# WHEN THE ABILITY TO LIVE INDEPENDENTLY IS THREATENED: A PHENOMENOLOGICAL STUDY OF THE OLDER ADULT'S EXPERIENCE OF LIVING "AT RISK"

Ву

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#### **ABSTRACT**

By the year 2031, the proportion of the population aged 65 and over will comprise approximately 23.8% of Canada's population (Government of Canada, 1991). Currently, this group of older individuals uses a large amount of medical and social services because of its multiple medical and social problems, functional impairments and emotional disorders (Alexander, 1990). One result of the availability and use of these services is that many older adults are now living at home in the community in situations of "risk." The existence of multiple problems or risk factors threatens the older adult's ability to continue living independently in that they represent the potential for a decline in health status and functional abilities which, in turn, may result in admission to an acute or long-term care facility.

A review of the literature reveals that the emphasis of research in the area of risk has been on: (i) identifying risk factors for hospital admission and institutional placement, (ii) targeting older adults for specific programs, and (iii) evaluating the effectiveness of treatment programs for reducing or managing risk factors. There is a paucity of information on the subjective experience of risk from the perspective of the older adult.

The purpose of this study was to describe the experience of older adults whose ability to live independently is threatened by the presence of one or more risk factors. The phenomenological perspective of qualitative research was used for this study. This approach seeks to study phenomena as they are experienced in everyday life. Individuals aged 65 or older were contacted through a Short Stay Assessment and Treatment Centre. A community health care professional used a risk factor screening tool to determine that participants were living "at risk." Six individuals participated in the study. Data were collected from a range of sources including two unstructured interviews with each participant, documentary data sources and the researcher's observations.

Analysis of the data revealed that risk as a concept had meaning and utility for health care professionals only. It was discovered that what were "risk factors" and living "at risk" for the health care professional were interpreted as "losses" and coping with losses by the participants.

Participants experienced four types of losses: the loss of functional abilities, loss of meaningful relationships, loss of meaningful activity and the loss of independence and control. These losses were perceived by participants as being irrevocable and interrelated. Furthermore, it was found that participants used a variety of strategies in coping with these

losses. These strategies formed two distinct and opposing patterns: engaging and enduring. The findings also revealed that one particular risk factor, that is, a change in mental status, affected the nature of the data obtained in the study in that they were often scant and lacking in depth or richness. This finding has implications for conducting qualitative research with older adults experiencing such a change. Finally, the implications for nursing practice, education an research were identified in light of the findings.

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#### CHAPTER ONE: INTRODUCTION

#### Background and Significance of the Problem

In 1986, individuals over the age of 65 comprised 10.7% of Canada's population (Chappell, 1990). By the year 2031, the proportion of the population aged 65 and over will have increased dramatically to almost a quarter of the total population (23.8%) (Government of Canada, 1991). Within this older population, the biggest jump will be for the "old old," that is, those aged 75 and over (11.3%).

Currently, older individuals use many medical and social services because of their multiple medical and social problems, functional impairments and emotional disorders (Alexander, 1990). The health care system has responded to the demand for these services by implementing a number of care programs designed to stabilize the older individual's medical and social situation and to prevent inappropriate utilization of emergency and acute care services. Examples of these programs include:

(i) acute hospital services, such as multidisciplinary geriatric consultation teams, discharge planning units and quick response programs and (ii) community-based services, such as geriatric assessment and treatment centres and home support services, which, in turn, include home nursing

care, physiotherapy and occupational therapy, adult day care and homemaker assistance.

One result of these efforts is that many older adults are now living at home in the community in situations of "risk." That is, the complexity of their medical, functional, social and emotional states has resulted in a situation in which these individuals are at risk for and require assistance to prevent:

- progression of acute or chronic illness with subsequent decline in functional abilities;
- admission or readmission to an acute care hospital;
- 3. premature admission to a long-term care facility.

Each of the above scenarios represents a threat to the older adult's ability to continue to live independently in the community.

In response to these threats, health care professionals have identified risk factors and have engaged in efforts to quantify an individual's degree of risk in order to: (i) ensure efficient and effective utilization of resources; (ii) evaluate program effectiveness by measuring changes in degree of risk over time; and (iii) target those individuals who are appropriate for specialized programs. Accordingly, most research to date has identified specific, objective, physical, functional and psychosocial factors that contribute to risk, some of which are amenable to treatment

and some of which are not. The risk factors identified with admission to nursing homes and early unplanned readmission to hospital include greater age, the use of aids for ambulation, mental impairment, living alone and needing assistance in the instrumental activities of daily living (for example, meal preparation, housework, shopping, etc.) (Brocklehurst, Carty, Leeming & Robinson, 1978; Colerick & George, 1986; Green & Ondrich, 1990; Rowland, Maitra, Richardson, Hudson & Woodhouse, 1990; Williams & Fitton, 1988). Other studies have been conducted for the purpose of targeting those older adults in acute care hospitals who are at greatest risk for iatrogenic illness, hospital-acquired disability or nursing home placement (Hogan & Fox, 1990; Winograd, Gerety, Brown & Kolodny, 1988). The risk factors identified in these studies include those mentioned above plus additional factors that occur as a result of illness and hospitalization. These are chronic and disabling illness, urinary incontinence, malnutrition, complications from prolonged bedrest and polypharmacy, depression and acute confusional state. The consequence for the hospitalized older adult in experiencing one or more of these risk factors is the possibility of not being able to return to independent living in the community.

Nurses in many areas of practice must have a knowledge of the factors, such as those identified above, that affect the ability of older

adults to live independently. The hospital-based nurse can use this knowledge to: (i) identify older adults who are at risk for iatrogenic complications and possible long term institutional placement; and (ii) work with older adults, their families and other health care professionals to prevent development of such complications and to ensure a return to independent living. Similarly, community-based nurses can work with older adults to manage those risk factors that have the potential to interfere with their ability to continue to live in the community. However, it is of equal importance for nurses to have knowledge of a different nature if they are to be effective in supporting the efforts of older adults to remain independent. That knowledge is an understanding of the older adult's perspective and subjective experience of living in situations in which risk factors are present because it is this experience that influences the individual's behaviours in managing those risk factors (Omery, 1983).

#### The Problem

Risk is a term or concept used by health care professionals to describe individuals whose physical, mental or functional status, social situation or physical environment present a threat to life, health, safety and independent living. Nevertheless, despite what is known about risk from the perspective of the health care professional, there is a lack of

knowledge available on the subjective experience of living "at risk" from the perspective of the older adult.

### **Conceptual Framework**

Two explanatory models of behaviour provide the foundation for the conceptual framework that will guide this study. The following description of these models illustrates why it is important for nurses to achieve an understanding of the older adult's subjective experience of risk.

The first, an explanatory model by Kleinman (1978), proposes that the health care system is composed of three structural arenas within which illness is experienced and explained, namely, the professional (health care professionals and institutions), the popular (individual, family and community) and the folk (non-professional healers). Whereas health care professionals, in the professional arena, have defined risk and implemented programs to manage risk, the context of risk for the individual, the popular arena, has been relatively unexplored.

Nevertheless, the meanings and behaviours within this context influence the individuals' willingness to access and to participate in the professional arena.

The second model, the U.B.C. Model for Nursing (U.B.C. School of Nursing, 1980), views the individual as a behavioural system made up of

nine interrelated and interdependent subsystems: achieving, affective, ego-valuative, excretory, ingestive, protective, reparative, respiratory and satiative. Each subsystem is composed of: (i) an inner personal region, which represents a need and cognitive and executive abilities and (ii) a psychological environment, containing a goal and the personal, social and cultural forces affecting goal achievement and need satisfaction. Further, the UBC Model requires that the nurse understand the meaning of the forces affecting goal achievement from the perspective of the patient. This study considers risk factors to be forces that have meaning for the psychological environment of one or more subsystems and which, ultimately, affect the entire behavioural system. An understanding of the older adult's subjective experience of living with these risk factors will broaden the nurse's ability to predict their impact on individuals managing situations of risk.

## Introduction to the Methodology

The phenomenological perspective of qualitative research was used as the methodological approach to this study. Whereas the goal of traditional quantitative research methods is to determine the objective aspects of a phenomenon for the purpose of predicting and managing behaviour, the purpose of phenomenology is to study phenomena as they

are actually experienced in everyday life. An underlying assumption of phenomenology is that individuals' subjective interpretations of a situation are an important assessment of the reality of the experience for them (Oiler, 1986). To this end, the task of the researcher is to achieve an understanding of that experience from the subjective perspective of those involved and to use this understanding to develop a rich description that will communicate the experience to others (Omery, 1983). Developing this understanding requires that the researcher become fully engaged in the mind and feelings of the participants. Indeed, the social interaction required for this engagement between researcher and participant forms the foundation of phenomenological research. Furthermore, the researcher assumes the role of participant-observer, thus entering into the research process itself (Davis, 1978). This role necessitates that the researcher suspend or "bracket" her own beliefs and suppositions about the phenomenon being studied so as not to influence either the interviewing process or the interpretation of the data (Field & Morse, 1985). For the same reason, during the interviews, the researcher uses open-ended questions to elicit unbiased responses and to learn about concerns on issues important to the older adult's life. Phenomenology is an appropriate research method to answer the question posed by the study to

understand the concept of risk as it is lived and understood by the older adult in the community. A more detailed description of the process of analyzing data obtained through the phenomenological method is provided in Chapter Three.

#### **Context of the Study**

The Mount Saint Joseph Hospital Short Stay Assessment and Treatment Centre (SSATC) is a community-funded, hospital-based specialized multidisciplinary assessment unit. This unit works with older adults experiencing health-related problems which interfere with their ability to live independently. The SSATC often receives requests from community health care providers for "urgent" assessment of individuals who experience a sudden deterioration in health status. However, some of these individuals are often admitted to the emergency department or to acute care before they can be preassessed. In fact, a recent survey of SSATC clinical records revealed that 50% of the SSATC patients had been to the emergency room within eight weeks of their admission to the SSATC. An outreach project is currently being developed to provide service to these individuals in their homes (see Appendix A). One component of this project is development of an "at risk" screening profile to determine the degree of risk, as determined by a health care

professional, of individuals referred to the SSATC. A phenomenological study of the experience of individuals whom health care providers believe to be living at risk will contribute to the development of both a profile of the risk situation for the older adult and the outreach program itself.

#### **Purpose**

The purpose of this study is to describe the experience of older adults whose ability to live independently is threatened by the presence of one or more risk factors. The specific research question was "What is the lived experience of older adults in the community who have been identified by a health care professional as living "at risk?"

The specific questions that directed this study are:

- 1. What has it been like to experience some recent changes in your health?
- 2. What aspects of your daily life would you say are most affected?
- 3. What are your major concerns right now about managing here at home?
- 4. How do you manage with washing, dressing, going to the bathroom, cooking, cleaning, shopping, banking?
- 5. Is there anything you cannot do now that you want to do?

- 6. Have you ever experienced problems or situations like this before? If so, in what ways is this experience the same or different from earlier ones?
- 7. What would help you to be able to stay in your home?

  Descriptions by these participants about their living situations,
  health problems and the type of assistance they want and require can
  assist the nurses in helping clients manage their daily lives. Furthermore,
  the results of this study will enable nurses and other health care
  professionals to plan and implement programs for older adults living at
  home.

#### **Definition of Terms**

The following terms are defined for the purpose of this study.

1. **older adult:** an individual, 65 years of age or older, who has been referred to the Mount Saint Joseph Short Stay Assessment and Treatment Centre (SSATC) by a community health care professional (for example, the individual's family physician, home care nurse, long-term care case manager) because of a decline in health status and functional ability. The individual must score above 24 on the Folstein Mini-Mental Status Exam (Folstein, Folstein & McHugh, 1975). A score below 24 indicates the presence of cognitive

- impairment which can adversely affect recall of detail, memory and comprehension (Folstein, Folstein & McHugh, 1975).
- 2. **risk factor:** a characteristic of the individual or the social or physical environment which predisposes the individual to: (i) deterioration in health status; (ii) a decline in functional ability; or (iii) the possibility of admission to an acute or long-term care facility. Depending upon the extent to which these factors affect health, safety and functional abilities, risk factors have the potential to threaten the individual's ability to live independently. See Appendix B for the risk factors and the empirical indicators of risk identified for use in this study.
- 3. **The situation of living "at risk":** the older adults' interpretations of their situations; the experience of living in a situation where one or more risk factors are present.
- 4. **SSATC community assessor:** a geriatric nurse clinician employed by the SSATC for the purpose of: (i) screening clients referred to the SSATC to determine their eligibility for admission; and (ii) conducting in-home, multi-dimensional preadmission assessments of potentially eligible clients.

#### Limitations

- The following limitations were identified at the outset of this study:
- 1. All of the participants are from the same geographical area. The SSATC accepts referrals for individuals living within a catchment area that includes the north and east sides of Vancouver, Burnaby and the area serviced by the Simon Fraser Health Unit. Consequently, the participants may represent a specialized subgroup of the population.
- 2. Problems associated with collecting data from older adults may affect the reliability of the data. These include: (i) hearing or visual limitations; (ii) fatigue; (iii) short attention span. Furthermore, McPherson (1983) suggests that "older people may be skeptical of research and may be ... likely to respond in socially approved directions" (p. 120).
- 3. Older adults may be unwilling to describe their "real" feelings or "true" perceptions of their heath status or living situation to a researcher who is a health care professional. They may be concerned that the researcher, if she identifies threats to their health and safety, will be obligated to report these threats to their

- physicians or to the SSATC health care professionals -- a situation that might affect their privacy and independence.
- 4. The restriction of participants to those individuals whose scores on the Folstein Mini-Mental Status Exam are greater than 24 eliminates from the study older adults who have various types of cognitive impairment. Because a recent change in mental status is an empirical indicator contributing to risk, this aspect of the phenomenon of risk will not be explored within the context of this study.

Three other factors have influenced the outcome of this study. First, the data presented reflect the experiences of the older adults who participated in the study. Consequently, the study is limited by the characteristics of these participants, including the number and type of risk factors present in each situation. In addition, in keeping with the phenomenological method, the findings are, therefore, generalizable only to the group of older adults studied. Finally, recruitment of participants was limited by a labour disruption at the referring agency and the necessity of completing the research investigation within the time constraints of a Master's thesis.

#### **Assumptions**

Two assumptions are identified in this study. The writer assumes, first, that older adults are concerned about their health status and functional limitations, as well as other risk factors that might be present in the situation, and second, that the information these adults gave to the researcher about these concerns is an accurate reporting of the meaning of the experience for them.

#### Summary

This study has been designed to explore the experience of living "at risk" from the perspective of older adults who are living in the community. To date, little information has been available on the subjective experience of the phenomenon of risk. Chapter One introduced the research problem and its significance, thereby providing a rationale for the study. In addition, it described the conceptual framework guiding the study, the context in which the study was conducted, and the methodological perspective. Finally, the first chapter outlined the assumptions and limitations of the study. Chapter Two presents a review of the literature relevant to the topic. Chapter Three describes the research method used in the study, and Chapter Four presents the findings and interpretation of the data. A discussion of the findings is presented in Chapter Five, and

Chapter Six presents the conclusions and implications of the research for nursing.

#### **CHAPTER TWO: LITERATURE REVIEW**

#### Introduction

This chapter presents a review of literature pertinent to the purpose of the study, the specific research method used to study the phenomenon of risk from the perspective of the older adult and the context in which the study was conducted. In order to answer the overall question -- What is the lived experience of "risk" from the perspective of the older adult living in the community? -- the researcher examined literature on the concept of risk as it relates to the older population. In addition, the conceptual framework guiding the methodological approach to the study directed the researcher to review the literature for qualitative studies conducted with older adults. Third, since this phenomenologic study of the particiants' lived experience of risk was conducted within the context of development of an outreach program for "at risk" older adults (see Appendix A), the researcher examined the literature on programs to reduce or manage risk. The scope of this literature review, is necessarily broad in order to present an overview of information related to the above topics. To this end, the selected literature is organized into a discussion of the concept of risk, health care programs for reducing or managing risk, concepts associated with risk and research methods in nursing studies involving older adults.

#### The Concept of Risk

The literature abounds with descriptions and discussions of those factors that contribute to the degree of risk for the older adult. The theoretical and research literature can be categorized into four general topic areas:

- factors associated with admission to long-term care facilities or nursing homes;
- factors that influence the older adult's length of stay in an acute hospital or unplanned readmission to that hospital;
- 3. health care programs designed to manage risk factors to prevent admission or readmission to acute care or admission to a long-term care facility; and
- 4. concepts associated with risk.

# Factors Associated with Admission to Long-Term Care Facilities or Nursing Homes

Researchers in medicine, psychology and epidemiology have identified a number of risk factors associated with admission to long-term care facilities or nursing homes. The risk factors, or individual characteristics, found to be significantly related to nursing home admission are consistent across studies. Branch and Jette (1982) found that the

probability of nursing home admission was greatest for persons who were older, used aids for ambulation, were cognitively impaired, living alone and who needed assistance in instrumental activities of daily living. While also identifying the above characteristics, Cohen, Tell and Wallack (1986) discovered that being bed bound, widowed or single and being a welfare recipient all contributed to the risk of nursing home entry. The findings of Kane and Matthias (1984), in a landmark retrospective study of patients discharged from hospital, supported the above characteristics as being predictive of nursing home admission. Moreover, these researchers found that gender (women were at greater risk), race, various hospital admission diagnoses and treatment categories (e.g., orthopedic surgery) also were risk factors for nursing home admission.

While each of the above studies differs in the populations from which the data were drawn and in the research methods, the results have contributed to an understanding of those factors that contribute to nursing home use. As is emphasized in all of the studies, the ability to identify individual characteristics, or risk factors, associated with nursing home admission "can be a planning and case managing tool in targeting individuals who are at greatest risk of admission" (Green & Ondrich, 1990, p. \$256.). This same rationale has been applied to studies of hospitalized

and recently discharged older adults. The studies described in the following section were directed toward targeting those older adults in acute care hospitals who are at greatest risk for prolonged hospital stay or unplanned readmission to hospital.

