

**Factors Associated with the Non-Use of Respite Services
by Cognitively Impaired Older Adults and their Informal Caregivers**

by

Nina M. Labun

**A Thesis
Submitted to the Faculty of Graduate Studies
in Partial Fulfillment of the Requirements
for the Degree of**

MASTER OF NURSING

**Faculty of Nursing
University of Manitoba
Winnipeg, Manitoba**

©August, 2000



National Library
of Canada

Acquisitions and
Bibliographic Services

395 Wellington Street
Ottawa ON K1A 0N4
Canada

Bibliothèque nationale
du Canada

Acquisitions et
services bibliographiques

395, rue Wellington
Ottawa ON K1A 0N4
Canada

Your file Votre référence

Our file Notre référence

The author has granted a non-exclusive licence allowing the National Library of Canada to reproduce, loan, distribute or sell copies of this thesis in microform, paper or electronic formats.

The author retains ownership of the copyright in this thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without the author's permission.

L'auteur a accordé une licence non exclusive permettant à la Bibliothèque nationale du Canada de reproduire, prêter, distribuer ou vendre des copies de cette thèse sous la forme de microfiche/film, de reproduction sur papier ou sur format électronique.

L'auteur conserve la propriété du droit d'auteur qui protège cette thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

0-612-53169-4

Canada

**THE UNIVERSITY OF MANITOBA
FACULTY OF GRADUATE STUDIES

COPYRIGHT PERMISSION PAGE**

**Factors Associated with the Non-Use of Respite Services by Cognitively Impaired Older
Adults and their Informal Caregivers**

BY

Nina M. Labun

**A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University
of Manitoba in partial fulfillment of the requirements of the degree**

of

Master of Nursing

NINA M. LABUN © 2000

Permission has been granted to the Library of The University of Manitoba to lend or sell copies of this thesis/practicum, to the National Library of Canada to microfilm this thesis/practicum and to lend or sell copies of the film, and to Dissertations Abstracts International to publish an abstract of this thesis/practicum.

The author reserves other publication rights, and neither this thesis/practicum nor extensive extracts from it may be printed or otherwise reproduced without the author's written permission.

Abstract

The predominance of cognitive impairment among older adults coupled with a shift toward reliance on informal caregiving has increased interest in determining factors associated with the use of community-based service. The challenges of providing care to older adults with cognitive impairment are particularly demanding. It is unclear however, that cognitive impairment results in an increased need for services. Rather it appears that informal caregivers are reluctant to use services. In particular, respite services are the most frequently requested yet consistently under-utilized service. Few studies have explored caregivers' apparent reluctance to use respite services.

This study of respite service non-use was a secondary analysis of data from the Manitoba Study of Health and Aging (MSHA-2) conducted in 1996-97. This study used a sub-sample of 132 community-dwelling older adults with cognitive impairment and their informal caregivers. The Stress Process Model was used as an organizing framework to understand the experiences of caregiving. Multivariate analysis focused on describing the factors associated with the reasons for non-use of four respite services: adult day centre, in-home respite, hospital respite, and personal care home respite.

Findings from this study revealed that the majority of caregivers indicated they did not use respite services because they were unaware of the services. Caregivers who were not aware of particular respite services were more likely to be male, married, and have fewer years of formal education.

Results of this study provide insights for respite service delivery and the appropriate targeting of services to isolated caregivers that may have never sought formal assistance.

Acknowledgements

I gratefully acknowledge the assistance of the members of my thesis committee.

Dr. Pamela Hawranik (Chair) for your exceptional guidance and support; Professor Nettie Peters (Internal Member) for your encouraging words; and Dr. Laurel Strain (External Member) for your expertise and careful attention to detail.

I would also like to acknowledge the financial support received for this project from the University of Manitoba and the Manitoba Health Research Council.

Special thanks are extended to the staff at the University of Manitoba Centre on Aging. Your commitment to advancing the field of gerontology was an inspiration for me as I began this study. In particular, I thank Audrey Blandford for her technical support and guidance with the statistical analysis.

Finally, I acknowledge the love, support, and prayers of my family, friends, and colleagues throughout my years of study. My very special thanks to those who are always in my heart – my husband Jon and young son Willem. Your never ending patience and support were immeasurable.

