderly care recipients’ experiences of home care. Through continuous reflection on my position as an occupational therapist and focusing more on my role of a qualitative researcher, I was able to challenge my first assumption
as this was not supported by the participants’ transcripts. The second assumption however, was confirmed by the emerging themes.

All of the participants were aware that I was an occupational therapist working for Providence Health Care and that I had no connection to any of the CHC. They all knew that this study was part of my master degree program. They were aware that I was independent from the CHC system and their participation would not have any consequences on their services. However, as an occupational therapist, there was a high possibility that the participants’ would perceive me as an authority figure in the position of power. Consequently, they might have not shared their honest accounts of their experiences or they might have felt that they had to participate in the study. To minimize the effects of this positionality, the letter of invitation to participate in the study were distributed to the prospective participants by CHC occupational therapists. During the initial phase of my encounter with the participants, I reinforced the content of the consent form and emphasized that their participation and feedback would not affect their future home care services. The confidentiality of their identity and information were also emphasized. I believe that most of the participants were eager to share their stories in an attempt to voice their concerns regarding the recent cuts to the health care services and to emphasis the importance of some of the home care services in maintaining them in the community and away from hospitals. Throughout the study, I have attempted to maintain reflexivity and critically examine my role in the research process and how my positioning has influenced and informed the type and quality of data collected and analyzed. A combination of reflexivity, peer review and member checking processes have enhanced the rigor of this study and contributed to the overall trustworthiness of the study. The next
two chapters present the findings of the study comprising the themes which emerged from the participants’ accounts.
Chapter Four: The Importance of Home, Neighborhood and Community Resources

“I can’t survive in nursing home. I’ll die fast, I know myself, so home and living in my home here means staying alive and survival for me. I have everything I need here”.
(Mike)

The main objectives of this study were to gain insight into the care recipients’ experiences of home care OT (particularly home modifications recommended by occupational therapists) and the ways OT home care services have impacted their lives. As the participants reflected on their experiences and shared their stories, it became evident that their experiences and the perceived impact of home care OT services on their life could only be understood in the broader context of their living and housing conditions, particularly their socio-economic status and available community resources.

All of the participants in the study talked about their struggle to maintain their abilities and resources in order to remain in their homes. The participants with low socio-economic status (Mike, Michelle, Rose, Patti and Andrea) emphasized the importance of continued home support services in enabling them to live in their homes and communities. They were all concerned with the recent cuts to home care services and expressed fear regarding loss of their existing home support services.

All the participants identified limited accessibility in their communities and neighborhoods due to environmental barriers as a problem and the increasing impact of these physical environmental barriers on their lives as their disabling conditions progressed. It was evident that their homes and neighborhoods became increasingly important to them. They all expressed that their survival in the community depended on overcoming environmental barriers and having continuous access to home support
services. In this chapter, the participants’ socio-economic status, their living and housing conditions, the extent of their reliance on home support services and renegotiating of the meaning of home and neighborhood will be discussed. It should be emphasized that these issues are interconnected and form the contexts of the participants’ experiences of home care OT services that will be discussed in the next chapter.

Socio-economic status, living and housing conditions

Throughout the interviews, and with the completion of observation of the participants’ living and housing conditions, it became evident that those participants who expressed having limited financial resources and limited or no informal or family support were more dependent on the home care services to “survive” at home. However, among these participants, those with better housing conditions and wheelchair accessible homes were able to do more for themselves and described a better quality of life. This was well illustrated by Mike’s words. He described his home as an accessible well designed home with all of his needed equipment in place. Mike lives alone in a BC housing project for people with disability; his bachelor suite is wheelchair accessible and due to his long-term disabling condition (multiple-sclerosis), Mike has received full coverage of the cost of all the required equipment from the Ministry of Health. He has no family or friends in town and his only source of community support is the home care providers. He described his housing condition as follows:

This building is for seniors but has several floors for handicapped and on this floor all the suites are wheelchair accessible. Stove and sink, cupboard and drawer are low so I can reach them in my wheelchair. There is a walk in shower with grab bars, shower seat, hand shower, toilet railings and frame so I can pull myself up, low sink and taps in the washroom ... and with this set-up, I can live independently on my own with the help of homemakers, I’m comfortable here.
In terms of his financial status and the ability to pay for the equipment he said that without the full coverage of the cost by the ministry, he would not be able to afford them and therefore he would not be able to live “independently” in his home. When asked if he was able to afford the equipment he stated:

Government paid for everything. I was a machinist before becoming handicapped with Multiple Sclerosis, so at fifty years old I had to go under disability pension and now I get Canada Pension. I survive month to month. I can’t afford paying for cable or anything else except rent and food.

As Mike said, access to a well designed wheelchair accessible home with all his needed equipment in place made it possible for him to live a “comfortable and independent” life. However, without full coverage for his equipment he would not have been able to remain in his home. He expressed this clearly when he said, “I have everything I need here. Without these equipment and homemakers I know I would end up in Pearson hospital (care facility)”.  

In comparison to Mike’s home, Rose’s bachelor suite was much smaller and was not wheelchair accessible. Rose also lives alone in a BC housing project for older adults with low income. At the time of the interview, Rose was awaiting approval from Red Cross Aids to Independent Living program (AIL) for a wheelchair as her existing wheelchair was quite worn out and unsafe to take outdoors. Rose, a retired nurse and a resourceful person expressed that she has been successful in improving the physical condition of her home and with few environmental modifications she can do her basic daily tasks independently. Rose expressed gratitude about living independently in her
home for thirty five years and being able to obtain resources to remain in her home as her disabling condition (arthritis and chronic pain) progressed. She said:

I've been in this suite for thirty-five years and there is no way I'm going to move now. But I've burnt myself twice. The old stove was up to here (demonstrating the height of the old stove being beyond her reach); now the caretaker here is marvellous. He saw me one day with my reacher here turning and turning the stove thing...he brought me a stove from the other building for handicapped people and this one has all the dials right on the side and I can just reach out and touch them in my wheelchair...also I couldn't reach the heat thing, I told him...and he got the engineer and electrician and they came and this is what they did (pointing to the heat control unit). I can reach it as I go by in my wheelchair.

However, it should be noted that except for these changes the rest of Rose’s small suite was not wheelchair accessible although due to chronic pain and poor mobility, Rose uses a wheelchair consistently. As she mentioned throughout the interview, Rose spends most of her waking hours in her wheelchair but she is able to transfer independently to her chair, bed and toilet with grab bars and she is able to stand for a few minutes at a time. Rose explained that the kitchen cabinets, refrigerator and sink are not wheelchair accessible and if objects and/or items are not placed within her reach on the counter or on the lower shelves of the fridge then she has to wait for homemakers to assist her with reaching and doing tasks in the kitchen.

In terms of financial status, Rose explained that she does not have “extra money” to pay for the wheelchair prescribed by the OT and she has to wait for approval from the Red Cross Aids to Independent Living (AIL) program. She further identified that she is dependent on government and aid agencies for her required equipment and the waitlist has been a limiting factor for her as she cannot go outdoors and she has been experiencing increased shoulder pain because of her increased difficulty with moving her
existing “heavy and worn out” wheelchair. Rose explained that her sources of income are old age pension, Canada Pension Plan and Guaranteed Annual Income supplement and that her monthly income covers only her basic needs including her rent, bills, food and her medications. Rose reported that some of her essential medications (non-generic) are not covered by Health Canada and therefore she spends a big portion of her income on medications. She expressed that she does not have “extra money” or family support to be able to pay for her needed equipment or hire private home help. She explained:

These equipment were covered by I think, they call it long-term disability insurance plan that I’ve got. Every time I get my statement from the bank, I look to see if the income cheques have come up but no it hasn’t happened yet...I worked hard when I worked. I worked double shift, I worked overtime. I was there like a bunny when there was a need...now I have to wait for everything.

Despite the fact that the extent of Rose’s physical disability was much less than Mike’s disability, it was evident that his housing condition and resources provided him with a more comfortable home tailored to his needs and limitations. As Mike said, despite his severe physical disability, his accessible home, assistive equipment and the help of daily homemakers made it possible for him to do most of his daily tasks on his own. In comparison to Rose’s case, Mike reported more comfort and satisfaction with his home.

Similar to Mike and Rose, Patti also lives alone in a BC housing project, in a small one bedroom suite. She uses a walker inside her home and scooter for outdoor mobility. Patti’s suite is not wheelchair accessible and her walker, oxygen tank, scooter and footrest occupied most of her living space. Patti explained that the equipment prescribed by the occupational therapist made her life easier and more manageable. However, at the time of the interview she was also awaiting approval from the Ministry of Health for a “better” scooter prescribed by the occupational therapist. Similar to Mike
and Rose, Patti also reported low income and being dependent on aid agencies and government for funding of her needed equipment and home support services. Patti said that she feels comfortable at her home with her existing set up and home care support services. She said, “I am comfortable here and as long as I could I keep doing as much as I can for myself, when I am in trouble, they (home care providers) help me and that’s why I am coping”.

When talking about her financial means she said:

The Ministry of Health in Victoria paid for the equipment. Christine (the occupational therapist) did the application and paper work. I am considered as senior with low income, I only get old age pension...it’s (the scooter) the extension of my legs...I used to go all the way to my lung doctor...but not anymore because it’s older now, it doesn’t go that far anymore.

Patti identified that despite her financial limitation and her physical limitation, she was managing to live “independently” at her home and that she would be able to continue do so with the help of home care providers and the existing community resources available to her.