# Factors Associated with Prolonged Hospital Stay or Unplanned Readmission to Hospital

The pressure to limit use of acute care services has spurred, in recent years, an interest in identifying factors on hospital admission predictive of short and long-term outcomes for older patients as well as in examining reasons for unplanned readmission to hospital. Consequently, many studies have been conducted to identify predictors for hospital readmission, rates of readmission and factors affecting early unplanned readmission of older adults (Graham & Livesley, 1988; Incalzi et al., 1992; Narain et al., 1988; Rowland, Maitra, Richardson, Hudson & Woodhouse, 1990; Vinson, Rich, Sperry, Shah & McNamara, 1990; Williams & Fitton, 1988; Winograd, Gerety, Brown & Kolodny, 1988). These studies on hospital readmission are similar to those which identified risk factors for admission to nursing homes in that they too vary with regard to the type of acute care facility in which the study was conducted, the study design, the age range of the subjects, the sample size and the outcome of

hospitalization measured. Nevertheless, the risk factors associated with hospital readmission identified in these studies are comparable across studies and similar to the risk factors associated with nursing home placement. The three specific studies discussed below are representative of the studies on readmission to hospital and are mentioned here to highlight the specific risk factors identified in all of the studies.

The first study, by Narain and colleagues (1988), presents a summary of the literature on studies of hospital outcomes for older patients. The authors report that the various studies on hospital outcomes have shown that specific factors are related to increased in-hospital mortality, mortality at six month follow-up and prolonged hospital stay. Those factors include advanced age, low functional and mental status, poor social support, multiple prior hospital admissions, multiple medications, certain medical diagnoses, such as cardiovascular disorders and neurologic disease, falls and incontinence. In their own prospective multivariate study of hospitalized elderly patients at an acute care Veterans Administration hospital, these authors found that the risk factors identified in the previous studies were, in fact, predictive of poor hospital outcome. In addition, they identified that patients with children as caregivers were more likely to

be rehospitalized within six months than patients with spouses as caregivers.

In the second study, Graham and Livesley (1983) examined the frequency and causes of readmission of patients to a geriatric medical unit within twelve months of their previous discharge. They found that, over the course of one year, readmissions accounted for 24.8% of all patients admitted. As a result of their findings, the authors concluded that readmissions were related to factors associated with "unavoidable clinical deterioration, inadequate medical management in the community, non-compliance of the patient, social problems and inadequate rehabilitation" (p. 404). Graham and Livesley (1983) propose that readmission could have been prevented in 47.7% of these patients had the predisposing factors for readmission been identified and corrected prior to discharge from hospital.

The third study, by Williams and Fitton (1988), compared a group of elderly patients who had an unplanned readmission with a matched control sample of patients who were not readmitted. They found that the unplanned readmission rate was 6% and that 59% of those readmissions were avoidable. In addition, patients who were readmitted showed significant differences from those who were not readmitted. Readmitted

patients, for example, had lower income, multiple previous hospital admissions, were receiving home nursing care, and had caregiver problems.

In summary, the results of these three studies support the claim that certain identifiable characteristics of older adults and their living situations predispose them to readmission to the hospital. The results also suggest that readmission of older adults to acute care hospitals is, in many cases, preventable. Furthermore, such prevention is dependent upon early detection of those older adults exhibiting the characteristics or living in the specific circumstances that place them at risk for readmission. The results of these and other studies have led to the development of various types of health care programs designed to reduce or to manage the characteristics of older adults that contribute to their risk of hospital admission and/or readmission or long-term institutional placement. The next section presents a review of the literature pertinent to those programs.

## Health Care Programs for Reducing and/or Managing Risk

The literature describes community outreach and hospital programs that have been implemented specifically for the purpose of reducing the older adult's degree of risk for hospitalization or institutional placement.

These programs range from demonstration projects to established services

and differ with regard to their specific treatment objectives, the category and number of health care professionals involved in the program, the type of service provided, the methods of program evaluation and the degree of rigor with which the programs were evaluated. The following discussion provides a general overview of the nature of the programs designed to prevent or manage risk.

#### **Outreach Programs**

Most outreach services to date have been developed to assess and treat the mental health problems of older adults. The prevalence of mental health problems and the resulting need for such services is well documented in the literature. Wasylenki, Harrison, Britnell & Hood (1984) state that older adults, particularly those over the age of 75, are the group most at risk for mental health problems. Beattie (1988) reports the rate of dementia at 5 to 10% for persons over age 65 and 20 to 30% for those over age 80. Donnelly (1988) estimates that 13% of older adults require intervention for depression. However, despite the prevalence of mental problems, older adults have traditionally underutilized mental health services (Pruchno, 1983). This underutilization has been attributed to older adults' concerns about the stigma associated with mental problems and health professionals' negative stereotypes about older people

(Eisdorfer, 1977; Kermis, 1986; Mumford, Schleshinger, Glass, Patrick & Cuerdon, 1984).

Mental health outreach services designed to offer assessment and treatment to older adults in their homes have increased accessibility to the services and have resulted in both resolving or stabilizing of treatable mental health problems and preventing hospitalization or institutionalization (Brown & Lieff, 1982; Campbell & Chenoweth, 1981; Geisz, 1990; Houston, 1983; Knight, 1983; Kyle, Drummond & White, 1987; Levy, 1985; Reiffler, 1982; Santos, 1983; Wargon & Schulman, 1987; Wasylenki, Harrison, Britnell & Hood, 1984).

A number of authors recommend in-home geriatric medical care based on the mental health outreach model. Arcand and Williamson (1981) report that home visiting by geriatric physicians has been standard practice in the United Kingdom for decades. In a study to describe the characteristics of patients visited in their homes, as well as the patient outcomes of the visits, these authors concluded that a home visit is useful for assessing the needs of patients and caregivers. In addition, the information obtained about individuals' social, nursing, medical, psychiatric and rehabilitation needs assists health care professionals with post-discharge planning when these individuals are admitted to hospital.

Clarfield & Bergman (1991) initiated a medical services home care program for housebound elderly who did not have a primary care physician. The goals of the service were "patient identification, clinical assessment, medical and social stabilization, matching of the housebound patient with a nearby family physician willing and able to provide home care and provision of a back-up service to the physician for consultation and help in arranging admission to hospital if necessary" (p. 40). One year after initiating the medical home care program, Clarfield and Bergman (1991) surveyed a sample (n=35) of 105 discharged patients: 24 persons (60%) were still at home, and only 1 (3%) was in a long-term care institution.

Rossman (1988) and Burton (1985) present arguments in favor of physicians assessing and treating older adults at home. Rossman (1988) reports the results of studies indicating that older patients suffering from conditions such as heart disease and cancer actually do better at home than comparable patients in hospital (p. 349). Also, Rossman (1988) believes that because older adults in hospital are at risk for iatrogenic illness and hospital-acquired disability, they are best treated in the familiar environment of their homes. Burton (1985) extends the above argument to state that other characteristics of older adults make home-based

treatment a necessity. First, the elderly who are frail or those with terminal illness experience difficulties with transportation to health care facilities. Second, the social support structure, the physical environment and the patient's functional status in the home are critical to the care of the older patient. This author believes that those same arguments could be made for provision of nursing care in the home.

Finally, other outreach services investigated in the literature include:

- consultative geriatric assessment within a health maintenance organization (Epstein et al., 1990);
- 2. geriatric primary-care outreach located in residential complexes such as apartment buildings (Foster & Moses, 1987);
- 3. non-medical home-based services (Hereford, 1989);
- 4. hospital-based clinics for screening and education (Gerardi, 1982; Yehida, 1990; Zink & Bissonnette, 1990); and
- 5. home-based medical assessment and treatment (Clarfield & Bergman, 1991; Cohen & Kelsey, 1990; Currie, James, Friedman, Warshaw, 1981).

With the exception of the home-based medical care which provides medical care only, the goal of these programs is to provide health screening, patient education, assistance with home maintenance activities,

friendly visiting and peer counselling. All of the programs are based on the belief that services to older adults must be accessible, are best provided in the home, will foster independence and will prevent institutionalization.

In conclusion, despite the reported value of all of the programs described above, there is a paucity of information on both their cost benefit and effectiveness in reducing hospitalization and institutionalization. Currie, James, Friedman & Warshaw (1981) argue that the beneficial impact of home health care on the pattern of institutionalization can only be hypothesized owing to the difficulty in conducting program evaluation studies. These authors believe that the large number of subjects and the extensive length of observation time required prohibit such studies.

## <u>Institutional Programs</u>

Health care professionals in the hospital sector have implemented a number of programs to promote early discharge, to prevent readmission and to prevent inappropriate admission to emergency services. A comprehensive review of these programs appears in two recent articles: in the first article, Weinberger and Oddone (1989) review and summarize research on hospital readmissions and evaluate the strategies used for

"reducing readmissions among medical and geriatric patients" (p. 255); in the second, Hogan (1990) evaluates studies of geriatric consultation programs in acute care and the reported impact of these programs on the clinical status of elderly hospitalized patients. The following is a brief summary of the findings of these authors.

Weinberger and Oddone (1989) discuss the importance of developing program strategies that will prevent costly readmission to hospital and still maintain quality of care. In their analysis of the literature related to predictors of hospital readmissions, they report that readmissions:

- 1. occur within the first 30 days after discharge;
- 2. account for a major component of health care expenditures;
- 3. occur for problems that arose during the original hospitalization;
- 4. are frequently preventable.

They categorize efforts to prevent hospital readmissions as:

- ambulatory care interventions such as patient education programs, ensuring patients keep appointments and receive continuous care, geriatric care units;
- 2. post-discharge home monitoring strategies such as in-home followup by clinical and non-clinical personnel;

- 3. in-patient strategies such as geriatric consultation units and teams;
- 4. multifaceted intervention strategies such as a combination of two or more of the above strategies depending on the patient's needs.

The authors conclude that "the cost-effectiveness of interventions may be enhanced by targeting them to patients at high risk of readmission" (p. 259) and by implementing programs for elderly hospital in-patients. In addition, they recommend the development of validated predictive models for readmission that "can serve as a valuable clinical tool for targeting high-risk patients who may benefit from interventions aimed at decreasing readmissions" (p. 256).

In the second article, Hogan (1990) critically examines nine studies of the clinical impact of geriatric consultation teams. Hogan (1990) reports that these studies varied with regard to design (some were descriptive, others were quasi-experimental or experimental), evaluation formats, service composition and methods, target patient populations and/or specific local factors (for example, patient location, existing quality of care, staffing). Because of methodological variations in the studies, Hogan (1990) concludes that it is difficult to evaluate the utility of the consultation teams. He does, however, recommend that further research

be conducted to target populations appropriate for specialized geriatric services and to assess the impact of these services over the long term.

On the whole, researchers in various disciplines have studied the concept of risk in older adults from different perspectives and for different reasons. Physicians, epidemiologists and social science researchers have conducted studies: (i) to identify factors related to admissions to facilities; (ii) to implement and evaluate strategies to eliminate risk factors; (iii) to target individuals for specialized services; and (iv) to provide a basis for program and policy development. It should be noted that nurses for the most part, have not engaged in studies designed specifically to describe and to classify risk factors per se. In fact, the term "risk factor" does not appear as extensively in the nursing literature as it does in other gerontological literature. The individual risk factors themselves, however, do concern nurses. The next section outlines concepts related to risk and risk factors as they appear in the nursing literature.

# Concepts Associated with Risk

It could be argued that most of the phenomena investigated by nurse researchers in gerontology relate to the concept of risk or to the risk factors identified earlier in this review. Consequently, a comprehensive review of the research and theoretical literature on concepts related to risk

is beyond the scope of this thesis. The following discussion, therefore, focuses on examples of risk and related concepts from the literature.

The term "risk" appears in the gerontological nursing literature primarily in relation to patients at risk for falls and skin breakdown. Some nursing studies have been conducted which seek to determine the incidence of falls and the characteristics of persons who fall (Barbieri, 1983 and Venglarik & Adams, 1985). Moss (1992) discusses risk in relation to injury of older adults at home and has developed a data collection tool for risk factors for home injuries. Early research on pressure sores focused on the development and use of at-risk scales (Braden & Bergstrom, 1989; Gosnell, 1973, Norton, McLaren & Exton-Smith, 1975). Otherwise, as stated previously, risk as a concept, in and of itself, is not widely used in gerontological nursing literature.

Burnside (1988) and Adams (1986) summarize studies in which nurses have investigated phenomena related to older adults. Studies reported by Burnside (1988) that relate directly to the risk factors discussed previously involve subject areas such as (i) falls (Barbieri, 1983) in which the investigator identified characteristics of individuals who fell; (ii) life events and life change events (Muhlenkamp, Cress & Flood, 1975) in which the perception of life change events and perceived control by the elderly were studied; and (iii) evaluation of health services (Sullivan &

Armignacco, 1979) in which the effectiveness of a comprehensive health program for well elders provided by community health nurses was evaluated.

Adams (1986) has organized her review of the findings of gerontological nursing studies into the following categories: (i) enabling physical functioning in activities of daily living; (ii) enhancing self-esteem; and (iii) optimizing care environments (p. 79). The studies cited by Adams which provide examples of concepts associated with risk within these categories include:

- 1. mobility (Basset, McClamrock & Schmelzer, 1982);
- 2. altered status (Roslanie & Fitzpatrick, 1979);
- 3. social support (Fuller & Larson, 1980);
- 4. privacy (Roosa, 1982); and
- 5. family caregiving (Archbold, 1980; Hirschfeld, 1983 & Phillips, 1983).

Concepts associated with risk also appear in the theoretical literature. Such concepts as loss, powerlessness, isolation, decreased mobility, alterations in body image and changing lifestyle are used to describe those factors that influence the ability of the older adult to adapt to altered physical, social and, perhaps, environmental circumstances

(Badger, Cameron & Evers, 1989; Berger & King, 1990; Burnside, 1988; Gerardi, 1982; Giorella & Bevil, 1985; Taira, 1988). According to these theorists, the role of nursing is to assist older adults to manage those factors that affect their ability to adapt to altered circumstances.

The above discussion illustrates that concepts related to risk are widely represented in the gerontological nursing literature. Moreover, there exists a substantial body of nursing research associated with these concepts. The majority of research studies, however, used quantitative strategies and research instruments borrowed from research in gerontology in other disciplines. The next section presents an examination of the research methods used in nursing studies of older adults as they relate to the use of quantitative strategies and the need for qualitative research on the experiences of older adults.

# **Research Methods in Nursing Studies Involving Older Adults**

The conceptual framework that guides this study is based upon explanatory models of behaviour. These explanatory models, in turn, influenced the choice of research method, that is, phenomenology, because the researcher seeks to understand the subjective experience of participants. However, the research with older adults generally has not been designed to explore subjective experience of phenomena. Instead,

quantitative research designs have been the primary modes of inquiry into the problems of older adults in all of the disciplines that conduct gerontological research. This final section of the literature review addresses two specific concerns that have arisen as a result of the prevailing use of quantitative methods in studies involving older adults. The first concern relates to the use of quantitative methods in general. The second concern has to do with the need for research related to the subjective experiences of older adults.

## Use of Quantitative Methods

The quantitative designs that have been used in gerontological research range from survey approaches to experimental and quasi-experimental methods. However, Strieb (1983) and Adams (1986) believe that researchers must now reexamine their reliance on traditional methods, particularly in research related to the elderly.

The focus of most gerontological research has been on the youngold in the community and on institutionalized older adults. Indeed, most studies consider persons age 65 and over as if they represent a homogeneous population when, in fact, marked differences exist between the healthy 65 year old and the homebound 85 year old. Strieb (1983) argues that the old-old, those over age 75, who live in the community, have been neglected in research studies because they are more difficult to locate and to interview. Strieb (1983) concludes that "most of the aggregate data on the aged are based on ... the rational, functioning older person -- the healthier, more active, more vocal elderly" (p. 41). Therefore, according to Strieb (1983, researchers must now engage in studies of the old-old; studies which necessitate new ways of obtaining data. These new ways, he states, are the qualitative methods of research.

Adams (1986), in her critique of gerontological nursing research, suggests that the choice of research instruments is a weakness in many of the studies. Some instruments used in nursing studies have been taken from other disciplines, others have required that the older subjects be mentally competent. Adams (1986) suggests, therefore, that the measurement tools used "did not test the [nursing] phenomena proposed for study" (p. 94). Implicit in her remarks about the use of borrowed instruments is the belief that they should not be used until, or unless, "study concepts are operationalized specifically for clinical nursing phenomena" (p. 94).

The use of quantitative methods in gerontological nursing research is evident in Burnside's (1988) summary of studies related to the elderly. While the number and types of studies reported are too numerous to

discuss, in reviewing her summary, one can see that quantitative methods have been used to identify, describe, explore and make predictions about phenomena related to older adults and nurses who work with older adults. For example, she claims that prevalence surveys were used to investigate falls, accidents, evidence of confusion and types of foot problems.

Other reported studies cited by Burnside (1988) used instruments to measure phenomena in areas such as attitudes of nurses toward older persons, subjects' self-rated physical and mental health, life change events, morale and life satisfaction, relocation and disengagement.

The Need for Qualitative Research Concerning the Older Adult

There is some evidence in the literature that nurse researchers in gerontology are beginning to use qualitative methods of inquiry to study the phenomena of concern to older adults (Folden, 1990; Magilvy, Brown & Dydyn, 1988; Murphy & Freston, 1991; Trice, 1990; and Van Maanen, 1988). Murphy & Freston (1991), in a study which analyzed theory-research linkages in published gerontologic nursing studies conducted between 1983 to 1989, found eleven qualitative studies, three of which used grounded theory methods.

Folden (1990) and Magilvy, Brown and Dydyn (1988) used ethnographic methods to study phenomena related to older adults living

at home. Folden (1990) explored the meaning of being homebound for frail older adults whose health and functional problems resulted in their being unable to leave their homes. Qualitative analysis of the experience of these older adults reflected an underlying theme of loss. However, Folden (1990) states that the perceptions of these informants of being homebound also reflected an acceptance of their condition. In other words, being homebound was not perceived as a negative consequence of their illnesses.

Magilvy, Brown and Dydyn (1988) sought to gain an understanding of the experience of home health care from the perspective of frail older clients. The findings of this study were that "although initially assistive, home health care was perceived to support dependency as the patients became more well and able to undertake self-care" (p. 140). Both this study and the one by Folden (1990) suggest that feelings of independence and personal control are important for frail older adults and that, once again, being homebound may not be the negative experience that many health care professionals believe it to be.

Finally, Trice (1990) and van Maanen (1988) used the phenomenological approach to study meaningful life experience and the meaning of health respectively. Trice (1990) developed an exhaustive description of a meaningful experience based on the perceptions of the participants about those aspects of various experiences through which these individuals derived a sense that their lives were meaningful. van Maanen (1988) conducted two studies designed to explore the meaning and significance of health for older adults. At first, conducting her study with American subjects (1983-1985), van Maanen (1988) then replicated the study with a sample of British elderly (1986). The accounts of both groups reflected the importance of independence and personal choice, findings consistent with those of the studies mentioned previously.