Table of Contents

Abstract	i
Acknowledgements	ii
List of Figures	v
List of Tables	vi
Chapter One - Statement of the Problem	1
Chapter Two – Conceptual Framework and Literature Review	5
Overview of the Literature Review	5
Conceptual Frameworks	7
Literature Review	13
Stressors	24
Moderators	38
Conclusions of Literature Review	46
Chapter Three - Research Methodology	48
Research Questions	48
Study Design	49
Definition of Variables	52
Measurement of Variables	54
Data Analysis	66
Ethical Considerations	70
Chapter Four - Study Findings	71
Sample Characteristics	71
Use of Respite Services	82
Comparison of Service Users and Non-Users	83
Reasons for Non-use of Respite Services	89
Results of Bivariate Analysis of Reasons for Non-Use	90
Results of Testing for Multicollinearity	95
Multivariable Findings	95
Chapter Five – Summary and Discussion	106
Overview of Study	106
Summary of Findings	107
Study Limitations	116

Recommendations for Future Research	118
Implications for Nursing	120
Summary	122
References	123
Appendix A	137
Appendix B	139
Appendix C	143
Appendix D	145
Appendix E	147
Appendix F	150
Appendix G	153
Appendix H	155
Appendix I	157
Appendix J	159
Appendix K	168
Appendix L	185

List of Figures

Figure 1 – Anderson Newman Framework for Health Services Utilization	8
Figure 2 – Individual Determinants of the Anderson-Newman Model	9
Figure 3 – Stress Process Model	11

List of Tables

Table 1 - Characteristics of Sample: Background Characteristics _____	72
Table 2 - Characteristics of Sample: Objective Stressors _____	75
Table 3 – Characteristics of Sample: Subjective Stressors _____	78
Table 4 – Characteristics of Sample: Moderators _____	79
Table 5 – Use of Respite Services _____	82
Table 6 – Comparison of Users and Non-Users of Respite Services Combined: Background Characteristics _____	84
Table 7 – Comparison of Users and Non-Users of Respite Services Combined: Objective Stressors _____	85
Table 8 – Comparison of Users and Non-Users by Type of Cognitive Impairment _____	86
Table 9 – Comparison of Users and Non-Users of Respite Services Combined: Subjective Stressors _____	87
Table 10 – Comparison of Users and Non-Users of Respite Services Combined: Moderators _____	88
Table 11 – Reasons Reported by Caregivers for the Non-Use of Respite Services _____	90
Table 12 – Bivariate Results – Characteristics of Caregivers Not Aware of Adult Day Centre Compared to Other Reasons _____	91
Table 13 – Bivariate Results – Characteristics of Caregivers Not Aware of In-Home Respite Compared to Other Reasons _____	92
Table 14 – Bivariate Results – Characteristics of Caregivers Not Aware of Hospital Respite Compared to Other Reasons _____	93
Table 15 – Bivariate Results – Characteristics of Caregivers Not Aware of PCH Respite Compared to Other Reasons _____	94
Table 16 – Variables Selected for Inclusion in Logistic Regression Models _____	96
Table 17 – Stepwise Logistic Regression Model for Adult Day Centre _____	97

Table 18 – Stepwise Logistic Regression Model for In-Home Respite _____	99
Table 19 – Stepwise Logistic Regression Model for Hospital Respite _____	101
Table 20 – Stepwise Logistic Regression Model for PCH Respite _____	103
Table 21 – Summary of Multivariate Analysis _____	105

Chapter One -Statement of the Problem

The predominance of cognitive impairment among older adults coupled with a shift toward reliance on informal caregiving has increased interest in determining factors associated with the use of formal community-based services. The aging of society and the prevalence of dementia among older adults suggests that the difficulties associated with cognitive loss will affect an increasing number of older adults, their caregivers and the health care system (Patterson, 1999). The care provided by family members, friends, and neighbors now plays a central role in the long-term care of older adults living in the community. The absence of informal care by family and friends is a contributing factor to the institutionalization of older adults (Chappell, 1993b).

The challenges of providing care to older adults with cognitive impairment are particularly demanding. Caregivers of the cognitively impaired generally provide assistance over extended periods of time to a family member suffering from an unpredictable disease characterized by progressive decline and severe personality and behavioural changes (Caserta, Lund, Wright & Redburn, 1987; Chenoweth & Spencer, 1986). Caregiving to older adults with cognitive impairment may threaten both the well-being of older adults and their caregivers. Complementing informal care with formal community support services may minimize the burden of caring for a cognitively impaired older adult, and reduce the risk of a caregiver requiring health care because of excessive strain.

Although the demands on informal caregivers have led to the development of a wide range of formal services aimed at enhancing and maintaining caregiving relationships, it is unclear that cognitive impairment results in an increased need for

services (Biegel, Bass, Schulz & Morycz, 1993; Caserta et al., 1987; CSHA, 1994; Crowell et al., 1996). Rather, the most consistent finding concerning the use of formal services is that few caregivers use services, and if they do use services it is only minimally (Noelker & Bass, 1989; Swan & Estes, 1990). Furthermore, the rates of service use amongst caregivers to older adults with cognitive impairment are generally lower in comparison to other caregivers (Birkel & Jones, 1989; Caserta et al.; Stephens, 1993; see exception Ory, Hoffman, Yee, Tennstedt & Schulz, 1999). Although family caregiving to older adults with cognitive impairment is typically stressful and demanding, management of functional and behavioral problems may also be a barrier to service use (Birkel & Jones).