Among the participants with low income, Michelle reported very limited financial means. This was evident through observation of her living space. Michelle lives with her elderly husband and an adult son who has a mental disability in a small two-storey town house in a BC housing project in Vancouver downtown east side. Michelle mentioned that she moved to Vancouver from the First Nation reserve lands of northern BC with her family when their kids were small. Michelle’s home was small, not wheelchair accessible and bedrooms were located upstairs. Due to her poor mobility, Michelle is unable to ascend or descend stairs and consequently she sleeps on the sofa in her living room. Their space was small, cluttered (due to lack of storage space) and there was limited natural
light. Their furniture was worn out and took most of their living space. Michelle talked about the overall poor condition of her home and their inability to look after the household tasks due to her own and her husband’s weakness and frailty. She also talked about their limited resources and financial means to be able to get new household items and improve their living condition. She explained her situation with these words:

I just need more help at home. Nobody can clean here or help me with my washing. I’m very weak and can’t walk much any more. I don’t go anywhere; I just stay here on this sofa; it’s low and it’s hard to get up from it but that’s all I have. But I like it here; we are used to it (her home and neighbourhood). She (occupational therapist) is trying to get me a wheelchair so that I could go out with my family.

In terms of their financial means, she said:

Since we moved out of the reserve, we don’t get anything from our Band. So it’s just with our Care Card. I didn’t have money for wheelchair or other things so she (occupational therapist) got them for me through Health Canada and Red Cross. My older son...helps with cash money whenever he sells his artwork. The others can’t help; they don’t have a lot of money. So it’s hard to get by sometimes.

Similarly, Andrea expressed concern regarding her financial abilities. At the time of interview she was also awaiting approval for a motorised wheelchair prescribed by the occupational therapist to enable her to sit upright and to do short outdoor trips. As is evident by Andrea’s words, she is also dependent on aid and government agencies for the funding of her needed equipment and home support services. She stated, “I have to get special coverage because I’m on old age pension now...things have changed, it takes longer to get things passed for approval”. However, in contrast to Michelle’s home setting, Andrea’s home is wheelchair accessible, large and bright with most of her needed equipment in place. Andrea expressed more comfort and satisfaction with her housing
condition. As mentioned earlier, she lives alone in a large, bright and spacious one bedroom wheelchair accessible townhouse in a co-op housing complex. Despite her chronic disabling condition of cerebral palsy since birth, Andrea has been able to finish university education and work as a social worker for few years. She considers herself a resourceful person who has been able to stay informed, obtain resources (appropriate housing), fulfill her needs and be a “survivor”. This was evident when she said:

As I got older and weaker I moved to this Co-op. They don’t allow animals in senior housing, they didn’t at the time, I will not give up my cat, but this co-op allows that. This is the best unit in the whole coop and it was designed for handicapped person...the whole coop as a whole is accessible...there are ramps to go down to lower level and there is an elevator as well, so I can get into and visit somebody which is nice.

Similar to Mike’s case, despite Andrea’s severe physical disability, she was comfortable at her home. She had most of her needed equipment and daily home support services in place at home. She emphasised that with the help of homemakers and her accessible home, she would be able to remain in her home for the remaining days of her life. She said:

I have pericare twice a day and usually I get up in my wheelchair and when the person (homemaker) comes in the afternoon I usually get back to bed...it (ceiling lift) is wonderful because nobody needs to take any weight. So this is a very well designed Co-op...I feel at home and very comfortable here.

The rest of the participants; Ken, Ron and Cameron identified themselves as having an average income (middle class families) with the exception of Melissa who obviously has above average financial means. Melissa lives in her own big house in the affluent Vancouver west side district with private twenty-four hour home support services. This group of participants did not express much concern about their financial
means. They all reported comfortable lives at home. Ken and Ron both live in spacious and modern homes in two different Co-op housing complexes. Ken lives alone in a one-bedroom townhouse and he reported that the Department of Veteran Affairs (DVA) covered all of the cost of his needed equipment and provided him with homemaking services. He emphasised that these resources and his modern and comfortable home made it possible for him to remain in his home despite his poor mobility and decreased ability to do his daily tasks at home. Ken talked about his two daughters who live close by in the neighbourhood, saying that they are very supportive and helpful and their support makes it easier for him to function in the community. He stated:

I like it here, everything is close, my kids are also close to me and they visit me...I can move in here much better (compare to his old house with lots of stairs), everything is on one level...I can go out with my wheelchair because there are ramps around...I’ve got everything; a bath lift, grab bars, special mat and chair...I was qualified for the equipment, which she (occupational therapist) helped us to get. My kids are close to me and they often visit me...so I can cope with my problems.

In terms of financial means, at the time of the interview, Ken did not express significant concern about his ability to cope on his own. However, he did articulate concern regarding the possibility of requiring increased home support services as his condition deteriorates. Ken had a history of strokes and experiences significant one-sided weakness, poor balance and impaired mobility. He relied heavily on the support of his daughters and homemakers provided by the DVA to live “independently” at home. He expressed gratitude about the DVA funding and services when he said:

Lyn (occupational therapist) organised everything. They (DVA) paid for everything...when homemakers are here and they have time to take me out, I go out...it’s nice but without the homemakers I know I won’t be able to do that.
Ron is also a DVA client but he lives with his wife in a modern, large and bright one-bed room apartment in Co-op housing. Ron has a heart condition and has a pacemaker, diabetes and arthritis so his endurance is low and he has “good days and bad days”. However, he is able to mobilise independently without any mobility aids indoors and with a walker for outdoor mobility. He also has the support of his daughter who lives close to them and assists them as needed. Ron explained that he needed DVA funding for the prescribed equipment (scooter, walker and bathroom safety devices) but in terms of home support services, he stated that the assistance of his wife, daughter and family is enough. Therefore, he does not rely on formal homemaking services. He emphasised this when he said:

We try to be as independent as we can. It may take us a while but we get them done and we don’t need outside help, not at the moment...I want to be as reliant as possible on myself...but I have to get my diabetic syringes filled and I get my daughter to do them once a month.

In terms of his home setting and condition he said:

We are happy here, my daughter lives close by...I have everything I need, we like it here. Our grandchildren coming around and great grand children coming around on weekends, which is great.

Among this group of participants with an average income and “ok” financial means, Cameron is the only one who lives in a private (home) facility with meals, cleaning and transportation services available to him. This is an assisted living facility in Burnaby. It has to be noted that residents of an assisted living facility must be independent with their activities of daily living and their personal hygiene tasks. Cameron has a chronic heart condition, prostate cancer and hip joint arthritis but he mobilises independently with a cane and he is independent with his daily tasks. His wife lives in a
nursing home due to severe Alzheimer’s disease. He is also a DVA client. However, he mentioned that he has enough money to afford his place (private facility) and the prescribed equipment and he also has financial support from his son and daughter. Therefore, he did not have to wait for DVA funding. When asked about funding he said:

I pay fifteen hundred dollars a month and for this amount, food and cleaning services are included; it’s cheaper than owning a house. They call it independent living senior complex...I can manage here and I’m close to my family, so it’s ok...my son dealt with the cost, it wasn’t much for us...we didn’t bother with getting funding.

In terms of housing condition, Cameron’s bachelor suite was furnished with good quality items such as a high bed, sofa, armchair and all the necessary appliances including dishwasher and microwave. His bathroom was equipped with grab bars, bath chair, non-slip mat and raised toilet seat. He has access to a call bell for emergency management with twenty-four hour nursing services available in his home facility. Cameron sold his “big house” in Kelowna and moved to this facility a year ago after his wife was placed in a nursing home in PortCoquitlam close to where his daughter lives. He stated he is comfortable in his new home but he also mentioned that the main reason for his move was “to be closer” to his “kids and wife” as he said, “it’s no problem for me to live here...I’m used to it now. Services is sufficient”. His analogy of his new living condition was “it’s like living in a hotel”.

As noted earlier, among this group of participants, Melissa was the only one who lives in her own big house in an affluent area of Vancouver. She is a retired community health nurse with no family in Vancouver, but has a private twenty-four hour live-in home support worker. She experiences severe Parkinson’s symptoms including hand tremor and poor mobility and balance. Throughout the interview, Melissa emphasised the
importance of mobility aids and equipment prescribed by the occupational therapist and
the help of home support workers in enabling her to remain in her beautiful home.

Melissa’s house is spacious with good natural light. Glass windows with a very beautiful
view of mountain and the city cover the balcony on the north side of her living room. She
has a lift chair, wheeled walker; handrails by her bed and by the doorknobs, commode in
her bedroom and all of her needed safety equipment in the bathroom. She was very proud
of being able to live in her home despite her severe physical disability. This was evident
by her words:

I am progressively getting to the late life stage. I am at the late life stage of
Parkinson’s now...and of course now I’m not able to do as much as I used
to...this lift chair, I press the button and there it goes and I’m able to get up...at
night the commode is specially most helpful...now I can’t do without my walker,
I hold onto it with my dear life. It’s a great thing...and then I have adjustments
(safety equipment) in the bathroom and I have bars on my doors so I can hold on
and get through...but I need personal care, I have help so I’m managing quite
well...and I live independent but you know I have to be dependent on a lot of
people to be independent, I’m happy and that’s the main thing. At least that’s the
way I feel. I am happy about what I’ve achieved and I’m proud that I’ve saved for
my old age.