In summary, the above studies illustrate that qualitative methods of inquiry enable nurse researchers to acquire in-depth information on older adults' lived experience of phenomena. However, the review of the literature also shows that such research, particularly with old-old and frail older adults, is in its infancy in gerontological nursing.

# Summary

This chapter reviewed literature which provides information on the concept of risk and on qualitative research methods as they have been used in studies with older participants. The literature shows that the concept of risk appears in the literature of many fields, predominantly medicine, epidemiology and the social sciences. The emphasis of research in those fields to date has been on: (i) identifying risk factors for hospital

admission and long-term institutional placement; (ii) targeting older adults for specific programs and (iii) evaluating the effectiveness of programs in preventing readmission to hospital and institutional placement. Despite the great number of studies on risk and risk factors, there is a paucity of information on the subjective experience of risk from the perspective of the individual.

The concepts of risk and risk factors as they are used in the above studies, appear to have no equivalent in the nursing literature. However, because the concept of risk is so multidimensional, many concepts in nursing, such as loss, powerlessness and immobility, can be said to be related to risk. Currently, the writings on these concepts are largely theoretical in nature and represent the assumptions and opinions of the authors rather than research findings. Furthermore, these concepts are only indirectly related to the notion of risk as it is used in this study.

The research literature in gerontology in all of the disciplines, including nursing, revealed a paucity of studies using qualitative methods to study the experiences of older adults. Most research studies have used quantitative approaches to study aggregate populations of primarily young-old persons. Moreover, nurse researchers have borrowed research instruments developed for use in other disciplines. These instruments have

not, in most cases, been adapted to measure phenomena specific to nursing. One can conclude from this review of the literature that it is important now to ask the questions and to use the research methods that will enable nurses to understand the meaning of experience of various phenomena for older adults.

#### **CHAPTER THREE: METHODOLOGY**

#### Introduction

The phenomenological method was chosen for this study of older adults' lived experience of risk because this research method enables the researcher to explore the meaning of living "at risk" from the perspective of the participants. The following discussion outlines the procedures that were applied for selection and recruitment of participants, data collection and analysis and protection of the human rights of participants.

# **Selection of Participants**

The principle of theoretical sampling was used to select participants for the study. This principle provides direction to the researcher to select participants based on their ability to provide data representative of the phenomenon under investigation (Field & Morse, 1985, p. 95). For the purpose of this study, that is, to describe the experience of living "at risk" from the perspective of the older adult living at home, potential participants must be identified by a health care professional as living in a situation in which one or more risk factors affect their ability to live independently. The following is a description of the selection criteria, the rationale for use of those criteria and the procedure for recruitment of the participants and the sample size.

## Selection Criteria

The following selection criteria were developed and used to ensure that the participants in the study were, in fact, experiencing difficulties with independent living, and would, therefore, be knowledgeable about that phenomenon.

To this end, informants were selected who:

- 1. were 65 years of age or older.
- 2. were eligible for admission to the SSATC Day Hospital Program.
- 3. had a SSATC preadmission assessment completed before risk factors were determined and the individual identified as a potential subject.
- 4. were living in a situation where one or more risk factors were present (see Appendix C) that posed a threat to the individual's ability to live independently.
- 5. scored above 24 on the Folstein Mini-Mental Status Exam when administered by the community assessor during the preadmission assessment.
- 6. resided in a house or apartment, not a care facility.
- 7. understood and spoke English.

## Rationale for the Selection Criteria

The purpose of the SSATC is to work with older adults experiencing health-related problems that interfere with the ability to live independently. Following referral to the SSATC, the centre's community assessor conducts a multidimensional health and functional assessment of the older person in his or her place of residence. The Folstein Mini-Mental Status Examination, one component of that assessment, is used as an initial screening test of cognitive functioning. During this time of preassessment, the assessor also generates a list of the client's presenting problems and determines the urgency with which the individual should be admitted to the SSATC program. This degree of urgency is based upon the assessor's clinical judgement as to whether or not the health and safety of the older adult is threatened by factors present in the current situation. As was mentioned in Chapter One, the assessor, along with other health care professionals in the SSATC, have developed a risk screening tool in order to identify those individuals who require immediate assessment and treatment in order to prevent a sudden deterioration in health status. Therefore, the SSATC risk factor screening tool was used in this study for two reasons. First, use of the tool to identify the presence of risk factors would ensure selection of participants who were perceived by a health care professional to be living in situations of risk. Second, the Folstein Mini-Mental Status Examination would screen out potential participants whose cognitive impairments might affect their ability to describe their current situations to the depth required by the phenomenological approach to this study. Because the focus of the study was on individuals who were striving to live independently in the community, participants were required to live in a house or apartment, not a care facility. The fact that the researcher only speaks English required that the participants be fluent in English so that they could express their thoughts and feelings and be understood by the researcher. Finally, selecting participants who were 65 years of age or older ensured that the experience of risk was described from the perspective of older adults.

## Recruitment Procedure

A specific procedure for recruiting participants was planned and implemented. The SSATC community assessor, having participated in the development of the risk screening tool, already possessed both the theoretical and the clinical knowledge related to risk factors that threaten older adults' ability to live independently. As a result, she required very little introduction to the concept of risk. That fact notwithstanding, the assessor did receive an in-depth explanation of the study and the selection

criteria by the researcher. In addition, the researcher provided the assessor with a written form outlining: (i) the procedure for recruitment, as well as criteria for selection, of participants; (ii) the definition of risk factor as it is used in this study and (iii) a list of the empirical indicators of risk as they are identified on the SSATC screening tool (see Appendix C). To recruit subjects, the assessor, after completing the preadmission assessment, used the list of risk factors and the selection criteria to determine the individual's eligibility for participation in the study. Once the assessor determined the individual to be eligible, she explained the purpose of the study and asked the individual's permission to be contacted by the researcher. If the individual agreed, the assessor then completed the risk factor form for later use by the researcher. At this point, the researcher contacted the individuals by telephone and gave them further information about the study. The researcher made home visits to those individuals who agreed to participate and provided them with a letter of explanation (see Appendix D), answered questions about the study and formally secured their agreement to participate in writing (see Appendix E).

# Sample Size

The researcher anticipated that a sample size of eight to ten participants would be required to achieve theoretical saturation. However,

circumstances arose which resulted in a final sample size of six participants. First, some of the characteristics of the individuals referred to the SSATC prevented them from meeting the study's selection criteria. The SSATC accepts referrals from a community catchment area where many older adults are non-English speaking. Consequently, while many of these older persons were living "at risk" and, as such, were appropriate for the study, they could not be selected. Second, during the period of the study, many individuals referred to the SSATC had a Folstein MMSE score of less than 24, thus rendering them ineligible for participation. However, despite these circumstances, basic meaning units and similar themes began to emerge from the data after the researcher had interviewed only four participants. According to Field and Morse (1985), in qualitative research: "data are collected until no new information is obtained" (p. 94); the researcher continues to select and to interview participants until repetitions in the data appear and no new themes emerge during the data analysis which occurs simultaneously with data collection. Thus, the researcher determined that the data obtained from six participants was sufficient to answer the question posed by this study.

#### **Data Collection**

West, Bondy and Hutchinson (1991) propose that "because the elders' words and actions can be so difficult to interpret, it is essential to have a large quantity of data and more than one kind of data" (p. 176). For this reason, the researcher collected various data from a range of sources. Those sources and the rationale for their use in this study, as well as the data collection process itself, are described below.

## Sources of Data

Data were collected from three sources throughout the course of this study: (i) the narrative accounts by the participants, (ii) observations by the researcher of the participants and their physical environments and (iii) documentary data sources that provided information relevant to the study.

#### Narrative Accounts

These data, which represent the thoughts, feelings and experience of the participants, were obtained through interviews conducted in the participants' homes. Being with older persons, in the environments in which they live every day enabled the researcher to achieve an understanding of the participants' experience in remaining independent. The interviews, ranging in length from thirty minutes to two hours, were

audiotaped and the verbatim transcriptions compiled for data analysis. While the interviews were, for the most part, unstructured, a list of trigger questions derived from the identified risk factors (see Appendix F) were used to encourage participants to discuss, in depth, issues of importance to them. However, a more directed interviewing approach of using more probing questions was used for three subjects whose responses to openended questions were minimal, thus resulting in unclear and insufficient data.

Second interviews with each subject occurred four weeks after the initial interviews. At that time, data collection occurred simultaneously with data analysis as themes and shared meanings emerged from the data. The researcher searched for themes within each person's accounts and compared and contrasted all of the accounts for similarities and differences in themes and shared meaning. At this point, the researcher, during the second interviews, was able to ask participants questions related to the emerging themes.

#### Researcher's Observations

Another source of data for this study were the field notes maintained by the researcher throughout the data collection process.

Following each interview, the researcher documented observations related

to the participants': (i) physical appearance; (ii) mental status, including affect, cognition and mood; (iii) home environment; and (iv) surrounding neighbourhood. The researcher also documented notes pertaining to the content of the conversations that occurred before and after the interviews. These notes enabled the researcher to capture both the context of the interview and her own reactions in relation to the behaviour and experience of the participants. Consequently, the researcher's observations of the participants' physical, mental and environmental characteristics as mentioned above facilitated her interpretation and validation of the data.

Documentary Data Sources

The final sources of data for this study were materials containing information relevant to the study. These were the risk factor screening tool completed by the community assessor and a demographic form (see Appendix G) on which was recorded the participant's age, sex, medical diagnoses, Folstein MMSE score, the reason for the referral of the participant to the SSATC and a summary of the risk factors as identified above. Once again, the researcher used these data to develop an understanding of each participant's unique living experience. The researcher also used the risk factors specific for each participant as a focus

for the trigger questions to begin discussion of the person's current situation.

# **Data Analysis**

As mentioned previously, analysis of the data occurred throughout the data collection process. The participants' descriptions of their experiences were analyzed using a process of constant comparative analysis. A major characteristic of the phenomenological method is that major categories of data, themes and concepts are generated from the data by the researcher throughout the research process. The researcher moves back and forth from the transcripts to themes, from one subject's account to another subject's account in order to identify common themes and differences and, finally, to identify common patterns of meaning. The following method, as described by Giorgi (1975) and Field and Morse (1985), was used to guide data analysis in this study:

 Following transcription of the interview, the researcher replayed the audiotape and compared it to the transcript. Changes in tone of voice, significant pauses and inflections which may indicated emotion or the importance of the topic were noted on the transcript.

- 2. The researcher reread the transcript to get a sense of the meaning of the whole experience of the participant.
- 3. The researcher began to analyze the data on the transcript by (i) identifying meaning units from concrete data; (ii) relating the meaning units to the whole experience; (iii) reflecting on the meaning units; (iv) clustering the meaning units into themes or concepts; and, finally, (v) synthesizing the concepts into a description of the participant's experience.

The criteria of credibility and auditability, rather than the more traditional reliability and validity techniques, were used to achieve scientific rigor in the analysis of the data. The following strategies were used to ensure credibility and auditability and to control for bias in the interpretation of the data: (i) conducting a second interview with each participant to clarify the researcher's interpretation of the data, to prevent emphasis on "non-recurring, idiosyncratic statements or behaviour" (Benner, 1985, p. 11); (ii) presenting data from the transcripts that support the findings; (iii) obtaining consensual validation from members of the thesis committee for subsets of data "to guard against the importation of meanings not actually supported by the text" (Benner, 1985, p. 11); and (iv) striving to maintain, throughout the processes of data collection and

analysis, a decision-trail to enable readers of the research to see how decisions regarding the data were made (Sandelowski, 1986, p. 33). However, the verbal data obtained from the participants in this study was often scant and superficial. As a result, in order to construct an interpretation of the participants' experience of risk, the researcher was required to use her observations of the participants' behaviours and physical surroundings as well as the data provided by the documentary sources. Moreover, in a further effort to control for bias in her interpretation, the researcher reviewed her interpretation of these data with two clinical nursing experts in gerontology.

Finally, the researcher analyzed the data from the risk factor forms completed by the community assessor during her preadmission assessment of each participant. These data were analyzed to determine the type and frequency of occurrence of risk factors experienced by the participants in the study.

### **Ethical Considerations**

The researcher obtained approval for the study from The University of British Columbia Behavioural Sciences Screening Committee for Research and Other Studies Involving Human Subjects. The researcher also obtained

permission from the health care agency through which participants were recruited.

Participants who met the selection criteria and who, when approached by the community assessor, agreed to participate in the study were provided with a written description of the study (see Appendix D) followed by a verbal explanation by the researcher. Both the written and verbal information stated that the individuals' participation in the study was voluntary and that a refusal to participate would not influence any care they were currently receiving or might require. If individuals agreed to participate, they could refuse to answer any questions asked, request to have information removed from the audiotape, or withdraw from the study at any time. The researcher also informed participants about the details of the participation required; that is, two visits to their home by the researcher and two audiotaped interviews regarding aspects of their current living situation. Finally, the participants signed a consent form (see Appendix E), a copy of which they received.

Confidentiality was maintained throughout the course of the study.

Only the researcher knew the identity of the participants whose names

were eliminated from the audiotapes and coded on the transcripts and

demographic sheets. Access to the tapes and transcriptions has been

limited to the researcher, the members of her thesis committee and her typist. The researcher will destroy the audiotapes when the study is completed and the scholarly reports are written.

# Summary

In this chapter, the methodology for this study was described.

Included was a discussion of participant selection, data collection, data analysis and ethical considerations.

# CHAPTER FOUR: FINDINGS AND INTERPRETATION Introduction

This chapter presents the findings of the research on living "at risk" derived from the data obtained from three data sources: (i) the narrative accounts by the participants, (ii) observations by the researcher of the participants and their physical environments, and (iii) documentary data sources which included the participants' clinical records at the SSATC and the risk factor forms (see Appendix C) completed by the community assessor for each participant. These data are interpreted by the researcher in order to describe the meaning of living "at risk" from the perspective of the older adult living at home. This description of living "at risk" evolved from a constant comparative analysis of the participants' explanations of their experiences in relation to the specific questions that directed the study, the researcher's observations and the documentary data sources. In addition, the researcher validated the interpretation of living "at risk" during second interviews with the participants and with two clinical nursing experts in gerontology.

The findings of this study suggest that the participants did not perceive the risk factors present in their situations as threats to independent living. For the health care professional, living "at risk" means

living in a situation where the presence of one or more risk factors threatens the individual's ability to continue to live independently. Hanks, McLeod and Urdang (1986) define threat as an "indication of imminent harm, danger or pain" (p. 1586). Risk factors, then, are threats to independent living in that they represent the potential for decline in older adults' health status or functional abilities which, in turn, may result in admission to an acute or long-term care facility.

However, two aspects of the participants' experiences related to independent living were different from the notions of health care professionals about independent living described above. First, the participants discussed concerns and experiences related to their past and present living situations, not concerns related to their being vulnerable to future harm. They mentioned the future only within the context of their feelings about their own death; that is, the future had meaning in relation to the participants' mortality, not to a potential loss of independence.

The second aspect of the participants' experiences related to independent living was that not only did the participants fail to talk about the possibility of their losing their independence in the future, but they also did not talk about the possibility of losing their independence in the present. Rather, their discussions focused on efforts to cope with changes

in their day-to-day lives as a result of declining health and functional abilities.

Risk factors, then, were not viewed by the participants as threats to independent living but were described and experienced as losses. These losses were related to both the direct consequences of recent changes in health and functional ability and the cumulative effect of many years of health, functional and life changes.

All of the participants had experienced recent changes in their health and functional status. Indeed, these changes and the participants' resulting inability to manage their activities of daily living constituted the reasons for the participants' referral to the Short Stay Assessment and Treatment Centre (SSATC) by a family member or community health care professional. At the time of this study, all of the participants were attending the SSATC's Day Hospital Program where they were participating in various diagnostic and treatment regimes. While the participants discussed concerns related to these changes and treatments and the effects of these changes on their lives, they interpreted the changes as losses. It would seem, therefore, that what are "risk factors" and living "at risk" for the health care professional are interpreted as "losses" and coping with losses by the older adult.

One of the recent changes experienced by all of the participants was a change in their mental status. Consequently, the ability of some of the participants to describe their thoughts and feelings, other than superficially, was affected by the presence of cognitive impairment and/or depression. The result was that not only did the participants experience multiple losses, but also some of them had difficulty in verbally communicating that experience to others. This difficulty contributed to the complexity of the loss experience for those participants. Furthermore, it affected the nature of the data obtained in the study in that it was often scant and lacking in depth or richness.

While each participant's experience of loss was unique in that the number and combination of losses were different, the experiences were similar in that multiple losses created experiences that were both complex and challenging. Similarities also existed with regard to the characteristics of the losses and in the strategies used to cope with the losses. Moreover, as mentioned above, the specific loss of the ability to articulate one's thoughts and feelings further contributed to the complexity of the loss experience.

The loss experience as articulated in this chapter was a complex one owing to a combination of the characteristics of the participants and the

nature of the losses. Furthermore, the interpretation by the researcher of that complex experience of loss was complicated by the presence of one specific participant characteristic; that is, a change in mental status. Two general patterns emerged as participants engaged in coping strategies to respond to these complex situations. In meeting the challenge of coping with multiple losses, participants used strategies either to remain actively engaged in their world or to endure the consequences of the losses in their lives. For these reasons, the findings of this study have been organized and presented as a description of the complexity of the loss experience and the coping strategies used by the participants in responding to their losses.

# The Complexity of the Loss Experience

As has been mentioned, the risk factors interpreted by health care professionals as threats to independent living were experienced and described as losses by the participants. These losses were related to the effects of individual risk factors and the cumulative effect of multiple risk factors. Moreover, the types and characteristics of these losses resulted in complex situations of loss for the participants. The specific loss of cognitive ability affected some participants' ability to verbally communicate their experience to others. Another consequence of this

particular inability was that the researcher was required to use a range of data sources in addition to interview data in order to interpret the participants' subjective experience of living "at risk." This section presents the findings related to the two factors that contributed to the complexity of the loss experience: the characteristics of the participants and the type and characteristics of the losses they experienced. In addition, the effect of the change in the mental status of participants on the nature of the data obtained in the study is discussed.

# Characteristics of the Participants

This description of the characteristics of the participants evolved from the data collected from the SSATC clinical records, the risk factors identified for each participant by the community assessor, the researcher's observations of the participants and descriptions by the participants themselves. Five women and one man, all Caucasian, participated in this study. Their ages ranged from 73 to 89 years, with a mean age of 82 years. At the time of this study, the mean number of chronic illnesses per participant was 4.3. In terms of living arrangements, five of the participants lived alone. Four of the women lived in apartments, one woman lived with her daughter and 12-year-old great-grandson in a small house, and the male participant lived alone in a large house. The

individuals' scores on the Folstein Mini-Mental Status Examination ranged from 25/30 to 30/30.