Despite the sizeable body of research on formal service utilization by older adults and their caregivers, little attention has been given to the non-users of formal services. Indeed, only three research studies were found that explored the non-use of formal, community-based services by older adults with cognitive impairment (Adler, Kuskowski & Mortimer, 1995; George, 1988; Hamilton, Braun, Kerber, Thurlow & Schwieterman, 1996). Findings from these studies suggested that informal caregivers of cognitively impaired older adults demonstrated a sense of caregiving mastery and a reluctance to seek assistance despite an awareness of available services. These conclusions are limited however, by small sample sizes, convenience sampling, and a focus on specific services. Furthermore, the Canadian experience of informal caregiving and formal service use may represent a unique situation because of the increasing availability of homecare services within the system of comprehensive health coverage. In particular, Manitoba's extensive publicly funded homecare system may influence patterns of service use.

The lack of research investigating the non-use of services by older adults with cognitive impairment and their caregivers represents a gap in our understanding of the relationships between service needs and cognitive impairment. The challenge for health professionals is to encourage the appropriate use of formal services intended to assist older adults and provide relief to caregivers. The central role of nurses in assessing service needs and coordinating the delivery of community-based health services necessitates an understanding of low rates of service use and the reasons for non-use. This knowledge may have implications for service delivery and the targeting of services to high-risk, cognitively impaired older adults and their caregivers.

This study examines the non-use of formal community-based services by community-dwelling cognitively impaired older adults and their informal caregivers. Specifically, this study focuses on the limited use of respite services and the factors associated with reasons for the non-use of services. Respite services examined include adult day centre, in-home respite, hospital respite, and personal care home respite. These respite services are seen as formal services specifically intended to minimize the negative consequences of caregiving for the caregiver (Strang & Haughey, 1998). “The underlying assumption of respite care is that it reduces caregiver stress and burden, thereby facilitating the caregiving process and allowing the person with dementia to be maintained in the community” (Flint, 1995, p. 514). Despite this, evidence suggests that respite services are the most frequently requested yet consistently under-utilized services (Canadian Association for Community Care, 1998; Chappell, 1993a; Strang & Haughey). An exploration of reasons cited by caregivers not using respite services may provide

some understanding to an apparent contradiction of demand for services not evidenced by use.

This investigation of respite service non-use is a secondary analysis of data collected in the Manitoba Study of Health and Aging- 2 (MSHA-2). Characteristics of users and non-users of four respite services are described, the association between cognitive impairment and non-use examined, and reasons for not using respite services explored.

Chapter Two – Conceptual Framework and Literature Review

Overview of the Literature Review

There is a substantial body of literature examining the determinants of health service utilization by older adults. Early research in the area focused on older adults' use of ambulatory and acute care services. Services included in these studies tended to be traditional medical services such as hospital and physician care (Shapiro & Roos, 1989; Wan & Odell, 1981). More recently, the focus has shifted to the analysis of factors related to the use of community-based services (Crowell et al., 1996; Diwan, Berger & Kelly, 1997; Johnson & Wolinsky, 1996; Starrett, Rogers & Walters, 1989). Formal services in these studies are wide ranging and include both in-home and out-of-home support services such as professional nursing care, homemaker services, day hospitals, and various types of respite care.

The increasing focus on understanding the predictors and patterns of community-based service use can be attributed to a number of trends. Foremost, is the increasing elderly population and the recognition that as a group, older adults are disproportionately high users of health services. In part, a greater utilization of health care services by older adults is observed because they have the highest morbidity rates of all age groups (Chui, 1996). In particular, the relatively high rates of institutionalization in Canada and the associated costs have spurred interest in community-based alternative care models such as home care (Crowell et al., 1996; CSHA, 1994; Shapiro & Tate, 1997). These shifts to the provision of community-based health care services coupled with an increasing reliance on informal sources of support have also contributed to a greater interest in the patterns of service use by older adults and their caregivers. The contributions of informal

caregivers are well documented with as much as 80-90% of assistance coming from informal caregivers (Chappell, 1985; Denton, 1997). The role of informal support in providing assistance to older adults with dementia is particularly significant. Current estimates suggest that 50% of seniors with dementia live in the community with the majority receiving assistance from informal caregivers (National Advisory Council on Aging, 1996). Although dementia affects both the older adult and their caregiver, it is unclear that dementia results in a greater demand for services. Rather, it appears that informal caregivers are reluctant to access services (George, 1988; McCabe, Sand, Yeaworth & Nieveen, 1995; Silverstein, 1984).

In attempting to understand service use by older adults and their caregivers, researchers have examined the effects of numerous variables on service use patterns. These factors can be generally classified as socio-demographic, family, and health characteristics of both older adults and their caregivers. Most frequently, these factors have been conceptualized within the context of the Andersen model of health services utilization (Andersen, 1968; Andersen & Newman 1973). More recently however, the Stress Process model has been adopted to examine the caregiving experience and the use of formal services as a response to stressors associated with providing assistance (Pearlin, Lieberman, Menaghan & Mullan, 1981).