All the participants of the study identified the importance of home care OT
services (in varying degree) in enabling them to function at their highest possible capacity
and to remain in their homes. The following section describes the participants’ reliance
on home care services and community resources.

Reliance on home care services and community resources

Most of the participants said that they benefited from occupational therapy
services and were able to do better with the prescribed equipment and home
modifications but, in addition to OT services, they all clearly emphasised their increasing
need of home making services to remain at their homes. Throughout the interviews, as the participants shared their stories, it became evident that those participants with limited financial means and family support were most dependent on the home care services including OT and homemaking services. All the participants talked about the importance of home care OT intervention, particularly the role of OTs in providing mobility aids and safety interventions at home. However, it became evident that as the participants' conditions deteriorated their reliance on other home care services, particularly homemaking services continued to increase.

Among the participants with low socio-economic status, Mike, Andrea and Rose were the most dependent on the long-term home care services. These participants experience chronic deteriorating conditions. They have no informal or family social support. The above participants expressed significant concern about the recent cut of home care services. These participants expressed significant fear of further loss of home support services, particularly homemaking services and consequent inability to cope. This fear is illustrated by Mike’s words:

To live on my own I need the help of homemakers more than anything else because they change my bedding, clothing and shower me and put my eye drop...I’m getting worse with my allergy because homemakers used to mop the floor and do dusting every week but with the new system, homemakers can’t mop the floor anymore so my allergy is bad. I get worry because if I don’t see well, I’m afraid that I won’t be able to cope, without them it is not possible for me to live, they are very important for my survival.

Andrea expressed similar concerns when she said:

Everything was pretty well covered...to the present provincial government that keep wanting to trim services back. You have to put a good fight to get things...because of my condition, I don’t think that I lose my hours of homemaking...but I need... pericare twice a day, these girls (homemakers) are
marvellous and take everything with stride so I try to not...make it more difficult for me and the homemakers.

Even though Rose’s extent of disability was less than Mike and Andrea, she was also very dependent on home care services and she particularly emphasised her need of homemaking services. She expressed a great deal of fear and anxiety regarding the recent cut of her homemaking hours when she said:

I find if I try to hurry, I’m afraid I’m going to have an accident. I’m going to fall; I’ve done it. So I have to take my own time...this is what the homemaker people who sit behind the desk...have no idea and they try to run my life...they think I just go in there (the tub) and the girl helps me and pull me back within two minutes. It takes me twenty minutes to get into the bath tub, let alone have a bath...they don’t understand that every move I make hurts...they cut me back now, they taken half an hour of Wednesday and half an hour of Friday...what they can you do in an hour, it’s an awful squeeze. If only they left it the way it was.

Among the participants with low socio-economic status, Patti and Michelle also expressed some concern regarding the recent cut of homemaking services. However, Michelle also relied on her husband in assisting her with daily tasks and even though Patti has no family to rely on, she has a circle of close friends who visit her and help her with tasks such as shopping. It was clear that to some extent these informal social supports contributed to their management at home. In this regard Patti said:

I have no family that could help me. They’ve all got their own problems...I have friends in the building and the neighbourhood...if something happens they would come...I have to tell you that from when Christine (the occupational therapist) and home support workers started to come here and help me to cope, I don’t have to go to hospital (as often as) before...so I think these people (home care providers) save the health care and government money and also help people with disability to live a better life.
Michelle’s main concern was the fact that due to limited homemaking support and recent cuts, her frail elderly husband has assumed the role of caregiver for her and their adult son with mental disability. Michelle’s worry was evident by her words:

My husband used to get some help for him when he came out of hospital but they stopped it and they said that he could walk so he doesn’t need it. But he is very sick, he walks slowly. He has to do it because we don’t have enough help. They shouldn’t take my husband’s help, since then we are worse, I’m worse.

Among the participants with average income and financial means, Ken was the only one who mentioned some degree of dependence on the formal homemaking services provided to him by the DVA. He talked about the support of his two daughters and in addition, the role of homemakers in maintaining him in his home when he said:

Last summer up to Christmas I was falling whenever I tried to get up and walk, my kids thought that I had to go and live in a nursing home... But I manage better with these (equipment) but of course I have homemakers...they help me with things that I need every day...so with their help I can walk again and hopefully get better. Without them and this equipment I wouldn’t be able to live on my own.

In comparison, Ron another DVA client expressed that he doesn’t want the formal homemaking services because he is able to manage with the help of his wife and daughter. When asked about home support services, he said, “We are managing ok so far. We try to be as independent as we can. A lot of things that get done here, my daughter does them”.

Cameron’s ability to pay for his private living arrangement (assisted living facility) and his ability to mobilise and do his daily tasks independently has made it possible for him to not be dependent on homemaking services. Throughout the interview, Cameron talked about the fact that, in addition to his own income and financial means, he
has the financial support of his son and daughter. As it was noted earlier, his son paid for the required equipment and he didn’t have to wait for the process of approval by DVA.

In the case of Melissa, despite the fact that she has no informal or family support and experiences severe physical limitation due to the end stage Parkinson’s disease, she is not dependent on the home care system for her needed home support services. Melissa’s financial means has enabled her to hire private homemakers to assist her on a twenty-four hour basis in her home. However, being a retired community nurse who worked for twenty-five years, she expressed her opinion about the recent cuts to home care services when she said:

They say this is cut and that is cut now but I have to say even with all the cuts because I’m in the position that I’m able to carry on and meet my needs but now that Mr. Campbell (the premier of British Columbia), he takes it all away from us, I can still manage but anyway God loves him. I feel very sorry for those seniors who live on low income and it’s a crime to cut from their services.

All of the participants, regardless of their socio-economic status, emphasised the importance of living “independently” on their own and at “home”. However, as the participants described their feeling about their homes and what home means to them, it became evident that as their conditions deteriorated over time, they renegotiated the meanings of home and neighbourhood. Most of the participants discussed the growing importance of their home setting and the ability to access their neighbourhood and community resources. These issues are discussed in next section.
Renegotiating the Meanings of Home and Neighbourhood

For the majority of the participants, home was not merely a dwelling anymore but a place for receiving health and personal care, a place to socialise, to be “independent”, to be “free” and comfortable, to belong, to be close to family, to have peace and privacy and mostly, as emphasised by all the participants of the study, home was a place to live that was not in a nursing home. As the participants talked about their homes, it became evident that they renegotiated the meaning of their homes.

At the same time as the participants’ experiences of physical disability increased, the physical features of their homes and neighbourhood and particularly environmental accessibility became increasingly significant to them. It became evident that as participants’ physical disability increased, they began to come to terms with the realities of their disability. They not only accepted most of the suggested home modifications but they all talked about the accessible features of their homes with pride and gratitude. For example Andrea said:

First I got motorised wheelchair and at that time I lived in a condo...OT made some recommendations about structural changes in my condo but...I felt that I didn’t need the wheelchair then. I felt that I was strong enough to mobilise with regular wheelchair...but I don’t think I can do that now...I had to give them permission to put one (ceiling lift) here because I was unable to transfer to my wheelchair.

Andrea also talked about her homemakers and how important they are in maintaining her at home. She expressed high regard for them and their job and the fact that she has to make sure that they are comfortable in her setting and she has to make sure to “not make it hard for them”. In this regard she said:

The OT recommended a cushion to be placed on the side to keep my legs from going out this way. It was hard to do and took me a long time to
do...because somebody has to do these things and if they don’t do it or...which makes life harder sometimes.... so I try to not have new changes that would make it more difficult for me and the homemakers.

When she was asked about the meaning of “home”, she talked about the accessibility of her home and took pride in being resourceful and successful in obtaining the “best unit in the whole Co-op” and the fact that “it was designed for handicapped person”. She talked about how the ceiling lifts make her life and the homemakers’ job easier. At the time of interview, Andrea highly valued the accessibility aspect of her home and she also expressed a sense of belonging to her community. She mentioned that she was a member on the board of directors for a few years and talked about the positive aspects of Co-op living. This was evident by her words as she said:

So this is a very well designed Co-op and if there is anything that needs to be done, people are very good about giving attention to the disabled people regardless of what the handicap is...I have been told that several blind people also live here, I know one lady with the dog. So from that point of view, I feel at home and very comfortable here in the Co-op and among these people.

As the participants’ mobility decreased, the importance of accessibility and resources in their neighbourhood increased. Seven out of nine participants emphasised the importance of the Handy Dart transportation services. The majority of the participants talked about the importance of ramps and avoiding environmental barriers when moving about outdoors. Some of the participants described their increasing difficulty in coping with the limited access to resources in their neighbourhood as their conditions deteriorated. Andrea expressed this point as she said:
I didn’t realise when I moved in that I am essentially a long way from shopping centre or stores in general. I have to go with handy-dart bus virtually anywhere I want to go...I never take the sky train or any other public transit, it’s difficult to use them as I need help into and out of them...I could zip around on Granville in my wheelchair (in her old neighbourhood where she was close to stores and other resources such as bank, health clinic and community centre).

Many participants expressed a sense of belonging to their communities and it was evident that they felt increasingly comfortable among people with similar conditions or limitations. For example, Patti has many friends in the building who use a scooter for outdoor mobility and they often visit Patti in her suite. She also talked about her increasing difficulty with outdoor mobility. In comparison to the past, she described how important it is to be close to amenities in her neighbourhood because she can’t travel long distances anymore. She stated:

I like the neighbourhood; I’ve been in this neighbourhood for about thirty-seven years. This project was built with people pressuring government for affordable housing...we made a lot of noise which was a good thing so they started to build these projects...when they finished this one, there was not even one tree, so people keep after them and got together and asked for these small gardens...we used to sit here or there (on the benches throughout the housing project) and visit this one and that one so we want to be able to do that again”.