Table 1 presents a summary of the type and frequency of risk factors identified by the community assessor during her preadmission assessment of the participants. The number of risk factors identified as present in each situation ranged from 4 to 9, with a mean number of risk factors at 6.5 per participant. This number of risk factors alone suggests that each participant's situation was a complicated one. As can be seen in Table 1, three of the participants were referred to the SSATC because of a change in mental status related to possible cognitive impairment and depression and three because of a change in physical status.

Several health problems were evident among the participants: visual and hearing impairments, cardiovascular, respiratory, musculoskeletal and metabolic disorders and, in the case of four participants, nutritional deficits. Of particular note is the fact that all six of the participants had depression identified either as a reason for referral or following an assessment by the geriatric psychiatrist. Indeed, many of the reasons for referral to the SSATC themselves suggested the existence of depression, such as anorexia, weight loss, disorientation and self-neglect.

Table 1: Type and Frequency of Occurrence of Risk Factors

Identified by the Community Health Care Professional

Risk Factor	Frequency
<ul> <li>Health Status</li> <li>change in physical status within the past 8 weeks</li> <li>change in mental status within the past 8 weeks</li> </ul>	3 3
<ul> <li>Medication Issues</li> <li>uses &gt; 3 prescription and OTC drugs</li> <li>uses psychotropic drugs</li> <li>takes 2 or more analgesics</li> </ul>	5 1 1
Discharge from acute care within past 8 weeks	1
<ul> <li>Self Care</li> <li>change in mobility</li> <li>unable to cook</li> <li>forgets to take drugs</li> </ul>	2 2 1
Hazards  • falls  • physical self-neglect  • nutritional deficits	2 1 4
Lifestyle Changes Within Past Six Months  • losses/bereavement • change in usual pattern of social contact	3 1
Social Support  Ives alone unwilling to accept home help unwilling to accept placement reports of family conflict	5 2 1 1

A change in health status was only one of the risk factors experienced by the participants. With regard to physical mobility, only

two participants were able to ambulate safely without the use of a mechanical aid. Of the other participants, two used Able walkers and one a cane. One woman could walk unaided, but she experienced "weakness" and "panic attacks." As a result, she lacked the confidence to walk outdoors. Another participant, although he often lost his balance and fell, did not use any mechanical aids in order to ambulate safely.

The participants varied with regard to their ability to engage in both the activities of daily living (ADL) required for basic self-care and the more complex instrumental activities of daily living (IADL) that are associated with independent life, such as shopping, banking, etc. As a result, individuals received home support services depending upon their particular requirements for assistance.

For example, one woman received two hours per week of home support for cleaning her apartment, while another woman received a full range of services designed to enable her to continue to live independently in her apartment. This range of services were coordinated so that the woman received assistance with personal care and meal preparation on a daily basis. These services included her attendance at an adult day care program twice a week, homemaker assistance for bathing, cleaning and laundry, and meals-on-wheels on those weekdays when she was not at the

day care, weekly visits from a home care nurse, daily phone calls from her grandson and weekend visits to her grandson's home.

In short, the characteristics of the participants depict a group of individuals who were "old old" and, in most cases, living alone. They had chronic health problems and, depending upon the degree to which their current health problems affected their functional abilities, experienced difficulty in managing both their ADL and their IADL. Lastly, participants had a number of risk factors present in their situations. These risk factors, in turn, resulted in a number of losses which are described below.

#### Losses

As mentioned previously, the number and type of losses experienced by each participant were unique. However, the participants' situations were similar in that they experienced four types of losses. Moreover, these losses possessed certain inherent characteristics. In this section, the types of losses experienced by the participants and the characteristics of these losses are described.

# Types of Losses

The actual losses experienced by the participants fell into four categories: the loss of functional abilities, the loss of meaningful

relationships, the loss of meaningful activity and the loss of independence and control.

The first category, the loss of functional abilities, refers to the loss of those abilities of the participants to engage in activities of daily living and instrumental activities of daily living. In other words, all of the participants, depending upon their underlying health status, experienced changes in their abilities to ambulate safety or independently, to engage in activities for personal care, such as bathing, doing laundry, cooking and to perform those instrumental activities that support independent living such as shopping, banking and attending social and recreational activities.

All of the participants described their lost abilities in terms of what they were no longer able to do. One woman explained that she had "difficulty walking. ... I'm not driving my car and that bothers me. ... I can't get out as much as I'd like." Another woman also experienced difficulty walking as a result of pain and foot drop caused by spinal stenosis. In addition, recent cataract surgery had failed to remove all of the cataract, so that her vision was impaired. In describing her current living experience, she said: "I'm spilling everything ... don't see no good. ... Can't go to my hairdresser. ... can't get this leg to manoeuvre onto a bus."

It is interesting to note that the one participant described not the loss of his own functional ability but that of his wife who had managed his activities of daily living. He stated that he was "not used to having to do everything for [himself]" and that his "biggest concern is looking after [himself] for food."

One woman interpreted her functional losses in terms of a loss of energy. For four months, she "could not eat" and lost twenty-three pounds. In addition to not eating, she also could not sleep, so that she had no energy during the day to engage in her usual activities. With the exception of this woman, who lived with her daughter and great-grandson, all of the participants received home support assistance to compensate for their functional losses.

The second type of loss experienced by the participants was the loss of meaningful relationships. Participants experienced the loss of meaningful relationships either through the death of or estrangement from loved ones. The lost relationships described by the participants were relationships with persons with whom the participants had been involved throughout their long lives. Participants described past relationships with their parents, siblings, friends, spouses and children. Their sense of loss appeared to be intensified by the fact that these relationships were

irreplaceable and, in some cases, by unresolved feelings of disappointment or anger. For example, one participant, in describing his wife's placement in an extended care unit, appeared to be angry at her for leaving him alone. He stated that his wife might as well be dead: "She goes to the hospital and she can't do anything else but be there. ... it's just like a tape recorder is broken and you can't put it together." Trying to describe the meaning, for him, of his wife's hospitalization, he said:

She goes and falls and has a stroke and her life stopped, and it's nothing. I had dreamed of her and I living together until one of us had died, passed away. But this is just, it's just like wanting to have, oh, I can't describe it.

The above excerpt from an interview transcript illustrates the difficulty that this participant experienced in expressing his feelings over his situation. In addition to his perception that he had lost his relationship with his wife, the participant also experienced cognitive deficits resulting in marked word-finding problems. These data suggest that this man may have been experiencing difficulty in resolving his feelings about his wife.

The other five participants had been widowed for many years. All five women mentioned the loss of their husbands, but only one woman expressed her unhappiness at not having her husband with her now. This

woman and her daughter had been estranged for three years, a situation foremost on her mind and the root of many of her current difficulties. Indeed, during the two interviews for this study, this woman's stories focused on her relationship with her daughter. She stated that estrangement from her daughter made her miss the support she would have received from her husband. "This is my biggest problem in my whole life. It was bad and sad to lose my husband. But, when I didn't have him to share it with, it was worse, you know." Another woman experienced a similar loss of relationship with her daughter. To her, that estrangement from her daughter represented not only the loss of her own child, but also the pleasure of knowing her grandchildren.

The third type of loss, that of meaningful activity, refers to activities from which the participants had previously derived a sense of competence, accomplishment and pleasure. The inability to participate in these activities was a result of the participants' declining health and functional abilities and the absence of intimate, supportive relationships, as discussed above.

Participants described losses related to social events, travelling, volunteer work and membership in community organizations. Their own difficulties with walking, driving a car and using public transportation, or

the absence of someone to help them, prevented the participants from engaging in activities that formerly had been meaningful and enjoyable. As one woman explained, "Now I can't travel. I used to get out and about and go to the island and this sort of thing, which at this point I can't do now ... these are the sorts of things I miss." Another woman, who had enjoyed entertaining in her home, stated that entertaining now "is a little difficult because [I find] it hard to stand too long in the kitchen." This woman experienced severe pain in her lower back and legs, which restricted her abilities to stand and walk. At the same time, it also restricted her ability to engage in her favourite social activity.

The final type of loss experienced by the participants is what the researcher has chosen to call the loss of independence and control. This sense of feeling independent and in control of one's life was a recurring theme in the stories of all the participants regardless of the number of losses they had experienced or the amount of home support they received.

Owing to functional limitations, the participants spent most of their time in their houses or apartments. They walked to nearby neighbourhood shopping areas by themselves but were dependent on assistance from others to leave their neighbourhoods for physician's appointments, social events, etc. In addition, the social world of the

participants was diminished by their infrequent interaction with individuals outside of their homes and also through the loss of family and friends. As mentioned previously, five of the participants were receiving home support services to assist them with activities of daily living and instrumental activities of daily living. The functional inabilities for which this assistance was required, as well as the assistance itself, represented a loss of personal control over daily living activities for the participants.

The inability to ambulate safely within and outside of their homes represented a loss of independence for these participants. Their feelings associated with this loss of independence reflected a loss of the sense of freedom to go outside whenever they wanted. As one woman explained, being able to "get up and go out whenever you felt like it is so important, you know. People don't appreciate their good legs until they don't have them."

The participants' comments on the cleaning, laundry and meal assistance they received appeared to reflect a frustration at not being able to perform these activities unaided and at not being able to control the manner in which others performed these activities. This frustration was evident in one woman's description of the assistance she received with cleaning her apartment:

I don't get enough things done that I should, you know. I mean I know I don't. She [the home support worker] doesn't ever, you know, wash the bathroom floor, behind the toilet never gets touched or anything, you know and I don't know if they think I don't notice it but I'm a hawk when it comes to things even if I don't say anything.

Some participants talked about the importance of feeling independent and in control of your life: "You don't want anybody controlling your life. [Despite all of the help I receive] I can still do what I like ... when I want to." In other words, they continued to be able to live alone even though they experienced severe functional disabilities for which they received a large amount of home support services. These individuals felt that, within the privacy of their own homes, they could do whatever they wanted whenever they wanted to do it. Their perception, then, was that they were still independent and controlling those aspects of their lives that were within their ability to do so.

As the four types of losses discussed above illustrate, the experience of loss pervaded every aspect of the participants' lives. However, their experience of the losses, regardless of the type, was also affected by certain characteristics inherent in all of the losses. The following section

discusses those characteristics and their effect on the complexity of the loss experience.

#### Characteristics of the Losses

Two central characteristics of the losses that intensified the subjective experience of loss for these participants were the irrevocable nature of many of the losses and their interrelatedness. The participants had experienced various lasting changes in their health status including physical, mental and functional changes. Viewed within the biopsychosocial context of aging, these changes and the resulting losses were irrevocable. Furthermore, these individual changes in abilities precipitated the experience of a number of additional interrelated losses.

The participants' stories revealed that they thought about the irrevocability of both their current and their past losses. With regard to current losses, the data seem to reflect an ambivalence about the irrevocable nature of the losses related to aging. On the one hand, participants accepted the changes in their abilities as a natural result of growing old. Their stories were punctuated with remarks such as "Well, at my age, what do you expect?" and "You have to accept these things ... after all, they're inevitable." On the other hand, participants were seeking a medical solution to their problems at the SSATC. While all the

participants expressed a belief that they were "not sick," at the same time they wanted to know the underlying causes of their current difficulties.

One woman stated that if she was sick she would "certainly wish [she] was dead." Another women explained that there was

nothing wrong with my body, I was thinking too much ... what can I do? I'm not sick, this is the aggravating part of it, you know, there's nothing wrong with me. They've [SSATC] done all the tests.

Implicit in this search for a cause was the notion that, if one were found, then perhaps some of the changes or losses could be reversed. This discrepancy between the participants' feeling about the changes in their health and functional abilities and their reasons for going to the SSATC led the researcher to conclude that the participants may have had ambivalent feelings about the irrevocable nature of their current losses.

The data also suggest that the participants reflected on the irrevocability of past relationships, and dreams and ambitions that would remain unfulfilled. The participants related stories about the relationships they had hoped to have with spouses who had died young, financial security they had not achieved or careers they had not pursued. One woman for example, talked about her "lost babies." As a young woman

she had experienced a miscarriage, losing twin girls. Now she often thought about those babies and wished that they were with her.

Another participant spoke of how much she missed her sister. This woman had been referred to the SSATC because of depression following the death of her sister, even though the sister had lived in Denmark and the two women had seen each other only twice in the past 70 years. Now she said, "I can't explain it ... I'm the last of the Mohicans." Her sense of loss was evident in her reflections on her relationship with her sister:

I still think about her. ... There were only the two [of us] there, my mother was sick in bed all the time that I can remember. She was always in bed. She died when I was eight years old and then it was just my sister and me. My dad got up early in the morning — five o'clock — went to work and then he got home during supper time. So her and I were alone. ... she always felt she was my mother, and I always felt that way too.

Relationships such as the one described above were irreplaceable. The loss of these relationships appeared to cause the participants to reflect on the irrevocable changes they were experiencing as they aged.

The second characteristic of the losses that contributed to the complexity of the loss experience was their interrelatedness. As was mentioned above, the losses appeared to having a cascading effect in that one loss led to another. The result was that all of the losses were connected.

The loss of functional ability combined with the loss of a meaningful relationship had a major impact on the ability to engage in meaningful activity. This combination was evident in the story of a woman who had to negotiate seventeen steps without falling just to get outside of her apartment. In addition, she was estranged from her daughter who lived in Edmonton. She described how these two factors had affected her ability to engage in the one activity from which she derived both a sense of accomplishment and a deep feeling of pleasure: shopping.

In the past, this participant had been outgoing and fun-loving. She travelled around Vancouver by bus, shopping for bargains and talking to the salespersons with whom she was acquainted. Shopping for her own groceries and successful bargain hunting represented a sense of accomplishment and competence for this woman. In contrast, when describing her current experience of grocery shopping, she stated:

I'm pretty slow, poking around. 'Course I have my walker but it's not very -- it takes a long time to put in an order when you're not on roller skates.

Moreover, when describing the former pleasure she had derived from shopping, the woman lamented the fact that the daughter from whom she was estranged lived near the Edmonton Mall. Her interpretation of the loss of her daughter also included the loss of pleasure she would have experienced in shopping at the Edmonton Mall if she could only visit her daughter.

My heart just breaks to think I can't walk around to go there and spend a few days just going in and out of that place.

And oh, all the stuff they got there ... I used to go down to Portland to shop and down to Seattle to shop, of course I shop till I drop, and that's the way it was. I used to just love every minute of it. Tired or not.

Thus, the characteristics of the losses can be interpreted as contributing to the complexity of the loss experience. The participants had experienced lasting changes in their health and functional abilities from which they knew there would be no recovery. Furthermore, they believed that people did not establish new, intimate relationships in old age.

Therefore, the relationships that the participants had lost were irreplaceable. Finally, the multiple losses they had experienced were so interrelated that it was difficult for participants to view individual losses separately. A factor which added further complexity to the loss experience, and to difficulties for the researcher in interpreting that experience, was the effect of certain losses on some participants' ability to describe their situations.

### The Nature of the Data

The final factor contributing to the complexity of the loss experience, as the findings of this study portray it, related to the nature of the data obtained in the study. The nature of the data was affected by the most noteworthy of the characteristics of the participants; that is, their mental status. As was mentioned previously, the specific mental status characteristics that most influenced the data were the participants' cognitive abilities and emotional states. As a result of cognitive impairment and/or depression, many of the participants exhibited a poverty of thought and expression. Consequently, during the interviews, most of the participants were unable to provide a detailed verbal description of their current living situations despite the fact that the researcher used probing questions in addition to open-ended questions. In

addition to the verbatim transcripts, the researcher, therefore, used a combination of her own observations as well as documentary data sources to provide further insight into the meaning of the participants' subjective experience of living with multiple losses.

With regard to cognitive impairment, two of the participants were assessed by the SSATC community assessor as having scores of 25/30 on the Folstein Mini-Mental Status Examination. A score above 24 on the Folstein MMSE is generally indicative of intact cognitive functioning. Consequently, a MMSE score above 24 was one of the criteria for eligibility for this study. One limitation of the MMSE is that it is a screening test only and may not, as was evident in this study, detect specific cognitive difficulties in every case. The individual items on the MMSE are designed to test functioning in various cognitive domains. The score on individual items within each domain contributes to a global score for the MMSE. Specific cognitive deficits have an impact upon this total score "only when they are sufficiently severe to interfere with other areas of cognitive functioning" (McFarlane, 1991, p. 11). Consequently, screening tests, such as the MMSE, that use global scores and cut-off scores to suggest impairment, can mask deficits in specific cognitive domains (Tsai & Tsuang, 1979). In addition, concerns have been raised about the

sensitivity of the MMSE in detecting focal deficits (Tsai & Tsuang, 1979) and deficits resulting from right hemisphere involvement (Dick, Guiloff & Stewart, 1984). Such was the case with two participants in this study. Following the participant interviews, the researcher's review of the SSATC clinical records revealed that more comprehensive neurobehavioural cognitive testing at the SSATC indicated that two participants experienced difficulties in areas of cognitive functioning that affected both their insight and ability to communicate their thoughts and feelings to others.

The first of these participants experienced mild to severe deficits in the areas of attention, judgement, repetition and word-finding.

Psychological tests suggested that this participant also suffered from moderate psychosocial impairment, possessed dependent personality traits, had achieved only a grade four education and would be at risk for suicide should his functional abilities decline any further. The second participant whose cognitive abilities affected her verbal communication, experienced a mild impairment in comprehension, judgement and naming abilities as well as severe memory impairment.

The following excerpt of a verbatim transcript from an interview with one participant demonstrates the minimal responses reflective of cognitive deficits obtained during some of the interviews:

R: You've experienced some changes in your health recently.<sup>1</sup>

Oh, I guess I have.

R: Can you tell me what those changes were?

No, I can't really tell you. ...

R: You're still losing your balance?

Once in a while, yes.

R: What's that like?

Well, it's just - just can't keep my balance.

R: Is there anything that helps? Do you use a walker?

No, I haven't.

R: Does [losing your balance] prevent you from going outside and doing things that you might want to do?

Not really.

R: You still go out.
Oh, yeah.

R: Every day?

Most days.

<sup>&</sup>lt;sup>1</sup>"R" is used to identify the researcher in the body of this chapter.