To understand service utilization, this review of the literature will focus on describing the factors associated with community-based service use and non-use by older adults and their caregivers. The findings relate the factors associated with community-based service use in general due to the lack of research studies focused specifically on the use of respite services, and the paucity of studies reporting factors associated with non-

use. The available literature on respite services focuses primarily on program evaluation and the effectiveness of services rather than addressing the factors associated with use and non-use. However, within the broader service utilization literature, respite services are included as one of several services in the analysis of factors associated with community-based service use. Where possible, specific findings related to respite services are highlighted.

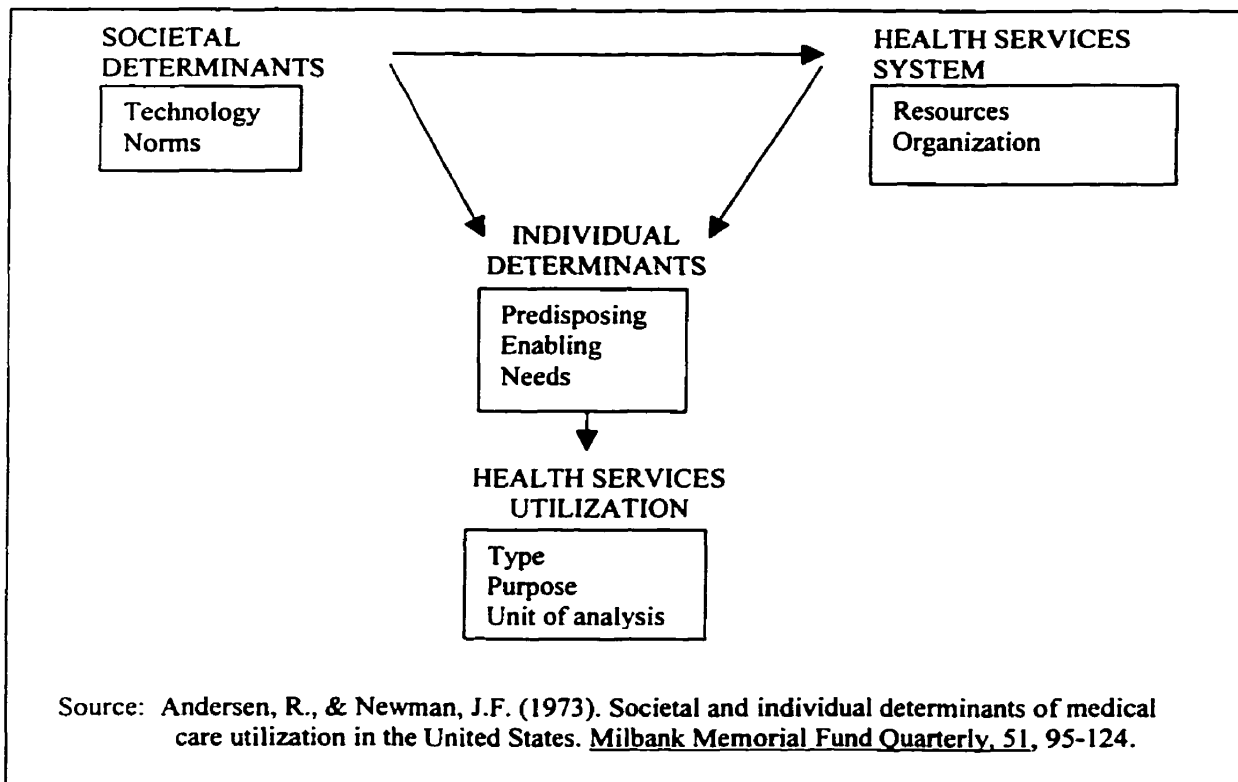
In this literature review, the terms community-based and formal services are used interchangeably to describe the use of non-acute, supportive services often referred to as homecare services. The use of institutional and acute medical services is not the focus of this review. The two dominant conceptual approaches to understanding service use patterns are presented, and the factors found to contribute to variations in service use are reviewed.

Conceptual Frameworks

In contrast to the array of findings observed in the literature related to the use of health services, there is little variation in the conceptual approaches used by researchers. The most widely adopted theoretical framework for research examining formal service use is the behavioural model outlined by Andersen and colleagues (Andersen, 1968; Andersen & Newman 1973). This model (Figure 1) suggests that the use of services is dependent upon individual determinants (e.g. illness level), societal determinants (e.g. technology), and the health services system (e.g. service resources). In particular, the model outlines a sequence of individual factors namely, predisposing, enabling, and needs factors that contribute to the types and volumes of services used. Predisposing factors refer to an individual's predisposition to use services, and include individual

characteristics such as age, gender, occupation, education and ethnicity. Enabling factors describe an individual's ability to secure services, and include family factors such as income and health insurance, as well as community factors such as the availability and accessibility of services. Needs factors refer to an individual's illness level or need for services. Needs factors include an assessment of both the perceived and evaluated symptoms and diagnosis of impairments.