When asked about the meaning of the “home”, Andrea, Patti, Mike, Ken, Ron and Melissa all expressed strong feeling about being at home and according to these participants that meant avoiding nursing home admission. Home meant “freedom” and the alternative to institutional living. Patti clearly expressed her feeling about her home with these words:

It (home) means my freedom, if I was in long-term care or nursing home, I know I would have give up, I’ve given up already a lot of my
Home as a Place for Providing Health Care

freedom...I'm happy that I've got a place to live and I'm comfortable here.

In response to what would she change (if anything) about her home and neighbourhood, she talked about poor amenities in her neighbourhood when she said:

We used to have benches around (outdoors, in the neighbourhood) so when people get tired of walking around they could rest and visit each other in the yard but because of homeless sleeping on the benches, they took them away...but people are asking for built-in stools or chairs...because we need something to rest on, specially older and disabled...a few more vegetable stores and grocery shops close by in the neighbourhood because it's getting hard to drive to commercial drive for small things.

Mike's home also meant his freedom and survival to him. He expressed himself with these strong words:

I like to live by myself, I hate noise and I can't live in a nursing home, I know I won't survive...I'm comfortable here...I can't survive in a nursing home. I'll die fast, I know myself, so home and living in my home here means staying alive and survival for me.

He also talked about other factors that enabled him to live "at home". He was very appreciative of services that he has been receiving in his home. He particularly was happy about the OT recommendation to move from his old apartment to his current wheelchair accessible suite. He said:

But moving here was a good recommendation, I have everything I need here. It's a good home for me. I know that I can help myself better in here than anybody else. Without these equipment and homemakers I know I would end up in Pearson Hospital (subsidised facility).
Similarly Ken saw his recent move from his old house to his current rented town house as an alternative to living in a nursing home. He talked about issues such as environmental accessibility, being on his own, in control and close to his family when he talked about his home and said:

Last summer up to Christmas I was falling whenever I tried to get up and walk, my kids thought that I had to go and live in a nursing home...so now I got a bath lift, grab bars...I’m able to get out of tub without falling. I sold my house when my wife passed away. I couldn’t stay there...I found out that I couldn’t do stairs...and moved in here...I can move in here much better, everything is on one level and there is no stairs. So home for me is a place that I could be comfortable and cope with my problems. It’s my shelter, I can be on my own boss here...I like it here, everything is close, and my kids are close to me.

In terms of his current neighbourhood, he emphasised the environmental accessibility when he said, “I can go out with my wheelchair because there are ramps around here and the Champlain Mall is flat and I can get in there easy”.

Rose, a resourceful woman with a strong personality, talked about how important it is to have control over her life despite the fact that she needs help to remain at her home. She talked about her home with pride and expressed a sense of belonging when she said:

I’ve been in this suite for thirty-five years, and there is no way I’m going to move now. The only way I’m going out is feet first, I’m staying put...I have to do it my way (doing daily tasks at home with the help of homemakers) and that’s the only way I can do it and if you (referring to some of her previous homemakers) don’t like it, don’t come around.

Rose explained how she helped one of her neighbours who needed urgent medical attention using her lifeline services (emergency management services in lower mainland). She also offered another neighbour her own walker that she was
not using anymore and in return the neighbour brought her fresh vegetables from her garden. She talked about helping her neighbours with a sense of belonging in her community/neighbourhood. This was evident through such statements as, “I was so mad because the walker was sitting here and I knew that there are people out here who would need it” or when she said:

I couldn’t just come back home and not doing anything knowing that (the neighbour needing immediate help), I couldn’t slept that night if that man couldn’t get help...this is a place for older people who don’t have high income, so it’s quiet and I like it here.

Both Ron and Michelle focused on their family as their main support and for them ‘home’ meant to live with their spouses and being close to the rest of their family. For example, Ron said, “We are happy here. I have everything I need...I don’t think I want to live in nursing home. I think I would be missing my family” or when Michelle said, “we are used to it (their home and neighbourhood), I like it here...my kids come once in a while when they can”.

She also expressed a sense of belonging to her neighbourhood when she said, “we’re close to cheap shops and stores and Indian community centre and my church is not far from here”.

Melissa expressed a strong feeling of pride in her home and her ability to remain in her home and avoid nursing home/ institutional living despite her severe physical disability. She said:

It (home) means everything, I live independent. I’m happy and that’s the main thing...I can’t sleep very well at night and can’t get up on my own anymore, before I was able to get up and walk around but now home support workers help me do that. Now, could you have that in a nursing home? Of course not...I am sitting here like the queen of Sheba and to the certain extent I am pretty proud...it’s so important for me to feel
comfortable in my own home. I mean it is nothing worse than taking you out of your surroundings.

As mentioned earlier, Cameron was the only participant who lives in a private assisted living facility. Similar to Ken, Cameron talked about his recent move from his own house in Kelowna to the private facility to be close to his children and wife who lives in a nursing home in PortCoquitlam. As Cameron shared his story, it became evident that he did not have strong feelings or attachment to his new home but he described how he was adjusting to the transition and having his daily needs met. In response to what his home and neighbourhood means to him, he responded:

Well this is the only home I've got now...I moved out here a year ago to be close to my kids and my wife...I tell you the truth, I look at it like this; it's just right for one person...at first I didn't like it but I realise that nobody bothers me here...I can manage here and I'm close to my family so it's ok.

However, Cameron stated that, in his current setting, he has the opportunity to socialize with interesting people and at the same time have the freedom to leave the facility (his home) for any length of time as he wishes. In this regard, he said:

I talk to people who are coming from different places, people who work here or live in this place. I mean I like to socialise with people and I can do that here...this is different from nursing home though; in nursing home you would be more disciplined. I believe there are more people there to make sure you are in line...here you have more individual freedom. For example, if tomorrow I want to go to Alaska on a cruise ship, it's my business.
In terms of neighbourhood, Cameron was the only one who did not express a sense of belonging when he said:

To tell you the truth, the neighbourhood here means nothing to me because I have no contact what so ever with anyone so called neighbours but the people in here, I know a lot of them...I mean, if you’re going to volunteer (moving to a facility voluntarily), you got yourself to thank for whatever you’re facing. So it’s the same thing here, I don’t complaint.

The participants with a higher socio-economic status or family support reported to be less dependent on home care support services. As these participants lived in neighbourhoods with less environmental barriers, they experienced less limitation as their disability progressed. In comparison, those participants with low socio-economic status reported relying on formal home care services. In addition, these participants lived in the neighbourhoods with more limited resources and a higher degree of environmental barriers such as lack of ramps or poor architectural design of their homes. As a result, they had more difficulty coping with these barriers as their disabling conditions progressed. However, among this group of participants, those who had access to funding and wheelchair accessible homes reported a better quality of life and more “independence” at home. In the next chapter I will describe how the participants experienced OT interventions in their homes.
Chapter five: The Experience of Home Care Occupational Therapy

“She understands and knows how to help me to live independently. She knows how important it is for me to live independently and over years had helped me to cope with MS… with these equipment, I can do these things and I can live by myself” (Mike)

All of the participants of the study reported having a positive experience of occupational therapy services. The majority of the participants talked about the impact of OT interventions in enabling them to function better at their homes. However, depending on each of the individual’s contexts, some participants emphasised OT services more than others. For example, Mike, Andrea, Melissa, Rose, Patti and Ken had extensive and continued OT involvement as their disability progressed. These participants reported great benefit from home care OT services. In comparison, Cameron, Ron and Michelle (despite her severe frailty) had less OT involvement. These participants needed fewer OT equipment recommendations and interventions, and consequently they reported less benefit from OT services. The participants of the study described varying degrees of impact of OT services, particularly home modifications on their daily lives.

Impact of OT services, in particular, home modifications on daily life

As the participants shared their stories throughout the interviews, it became evident that those participants with severe physical limitation (Mike, Andrea, Melissa, Patti, Rose and Ken), regardless of their financial abilities, have greatly benefited from home care occupational therapy services, particularly OT
interventions with a focus on home modifications and equipment. These interventions played an important role in the participants’ daily functioning. For example, in response to the question regarding the impact of OT services on his daily life, Mike stated:

I had a lot of problem getting up to position but after Avril (OT) gave me this bed and bed rails and the pole, now I can position myself on my own. With this equipment, I can do these things and I can live by myself. So everything has been positive for me so far.

In the case of Andrea, even though in the past she had not taken all the “OT recommendations word by word” she still talked about the positive impact of equipment and home modification on her daily functioning in recent years as her disability progressed. She said:

I fell off my wheelchair...so I hurt my knee and I spent the night dragging myself to the front door so I could call for help, that took me all night (big sigh) and then I got the bed moved into here (living room) and I had to give them permission to put one (ceiling lift) here (above her bed in the living room) because I was unable to transfer to my wheelchair. That was when the OT got involved and came to see me...it (her current wheelchair) is old, so I agreed to get a new wheelchair she (OT) recommended, it is in the process.

As an individual with Cerebral Palsy, Andrea had been involved with occupational therapy and other rehabilitation services throughout her life. During the interview, Andrea challenged the medical model of practice of health professionals including some of the OTs she encountered throughout her life. She criticized the way in which some practitioners view the body of disabled person as an object to be fixed when she said:

I had therapy and all sort of stuff as a child. I have been through it all my life. You know, so I am very glad now that I am a senior citizen, people don’t come dash in and say oh, here is a body we could do something for. No
thanks, no need to do that, but I think they (most of OTs) understand when people want to do their own thing... So it is the attitude of people that is hard to deal with and not the physical problem.