The other mental status characteristic that influenced the depth and richness of the data was the participants' emotional state. As stated previously, all of the participants had been diagnosed as suffering from a depression resulting from various circumstances ranging from extreme grief over the death of a family member to feelings of sadness over declining physical abilities. The participants, however, expressed their sadness mainly through facial expression and body language rather than verbal language, for example: stooped body posture, lack of eye contact, expressionless eyes, flat tone of voice or crying. Those who did verbalize their feelings expressed those feelings briefly and then changed the subject or otherwise avoided further discussion. For example, one woman matterof-factly described her unhappiness about her inability to bathe independently. She stated in a determined tone of voice, "You know, later, when I'm more confident, I should be able [to bathe] myself, I hope. I'm planning," and then she changed the subject. Another woman became so fatigued when she discussed the death of her sister that she closed her eyes and requested that the interview be terminated.

The effect on the data of the changes in participants' mental status, as well as the findings related to the other factors outlined in the preceding discussion, suggest that the experience of loss was a complex

one. The data also suggest that the characteristics of the participants and the type and characteristics of the losses also affected the participants' coping strategies in responding to the losses. The remainder of the discussion of the experience of living "at risk," as described by these participants, will elaborate on the nature of coping with the complex experience of loss.

## Coping with the Complexity of the Loss Experience

Participants used a variety of coping strategies in responding to their losses. The strategies varied with participants' health, physical, mental and functional abilities and their relationships with others. For example, the strategies used by individuals who experienced cognitive deficits affecting their insight, comprehension and judgement were different from those of participants who fully understood their situations or who could seek solutions to their problems. Furthermore, the data also led the researcher to speculate as to whether individual participants' current coping strategies reflected their personalities and a style of coping that had been developed and used over a lifetime. Hence, while the participants used a range of coping strategies, these strategies formed two different characteristic patterns of coping which the researcher has termed "engaging" and "enduring." The pattern of "engaging" included those

strategies by which individuals strived to remain mentally and physically involved in their worlds. In contrast, the pattern of "enduring" was characterized by passive responses whereby participants "endured" the consequences of the losses they had experienced. The discussion of coping will be organized in the context of these two characteristic patterns.

#### **Engaging**

The pattern that the researcher has conceptualized as "engaging" includes two specific coping strategies. The first, restructuring, involved the use of coping behaviours by which individuals restructured their activities of daily living as a result of the changes in their abilities. The second, refocusing, involved behaviours that enabled participants to focus their efforts on maintaining their remaining functional abilities and integrating changes in function and the resulting losses into a positive view of themselves.

## <u>Restructuring</u>

Participants using the strategy of restructuring engaged in coping behaviours to organize and conduct their day-to-day activities in order to be as independent as possible. These activities included personal care, cooking, shopping, recreational activities, etc. For these participants, being as active and self-reliant as possible was important for maintaining their

independence. Participants varied in their abilities to perform activities of daily living given the specific losses they had experienced. Some participants were able to wash, dress and prepare a simple meal only while others were able to shop and participate in community activities.

Regardless of their abilities, all of the participants established daily routines that gave structure to their lives. They described ways in which they had made adjustments in the routines or in their methods of performing tasks based on their limitations:

I do everything early [in the morning] so that by the evening when I'm tired I don't do it. And [then] I just have cold food, you know, like salads and things but I always have a full meal around one or two o'clock. Big meal, you know and especially meat ... Like this morning I was up early, I made my fruit salad and I made my carrot sticks so I've got that made for the week. You know, I sit here [at the kitchen table] and chop and chop and stick the garbage [can] there and then I don't have to stand ... Long as I don't have to stand I can get things done, but standing — three minutes and I'm finished.

As the information from the various data sources revealed, even those participants who were functionally able to just wash and dress maintained a highly structured routine. They found that this lent predictability to their lives and gave them a sense of control. Their routines revolved around the home support services they received, telephone calls from family or friends and their favourite television shows. Their home support services, usually homemakers and meals-on-wheels, followed an established weekly schedule. In addition, family members and friends phoned at designated times to chat or to "check-up" on the participant. Finally, the daily activities of washing, dressing, eating and talking on the telephone were scheduled so that the participants could watch specific television shows.

Thus, individuals strived to restructure their daily lives in order to maintain their maximum level of independence and a feeling of control over their lives. They structured their activities so that they could accomplish those tasks that they were capable of performing. They described ways in which they had made adjustments in their routines or in their methods of performing a task based on their limitations. The ability of these participants to engage in behaviours to restructure their daily lives was enhanced by their use of another coping strategy: refocusing.

## Refocusing

The data suggest that participants using this coping strategy directed their thoughts and energy toward positive action to manage their complex situations. Hence, they focused on maintaining or improving their remaining abilities rather than dwelling on their lost abilities. Their attitude was positive and determined. As one woman explained, "I have never let anything get me down and I still don't." The participants were able to refocus any frustration they may have felt about their disabilities into managing that disability. One woman was too afraid of falling to bathe independently. However, her attitude was positive and determined: "I'm still not brave enough to [bathe] by myself ... [but] one day I will!" In the meantime, she had a home support worker assist her with the weekly bath.

Refocusing also meant that participants brought a sense of purpose to their activities whether it involved just "getting through the day" or, as in one woman's situation, being able to continue to live in the family home. Maintaining this home was, for her, a way of providing her grandchildren and great-grandchildren with a sense of family history. This woman felt that, at this late stage in her life, providing her family with a sense of continuity gave her a sense of purpose. As she explained, the

most important thing for her was "to keep a home for [my grandchildren and great-grandchildren], a place where they can have roots."

Participants engaged in a number of behaviours to maintain or improve their functional abilities. They walked or exercised daily and tried to eat three balanced meals a day. Although ambulation was painful, difficult and sometimes unsafe, they maintained this ability by walking to nearby neighbourhood shopping areas or around the hallways in their apartment buildings. Some participants felt a sense of responsibility for improving their situations. They arranged for the installation of mechanical aids and equipment in their apartments to improve their mobility and enhance their safety when transferring onto the toilet and into the bathtub.

Finally, by refocusing, these individuals were able to integrate their current experiences into their sense of who they had been all their lives in order to achieve a coherent sense of self. They felt satisfied not only with their current situations but also with their lives as a whole:

I'm not traumatized by any of this, it's just sad you know ...

But it has to be, I mean, after all, it's life isn't it? .... I could
be so much worse off so I try to be philosophical about the
whole thing .... I look back and I had a nice husband and a

nice home [and my daughters] are good to me and I'm good to them, I think. So, you know, I could be so much worse off than I am now. All the people who haven't got that.

Thus, it appeared that participants who were able to refocus their thoughts and energy into incorporating the changes in their abilities into their lives, felt fortunate. Engaging in strategies by which they actively coped with the complex losses associated with aging created a means by which they felt satisfied with their current situations and their lives as a whole.

### <u>Enduring</u>

The coping pattern that the researcher has termed "enduring" includes the specific strategies of depending and withdrawing. These strategies involved participants' submitting to the structuring, by others, of their daily activities, physical and mental withdrawal from contact with others and inactivity. Participants utilizing "engaging" strategies may have accepted assistance from others but insisted on being in control. In contrast, individuals utilizing "enduring" strategies were physically or mentally unable to engage in the activities of daily living without the assistance of others but lacked the ability to control their lives. As they

explained, they "just can't change things and do better than [they're] doing now." Thus, withdrawal and dependence on others for decision-making, represented strategies by which these participants were coping with their inability to control their lives.

## <u>Withdrawing</u>

Participants utilizing this coping strategy exhibited a passive response to the changes in functional abilities experienced and the losses that were incurred as a result of these changes. These individuals seemed overwhelmed by their losses and thus were unable to mobilize themselves into positive action. They made no observable efforts to maintain or improve their functional abilities. One of the women, who was estranged from her daughter, did little else except rock in her chair all day wondering why and how they had drifted apart:

I let my mind get carried away with my troubles. ... She doesn't come to see me ... there must be something behind it. ... I think on it all the time.

While this woman repeatedly said that she had plans to do many things (such as move to a new municipality where she had friends, join a seniors' club, volunteer at the long-term care facility across the street from her apartment), she did not pursue any of her plans.

As this example illustrates, some participants seemed to withdraw, both physically and psychologically, from performing activities of daily living and from involvement in the world outside of their homes. They were unable to describe any daily routine; they had "no plans" and "no particular things to do." They did not watch television, read or keep in touch with others by telephone. Moreover, these individuals did not initiate leaving their homes or apartments on their own. Instead, they attended appointments, adult day care or family social occasions only if these outings were arranged and managed by someone else. As a result of this passivity and withdrawal, the lives of these participants lacked the structure, predictability and sense of purpose that was evident with persons who were using "engaging" coping strategies. Moreover, they were required to depend on others to manage these activities they were unable to manage on their own.

# **Depending**

The strategy of "depending" means that participants had to rely on others in order to compensate for their loss of functional abilities.

"Depending" differed from the "engaging" coping strategies in that these participants were not in control of the management of their daily lives. In other words, they were dependent on others, either family members or

community health care professionals, for both decision-making and direction. As the characteristics of the participants illustrated, some participants experienced the loss of cognitive abilities and supportive relationships. These losses affected the individuals' ability to make decisions and to independently perform the activities of daily living such as cooking, shopping, baking and housecleaning. As a result, these participants received many home support services. The participants' responses to this loss of independence and control ranged from comfortable acceptance to feelings of frustration and incompetence. One woman's calm acceptance of the structuring of her life by others arose from her love for her grandson. She had cared for him as a young boy and since that time they had maintained a relationship based on mutual love and devotion. Now, the grandson managed all of his grandmother's affairs and collaborated with health care professionals in providing services to his grandmother. The grandmother, in turn, gratefully accepted these services. When this woman told the story of her experience of having another person manage her life she said:

I think I've been fortunate. I have B. and his wife and kiddies ... I couldn't do without them .... I've always been independent, you know, more or less, when I was younger,

but you can't keep up forever you know. I'm very happy the way I am.

This woman's cognitive deficits interfered with her ability to conduct her daily activities on her own. However, the efforts of her grandson and various community health care professionals enabled her to continue living alone in her apartment.

Conversely, other participants felt useless as a result of having to depend on others. They said that the feeling of uselessness "is there every time [they] do anything." One man explained what it felt like to always be told by others what to do:

Well it's just this idea that you're told by everybody "Oh, you have to reconcile yourself to these things." Boy, you can reconcile yourself but it still won't alter the fact that you got to like it or not. I can't tell my troubles to anybody because they just say, "Well, you can't change things you have to live with them." ... Everybody in my family, my sister, and my brother, and — they just say, "Oh, you have to change your ways of living, you have to change your way of thinking." I can't do that. I can change but I can't change for the better.

Clearly, this man's feelings reflect an unhappiness about his losses and about others giving him advice about how he should manage his losses. However, despite his unhappiness, he depended on others for organizing and providing assistance with shopping, cooking, cleaning and finances.

Thus, participants who were depending on others for assistance differed in their feelings about this dependence. This difference can be partially explained by the nature of the relationships they had with those upon whom they were dependent. For some, their children or grandchildren provided supportive relationships that made them feel loved and cared for:

I have good kids ... my three darling daughters ... I couldn't do without them, you know, they keep track of me ... They won't let me get gloomy ... I'm very fortunate and I know it.

For others, depending represented a lack of control over their lives and feelings of sadness and despair over the effects of their losses.

Enduring strategies, then, were also ways in which individuals responded within the context of their current experience of loss. However, certain data also suggested that individuals' personalities and style of coping with events throughout their lives influenced the coping strategies

they used now. In other words, "engaging" and "enduring" reflected lifelong patterns of coping.

## **Engaging and Enduring**

The participants' descriptions of their current approach to coping with losses were similar to their descriptions of approaches they had used to manage problems all their lives. Individuals explained that they coped in a particular way because it was just "their nature" or because "they've always [approached life in] that way." In other words, "engagers" had always been proactive, determined and actively engaged in managing their lives. On the other hand, "endurers" had always been somewhat passive, withdrawn and reactive rather than proactive in responding to changing circumstances in their lives.

Individuals utilizing engaging strategies described events in their past lives that they had perceived and approached as a challenge. These descriptions reflected the same active, determined efforts in coping with past circumstances that they were attempting to employ now in their current circumstances. Individuals told stories about past adventures of working in the far north, struggling to survive during the Depression of the 1930s, raising their families and caring for their dying husbands.

Moreover, they felt a sense of satisfaction at having tackled these situations

in a positive way. One 79 year old woman travelled alone to Alert Bay in the 1930s to nurse and teach Innuit and logging families. Her stories revealed that she seemed to respond to her current losses with the same courage and humour that sustained her when living in the north. This woman described herself as "quite an independent person really. ... [I] always have been. ... So, [I'll] carry on now as best I can!"

Another woman exhibited attributes similar to the ones described above. She explained that during the Depression of the 1930s, everyone was "in the same boat so what was the use of being unhappy about it?" This woman, her family, and neighbours, responded to the losses on their farms by joining together to feed, clothe and support one another. This woman continues to demonstrate similar behaviours in that she has gathered a community of friends and family around her. She provides a home for her daughter, grandson and long-time family friend.

In contrast, those study participants who utilized "enduring" strategies described themselves and situations in their past lives that led the researcher to question whether these individuals had been passive, withdrawn and reliant on others throughout their lives. In their stories, they described past and current situations which they perceived as being

beyond their ability to control. These individuals expressed feelings of sadness and despair over the lack of control they have had over their lives.

One man felt that, through no fault of his own, he had never had any control over his life. He explained that if only "he had been born rich [then] his life would have been different" or "if only [he] had married a different woman." He stated that he had "never felt satisfied" with his life. "It's just my nature," he said, "[and] I just can't change it." To date, this man's coping strategies of "depending" and "withdrawing" had enabled him to function because his wife had managed his activities of daily living. However, his wife was now in an extended care unit and, hence, was unable to assist him to manage his current losses. Without the ability to develop new coping strategies and in the absence of a supportive relationship, this man could potentially succumb to the effects of multiple losses.

The feeling of not having control over your life was also evident in the story of one woman's reaction to having been referred to a psychiatrist because of her depression. Her reaction seemed to characterize the "enduring" pattern of coping in that the referral immobilized her as opposed to motivating her into action:

I was terribly annoyed ... it just kept me all the time not to cry ... But I just kept [my feelings] within [me]. I never told them what was bothering me.

When questioned about why she chose not to share her feelings about the referral with the health professionals involved, she replied that she didn't really know "what's holding [her] back." Furthermore, she explained, "I just stay away [from people and events]. [I've always been] too shy to push myself in. I'm a very lonely person, you know."

Each of the participants mentioned above appeared to feel that they have always lacked the ability and the control over their lives that would have enabled them to improve their situations. Now, faced with multiple and irrevocable losses, their apparently lifelong "enduring" pattern of coping appeared to pose a threat to their ability to live independently.

#### Summary

In this chapter, the findings related to the meaning of living "at risk" were presented. The findings revealed that the meaning of living "at risk" for health care professionals was different from the meaning for the participants in this study. For the health care professional, older adults living "at risk" are those whose ability to live independently is threatened by the presence of risk factors such as a decline in physical, mental and/or

functional ability and lack of social support. However, the participants interpreted risk factors as losses and the experience of living "at risk" was one of coping with the complex experience of loss.

The experience of loss was a complex one for the participants in this study as a result of the number and type of risk factors present in each participant's situation. These risk factors resulted in losses of functional abilities, meaningful relationships, meaningful activities and feelings of independence and control. The fact that many of these losses were irrevocable and occurred within the context of the participants' aging further complicated and intensified the participants' experience of loss. One particular loss, related to changes in mental status, affected some participants' ability to articulate their perception of their experience to others. It also affected the nature of the interview data collected in the study in that they were scant and superficial. In addition to the interviews, the researcher, therefore, used observational data and documentary data sources to interpret the experience of living with complex situations of loss.

The coping strategies used by participants in responding to their losses formed two distinct and opposing patterns. These patterns were "engaging" and "enduring." The first pattern, "engaging," involved the specific strategies of "restructuring" and "refocusing." In using these

strategies, participants were able to restructure their daily living activities in order to achieve a sense of predictability and purpose in their lives. They were able to focus on their remaining abilities, engage in activities to strengthen those abilities and remain actively involved, physically and/or mentally in their worlds. Lastly, they were able to incorporate their losses into a positive view of themselves.

"Withdrawing" and "depending" were the two coping strategies that formed the pattern of "enduring." Participants utilizing these strategies experienced an inertia, an inability to initiate behaviour to perform various activities of daily living. These individuals were dependent on others for assistance with cooking, cleaning, shopping and decision-making. However, they varied with regard to their degree of acceptance of the assistance. This varying degree of acceptance was reflected in feelings ranging from gratitude to resentment and was influenced by the presence of cognitive disability and social support.

Despite the understandable bias most might feel that engaging is better that enduring, the researcher must stress that one pattern of coping is not necessarily inherently better than the other. The data from this study do suggest that engaging coping strategies resulted in positive outcomes for participants. Indeed, these participants did experience a

sense of purpose and satisfaction with their lives as a whole. Moreover, they were able to muster affirmative responses to the losses they had experienced. By comparison, one might assume that participants who utilized enduring coping strategies would experience corresponding negative outcomes. However, that was not always the case. Depending on others for assistance with daily living was a satisfying outcome for the participant who relied on her grandson for that assistance. It would seem, therefore, that individuals utilizing enduring strategies could achieve positive outcomes with the provision of appropriate services or assistance.

In summary, the subjective experience of living "at risk" was one in which the older adult must cope with multiple and irrevocable losses. The differences in how these "risk factors" and losses were experienced appeared to be related to individuals' inner resources and to abilities they had developed throughout life. Their inner resources included personality characteristics and their physical, mental and functional abilities. In addition, the participants' current experience of loss was influenced by their experience of past losses and lifetime patterns of coping with loss. Finally, the irrevocability of the losses caused participants to reflect on their past lives and their own aging. Such reflection seemed to engender some

ambivalence about aging, particularly aging in the presence of multiple health problems and losses. As one woman so succinctly remarked:

Don't ever think that getting old is beautiful. That's the biggest crock there is ... and I know who said that — who made that saying. It was a 20 year old. It wasn't a person who was 75 or 80 that made that saying.

#### CHAPTER FIVE: DISCUSSION OF THE FINDINGS

### Introduction

This chapter provides a discussion of the findings of the study as presented in the previous chapter. The discussion focuses on the significance of the findings as they relate to the experience of community-dwelling older adults whose ability to live independently is threatened by the presence of one or more risk factors.