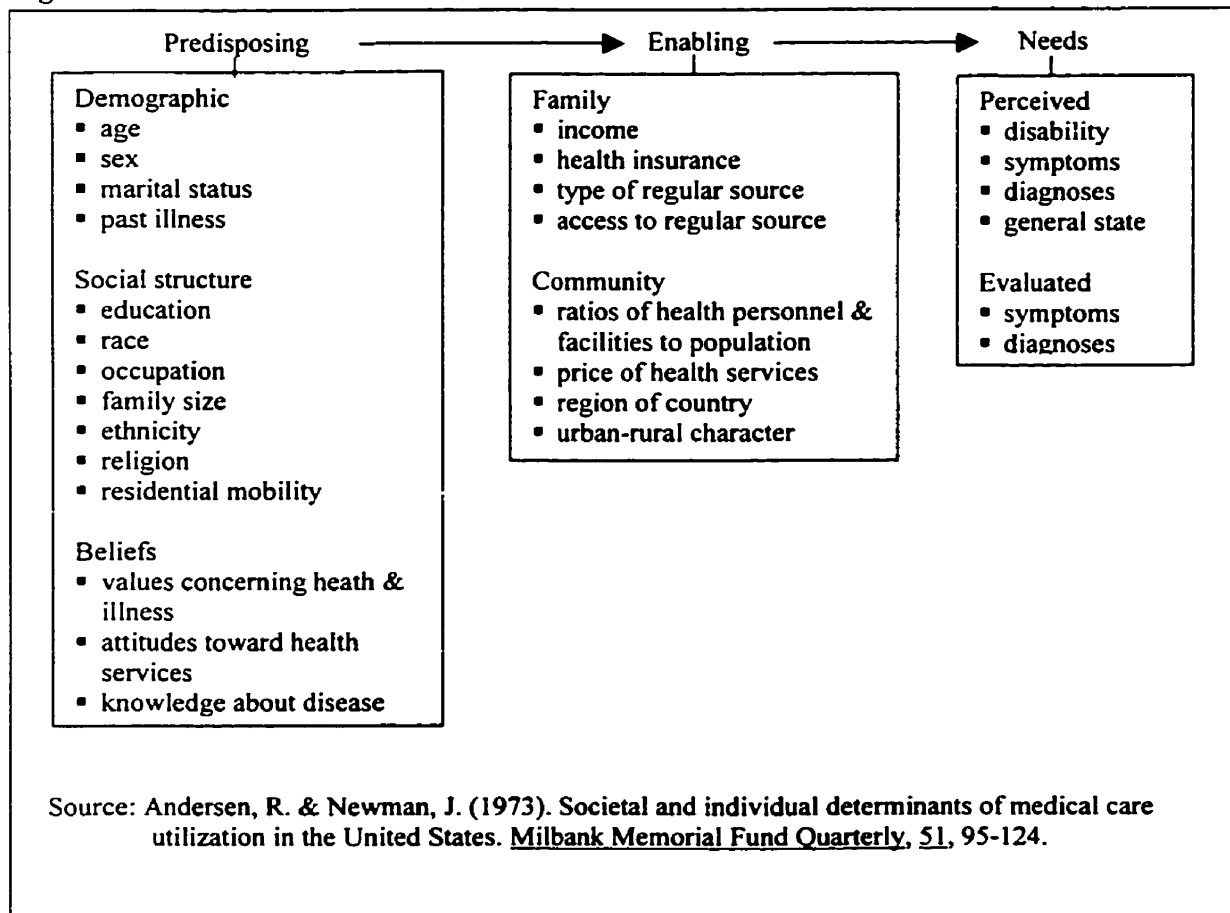
Figure 1: Anderson Newman Framework for Health Services Utilization



The Andersen model, which was originally developed to examine the use of medical services in the general population, has been subsequently applied as a framework for examining older adults' use of other formal community services. In particular, the family's role in identifying and accessing formal services for increasingly dependent older adults has been recognized (Gill, Hinrichsen & DiGiuseppe, 1998). Accordingly,

the original Andersen model has been modified to account for family related factors, such as social support that may influence an older adult's use of formal services. Bass and Noelker (1987) bifurcate the model to include predisposing, enabling, and needs factors of both the caregiver and the elderly care recipient. Predisposing factors are consistent with those in the original model, but also include predisposing factors related to the primary caregiver. Enabling factors are expanded to describe those resources that promote or inhibit service use. These may include locale of residence, proximity to services, and income of both the older adult and the caregiver. Needs factors are modified to include an assessment of caregiver stress and burden, in addition to the older adult's level of illness or impairment.