However, Andrea also talked about how she has come to terms with her increasing disability as she is getting older. She expressed the positive impact of recent OT involvement with her management at home when she said, “I think on the whole, my experience specially recently with Claudette (the OT) has been very good…very positive”. Furthermore, she talked about the motorised wheelchair that has been recommended by the OT and how the new wheelchair may improve her sitting tolerance and her ability to do some outings.

Patti also talked about the positive impact of OT services on her life. She expressed high regard for the OT who provided her with her needed equipment and “made her life easier at home”. She said:

Christine (OT) has been really good for me. She had them (a medical supplier) put blocks on my bed so that I can get in and out of bed easier, raised it…she also put a bar in the bathroom…to get on and off the bathtub and she put in a seat to extend the sitting area so I don’t have to bend my knees so far…these are really good, they save me my energy to get in and out.

Patti emphasised the fact that, since OT involvement and with the help of homemakers, she has had far fewer hospitalisations. She discussed the importance of home care including OT services in prevention of recurrent hospitalisations of people with chronic conditions and how this will “save the health care system money in long run”.

Similar to Andrea, Rose also has chosen to select and accept the OT recommendations that she has felt to be appropriate for her. For example, she told a
story regarding one of the OT recommendations that she was not willing to accept.

She said:

One thing that she told me, “If it’s too hard to work the wheelchair, I got one solution” and I said, oh...she said, “take off your carpet”. I said no...there is no dam way I’m going to do that...but we joke about it every time she phones me.

At the same time, Rose acknowledged the positive impact of other OT interventions, particularly the equipment that she has found to be valuable with her daily functioning. She expressed this point with these words:

She (OT) made life liveable for me. She got me the bed, she got me the wheelchair...this cushion, I never could get my back up against it (her old wheelchair cushion)...I sat on this, oh boy, that feels good. She put the wooden platform under the chair so makes the chair the same height as my wheelchair and then I could transfer. You know, little things like that ...make an awful difference. She has my name on the list for a new wheelchair...

Both Melissa and Ken talked about the importance of their safety equipment such as bath lift, chair lift and grab bars in keeping them safer at home and consequently they have been experiencing a better quality of life. Ken talked about how the move to his current home improved his mobility because he has no stairs to climb and also he has a ramp outside that was recommended by the OT. Similarly, Melissa talked about the fact that she has been experiencing less difficulty with transferring out of her chair because she has got a chair lift recommended by her home care OT. In response to the question about the impact (if any) of OT recommended home modifications, Melissa stated:

I am progressively getting to the late life stage...I can’t get up, they (OTs) got me this lift chair so I press the button and there it goes the chair and I’m able to get up and so especially at night, it’s most helpful...I can’t do without my
walker. I hold onto it with my dear life, it’s a great thing...and then I have adjustments in the bathroom...bars on my doors so I can hold on and get through ...I’ve had great services ...it makes you feel wonderful...they had absolutely positive impact on me.

Michelle expressed appreciation for the home care professionals and as a retired public nurse, she believed in the professional expertise when she said, “I welcome all of these suggestions you see, they are well trained people... I am a retired public health nurse and I welcome their suggestions, they’re valuable people”.

Ken also was very appreciative of the OT services and talked about the OT, who assisted him to obtain his needed equipment, with a great deal of respect. This was evident through his words:

I felt gratified because the person knew what she was doing...now I’m able to take bath and get out of tub without falling...she (OT) put a ramp out side the door so now I can go out in my wheelchair...I am very happy with what she did for me...I have a lot of respect for Lyn (the OT) and her knowledge. It has been very useful to me. I had a talk with her one day and she gets things only if you want them so she’s been respectful.

Among this group of the study participants (with severe disability and /or poor mobility) Michelle was the only one who did not report significant impact of OT interventions on her daily life. Instead, she focused on her family’s need of homemaking services and the negative impact of the recent cut of their home making services on her husband’s health. She briefly talked about OT intervention when she said:

It has been good but I can’t use the walker any more. I’m weak so it’s just sitting here. The wheelchair outside is from I think Red Cross but it’s hard to push it so she (OT) will get a better one so...I could go out with my family.
All of these participants discussed the positive impact of OT intervention, particularly home modification in combination with safety and/or mobility aids and equipment. At the same time, they emphasised their continued need for home support/homemaking services to be able to live “independently” at home. As they shared their stories, it became evident that initially, they had extensive involvement with OT. The focus of OT intervention was on the acquisition of equipment and in-home changes in order to improve the participants’ safety and function at home. By the time these interventions were completed, and as the participants’ conditions deteriorated further, their need for OT involvement decreased. On the other hand, at this stage of their life, they emphasised their need for home support/making services to be able to function safely at home.

In comparison to the above participants, Ron and Cameron were more mobile (they were walking indoors without use of any walking aids) and they needed minimal equipment at home. Therefore, they had only a few visits from home care OT. Both of them expressed satisfaction with OT services. However, in respond to the question of the impact of OT services on their daily life, they focused on their living arrangements and their social support. For example, Ron focused on his wife and daughter’s help and Cameron focused on the services available to him by the staff at the facility where he lives. In this regard, Ron said, “I was very satisfied with what she did totally. It all been good and helpful to me and my wife”. Similarly, Cameron expressed satisfaction with OT intervention when he said:

She explained what would make it easier for me and helped me to get the things that I needed, well there was no forcing involved. I mean, she is doing something for me and so I got the shower chair, grab bar...eventually I
bought a couple of the things that was working for me...I liked all of her recommendations.

The majority of the participants of the study talked about other roles that home care occupational therapists played in their lives. For many, home care occupational therapists provided social support or they acted as a valuable source of knowledge and information or as advocates. In the following section, these roles of occupational therapists will be discussed from the participants’ standpoint.

**OTs as advocates, source of knowledge and social support**

As the participants shared their accounts of their experiences of home care OT, they discussed how their therapists informed them about the resources that they have benefited from in recent years. Many reported that the OTs advocated on their behalf to obtain their needed equipment through government and/or aid agencies. Most of the participants talked about the social role of OTs throughout their interviews. Those participants who had more extensive OT involvement over a longer period of time (Mike, Andrea, Patti, Rose and Melissa) talked about the various roles played by the OTs. For example, Mike talked about how the OT informed him about resources that he didn’t know about and how she advocated on his behalf to get him the needed equipment and resources when he said:

Avril (OT) knows me for five years now. She helped me to get all these equipment...she recommended for me to move from the next door building...to this building...on this floor all the suite are wheelchair accessible...with this set-up I can live on my own with the help of homemakers.
He talked about the OT informing him about lifeline emergency services and handy dart transportation system. He said, “She (OT) helped me to get…and life line for emergency situations…Avril did all the work to get them for me”. He mentioned that he “can’t go out much” because he “gets tired fast” and that his only source of social contact is through his homemakers and the OT.

Similarly Andrea and Patti described the OTs to be a source of social support for them, as Andrea stated:

I think she treats people as individuals and we get along well and thoroughly enjoy each other company. We laugh a lot…having Claudette’s (OT) company and talking about my recent problems and situations has been positive even though I haven’t done any changes recently and discarded some of her instructions.

Andrea also acknowledged that the OT informed her about some of the community resources such as handy dart and volunteer shopping programs that she has been using for several years. She talked about the OT trying to get approval for a motorised wheelchair and how she has been working through different means to obtain the wheelchair. She was very appreciative of the OT effort and persuasion regarding this matter.

Patti also talked about the OT providing her with valuable information regarding community services and resources. For example, the OT referred her to home care physiotherapy when she fractured her elbow. The OT also advocated for her to be referred to the Arthritis Society by her family doctor. She explained:

Well she called my doctor and told them she thought that it would be a good idea to send me to the arthritis society…so then with her pushing behind my doctor, I got to go…for treatment…I am going to see people in orthotics at the Arthritis Society. Christine (OT) also asked my doctor to refer me to the program for exercise…I couldn’t
go to GF Strong but I got into Pearson Centre for pool and water exercises.

Patti further explained that the OT provided her with valuable information regarding Handy Dart, and government coverage of the cost of the incontinent pads that she needs on regular basis and how access to these resources improved her quality of life. In terms of community support, she included the OT as one of her main source of social support when she said:

I have friends in the building and the neighbourhood but they all got their own problems...my main support is Christine and people from the community health centre and homemakers...Christine drops in to see how I’m doing when she is here to see somebody else, so she checks on things and that’s reassuring and I feel that at least somebody is thinking about me.

Similarly, Rose expressed a sense of connection to the OT and considered her to be part of her social support network. She provided some examples to explain the resourcefulness and sociable features of the OT when she said:

Avril and I get along beautifully because I was rolling off my old bed and falling...I haven’t got enough money to get a new bed...she said don’t worry...about two days later she came with a guy with a hospital bed (through Red Cross AIL program)...now she is working on trying to get me a scooter. She phoned me to say happy birthday. I was so surprised because you know I didn’t expect it. She had the most input than anybody else than I know. I mean in a minute if I need any help, she is one of the first one that I call...I miss her not coming more often now...I never ran to any of these people who really appear to care. I hardly get to meet people anymore, but it just shows you the different type of people.