The chapter begins with a brief overview of how the findings relate to the explanatory models that guided the approach to the study. The remainder of the discussion is organized into three sections. The first two sections examine the findings on specific aspects of the phenomena of loss and coping with loss as they relate to older adults. The third section focuses on the findings related to the nature of the data obtained in the study and the issues that arise for conducting qualitative research with older adults. In addition to the literature discussed in Chapter Two, further studies and theoretical works will be employed to illustrate the research findings.

Two explanatory models of behaviour provided the theoretical underpinnings that guided the approach to this study. Both Kleinman's (1978) explanatory model of transactions in health care relationships and

the U.B.C. Model for Nursing (U.B.C. School of Nursing, 1980) provided direction for the researcher to explore individuals' interpretations of the experience of living "at risk."

As was discussed in Chapter Two, most studies on risk as it relates to older adults have focused on identifying those causes or risk factors associated with prolonged hospital stay, readmission to hospital or institutional placement. Other studies have used risk factor screening measures to target older adults for specific treatment programs. Still others have evaluated a wide range of treatment programs based on their effectiveness in reducing or managing risk. Indeed, there now exists a substantive body of knowledge on risk and older adults. However, within the context of Kleinman's model, this knowledge has been developed within the professional arena. In other words, our current understanding of risk is based on the opinions and theories of health care professionals.

The themes that were revealed in the findings of this study provide insight into the concept of risk from another arena, that is, the popular arena of individuals' beliefs, values and experience. The subjective experiences of the participants in this study suggest that the concept of risk, as it has been previously explored in the professional arena, has meaning and utility for health care professionals only. In fact, the findings

indicate that older adults do not have a subjective perception of risk per se or of themselves as individuals who are living "at risk." Instead, what health care professionals term "risk factors" are experienced by older adults as losses. Viewed within the context of the U.B.C. Model for Nursing (U.B.C. School of Nursing, 1980), the experience of loss is perceived and the meaning of loss is interpreted within the psychological environment. The psychological environment is really the life space (Lewin, 1935) or, in other words, that part of the world that impinges upon the self. Certain events, such as the experience of loss, can trigger changes in the life space. During these periods of change, individuals are required to restructure their ways of looking at the world and develop coping strategies to live in this changed world.

It is a widely accepted view that loss is a common occurrence among older adults. However, it is beyond the scope of this Chapter to review in detail the nature of loss as it relates to aging. Instead, the discussion begins with an examination of three aspects of loss related to the findings in this study: (i) the experience of multiple and concurrent losses, (ii) the vulnerability of older adults to loss and (iii) depression.

### **Older Adults and Loss**

The findings of this study reveal that the participants exhibited characteristics that reflect the risk factors identified in the literature (see Appendix B). As the discussion of the existing studies on risk in Chapter Two demonstrated, the term "risk factor" pertains to certain conditions that have the potential to cause a decline in an individual's health and functional status which could result in acute hospitalization or long-term placement. As can be seen in Appendix B, these conditions, or risk factors, are multiple and varied. They range from changes in health status to caregiver disability. However, as was previously mentioned, the notion of "risk" had no subjective meaning for the participants in the study. Rather, the significance of the occurrence of risk factors was due to the fact that they resulted in losses: specifically, losses of functional abilities, meaningful relationships, meaningful activity, independence and feelings of control over one's life.

The U.B.C. Model for Nursing (1980) defines a loss as "being without that which has or could have meaning for the individual" (p. 41). Furthermore, according to the U.B.C. Model, loss can be the result of both predictable maturational events or unpredictable, sudden events (p. 41). Many losses associated with growing old are predictable such as retirement

and widowhood. The individuals in this study had experienced many developmentally predictable losses such as the ones mentioned above. Moreover, these older adults had experienced many unpredictable losses both in the past and at the time of the study. The unpredictable losses that occurred in the past included estrangement from children, episodes of acute illness, onset of chronic illnesses and functional disabilities. The more recent unpredictable losses related to the current changes in their health and functional abilities (see Table 1, p. 65) which had precipitated treatment at the SSATC. Each of the recent changes experienced by the individuals in this study represented new losses and contributed to the complexity of the loss experience. This experience of multiple losses reflects the phenomenon of concurrent losses as described by Dimond (1981). Dimond defines concurrent losses as losses that are experienced in close proximity or during a specific period. The combination of concurrent losses experienced by the older adults in this study pervaded every aspect of their lives, from personal care to financial management.

The specific loss of mobility experienced by participants resulted in many concurrent losses, one of which was the loss of independence. This loss of independence as a result of physical immobility was a recurrent theme in other studies of older adults living in the community. Studies by Foldman (1991) and Magilvy, Brown and Dyden (1988) revealed findings that reflected an underlying theme of loss with the core loss being that of independence. In Foldman's study, the loss of independence caused by physical disabilities produced concurrent losses in social networks, financial independence and personal control. The findings of Magilvy and colleagues indicated that mobility was considered to be crucial for maintaining independence and was closely related to the ability to maintain other lifestyle activities such as socializing.

The second aspect of loss associated with aging is what theorists believe to be older adults' vulnerability to loss (Agee, 1980; Richter, 1984; Schneider, 1984). This vulnerability is related to factors that occur within the context of aging. As a result of diminished perceptual and other adaptive capacities, the aged are more susceptible to the deleterious effects of physical, functional and social changes.

The vulnerability of older adults to loss is also exacerbated by the fact that new losses can occur which are beyond their control. For example, demolition of low-rental housing could result in loss of a home or the high cost of food could ultimately result in severe nutritional deficits and a loss of health.

Schneider (1984) proposes that the factors contributing to the vulnerability of older adults to loss include (i) decreased resiliency as a result of health, functional and social problems, (ii) lack of access to new sources of life and energy and (iii) lack of opportunity to replace the actual loss or to find a suitable substitute. Certainly all of these factors were evident among the participants in this study. They had all experienced multiple losses associated with health, functional and social problems. Moreover, the fact that they spent most of their time in their homes meant that they were unable to seek opportunities to form new attachments to replace their lost relationships. Many of the participants, too, did not have the internal or external resources to manage new losses.

The final factor that influences the older adults' vulnerability to loss is the fact that aging individuals experiencing multiple and concurrent losses have little time to grieve between losses (Browning, 1990). Each loss, then, increases the person's vulnerability to the next loss. Moreover, the accumulation of losses may be greater with older adults because they do not experience the same gains and opportunities as younger people to offset the losses (Matteson & McConnell, 1988).

The third aspect of loss reflected in the findings of this study relates to depression. The interrelated biological, psychological and social

changes that occur with aging place the older adult "at risk" for development of depression. As a result, depression can be viewed as almost an inherent characteristic of the older adult's experience of loss and as either a response to loss or a cause of concurrent losses.

The actual prevalence of depression in older adults can only be estimated as systematically collected data on depression in Canada's older population is unavailable (Government of Canada, 1988). In addition, depression is often underdiagnosed or misdiagnosed in aged individuals as they frequently present with somatic complaints or symptoms that are mistaken for normal changes in aging or dementia (Browning, 1990). Misdiagnosis of depression in this age group may result in lack of appropriate treatment, premature institutional placement or self-neglect resulting in increased morbidity or mortality. From the researcher's perspective, Figure 1 represents one way in which the vicious cycle of depression may occur with depressed older adults.

Following their admission to the SSATC and an assessment by the geriatric psychiatrist, all of the participants in this study were diagnosed as suffering from a depression. It is not surprising that the individual participants were depressed given the multiple health and functional

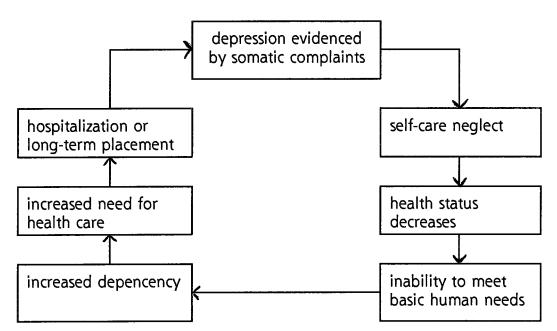


Figure 1. The cycle of depression in older adults

changes, chronic illnesses and losses they had experienced. The fact that all six participants were diagnosed as depressed is noteworthy, however, and supports the belief that depression is a widespread problem among older adults (Burnside, 1988; Carnevali & Patrick, 1986; Chaisson-Stewart, 1985). Thus, the conclusion can be drawn that depression is a significant risk factor for the loss of older adults' ability to live independently in the community.

In summary, as they age, individuals experience both predictable and unpredictable life changes. Predictable life changes usually occur over a long period of time throughout a person's lifetime. As a result, the

losses associated with these changes are often anticipated and the adjustment to the losses can be gradually managed. On the other hand, the vulnerability of the old to loss and the multiple biopsychosocial changes that occur with aging place this age group at high risk for the experience of sudden, unpredictable losses. These unpredictable losses occur over short periods of time and are lasting and cumulative in their effects. The participants in this study were found to have experienced multiple and concurrent losses resulting in complex situations of loss. The next section presents a discussion of the findings as they relate to the participants' efforts to cope with the complexity of the loss experience.

## **Coping With Loss**

There exists a substantial body of literature on the nature of coping. This literature includes theories and empirical research related to

(i) definitions of coping and the process of coping (Downe-Wamboldt,

1991; Lazarus & Folkman, 1984; Lipowski, 1969), (ii) coping styles and the coping tasks of chronically ill persons (Herth, 1990; Miller, 1983) and

(iii) factors that affect coping (Dimond, 1984; Herth, 1990; Kogan, 1990;

Miller, 1983; Parkes, 1971). In this section, definitions of coping and the factors that affect coping as they relate to the findings of this study are

presented. In addition, the findings related to older adults' use of lifetime patterns of coping are discussed.

Lipowski (1969) defines coping as a composite of all of the cognitive and motor activities used by sick persons to preserve their physical and psychological integrity, to recover from reversible functional impairments and to compensate for irreversible losses. Lazarus and Folkman (1984) define coping within the context of psychologic stress theory as the cognitive and behavioural strategies used to manage demands deemed by the individual to be taxing or beyond their current resources. According to Lazarus and Folkman, individuals first cognitively appraise these demands in terms of their threat to well-being. This cognitive appraisal is determined by a combination of personal, social and situational factors. Thus, depending on the factors present in each individual's life, similar events or losses may be appraised differently by different individuals. Lazarus and Folkman further contend that coping is a process as opposed to an outcome and that no one coping strategy is better than another.

The factors identified by Miller (1983) as having an impact on coping strategies are similar to those described by Lazarus and Folkman (1984). Miller (1983) describes (i) intrapersonal factors such as age,

personality, values, emotional state and cognitive capacity and
(ii) environmental factors such as social support, access to health services
and physical and financial resources. However, Miller suggests an
additional category of factors that affect coping. This category includes
illness-related factors such as the type of illness, the degree of impairment,
the rate of onset and the meaning of the illness to the individual. She
proposes that, ultimately, it is the meaning of the illness to the individual
that influences the amount of "coping energy" (p. 18) required to cope
effectively with the effects of the illness. Furthermore, Miller believes that
coping is effective when the strategy utilized

resolves the uncomfortable feelings associated with the threat and/or loss, preserves the integrity of the individual, and preserves the ability of the individual to function effectively in relationships, life roles, and maintenance of a positive self-concept (pp. 16-17).

Several findings from this study were consonant with the views of the authors as described above. First, in managing their experience of loss, participants employed coping strategies which, overall, formed the two distinct patterns of engaging and enduring. Engaging strategies were those by which individuals restructured their daily lives to incorporate

changes in their abilities and refocused their thoughts and energy into being actively involved in their worlds. In contrast, enduring strategies were those by which individuals submitted to the structuring of their lives by others and passively endured the consequences of the losses they had experienced. Second, these coping strategies were not inherently effective or ineffective. Rather, the effectiveness of a coping strategy was based on whether or not the participant was satisfied with his or her situation. Third, the meaning ascribed to the loss experience and the ability to engage in specific coping behaviours were influenced by the combination of intrapersonal, environmental and illness-related factors interacting in each participant's situation. In this study, those factors included physical and functional abilities, cognitive abilities and involvement of family members and community health care professionals. Thus, in order to understand the individual's experience of loss, one must strive to understand the biopsychosocial context in which that loss is experienced.

Lastly, the findings of this study have caused the researcher to contemplate the role of one intrapersonal factor, that is, personality, on the current and past coping patterns of older adults. Interest in the relationship between personality and health dates back to Hippocrates who described the four basic bodily fluids, or humours, as the basis of

personality. While the search for humoural balance has long been discredited, many theorists continue to ponder the relationships between personality, behaviour and health. With regard to older adults, these ponderings, however, tend to be theoretical and philosophical in nature.

Personality theory is one way of conceiving and describing behaviour. Lazarus and Monat (1979) define personality as the "underlying, relatively stable, psychological structures that organize human experience and shape a person's actions and reactions to the environment" (p. 1). The focus of many personality theorists is on the stable, internal attributes of a person that determine behaviour. By uncovering the nature of these internal attributes, personality theory strives to explain the differences in people. Why is it, for example, that one individual will react differently from another in the same situation? Why is it that some people are able to muster positive responses to a loss and others are immobilized? Many personality theorists propose that the determinants of our behaviour reside within us.

Carnevali and Patrick (1986) state that personality theories help to explain the continuity of a person's behaviour over time. Furthermore, these authors suggest that an underlying assumption of personality theory is that much can be learned about the current behaviour of individuals by

knowing about their past behaviours. As their stories about their current and past experiences revealed, the participants in this study appeared to have engaged in the same characteristic pattern of coping throughout their lives. In other words, the "engagers" had always tackled life's problems in an active, determined manner. On the other hand, the "endurers" had always passively "gone along" with whatever life brought their way.

Most of the literature on personality and aging is theoretical in nature. Moreover, while many studies have been conducted on individual personality constructs or traits, the author found a dearth of studies on the relationship between personality and coping styles of older adults.

Kogan (1990) conducted an extensive review of the personality and aging literature according to what he believed were three dominant traditions within the field -- the trait, developmental and contextual models of personality. Kogan concluded that generalizations about the stability and change of personality traits over time are necessarily limited due to the small number of studies available. Kogan also states that there is a conspicuous lack of discussion in the literature regarding the role of personality as a predictor of life outcomes in old age.

van Maanen (1988) in her study of the meaning of health for American and British older adults, reported that the findings from the British informants led her to question if personal characteristics played "a dominant role in the way people cope with illness and disease" (p. 704). van Maanen stated that while the scope of her research did not justify a generalization, she recommended further investigation into this phenomenon.

The findings of this study, considered within the context of personality theory, raise many interesting questions related to the coping strategies of older adults. For example:

- To what degree does personality influence an older adult's choice and use of specific coping strategies?
- If older adults use lifelong coping strategies, can they learn to use, or will they choose to use, new coping strategies?
- What is the relationship between various cognitive impairments and the use of familiar coping strategies?

These questions represent just a few of the areas on older adults and coping that remain to be explored.

# Issues in Conducting Qualitative Research with Older Adults

The aim of phenomenological research is to understand the human experience of a phenomenon from the individual's particular perspective (Knaack, 1984). Despite the difficulties in collecting and interpreting

qualitative data from older adults, it is widely recognized that there is a growing need for such research with this population (Covey, 1985; Stieb, 1983). However, certain issues arise which must be considered when designing qualitative studies for older adults. These issues relate to the (i) characteristics of the participants, (ii) the role of the researcher, (iii) informed consent and (iv) the need to adapt the techniques and procedures for qualitative studies.

The first issue concerns the characteristics of older adults and the possible effects of those characteristics on the validity of the data and the process of data collection. As was illustrated in the previous chapter, the mental status of the participants, especially the presence of cognitive impairment, affected their ability to articulate their subjective experience to the researcher. The minimal responses of some of the participants during the research interviews resulted in a paucity of verbal data.

Consequently, the researcher experienced difficulty in identifying conceptual themes from this data source alone during the process of data analysis. For this reason, other documentary data sources, such as the clinical records, field notes and risk factor forms, were used to facilitate interpretations of the subjective experience of the participants. In an effort to enhance the objectivity and credibility of the interpretation, the

researcher also consulted with two clinical nurse specialists in gerontology regarding the emerging themes.

West, Bondy and Hutchinson (1991) encountered similar difficulties when interviewing institutionalized older adults. These authors found that specific characteristics of "impaired institutionalized elders threaten the validity of studies which seek to uncover elders' views of reality" (p. 172) and result in problematic data. According to West and associates, the characteristics of older adults that pose a threat to the validity of qualitative studies are:

- physical characteristics such as pain, impaired vision and hearing and urinary frequency which make the elders' physical movements difficult to interpret or limit their participation time in the study;
- cognitive factors such as disorientation and poor memory which affect the nature of the data gathered in the study;
- affective characteristics such as a flat affect which result in an absence of clues about the participants' thoughts and feelings;
- personal characteristics such as socioeconomic, educational,
   career and ethnic backgrounds which influence the language

and the manner in which participants express themselves; expressions that may be difficult for researchers to understand.

These authors categorized the problematic data obtained from participants exhibiting these characteristics as insufficient, unclear, sometimes socially acceptable rather than factual and emotionally charged.

The participants in this study exhibited many of the physical, cognitive and affective characteristics just described. One example of how physical characteristics affected the interview process occurred with a participant who had recently undergone cataract surgery. Throughout the entire interview, this woman wore dark sunglasses as the light irritated her eyes. The researcher, therefore, was unable to use the expression in the woman's eyes and facial expressions as cues to her thoughts and feelings.

The increasing prevalence of cognitive impairment in persons over the age of 65 also has implications for conducting research with older adults. The prevalence of cognitive impairment is age-dependent, the rates varying from 12.1% to 22% among those over 80 years of age and up to 47% among those aged 90 and over (Canadian Task Force on the Periodic Health Examination, 1991). Thus, the probability is high that studies involving individuals over 80 years of age may include participants

who have some degree of cognitive impairment. Such was the case in this study. Despite the fact that the Folstein Mini-Mental Status Examination was used to screen prospective participants, two individuals experienced cognitive deficits. Furthermore, all of the participants experienced depression and the two mentioned above had this disorder superimposed on existing deficits. These deficits reduced the participants' ability to communicate their thoughts and feelings in detail. Hence, the data lacked depth and richness. In addition to the problem of their providing insufficient data, persons who are aware of their cognitive deficits may give incorrect answers or fabricate stories to avoid showing their impairments to the researcher (Zimmer et al., 1985).

Other characteristics of older adults that must be considered in the design of studies include less acute hearing, impaired vision and physical impairments (Covey, 1985; West, Bondy & Hutchinson, 1991; Zimmer et al., 1985). Moreover, older adults can become easily fatigued and may not be able to participate in intensive interviews for long periods of time. In this study, the average length of each interview was forty-five minutes. By that time, most participants were tired or felt that they had said all that they had to say.