Figure 2: Individual Determinants of Anderson-Newman Model of Health Service Use

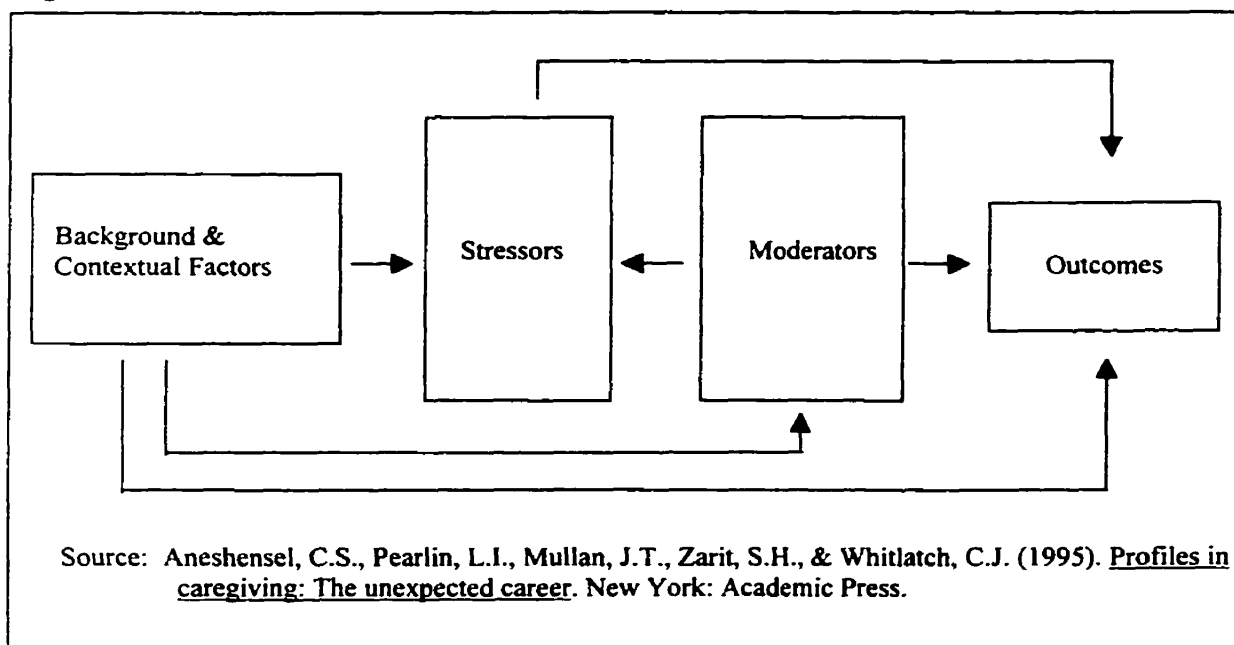


Despite the widespread use of both the Andersen and modified version of the Andersen model, this conceptual approach has had limited success in explaining service use. It is noted that the Andersen model has demonstrated minimal explanatory power and generally accounted for a variance in service use ranging from 9% to 27% (Stephens, 1993; Wan & Arling, 1983; Wolinsky & Arnold, 1988). This may in part be a result of borrowing the model from the analysis of medical services and applying it to the examination of patterns of community-based service use. Or, it may be related to the lack of specified relationships among the sets of variables within the model (Mui & Burnette, 1994). Where there has been consistency in findings, it has been in relation to the role of needs factors, particularly limitations in functional status due to health problems, as the strongest predictors of both acute medical and community-based service use (Penning, 1995b; Strain, 1991; Wolinsky & Arnold, 1988). Mullan (1993) suggests this is not surprising as the model assumes a need for services without defining what constitutes a need for services. This becomes especially problematic in relation to the use of non-medical and more discretionary services. Individuals and caregivers will have unique assessments of optimal functioning and their need to access sources of formal assistance. Furthermore, should caregivers express little need to use services, other predisposing and enabling factors have been found to demonstrate minimal influence in explaining service use (Mullan, 1993).

An alternative approach to understanding the process by which older adults and their caregivers seek services considers the analysis of service use within a stress framework. This framework, outlined and refined by Pearlin and colleagues (Pearlin et al., 1981; Pearlin, 1989; Pearlin, Mullan, Semple & Skaff, 1990; Aneshensel, Pearlin,

Mullan, Zarit & Whitlatch, 1995), specifies four domains of the basic Stress Process model, namely background and contextual factors, stressors, moderating factors, and outcomes (Figure 3).

Figure 3: Stress Process Model



Background factors describe individual characteristics such as age and gender that may influence the extent and/or likelihood of exposure to stressors. Stressors are defined as “the problematic and difficult circumstances experienced by caregivers” (Aneshensel et al., p. 34). This includes both primary stressors that originate directly from the caregiving experience and secondary stressors that are a consequence of the primary stressors. For example, a secondary stressor such as work difficulties due to absenteeism, may arise as a result of a primary stressor associated with an increasingly complex caregiving situation. Moderators are those factors that have an effect on the outcome or manifestation of the stressors. Furthermore, moderators are seen as affecting the stress process not only by directly influencing the outcome, but also interacting with the

stressors themselves. Moderators include any social, personal, and material resources that regulate the relationship between stressors and the outcomes. Outcomes are simply the consequences of the stressors. These are broadly defined as the effects on an individual's well-being, their physical and mental health, and their ability to sustain their social role.