Melissa expressed more connection to her private homemaker/companion as she spends most of her time with this companion but she also felt that home care professionals including OTs brought a social component to her life when she said:
She is a gem. I know Mary (her companion) for many years. She is a personal friend of mine...she is my private help and a friend...they (home care OTs) valuable people and you know we get to chat whenever they come, that I really enjoy too. So it’s a breath of fresh air. Everybody has a different personality and of course the minute that they come in I start to analyse them (smiling).

Throughout the interview sessions, it became evident that those participants who had no family/informal support or limited family involvement relied on home care providers, particularly OTs and homemakers for social support. In the above cases, all of the participants have established relationships with their OTs and homemakers. They perceived the OTs as a source of community support and they reported to turn to them “when in trouble”. Among the participants with family support and involvement, Cameron was the only one who expressed to benefit from the OT home visits in regard to socialisation. He valued the OT knowledge and expertise and he also talked about OT visits providing him with opportunity to socialise with people other than the residents of his home facility. He expressed these points when he said:

Well, she (the OT) is got a lot of information, I learned a lot just by talking to her, she is also a very nice lady, and I got to know her. I found out that she has a little son and every time she comes around I ask her how her son doing. Last time she told me that he is turning to a little devil (laughing). I like to talk to different people. I’m a sociable person, you know.

In contrast, Ken, Ron and Michelle did not emphasize on the socialisation aspect of OT home visits and interventions. Both Ron and Michelle live with their spouses and Ken’s daughters are very involved with his care and visit him quite often. Therefore, their families were their main social support. However, this group of participants put more emphasis on the role of OTs as advocates and sources of
knowledge. For example, Michelle said, “I didn’t have money for wheelchair or other things so she got them for me through Health Canada” (as she could not get any financial support from her band). She also relied on the OT to advocate on her behalf for more homemaking services. This was exemplified when she said, “I told her (the OT) that we need help in the home...my husband can’t do it anymore. He has cancer...I’m worried about him...she is nice and helpful”.

Ron reported that the OT has informed them about Handy Dart and taxi savers programs, which they have been using to do their shopping, and managing their medical appointments. Ken expressed his respect for the OT when he said, “she told me that I was qualified for...equipment, she was very serious and efficient...and I have a lot of respect for Lyn (the OT) and her knowledge”.

Those participants with severe disability regardless of their socio-economic status discussed the benefit of OT interventions particularly home modification and assistive equipment. They emphasised the positive impact of home care OT services on their daily life. Some of the participants described how they have adjusted to their increasing need of assistive equipment and technology to be able to cope with their physical limitations. They have become more receptive to the recommended in-home changes because their modified homes have provided them with an alternative to institutional living. At the time of interviews, some of these participants expressed gratitude regarding the accessibility features of their homes despite their initial reservations regarding equipment and in-home changes. The participants with chronic disabling conditions had to make further adjustments as they have aged and faced increasing limitations. Moreover, these participants discussed the multi-
faceted roles of home care occupational therapists in their life. Specifically, they discussed how OTs acted as advocates, sources of knowledge and social support.
Chapter Six: Discussion of Findings

As an occupational therapist working with older adults, I have encountered many individuals who had reservations about home care OT services. In my work place (geriatric hospital) most of the elderly care recipients have required persuasion to accept assistive devices or equipment such as walkers or raised toilet seats. Frequently, I have been challenged by the care recipients to consider their personal views about their needs for equipment and OT home visits. This study is an attempt to critically explore these challenges and to better understand care recipients' experiences of home care OT.

Research in the field of home care OT has focused mainly on efficacy studies and despite the “client-centered” practice guidelines of OT, little attempt has been made to understand the care recipients' experiences of home care OT from their standpoint.

The main objectives of this study were to gain insight into the care recipients' experiences of home care OT particularly home modifications and the ways OT services have impacted their life. To achieve these objectives, aspects of the care recipients' contexts including their socio-economic status and living conditions, the meaning of home and neighbourhood were also explored.

A qualitative research approach and particularly semi-structured interviews were used to examine the research questions. This approach proved to be appropriate as the participants were able to share and recount different aspects of their experiences of home care OT in a free style guided conversations during the interview sessions. As a result, they were able to share important aspects of their experiences.
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All of the participants described the positive impact of OT interventions on their lives. Those participants with poor socio-economic status and severe disability described significant benefit from home care OT interventions. In addition to the traditional role of home care OT in providing equipment and home modifications, the participants discussed the multi-faceted role of occupational therapists as social support, resource and advocate. They described a dynamic process involving the shifting roles of OT based on their needs and their relationship with individual occupational therapist. Based on the participants’ stories, the traditional role of home care OT as a therapist prescribing equipment and home modifications shifted to other roles once traditional interventions were completed.

Among this group of participants, those who had access to funding and wheelchair accessible homes described the most positive experience of home care OT. These participants valued OT interventions in enabling them to remain at their homes and be independent. They defined independence as being able to remain in their homes and have control over their lives. They acknowledged their need for equipment, in-home modifications, as well as homemaking services to enable them to remain in their homes. Their definition of independence does not reflect the traditional OT definition of independence as one’s ability to perform occupation (daily tasks) without another person’s assistance. These participants emphasised their continued need of home support/making services in order to remain in their homes and avoid institutional living.

The participants with average and/or higher than average socio-economic status also described positive experiences of home care OT and the enabling impact of OT services on their daily lives. Among this group, those who experienced severe disability
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reported significant impact of OT interventions in terms of OT expertise in providing them with appropriate recommendations. However, unlike the participants with low socio-economic status, this group was not dependent on funding agencies or OTs in advocating for their needed equipment and services. Those participants who had the support of their families or other informal source of social support did not focus on the social role of OTs.

As the participants’ disabling condition progressed, their homes and neighbourhoods became increasingly more important to them. The architectural barriers of their homes and neighbourhoods became more prominent and they experienced more difficulty coping with these barriers as their disability progressed.

Regardless of their socio-economic status, those participants who had access to wheelchair accessible homes and neighbourhoods and with their required assistive equipment in place reported a better quality of life. With the help of homemakers, these participants expressed to be at a lower risk for nursing home admission. Most of the participants renegotiated the meaning of their homes and neighbourhoods as their disability progressed. Home meant an alternative to nursing/institutional living. This was extremely important to all of the participants and those who lived in their own homes expressed more attachment and a sense of belonging to their communities. Most of these participants lived in Co-op or BC housing projects where large portions of residents are people with low income and/or disability. As their condition deteriorated, participants felt closer to their neighbours with common experiences of disabilities. Therefore, they felt “in place” and they intended to remain within their communities for as long as they could.
Participants who were dependent on homemaking services described their effort to make their homes comfortable for their homemakers.

Those participants who lived in homes with good housing condition in neighbourhoods with fewer barriers, presented as being less confined and they generally appeared to cope better with their progressive disabling conditions. For participants with poor housing and living conditions, OT played an important role in advocating on their behalf to improve their conditions or locate resources and funding for their needed resources.

**Theoretical/conceptual considerations**

In this section I will review the theoretical/conceptual approaches informing the interpretation of the data. The insights gained from the participants’ accounts of their experiences will be used to inform these conceptual ideas related to individual experience, home, place and context.

**Individual experience**

The Canadian Association of Occupational Therapists (CAOT, 1997) defines client-centered practice as a collaborative approach in which occupational therapists demonstrate respect for clients, involve them in decision making, advocate with and for clients in meeting their needs, and otherwise recognise clients’ experience and knowledge.

The conceptual models of OT practice such as the Canadian Model of Occupational Performance (CMOP) (CAOT, 1997) and the Model of Human Occupation
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(MOHO) (Kielhofner, 1995; Kielhofner & Forsyth, 1997) place the client at the center of health care provision. However, despite the fact that the OT ethic of caring emphasises the centrality of the individual, the ultimate role of the individual in health care decision-making has not been examined within OT literature (Gage & Polatajko, 1995; O’Brien, Dyck, Caron & Mortenson, 2002).

Miller (1992) and Hamlin, Loukas, Froehlich and MacRae (1992) have emphasised the compatibility of feminism with the OT’s philosophical base. However, they have asserted that despite the emphasis of an individual-focused approach, there is a lack of exploration of the individual’s accounts of experiences in generating knowledge in OT.

Many participants from a different perspective discussed the issue of “independence” and “reliance on community resources”. For these participants, “independence” meant to be able to live in their homes with continuous support of homemakers and with their needed equipment in place. Moreover, “independence” meant having control and choice in their lives and therefore, the only desirable alternative to institutional/nursing home living. These findings inform the conceptual ideas of interdependence, communitarian approach, care giver and receiver choice, the importance of the diversity of the individual’s everyday life experiences in generating knowledge, interconnection between social, economical, cultural and political factors in shaping the individual experience of disability in our society drawn from feminist sociology (Dyck, 1995; O’Brien et al., 2002; Thorne et al., 1997; Morris, 1992, 1991; Peter, 2000; Stuart, 1992; Crow, 1996; Barnes & Mercer, 1996).
The concept of home as a place for providing health care, particularly from the care recipient's standpoint has not been studied in the OT research literature. A review of the OT literature revealed very few studies addressing issues related to home, environment, housing and resources. The main objectives of this study were to gain a better understanding of the care recipient's experiences of home care OT and the ways home care OT interventions have impacted their lives. In order to achieve these objectives, the participants' contexts particularly their physical and social environments (their home space, place, neighbourhood and community resources) and their socio-economic status were explored.