The second issue that arises in relation to conducting research with older adults is confusion regarding the role of the researcher. In a phenomenological study involving older adults who had experienced a hip fracture, Ramhoj and de Oliveira (1991) found that some participants viewed their involvement in the research study as part of the rehabilitation process. Furthermore, they considered the researchers as "experts" and looked to them for advice. Robinson and Thorne (1988) suggest that this confusion over the differences in the role of the nurse researcher versus the role of the nurse clinician is not uncommon as the "lay public is much less aware of these subtle differences, and therefore likely to confuse the roles" (p.67). This misinterpretation of the researcher's role is particularly significant when individuals are receiving services from a variety of health care professionals. In this study, all of the participants had many people involved in their lives. As clients of the continuing care program, they had a case manager, home support workers and supervisors from the home support agencies. Some individuals were also receiving home nursing care and physical or occupational therapies. Finally, the participants were attending the day hospital at the SSATC where they were receiving treatment from a variety of health care professionals. Initially, participants thought that the researcher was associated with the SSATC. As a result, she was required to repeatedly explain her role and the purpose of the study throughout the course of the research.

The consequences of confusion over the role of the researcher may be twofold. First, the participants could respond with what West, Hutchinson and Bondy (1991) term socially acceptable data. In other words, they could express feelings and beliefs they believe are expected by or acceptable to the researcher. This particular consequence threatens the validity of the data. The second consequence is that the participants may perceive the research study itself and/or the researcher as a threat. As Covey (1985) suggests, "when chronic illness, fears of dependency [and] humiliation are present, the field worker can also expect some degree of perceived threat" (p. 43). This consequence, too, can lead to biased responses or even refusal to participate or continue in a research study.

The final issue in conducting research with older adults is the ethical issue of obtaining informed consent. Ramos (1989) believes that obtaining truly informed consent in qualitative research is "practically impossible [as] the direction that the research will take is largely unknown" (p. 60). Hence, Ramos recommends that the researcher and respondent engage in on-going dialogue and mutual decision-making about the research throughout the research process. However, obtaining and engaging in this

process of informed consent creates a challenge in studies involving older adults.

Many older adults may give verbal consent to participate in a study but refuse to sign consent forms (Hoffman, Marron, Fillit & Libow, 1983). Still others may interpret consent forms as quasi-legal documents and be reluctant to sign (Zimmer et al., 1985). Keith and Landis (cited in Covey, 1985) suggest that older adults living with relatives may hesitate to discuss their experiences with others. However, the most complicated ethical dilemma for researchers arises in those situations where individuals may be cognitively impaired or whose competency is reduced.

The prevailing general tendency in clinical practice and research has been to assume that competency to give informed consent is a global capacity that one either does or does not have. Currently, however, professionals in the health sciences, law and medical ethics have recognized that competency encompasses distinct types of decision-making related to different tasks. For example, an individual may be competent to consent to medical treatment but incompetent to manage financial affairs. The ability to make these different types of decisions relates to the specific cognitive processes illustrated in Figure 2. It is the nature and severity of the impairments in each of these processes that determine the person's

Figure 2. Cognitive processes underlying competency

	Γ	Wandering Attention
ATTENTION		wandering Attention
		Drifting Attention
	_	
		Spontaneous Speech
LANGUAGE		Auditory Comprehension
		Writing
		Reading Comprehension
	_	
MEMORY		Recent
		Remote
	_	
FRONTAL LOBE FUNCTION		Awareness
		Judgement

Source:

Freedman, M., Stuss, D. & Gordon, M. (1991). Assessment of competency: The role of neurobehavioral deficits. <u>Annals of Internal Medicine</u>, <u>115(3)</u>, p. 207.

ability to make decisions (Freedman, Stuss & Gordon, 1991). For example, individuals with wandering attention are easily distracted and unable to maintain a fixed attention. This disorder is most often due to metabolic or toxic brain dysfunction such as that caused by hyponatremia (Freedman,

Stuss & Gordon, 1991). In this situation, competency depends on the person's ability to attend long enough to reliably process and respond to relevant information. If that ability is present and the abilities to comprehend information and make judgements are intact, the person may be considered competent to give informed consent. Researchers, then, in view of the deficit in wandering attention and the remaining abilities in comprehension and judgement, could obtain the individual's consent to participate in the study. In this case the researcher could avoid long explanations on questions and reassess the reliability of the consent by reassessing the person on a number of occasions.

This current thinking on the nature of competency means that the task of clinicians and researchers is to identify specific patient deficits and areas of preserved function that can be used to overcome limitations in making informed decisions. Freedman, Stuss and Gordon (1991) have developed a set of guidelines for systematic assessment of both the individual cognitive processes underlying competency and the presence of compensatory abilities that could be used to bypass any impairments in cognitive function. These guidelines may be useful for research with older adults in that individuals with impairments need not necessarily be excluded from participation in studies based on a global assessment of the

ability to give consent. This would seem to be particularly relevant for studies involving community-dwelling older adults. For studies involving institutionalized, perhaps cognitively impaired, older adults consent may be obtained from family members. Researchers could also obtain consent from family members for an older adult living in the community. Ultimately, however, it is the individuals themselves who will, or will not, invite you into their homes.

Considerations for the design of qualitative studies with older adults based on their characteristics and needs have been recommended by several researchers (Covey, 1985; Hoffman, Marron, Fillet & Libow (1983); Stieb, 1983; West, Bondy & Hutchinson, 1991; Zimmer et al., 1985). These considerations relate to the time involved in conducting studies with older adults and the need to adapt research procedures and techniques based on the characteristics of older adults.

The first consideration is that, generally, more time may be required to conduct qualitative research with older adults. Community-dwelling and mainly homebound older individuals are difficult to locate especially if they are not receiving home support services. Consequently, the process of gaining access to participants may be time-consuming. Obtaining older adults' consent to participate in the study may also be a lengthy process.

The researcher may need to make several introductory phone calls and home visits to establish a relationship with the older adult, to discuss the research, perhaps conduct a mental status assessment and obtain consent. Alternatively, as was the case in this study, the researcher may have to wait for referrals to a health care agency and/or rely on health care professionals already involved with the individuals to conduct the initial screening assessments. Because the characteristics of the participants may preclude their engaging in lengthy interviews, the researcher may be required to increase the frequency of contacts and decrease the time of each contact.

The procedures for obtaining consent from participants can also be adapted to meet the needs of older adults. Information on introductory letters and consent forms can be written in large print in easily understood language. As has been mentioned, some older adults may verbally consent to participate in a study but refuse to sign a consent form. One might wonder, then, if verbal consent would be appropriate in certain situations. The researcher could, for example, plan to accept oral consent that was witnessed and subsequently documented by the witness and researcher. Lastly, special care must be taken with regard to obtaining consent from older adults experiencing varying degrees of cognitive

impairment. Researchers may need to make repeated visits and reassessments with individuals in order to reaffirm their competency to give consent to participate in the study. Indeed, the researcher may have multiple persons assess the individuals to both ensure competency and safeguard the interests of participants.

Another methodological consideration is that the researcher may need to recruit a larger sample size initially than would be required with younger participants. A larger sample size would allow for attrition of participants through acute illness and voluntary withdrawal. Furthermore, and importantly for qualitative analysis, more participants would ensure theoretical saturation of data (West, Bondy & Hutchinson, 1991). Again, as was the case in this study, it is difficult to obtain sufficient data from the interviews with cognitively impaired older adults to be able to interpret their experiences.

The problem of having enough interpretable data can also be managed by increasing the sources of data. The researcher's observations and the medical, social and psychological data available from clinical records and involved health care professionals help to create a " thorough and interpretable picture of the phenomenon under investigation" (West,

Bondy & Hutchinson, 1991, p. 176). Furthermore, use of multiple data sources is one method of checking the validity of the interview data.

The final consideration for researchers in planning research with older adults relates to the personality of the researcher and the relationship between the researcher and the participant. Kaye, Lawton & Kaye (1990) found that the personality of the interviewer had implications for recruitment of subjects into a study in that "pleasant, nonthreatening individuals... [had] a better chance of enlisting participants" (p. 105). Burns & Grave (1987) state that empathy and intuition are important skills in qualitative research in order for the researcher to become closely involved in the participant's experience.

The cultivation of this closeness and the researcher-participant relationship itself require thoughtful consideration and planning by the researcher. As was mentioned previously, participants may not be able to make the distinction between the clinical and research roles of the nurse. For the homebound, isolated older adult, the relationship with the researcher may be an important source of social and psychological support. Robinson and Thorne (1988) believe that, because the nurse's research and clinical roles are "inextricably linked' (p. 73), qualitative researchers should deliberately blend the roles and implement strategies to

ensure both the ethical integrity of the study and the validity of the findings. Toward this end, the researcher should be prepared to function in a clinical role as required. The researcher, then, assumes an ethical obligation to continually ensure the participants' well-being and to "account for the particular influence of the intervention on data construction" (Robinson & Thorne, 1988, p. 73).

### Summary

In this chapter, the findings of the study were discussed. The phenomena of loss and coping with loss as they relate to older adults were addressed. In addition, the issues that arise in conducting qualitative research with older adults were examined.

The participants in this study experience multiple, predictable and unpredictable losses. The vulnerability of older adults to the experience of loss as well as the phenomenon of concurrent losses was supported in the literature. The existence of depression as an inherent component of the older adults' experience of loss was discussed. The literature supported the prevailing belief among health care professionals that depression represents a threat to older adults' ability to live independently in the community.

Participants used a variety of coping strategies in managing their experience of loss. Overall, those strategies formed two distinct and opposing patterns that the researcher has termed "engaging" and "enduring." Engaging strategies enable the participants to feel "in control" of their lives and remain actively involved in the world. In contrast, participants utilizing enduring strategies withdrew from such active involvement and relied on others for decision making and the structuring of their daily lives. The findings also suggested that participants' had engaged in the same pattern of coping throughout their lives. Thus, it is interesting to speculate on the relationship between personality and the coping strategies employed by older adults. While there exists a substantial body of both theoretical and research literature on the nature of coping, most of the literature on personality and aging was based on theoretical or philosophical arguments.

Many of the characteristics of the participants, especially the change in mental status, affected the nature of the data obtained in this study. The experience of depression and/or cognitive impairment affected some participants' ability to articulate their thoughts and feelings resulting in scant and superficial interview data. The findings of this study on the characteristics of older adults raise several issues for conducting research

with this population. These issues relate to: (i) adapting the research method to suit the capabilities of older adults, (ii) the role of the researcher(s) and (iii) obtaining informed consent. Recommendations for dealing with these issues concluded the discussion.

## CHAPTER SIX: SUMMARY, CONCLUSIONS AND IMPLICATIONS Summary

The purpose of this study was to gain an understanding of the experience of living "at risk" from the perspective of community-dwelling older adults whose ability to live independently is threatened by the presence of one or more risk factors. Risk is a concept used by health care professionals to describe individuals whose physical, mental or functional status, social situation or physical environment present a threat to health, safety and, ultimately, independent living. The theoretical and research literature has identified the specific objective physical, functional and psychosocial factors that contribute to risk. The aim of these efforts by theorists, researchers and clinicians in identifying risk factors and also in guantifying an individual's degree of risk has been to: (i) ensure efficient and effective use of health care resources; (ii) evaluate the effectiveness of treatment programs by measuring changes in degree of risk over time; and (iii) target those individuals who are appropriate for specialized programs. However, despite what is now known about risk from this theoretical and professional perspective, there is a paucity of knowledge available on older adults' subjective experience of living "at risk."

Individuals aged 75 years and over constitute a growing segment of Canada's older population. Currently, this group of "old old" individuals require and use many more medical, hospital and community services than younger persons. One result of these services is that many older adults are now living at home in situations of "risk." In other words, the presence of risk factors threaten older adults' ability to continue living independently in that they represent the potential for a decline in health status and functional abilities. This decline, in turn, may result in admission to an acute or long-term care facility.

Two explanatory models of behaviour (Kleinman, 1978 and The U.B.C. School of Nursing, 1980) provided the theoretical foundation for the approach to this study. Taking direction from these conceptual models, the researcher sought to understand individuals' experiences of living in situations of risk. As the number of older adults' increases, it becomes increasingly important for nurses to broaden their ability to interpret the impact of risk factors on peoples' lives and to assist individuals to manage situations of risk.

Phenomenology was the qualitative method chosen for this study.

The underlying assumption of phenomenology is that individuals'
subjective interpretations of a situation are an important assessment of the

reality of that experience for them (Oiler, 1986). Consequently, this method was deemed appropriate for enabling the researcher to understand the meaning of living "at risk" from the perspective of the older adult living in the community.

Six individuals participated in this study. These individuals had been referred to a geriatric short stay assessment and treatment centre (SSATC) because of a recent change in their health and functional status. A health care professional from this centre, during her preadmission assessment of these older adults, used a risk factor screening tool to determine that individuals were living "at risk." Data were collected from a range of sources including unstructured interviews with participants, the SSATC clinical records, risk factor forms, field notes and the researcher's observations. The interviews were audio-taped and subsequently transcribed verbatim. Analysis of data occurred simultaneously with data collection through a process of constant comparative analysis. As themes began to emerge, the researcher moved back and forth from the interview transcripts to the themes, from one participant's account to another participant's account until common patterns of meaning were identified. Once the themes were determined, the researcher re-interviewed the participants to elaborate, clarify and validate or refute the themes.

During the course of data collection, it became evident that one of the risk factors experienced by the participants, that is, a change in mental status, was influencing the nature of the data obtained during the interviews. The mental status of some participants, especially the presence of cognitive impairment, affected their ability to describe their experiences in detail. Consequently, the data from interviews with these participants was scant and superficial. The researcher, therefore, also used information from the documentary data sources mentioned above in constructing her interpretation of the risk experience. In addition, the researcher validated this interpretation with two clinical nurse specialists in gerontology throughout the process of data analysis.

The findings of this study revealed that the concept of risk per se had meaning for health care professionals only. Indeed, what were "risk factors" and living "at risk" for health care professionals were experienced by the participants as "losses" and coping with loss.

The experience of loss was a complex one for the individuals in this study owing to a combination of: (i) the losses incurred as a result of the risk factors present in each person's situation; (ii) the type and characteristics of those losses; and (iii) the specific loss of cognitive abilities and the resulting inability of some participants to articulate their

experience to others. Participants experienced losses of functional abilities, meaningful relationships and activities, independence and control. While both the number and the type of losses contributed to the development of a complex situation of loss, this complexity was further compounded by the finding that the losses were interrelated. Furthermore, the losses occurred within the biopsychosocial context of aging and, thus, were perceived by participants as being irrevocable and irreplaceable.

The findings also revealed that individuals used a variety of coping strategies in managing these complex situations of loss. These coping strategies varied with participants' health, physical, mental and functional abilities and their relationships with others. Moreover, these coping strategies were not inherently effective or ineffective. Rather, the effectiveness of a particular coping strategy was related to the participants' feelings of satisfaction with their situations.

While the participants used a range of coping strategies, these strategies formed two distinct patterns of coping: "engaging" and "enduring." The pattern of engaging included the specific coping strategies of restructuring and refocusing. The first, restructuring involved the use of coping behaviours by which individuals restructured their activities of daily living as a result of the losses they had experienced. The

second, refocusing, involved behaviours that enabled participants to focus their efforts on their remaining functional abilities and to integrate changes in function and the resulting losses into a positive view of themselves. In contrast, the pattern of enduring included the specific strategies of depending and withdrawing. In utilizing these strategies, participants submitted to the structuring, by others, of their daily activities, physical and mental withdrawal from contact with others and inactivity. All of the participants, regardless of their coping pattern, relied on others for assistance in various activities of daily living. However, participants using enduring strategies lacked the ability to control their lives whereas those using engaging strategies insisted on being in control.

Lastly, the findings indicated that the participants' current approach to coping with loss appeared to reflect approaches they had used to manage problems all their lives. Engagers had always tackled problems with energy and determination. On the other hand, endurers had always been passive and withdrawn when responding to changing circumstances in their lives.

## Conclusions

The study's findings suggest a number of conclusions about the experience of living "at risk" for older adults living in the community:

- 1. Risk is a concept that has meaning and utility for health care professionals and no subjective meaning for the older adults deemed by health care professionals to be "at risk". Older adults also do not perceive the risk factors present in their situations as threats to a potential loss of independent living. On the contrary, they view the risk factors within the context of their present everyday lives.
- The predictable and unpredictable changes in health status, functional abilities and social contacts that occur with older adults are experienced as losses.
- 3. Older adults experience complex situations of loss. This complexity is related to the phenomenon of concurrent loss and the interrelatedness of the losses. Furthermore, these losses occur within the biopsychosocial context of aging and are, therefore, irreversible.
- 4. Individuals possess a repertoire of coping strategies that all together form their own distinctive pattern of coping.

- Older adults, in responding to current losses, employ the same coping strategies they have used throughout their lives.
- 6. Coping strategies are not inherently effective or ineffective.

  The effectiveness of a coping strategy is determined by its outcome. For example, a coping strategy may be considered effective if it enables the individual to meet his or her basic human needs.
- 7. Certain characteristics of older adults raise issues with regard to the use of qualitative methods in conducting studies involving this population. Physical, cognitive, affective and personal characteristics may affect both the older adult's ability to participate in qualitative studies and the validity of the data. Consequently, the procedures and techniques used in qualitative research must be adapted to suit the capabilities of older adults.

## **Implications for Nursing**

The findings of this study have implications for nursing practice, education and research. The implications discussed below derive from the following specific findings: (i) that "risk" is a concept that has meaning

only for health care professionals; (ii) the fact that all of the participants in this study experienced a change in mental status related to depression and/or cognitive impairment; and (iii) the coping strategies used by older adults to manage loss.

The finding that the concept of risk had meaning for health care professionals only has implications for development and implementation of clinical programs. This study was originally conceived as a result of the work of SSATC health care professionals in developing an "at risk" screening tool. The purpose of this tool was to enable the health care professionals to objectively determine the degree of risk of individuals referred to the SSATC and, thus, target them for specific programs. For example, individuals considered "high risk" for admission to an acute care hospital would be assessed by the SSATC staff within twenty-four hours. At the same time, it was thought that a phenomenological study involving individuals determined by these health care professionals to be living "at risk" would contribute to development of a profile of the risk situation. The finding that participants who are living "at risk" actually interpret their experience as one of loss and coping with loss does contribute to our understanding of the subjective experience of living in these complex situations. Clearly, theoretical and empirical knowledge related to loss,

age-related loss and coping with loss can be incorporated into the assessment, intervention and evaluation protocols of clinical programs. Nevertheless, the findings also support the notion that differences exist between health care professionals and their clients in how the same situation is perceived. Thus, it behooves nurses and other care professionals to remain cognizant of the fact that individuals' perceptions of their situations influence their willingness and ability to participate in clinical programs. This is especially important in the area of program evaluation. One tendency has been to assume that individuals who do not follow treatment regimes or participate in programs are noncompliant. In other words, the problem lies within the individual and not with the program itself: therefore, the individual needs to change, not the program. An alternative view is for health care professionals to consider how program protocols could be adjusted to meet the needs and wishes of the persons they were designed to assist.