Within this model, accessing and using formal health services is considered an outcome of the caregiving experience. That is, caregiving to an older adult is viewed as a potentially difficult situation wherein the manifestations of stress may result in the use of formal services to complement or substitute informal care. The framework serves a two-fold purpose of describing the conditions and experiences that influence caregivers' well-being, as well as describing the observed variations in the effects of these experiences on care recipients. Unlike the Andersen model, this consideration of the caregiver-care receiver dyad permits a greater recognition of the central role of informal caregivers in assisting with the care of older adults. The stress framework places the decision to access formal care in the larger context of the caregiver's set of strategies and responses to a particular situation. This is particularly useful in describing the use of formal services in caregiving situations with cognitively impaired older adults because of the impact of this disease on the lives of family members (Mullan, 1993; Pearlin, Aneshensel, Mullan & Whitlatch, 1996). There is little debate that caregiving to older adults with progressive cognitive decline is a stressful, often unidirectional caregiving experience in which family caregivers are the primary links to formal services (Aneshensel et al., 1995; Pearlin et al., 1996).

Although the Stress Process model was not proposed specifically as a framework for the analysis of service utilization, the domains and relationships articulated within the

model permit an examination of the impacts of caregiving and the effects on the care recipient. Notably, the caregiver and care recipient factors outlined in the domains of the stress model and the determinants of the Andersen framework are similar; background and contextual factors parallel predisposing factors, stressors are similar to needs factors, and moderators are comparable to enabling factors. Mullan (1993) in fact integrates the components of both of these frameworks to explore the linkages between informal and formal care among Alzheimer's caregivers. In contrast to the Andersen framework however, the Stress Process model facilitates the analysis of caregiving outcomes by specifying the inter-relationships between the domains within the model. This outlines a process of experiences related to using health services in the context of a particular caregiving situation. As such, this model is used as a framework for this study, and guides the review of the literature examining the use of formal health services by older adults and their caregivers.

Literature Review

Outcomes

Beginning with a review of the outcomes provides a context for the subsequent discussion of the factors that may influence and contribute to variations in the outcomes. As stated, the outcome of interest is the utilization of respite services. Townsend (1993) suggests that defining service use is more complicated than it first appears because the meaning of services must be clarified and the measurement of service use established. Comparability between studies is limited by both differences in the services examined and differences in methods of measuring service use (Townsend).

Differences in service types, confounding of services with the delivery site, and differences in defining the client or target of a particular service contribute to unclear definitions of services across all service utilization studies. Descriptions of service types are often limited and unique to the jurisdiction where they are delivered. In a Dutch study of service use by dementia patients, services were only described generally as professional assistance with domiciliary and ambulatory care (Boersma, Eefsting, VandenBrink & VanTilburg, 1997). Other researchers describe the care as being provided by a home care agency without specifying the types of services examined (Chappell, 1985; Crowell et al., 1996).

With respect to respite services, it appears that definitions of respite care are relatively consistent. Based on the understanding of respite as a period of rest, respite care is defined as “any service or group of services designed to provide caregivers with temporary or short-term relief away from the disabled person” (Lawton, Brody & Saperstein, 1991, p. 15). A unique aspect of respite care is that the services are targeted to the caregiver rather than the care recipient; the client of respite care is in essence the caregiver (Warren & Cohen, 1985).

Four problem areas are noted in defining respite services: frequency of use, place of delivery, intended recipient of the service, and type of service. The frequency of service use and place of delivery are common issues across the service utilization literature. Although the Andersen model operationalized service use as the type, purpose, and frequency of use, most studies treat service use as a dichotomous outcome measure. The most prevalent method of measurement involves the aggregation of respondents as either users or non-users of a cluster of services. This can result however, in a group of

non-users including people who have never used a service, have not used the service within the time period studied, or who did not meet a minimum criteria of service use (Townsend, 1993). In addition, clustering services into a single category “. . . implies that different services are predicted by the same characteristics” (Biegel et al., 1993, p. 420). Similarly, a summary measure of service use only provides information on the total number of services used and minimal information on the user characteristics of particular types of formal care. Some studies have used both dichotomous and summary measures of service use (Mullan, 1993; Penning, 1995b).