Due to the lack of consideration of the above discussed concepts in OT literature, these concepts drawn from feminist sociology and social geography allow for a more comprehensive understanding of the individual's experience of disability and his or her involvement with the home care system including home care OT.

Participants acknowledged the importance of their homes and neighbourhoods and how the meaning of their homes changed over the course of their disabling conditions. Other studies have showed similar findings (Tamm, 1999; Teeland, 1998; Gardner, 2000; Dyck, 1995). For example, Dyck (1995) has demonstrated the changing meaning of home, neighbourhood and city spaces for women with Multiple Sclerosis. The increasing importance of home, neighbourhood and overcoming environmental barriers as the participants' disability progressed were emphasised by the majority of the study participants. These findings support the conclusion of Gant's (1997) study.
regarding the impact of environmental barriers and access to community resources on the quality of life of elderly people.

**Context**

Other studies conducted by social and medical geographers have addressed the multi-layered dimensions of disability experience, and the relationships between space, illness and disability from a comprehensive social and political standpoint (Kitchen, 1998; Bachner, 2000; Steward, 2000; Rowles, 1991; Evans et al., 2000; Lyon & Colquhoun, 1999). In this study, participants described their experiences of home care OT to be multi-faceted. They recounted the effect of their financial means, social support, access to resources and funding on their lives. Their insights confirm the concepts identified in the above-mentioned studies regarding the experience of a place and its impact on people’s health and well being. The importance of the physical condition of the home and socio-economic status on people’s ability to cope with illness and disability was discussed in the study by Evans, Hyndman, Stewart-Brown, Smith and Peterson (2000). Data from the participants’ stories reflect this point as the participants emphasised the correlation of the physical features of their homes with their coping abilities.

Data from this study (the participants’ insights) particularly informs the conceptual ideas presented in the Rowles (1991) study. Similar to Rowles’ study, many participants of this study have focused on the concepts of “life world” and “being in place”. Rowles (1991) argues that, emphasis on performance has tended to relegate the notion of being to a peripheral role; the life world not only includes the person’s current setting but also a space-time depth that is uniquely experienced within the personal
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history and being in place expresses immersion within such a lifeworld. These arguments were reflected by the participants of this study. For example, Rose, Melissa and Patti who have lived in their existing homes for many years attributed a variety of meanings to their homes. Their home settings represented a part of their identity and being. As noted earlier, these participants throughout the study expressed a sense of belonging and comfort. The concept of home as a personal dwelling and as a work place for home care providers was presented by Andrea when she talked about “not making it hard” for the homemakers to do their work. This concept has been discussed in Teeland’s study (1998) as well.

As participants shared their stories, during the feedback and analysis of data, it became evident that the participants’ contexts (their socio-economic status, living and housing conditions and social/community resources) have influenced their experiences of home care OT. Participants with low socio-economic status limited family support and poor access to resources were more dependent on the formal home care services including home care OT. These participants reported significant improvement of the quality of their lives as the result of obtaining assistive devices; mobility aids and other resources through home care OT. Occupational therapists acted as their advocate and a source of social support. In comparison, those participants with average or better than average socio-economic status or family support reported some benefits of occupational therapists’ expertise. These participants related to the OTs as professionals with valuable expertise. They did not have to rely on their therapist to obtain funding for their required equipment and they were not totally dependent on the OTs for social support. In addition some of these participants had professional background (for example, Melissa is a retired
community health nurse) and they related to the OTs as experts. Therefore, in these cases, OTs played their traditional role of expert and the extent of their involvement was limited to recommendation of equipment or some home modifications. Among these participants, those who had a good rapport with their occupational therapists and were allowed to make decisions about their recommendations tend to accept the OT interventions and use the recommended equipment consistently.

Some of these participants (e.g. Cameron and Melissa) have not relied on OTs to obtain funding on their behalf, as they were able to afford their needed equipment. Therefore, in these cases, OTs played a more traditional role of expert. It should be noted that occupational therapist in British Columbia access programs such as Red Cross Aids to Independent Living (AIL) to obtain equipment for those individuals who cannot afford them or do not have extended coverage through their health insurance plans. There are some other voluntary non-profit organizations such as MS society that provides equipment to specific population but their activities are not aligned with those of the government agencies. Moreover, these agencies have different eligibility criteria for equipment coverage. There is a lack of central regulatory body to ensure a universal and free access to equipment and prevent duplication of services. For example, sponsored immigrants are not eligible for equipment through AIL program regardless of their health and financial status. On the other hand some care recipients are eligible through several agencies such as DVA and Health Canada. There are inequities in benefits for people with low socio-economic status with basic government health coverage as compared to those who have comprehensive insurance coverage in addition to their basic health benefit through Health Canada.
The issue of “independence” and “reliance on community resources” were discussed by many participants from different perspectives. For these participants, “independence” meant to be able to live in their homes with the continued support of homemakers and with their needed equipment in place. Moreover, “independence” meant having control and choice in their lives and therefore, the only desirable alternative to institutional/nursing home living. These findings inform the conceptual ideas of interdependency, communitarian approach, care giver and receiver choice, the importance of the diversity of the individual’s everyday life experiences in generating knowledge, interconnection between social, economical, cultural and political factors in shaping the individual experience of disability in our society drawn from feminist sociology (Dyck, 1995; O’Brien et al., 2002; Thorne et al., 1997; Morris, 1992, 1991; Peter, 2000; Stuart, 1992; Crow, 1996; Barnes & Mercer, 1996).

**Implication for Occupational Therapy Practice**

The main goals of this study were to gain insight into the care recipients’ experiences of home care OT particularly home modifications and the ways OT interventions have impacted their lives. The insights provided by the participants of the study can be used to inform home care occupational therapy practice. Implications regarding particular aspects of OT practice (that have been emphasised in this study) specifically, client-centered practice, contexts, OT roles and home modifications will be discussed.
Client-centered Practice

In this study, the accounts of the participants’ experiences of home care OT generated information that could broaden OT knowledge base in the field of home care OT. As noted earlier, despite the client-centered principles of OT practice, the focus of home care OT research and practice has not been on the client’s experience. This study explored the individuals’ experiences of home care OT within their contexts of home, community and their socio-economic status. Within each emergent theme similarities and differences of the individuals’ experiences reflect the importance of a true client-centered approach to practice in home care. For example, within the theme of the impact of home modifications and access to equipment, and depending on their context, participants’ expressed a variety of ways home modifications impacted their lives.

Those participants with low socio-economic status built closer relationship with their therapists as they helped them with the process of obtaining their needed equipment. Those participants with less severe disability and better financial means placed less emphasis on the impact of the home modification and equipment, instead they emphasised the impact of their resources and/or daily assistance. The insights of the participants may be used to inform home care OT practice by encouraging consideration of the multiple dimensions of the care recipients’ experience. These considerations may highlight for occupational therapists the central foci of home modifications and prescription of equipment according to the individual’s unique circumstances.
Context

The findings of this study revealed the direct influence of the individuals’ context of living, housing condition, socio-economic status and resources on the experience of home care OT. Insights provided by the study participants support the client-centered approach of OT. However, despite the client-centered practice guidelines, the focus of OT home care research and practice has not been on the client’s experience.

The dynamic relationship between physical, social and cultural environment of the client has been emphasised in OT. However, the interconnection of these environmental factors with social, economic and political factors at the society level has not been adequately considered by the home care OTs. For example, participants discussed how their daily routine and coping strategies had been changed because of the recent policy changes in health care and the resultant cuts in home support services. Therefore, a more comprehensive understanding of the individual’s context at the community and society (at large) will improve the quality and scope of OT practice in the field of home health care.

OT roles

Participants described different roles that home care OT played in their lives. Depending on the context of each individual, occupational therapists assumed different roles. Some acted as an advocate to obtain funding for their clients’ needed equipment. Some of the occupational therapist acted more as social resource. These therapists have built rapport with their clients and maintained a friendly relationship with them. This has been instrumental in maintaining some of the care recipients in the community. The
findings of this study reveal no contradictory effect of OT as a result of assuming these different roles. On the contrary, assuming different roles depending on the needs and context of each individual strengthens the traditional role of OT as an expert and consequently, their clients adhered to the OT recommendations. In this study, those participants who perceived OTs as a source of social support and advocacy showed more acceptance for home modifications and equipment recommended by the OTs. It would be beneficial for OT practice to further explore the multi-faceted roles of therapists especially in the field of home care.

Home modifications

As discussed earlier in the study, the main focus of OT in home care is home modifications including the placement of safety or mobility equipment. All of the participants expressed that they benefited from home modifications and obtaining equipment. However, those participants with severe limitations and more OT involvement (who also have had good relationship with the OTs) expressed significant benefit from home modifications and equipment. However, as their disability progressed, they required home support services to use their equipment safely. Therefore, “independence” with assistive devices and equipment alone was not possible anymore. The help of homemakers in conjunction with OT interventions, particularly home modifications and with the use of equipment have made it possible for them to remain at their homes.

In general, those participants who desired the equipment described prolonged use of their equipment. The study findings would suggest that the issue of ‘compliance’ is
directly related to personal goals and a desire to have the equipment in their homes and the nature of their relationship with the OT. The term ‘compliance’ is widely used in the medical model of health care practice. This term is also widely used in home care OT literature to describe the client acceptance of treatment and/or usage of the prescribed equipment. However, the study participants identified issues such as choice and control and how these factors contributed to their decision to accept and use the equipment on an ongoing basis. Those (like Rose and Andrea) who were given the opportunity to select, accept or refuse interventions as they saw fit for them, have shown more compliance in the long run. Consideration of these findings may improve the outcome of home modifications and equipment prescription in home care OT.