The finding that all of the participants had experienced a change in mental status raises issues concerning not only qualitative research, as was discussed in Chapter Five, but also nursing practice. These issues relate to the assessment and treatment of older adults experiencing depression and cognitive impairment.

Depression was found to be one component of the loss experience for older adults. In addition, as has been mentioned, two of the six participants in this study experienced cognitive impairments despite the fact that their scores on the Folstein Mini-Mental Status Examination suggested otherwise. As the number of older adults increases, nurses need to recognize the importance of conducting both screening and comprehensive mental status assessments.

There are many reasons why nurses working in community and acute care settings must be especially aware of the need for early detection of impaired mental function. First, identification of cognitive deficits and their etiology that is, dementia, delirium or depression, has implications for intervention decisions and the individual's ability to follow a prescribed treatment regime. For example, delirium and depression are resolvable and the mild to moderate deficits that occur with a dementia are amenable to supportive interventions. If left untreated, these disorders could result in serious physical and functional complications. Second, research and experience tell us that individuals with unrecognized cognitive deficits are susceptible to a deterioration in mental, physical and functional abilities during acute hospitalization. Indeed, hospitalization itself will often trigger the development of a depression. Finally, early assessment of mental

status provides a baseline for future comparison of improvement or decline in cognitive functioning. This would prove especially important with respect to determining the individual's competency to make various types of decisions. For the reasons just described, nurses working with older adults must acquire knowledge related to cognitive functioning and the disorders that affect this functioning. At the same time, in addition to acquiring knowledge, nurses must develop skills in conducting mental status assessments.

One purpose of mental status assessment is to identify not only cognitive deficits but also areas of preserved cognitive function. Nurses do this in order to assist individuals to: (i) restore and preserve functioning; (ii) prevent or minimize disability; (iii) promote autonomy; and, ultimately (iv) enhance their quality of life. One aspect of mental status assessment involves the use of measurement instruments. Generally, instruments are valuable tools for screening, assessing and monitoring mental status. The use of reliable and valid instruments facilitates a systematic, comprehensive approach to assessment of mental status. Knowledge of the function, purpose and characteristics of instruments is important for determining their effectiveness in various clinical situations. For example, the Folstein Mini-Mental Status Examination may be incorporated into a nursing

assessment to screen for cognitive impairment. Similarly, a geriatric depression scale may be used to screen for depression. Other instruments could be utilized as warranted to conduct more in-depth assessments and facilitate nursing diagnosis. However, nurses must always be aware that instruments assist, but do not replace, clinical judgement.

The findings of this study have implications for community nurses working with older adults in their homes. These implications relate to the coping strategies used by older adults in managing their losses and the resources available to assist older adults to continue living in their homes.

The findings indicate that nurses should not have any preconceived beliefs about the inherent value of particular coping strategies. Instead, they must assess each individual's repertoire of coping strategies and the effectiveness of those strategies in enabling individuals to meet their basic human needs. This assessment must include individuals' perceptions of their situations and their satisfaction with the outcome of their particular coping pattern. Finally, nurses must conduct "coping histories" to determine the individuals' characteristic pattern of response to change throughout their lives. These histories would enhance nurses' understanding of individuals' current behaviours and assist nurses to identify individuals' specific abilities and disabilities.

The coping strategies evidenced in this study suggest that different types of nursing interventions may be required with individuals employing different strategies of coping. Consequently, nurses must recognize that their role may vary according to an individual's coping strategies. The engaging coping strategies, restructuring and refocusing, enabled participants to develop predictable daily routines, to incorporate their changes in abilities into these routines and to achieve a sense of control over their lives. Nurses need to work collaboratively with individuals utilizing these strategies. For example, nurses can ensure that these individuals maintain a sense of control over their lives through interventions such as jointly scheduling nursing visits to fit in with the older adults routines and providing information on community resources. Nurses can also tap into the creative potential of these individuals and enable them to remain actively involved in their community. For example, these older adults could become involved in supportive telephone networks or even in political lobbying via the telephone or letter writing. It would seem that, in working with individuals utilizing engaging strategies, the role of nursing is to facilitate individuals' own efforts to restructure and refocus. For individuals utilizing enduring coping strategies, the role of nursing may be guite different. As with the

individuals mentioned above, nurses would also employ interventions to maximize individuals' abilities. However, with more passive, withdrawn older adults, nurses may need to play a more direct role in providing care or in mobilizing other external resources to compensate for individuals' lost abilities.

In order to mobilize these resources, nurses must know what those resources are. An individual's external resources include their social support systems, social networks and the community services available to support older persons in their homes. Nurses must collaborate with individuals to develop a plan of care that utilizes a combination of appropriate and accessible resources. Nurses must also take care to individualize care plans keeping in mind the unique characteristics of each person. For example, an 89 year old man who has been withdrawn all of his life is unlikely to want to participate in aggregate meal programs or adult day care programs.

Finally, nurses must also be prepared to support the children of older adults. As the number of older adults increases, there also will be a generation of middle-aged children who may spend many years caring for dependent parents. Nurses, then, must assist these adult children by providing information on available community services, assisting to

implement and coordinate services and spearheading the development of, or participation in, peer support groups. Furthermore nurses, older adults and their families can become involved in the political arena by lobbying local governments for improved services for older adults.

The implications for nursing practice as discussed above are similar to the implications for the education of practising nurses and nursing students. Again, these implications arise from the findings related to coping and participants' changes in mental status.

At the present time, the education of nurses in the care of older adults includes a wide range of knowledge related to aging. Furthermore, nursing students now gain clinical experience in working with older adults in a variety of settings from acute care hospitals to community wellness programs. In all of their education programs, nursing students learn about human response to illness, change and loss. They learn about coping and about assisting individuals to develop new coping behaviours during times of illness or change. However, the findings of this study suggest that perhaps older adults use longstanding, familiar coping strategies during times of change rather than learning new coping strategies. Nursing students, as well as nurses already in practice, should be given an opportunity to explore this association between past and present patterns

of coping. Furthermore, they should be given experience in conducting coping histories. This experience would involve collecting collateral data from family, friends and involved health care professionals regarding the individual's history of coping with past life events.

The prevalence of depression and cognitive impairment among older adults requires that education programs include content on the agerelated changes in mental function, disorders that affect mental function and assessment and management of those disorders that lead to impaired mental function. Nurses must learn interventions to support the functioning of persons suffering from a dementia. These interventions include the creation of therapeutic physical environments. Education programs must also provide content on competency, both assessment of abilities related to competency and the ethical issues associated with competency. Finally, nursing students and practising nurses must have opportunities to expand their knowledge about the use of measurement instruments to facilitate the comprehensive assessment and management of problems in mental functioning. They must understand the purpose of instruments, how to evaluate the potential usefulness of an instrument for nursing practice and how to incorporate the use of an instrument into

nursing practice. Finally, opportunities should be provided for nurses to develop skills in the actual clinical application of measurement instruments.

The study of older adults' experience of living "at risk" involved only a small number of participants. The author's review of the literature revealed that the field of qualitative research involving studies of older adults is in its infancy. This study, then, provided only a beginning understanding of the experience of older adults in trying to live independently in the community. Importantly, however, this study supported the findings of other researchers in that qualitative research methods must be altered to suit the characteristics of this aged population.

The implications of the findings of this study for conducting qualitative research with older adults were discussed in Chapter Five.

Furthermore, in Chapter Five the author posed questions on the relationship between personality and the coping strategies used by older adults. These questions represent areas where further research would contribute to our knowledge about personality and aging. Such knowledge would enable nurses to better understand the inner resources used by individuals in coping with loss. Further research is also needed to achieve a greater understanding of older adults' unique experience of multiple and irrevocable loss. Finally, using qualitative methods of inquiry

to explore phenomena of concern to older adults would enable nurse researchers to develop and refine qualitative procedures and techniques for use with this population.

In conclusion, this study has described the meaning of living "at risk" for a group of community-dwelling older adults whose ability to live independently is threatened. The findings of this study will contribute to nurses' understanding of the experience of living in complex situations of loss. Furthermore, the findings will also contribute to nurse researchers' understanding of the issues that arise when conducting qualitative research with older adults.

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**APPENDIX A** 

### **APPENDIX A**

## THE CONTEXT OF THE STUDY

SHORT STAY ASSESSMENT AND TREATMENT CENTRE

for the Older Adult Who is Living "At Risk": A Community Outreach Project Development of a Mobile Geriatric Assessment and Care Planning Service

### PHASE II: DEVELOPING A PROFILE OF THE "AT RISK"INDIVIDUAL

# DEVELOPING, IMPLEMENTING AND EVALUATING THE PILOT SERVICE 1. establish the purpose, goals and objectives

PHASE III:

- 1. retrospective review of clinical records
- 1. develop an "at risk" screening tool using the criteria identified in the literature as being associated with risk. For the purposes of this project, detailed operational definitions have been developed for each of the empirical indicators of risk identified in Appendix A.

2. community focus group

assessment tools, documenta-

tion systems

2. develop referral process,

3. develop a program implementation plan

3. ongoing review of current referrals to the SSATC

- 4. develop evaluation mechanisms
- describe the experience of living "at risk" from the individual's perspective

**APPENDIX B** 

lives alone
waitlisted for placement
unwilling to accept placement
caregiver disability
family conflict
behavior which disrupts caregiving

Social Support

### APPENDIX B FACTORS ASSOCIATED WITH RISK

nent in a long extent to which veighted or

The following "RISK FACTORS" are identified in the 1. Progression of acute or chronic illness; 2. Prema term care institution. The degree of risk appears to those factors impact on the individual's health status tested for predictive sensitivity.  RISK FACTOR Health Status	The following "RISK FACTORS" are identified in the literature as being associated with the:  1. Progression of acute or chronic illness; 2. Premature admission to an acute care hospital; 3. Premature placementerm care institution. The degree of risk appears to relate to the number of factors present in the situation and the exthose factors impact on the individual's health status and functional ability. The individual factors have not been weitested for predictive sensitivity.  EXAMPLES OF EMPIRICAL INDICATORS  CTOR
Self-Care Management	<ul> <li>change in mental status</li> <li>medication issues</li> <li>discharge from acute care</li> <li>discharge from E.R.</li> <li>activities of daily living</li> <li>instrumental activities of daily living</li> <li>ability to follow prescribed treatment regime</li> </ul>
Hazards/Safety Awareness	<ul> <li>falls</li> <li>physical self-neglect</li> <li>physical, verbal, emotional neglect or abuse by others</li> <li>nutritional deficits</li> <li>environmental hazards</li> <li>financial crisis</li> </ul>
Lifestyle Changes	<ul> <li>relocation</li> <li>losses/bereavement</li> <li>change in usual patterns of social contact</li> <li>misuse of substances</li> </ul>

### **APPENDIX C**

### INFORMATION FOR THE S.S.A.T.C. COMMUNITY ASSESSOR

### Title of Study:

When the Ability to Live Independently is Threatened: A Phenomenological Study of the Older Adult's Experience of Living "At Risk."

### **Investigator:**

Phyllis Hunt, R.N., M.S.N. Student, Phone xxx-xxxx

### **Faculty Advisor:**

Sally Thorne, R.N., Ph.D., Phone xxx-xxxx

### **Procedure for Recruitment of Subjects:**

- The individual must reside in a house or apartment, not a care facility.
- 2. A preadmission assessment must be completed before the individual can be identified as a potential subject.
- 3. One or more of the risk factors identified below must be present in the situation. The risk factor(s) must pose a threat to the individual's ability to live independently.
- 4. Indicate the risk factor(s) present by circling the appropriate number.

- 5. The individual must refuse admission to the S.S.A.T.C. or will be admitted to the Day Program.
- 6. Explain the purpose of the study and ask permission for me to contact the individual by phone.

### **Criteria for Selection of Subjects:**

- 1. 65 years of age or older
- 2. male or female
- 3. fluency in English
- 4. Folstein MMSE score > 24
- 5. living in a situation in which one or more risk factors threaten the individual's ability to live independently.

### **RISK FACTOR:**

A characteristic of the individual or the social or physical environment which predisposes the individual to: (i) deterioration in health status; (ii) a decline in functional ability; or (iii) the possibility of admission to an acute or long-term care facility. Consequently, the individual's ability to live independently at home is threatened.

### RISK FACTORS: EMPIRICAL INDICATORS OF RISK:

### 1.0 **HEALTH STATUS**

- 1.1 <u>Change in physical status within past 8 weeks</u>

  deterioration in body system functioning; change may be acute, subacute or a change in a chronic condition.
- 1.2 Change in mental status within past 8 weeks
  appearance, mood/affect, thought content (i.e.,
  hallucinations), perceptual disturbances (i.e., delusions),
  evidence of depression, cognitive impairment, change in
  behaviour.

### 1.3 Medication Issues

includes the number of medications, the type or the combination

- uses 3 prescription drugs and OTC drugs.
- uses psychotropic drugs.
- uses 2 or more types of analgesics.
- 1.4 Discharge from acute hospital within past 8 weeks.
- 1.5 Discharge from emergency room within past 8 weeks.
- 1.6 Discharged on the Quick Response Program.

### 2.0 **SELF CARE MANAGEMENT**

Change within past 8 weeks in self-care ability or ability of caregiver to carry out

- 2.1 ADL (feeding, washing, dressing, toileting, mobility).
- 2.2 IADL (cooking, laundry, grocery shopping, finances).
- 2.3 prescribed treatment regime (medication, injections, dressings).

### 3.0 **HAZARDS**

Evidence or concern about

- 3.1 falls/liability to falls with a potential for serious injury.
- 3.2 physical self-neglect/physical, verbal, emotional neglect or abuse by others
- 3.3 nutritional deficits (e.g., weight loss, no food).
- 3.4 environmental hazards (e.g., wandering, stove, unsafe smoking, etc.).
- 3.5 financial crisis (e.g., rent in arrears, gives away money).

### 4.0 LIFESTYLE CHANGES within past 6 months

- 4.1 relocation.
- 4.2 losses/bereavement.
- 4.3 change in usual patterns of social contact
- 4.4 misuse of substances (e.g., alcohol/drugs)

### 5.0 **SOCIAL SUPPORT**

- 5.1 lives alone.
- 5.2 waitlisted for placement.
- 5.3 unwilling to accept service at home.
- 5.4 unwilling to accept placement.
- 5.5 reports of caregiver disability (e.g., burnout, illness).
- 5.6 behaviour which disrupts caregiving.
- 5.7 reports of family conflict.

### APPENDIX D

### **INTRODUCTORY LETTER**

My name is Phyllis Hunt. I am a Registered Nurse and a student in the Master of Science in Nursing program at the University of British Columbia. I am interested in learning about the experience of older adults living at home who may be having problems caring for themselves. It is important for nurses to understand what life is like for individuals in this situation so that appropriate assistance can be planned.

### My study will involve:

- 1. two interviews, each lasting from thirty to sixty minutes, conducted in your home;
- 2. a discussion of what it is like for you now that you have experienced a change in your health status;
- 3. tape recording of the interviews.

All the information obtained will be confidential. Your name will not appear on the tapes, transcripts or the completed study. Access to the tapes and typed manuscripts will be limited to my thesis advisors, my typist and me. All the tapes and transcripts will be destroyed when the study is completed.

Your participation is strictly voluntary, and your refusal to participate will not influence any care you currently receive or may require. If you do agree to participate in the study, you may refuse to answer any questions asked, request to have information removed from the audiotape, or withdraw from the study at any time.

If you have any questions about the study or the interviews, please contact me or my faculty advisor at the number listed below.

Thank you.

Phyllis Hunt, R.N.

Phyllis Hunt, R.N., B.N., xxx-xxxx Sally Thorne, R.N., Ph.D., Faculty Advisor, xxx-xxxx

### **APPENDIX E**

### PARTICIPANT CONSENT FORM

**Title of Study:** When the Ability to Live Independently is Threatened:

A Phenomenological Study of the Older Adult's

Experience of Living "At Risk."

Investigator: Phyllis Hunt, R.N., M.S.N. Student—Phone: xxx-xxxx

Faculty Advisor: Sally E. Thorne, R.N., Ph.D.—Phone: xxx-xxxx

I understand that the purpose of this study is to understand the experience of older adults, living at home, who have experienced a change in their health status or ability to care for themselves.

I understand that this study involves:

- 1. two visits to my home by Phyllis Hunt for an interview that will last from thirty to sixty minutes;
- 2. discussion of what it is like for me to live in my home now that I have had changes in my health and abilities;
- 3. tape recordings of the interviews.

I understand that the information obtained will be confidential and that all information will be destroyed once the study is completed.

I understand that my participation is voluntary; I may refuse to answer any questions asked, and may withdraw from the study at any time. I understand that my refusal would not jeopardize any care that I receive now or in the future.

I consent to participate in this	study as explained and acknowledge
receipt of an explanatory letter and a	copy of this consent form.
	••
DateS	Signature

### APPENDIX F INTERVIEW GUIDE

I understand that you've experienced some recent changes in your health and your ability to manage here at home.\*

- You've experienced some recent changes in your health. What has that been like for you?
- What aspects of your daily life would you say are most affected?
- What is your major concern right now in terms of your being able to manage here at home?
- What do you do to deal with washing, dressing, going to the bathroom, cooking, cleaning, shopping, banking?
- Is there anything you can't do now that you want to do?
- Have you ever experienced anything like this before? If so, in what ways is this experience the same or different from earlier ones?
- What would help you to be able to stay in your home?
- What is it like for you to talk to me about your living situation?
- \* Specific changes in health and functional abilities as identified on the clinical record may be mentioned to provide a focus for discussion.

### **APPENDIX G**

### **DEMOGRAPHIC INFORMATION**

CODE NO.:	AGE:	SEX:	
REASON FOR REFERRAL	TO SSATC:		
MEDICAL DX.:			
FOLSTEIN MMSE SCORE:			
RISK FACTORS IDENTIFIE		MMUNITY ASSESSOR:	