Limitations of the Study

Generalization of the findings of this study is limited due to the small number of participants. The experiences of the study participants may not represent the diversity of experiences of the care recipients in the larger communities at large. This study and the findings are exploratory and represent a snapshot. However, the participants’ experiences may be recognized as familiar by others involved with home care and the issues and concepts identified in this study can still be beneficial in improving home care services.

Due to the fact that participants were recruited by the home care occupational therapists within CHC, the therapists who recruited them knew most of the participants. This factor may have influenced the participants’ choice of participation and their feedback regarding the OT services and interventions. My position, as occupational therapist may also have influenced their feedback regarding the impact of OT services.
Finally, some of the participants in this study have experienced disability throughout their lives (e.g. Andrea with Cerebral Palsy and Mike with Multiple Sclerosis). These participants have had extensive OT involvement, community resources and equipment throughout their lives. Their experiences of home care OT at this stage of life (being “senior citizens” with life-long disability) may have not been representative of the general elderly population receiving OT services in the community.

**Direction for Future Research**

Further exploration of the influence of socio-economical and political contexts in which home care OT services are provided would contribute to the professional and theoretical development of OT in home care. Multidisciplinary research approaches would be useful as a way of broadening health care professionals’ perspectives in home care, and to better gain an understanding of the influences of the different individuals’ contexts in the society.

A combined qualitative and quantitative study would effectively contribute to an understanding of the experiences of the care recipients and measure the improvement of their function and quality of lives as the result of OT home modifications/interventions.

Inclusion of individuals from different cultural backgrounds in such studies may provide valuable insights regarding the influences of cultural issues on the individual’s experiences of home care OT.
REFERENCES
References


Appendix A

Letter of Introduction: Addressing CHC Managers

Date: May 30, 2003

Vancouver Community Health services
Dear Manager, Adult/Older Adult Program,

This letter provides you with information regarding a research study concerning occupational therapy home care services. The attached letter of advertisement/invitation explains the purpose of the study, the procedures involved and the potential benefits of the study to the home care clients receiving services from the Community Health Centers in the Greater Vancouver areas. These care recipients are being asked to participate in a qualitative study titled,

HOME AS A PLACE FOR PROVIDING HEALTH CARE: ELDERLY CARE RECIPIENTS’ EXPERIENCE

The purpose of this study is to describe the care recipients’ experiences of home care occupational therapy from their perspective. To participate, the care recipients must have received long-term care services and at least two home visits from a home care occupational therapists within the last twelve months. The participants must be cognitively competent to understand the purpose of the study, to comprehend the research questions, and voluntarily consent to participate in the study.

Similar to the enabling model of occupational therapy practice, this study is based on the client-centered approach. The main objectives of this study are to gain insight into the care recipients’ experiences of home care occupational therapy and the impacts of home-care occupational therapy services particularly home modifications on the care recipients’ daily life. To achieve a better understanding of the care recipients’ experience, this study will aim to describe different aspects of the care recipients’ experience; including the meanings of the ‘home’ to the care recipients; the living and housing conditions of the care recipients and the effects of these conditions on the quality and/or experience of home-care occupational therapy. Knowing the personal everyday experiences of people receiving home care is essential to improvement of the quality of home care services.
Appendix B

Letter of Introduction: Addressing CHC Occupational Therapists

Date: May 30, 2003

Dear Occupational Therapist,

You are being asked to share the attached letter of invitation with the home care clients receiving services from your Community Health Centre. These care recipients are being asked to participate in a qualitative study titled,

HOME AS A PLACE FOR PROVIDING HEALTH CARE: ELDERLY CARE RECIPIENTS’ EXPERIENCE

The main objectives of this study are to gain insight into the care recipients’ experiences of home-care occupational therapy particularly home modifications and to describe the impacts of home care occupational therapy services on the care recipients’ lives. To achieve these objectives, this study will aim to describe different aspects of the care recipients’ experiences of home-care occupational therapy; the meanings of the ‘home’ to the care recipients; the living and housing conditions of the care recipients and the effects of these conditions on the quality and/or experience of home-care occupational therapy.

A review of literature reveals that research in home care has mainly focused on efficacy studies, and the concept of home as a place for providing health care has not been adequately explored in occupational therapy. Concepts drawn from the client-centered model of practice, feminist sociology, and social geography will inform this study. The importance of an individual-focused approach in providing health care; the inclusion of experiential accounts in generating knowledge; and the social, cultural and symbolic meanings of home are themes from these disciplines relevant to this study.

There is a lack of clients’ accounts of their experiences in generating knowledge in home care research. Therefore, to understand better the care recipients’ experience of their disabilities and needs, their subjective account of their experiences of home-care occupational therapy need to be studied. This will contribute to improvement of the quality of home-care occupational therapy services that are meaningful to the care recipients. Furthermore, this study will enable home-care occupational therapists to reflect on the care recipients’ account of their experiences described in the study and their own practices to address issues surrounding home care in order to enhance compatibility between occupational therapy client-centered philosophy and their clients’ values and goals.
Date: May 30, 2003

Seeking volunteers to participate in a research study concerning occupational therapy home care services

Dear potential participant,

If you are an older adult sixty five years of age or older who live in your home alone, with your family or significant others in the community, you are invited to participate in a study titled,

HOME AS A PLACE FOR PROVIDING HEALTH CARE: ELDRLY CARE RECIPIENTS’ EXPERIENCE

To participate in this study you must be a long-term care recipient and have received at least two home visits from a home care occupational therapist within the last twelve months. You must be able to understand and communicate in English; and voluntarily consent to participate in the study.

The purpose of this study is to explore your views and experiences of occupational therapy services that you have received in your home. Home care is a fairly new field in our health care system. Very little is known about the views of care recipients on home care services. Particularly, the impact of home modifications and other in-home changes on home care recipients’ daily life has not been explored. To improve the quality of home care services; your knowledge is essential.

Your account of your experiences with home care services, particularly home modifications recommended by home-care occupational therapists will provide important information that could be used by all home-care professionals including occupational therapists to promote services that are meaningful to you. Knowledge generated from this study may enable the care providers to address their clients’ concerns, and to promote the care recipients’ rights to quality health care services and health care decision-making.
In order to better understand all aspects of care recipient experiences; this study also aims to gain some insight into the meanings of the home from the care recipients’ perspective; the living and housing conditions of the care recipients and the effects of these conditions on the quality and experience of home care occupational therapy.

**Study Procedure**

You understand that by becoming a volunteer to participate in this study, you agree to be interviewed by the co-investigator in your home. The researcher will visit you to answer any questions you might have about the study, and to participate in an interview.

You will be asked to describe your experiences of occupational therapy services and any home modifications that you have experienced in your home. You will also be asked to describe the impacts of occupational therapy services on your daily life. You will also be asked to share your knowledge of social support and resources available to you in your community.

You will then be asked to give a tour of your home to the researcher or if you are not able to do so, a family member or a friend may do this on your behalf. You understand that the interview and the tour of your home may take between one to two hours, and it could be done over several shorter sessions if you choose to do so. The session(s) will be scheduled at a time convenient to you.

You will allow the researcher to record the interview and conversations during the tour of your home with a tape recorder and to take notes of modifications to your home as the result of the occupational therapist’s recommendation.

**Confidentiality**

Any information resulting from this study will be kept strictly confidential. Participants will not be identified by name in any reports of the completed study. All documents including the audio taped interviews and conversations will be identified only by code number and kept in a locked filling cabinet. The information that might be transcribed on a soft (portable, floppy) computer disk will also be identified only by code number and kept in the same locked cabinet.

**Compensation**

There is no funding available for this research project, and unfortunately, the researcher is unable to offer any material remuneration or monetary compensation to the volunteers participating in this study.
Appendix E

Interview Guide

Semi-structured, in-depth interviews will be conducted with the home care recipients. The interviews will be conducted in a flexible and informal manner. A few open-ended questions will be asked to allow the participants to express themselves freely. The interview guide will be used to cover key questions. Following are some sample questions.

The experience of home-care OT services
What occupational therapy services have you received in your home?
Tell me about your experiences when you were visited by the occupational therapist; were there any occupational therapy recommendations and how did you feel about them?

The impacts of home-care OT services
Has there been any impact (positive and/or negative) on you or on your family as the result of recommended in-home changes and modifications?
Was there anything that you would have liked to be different in the way occupational therapy services were delivered to you?

The meanings of ‘home’ and neighborhood
Tell me about your place/your home? Prompting as required: What does ‘home’ mean to you? How long have you been living in this home? How do you feel about your neighborhood?
What would you change (if anything) about your home and your neighborhood?

The living and housing conditions including social and financial resources
With occupational therapy recommendations particularly equipment and home modifications, were you able to effort making these changes? If not were there any funding resources available to you?
Do you have family or friends close by who you can count on for help? What other social resources are available to you (e.g. Community health clinic, leisure activities centre, adult day programs, and public transit)? Can you access these resources? If not why not?

Observation Guide

Description of the observations
The care recipient, a family member or a friend will lead a tour of his/her home, and the researcher will take notes of the spatial layout, room size, household amenities and physical conditions, possible environmental barriers and hazards including clutters, lighting, noise, and temperature. The researcher will also take notes of any home modifications, and adaptive equipment recommended by the home care occupational therapist.