The place of service delivery also contributes to vague definitions of services when services are defined by where the service is delivered. Examples of this are the services of home care attendants and home support workers, or the services of home health aides and personal aides (Diwan et al., 1997; Shapiro & Tate, 1997). The site of delivery is clearly in-home, but differences, if any, in the specific services provided by these formal caregivers are not described. Many studies have categorized services based on their location and describe services as either in-home, out-of home, and linkage services (Biegel et al., 1993; Gill et al., 1998; Johnson & Wolinsky, 1996; McKinlay, Crawford & Tennstedt, 1995). Linkage care describes services and time spent managing caregiving activities in either in-home or out-of home settings.

Difficulties also arise when describing the delivery of respite care and the intended recipient. Many of the services that directly assist the older adult (e.g. assistance with homemaking), also indirectly benefit the caregiver. Services whose main objective is to provide caregivers a break have been classified as primary sources of respite, while services that provide relief through meeting other objectives have been described as

secondary sources (Canadian Association for Community Care, 1998). Townsend (1993) notes that the study of service use is influenced by how the clients are defined. Either noting for whom the service is intended, or outlining who has reported the use of services can clarify who the service is assisting. In their study, Biegel et al. (1993) specifically stated that caregivers reported service use, but that the services examined were intended for the older adult, although secondary benefits for the caregiver could occur. In other studies, the identification of the respondent reporting and benefiting from the use of services is notably absent (Kosloski & Montgomery, 1994; Montgomery, Kosloski, & Borgatta, 1988; Tennstedt, Crawford & McKinlay, 1993).

Finally, descriptions of respite care are particularly varied. In-home respite care may include companionship or the provision of homemaker and health care aide services. Out-of-home respite may include recreation and social programming for the older adult, and support groups and skills training for the caregiver (Canadian Association for Community Care, 1998). At times, very broad categories of services including day programs, in-home companions, and overnight sitters are representative of respite services (Rudin, 1994). Most often however, the service types identified as respite services are limited to adult day centre, in-home respite, and institutional respite (Adler et al., 1995; Burdz, Eaton & Bond, 1988; Cotrell, 1996; George, 1988; Lawton, Brody & Saperstein, 1989a; Mohide, Pringle, Streiner, Gilbert, Muir & Tew, 1990; Strang & Haughey, 1998).

Despite these measurement differences, there is a consistent pattern of low community-based service use by older adults and their caregivers. Although the availability of services varied considerably within and between provinces, the Canadian

Study of Health and Aging – 1 (CSHA, 1994) reported that the proportion of older adults with cognitive impairment not using any community-based services varied by region and ranged from 43% to 67%. In particular, older adults with dementia used few respite services. The low rates of respite service use are particularly surprising given the perceived burden of dementia on older adults and their caregivers (Fortinsky & Hathaway, 1990; Homer & Gilleard, 1994). Conclusions from a Canadian survey of respite programs suggest that “most seniors requiring help receive it from informal networks, and the support and respite needs of their caregivers are significant” (Canadian Association for Community Care, 1998). Despite these significant needs however, survey results from this evaluation of respite programs also found that respite services were under-utilized. Possible reasons for non-use were related to the limited availability of programs, the limited awareness of respite, the lack of government support for respite programs, and seniors’ fears about using respite programs (Canadian Association for Community Care).

For the most part, little is known about why a significant number of caregiver-care receiver pairs are not accessing services. Relatively few of the studies reviewed examined the characteristics of service non-users and factors associated with non-use (Adler et al., 1995; George, 1988; Hamilton et al., 1996). Of the three studies examining service non-use, only George focused solely on the non-use of respite services and observed that the failure to use services was related to concerns regarding future costs of institutionalization. Even those caregivers with relatively high incomes limited the use of respite services for fear that future needs would exceed their financial resources. These observed delays in the use of respite services related to cost may have more influence in

this American study than in Canadian studies where costs for services are usually minimal. Adler et al. reported results of a prospective study of institutional respite care and noted that less than half of the caregivers utilized respite. Those caregivers using respite services were caring for more functionally impaired older adults with dementia in comparison to caregivers not accessing services. Hamilton et al. examined the non-use of six community services including adult day centers, Alzheimer's support groups, nursing homes, meals on wheels, home health agencies, and senior citizen centers. They found a wide variation of factors that influenced caregivers in their decision not to use community services. Only a sense of personal caregiving competence emerged as significantly associated with the non-use of services.

Summary

Although it is generally accepted that respite care provides caregivers with periods of rest, there is a wide disparity in how respite services are defined and delivered. Respite service use can be reported generally as a dichotomous outcome or more specifically in terms of intensity and frequency of contact. The types of services described may be wide ranging and refer generally to in-home respite or describe specific tasks such as homemaking and companionship. As such, the intended recipient of respite care is often unclear.

The most consistent finding related to respite services is the limited use of these services by older adults and their caregivers. Despite the availability of respite services, caregivers demonstrate a reluctance to use respite services. Few studies however, have explored the factors related to respite service non-use by older adults and their caregivers.

Background and Contextual Factors

Returning to the beginning of the stress process model, the background and contextual factors can be considered the underlying framework of the model. These personal and situational characteristics of the older adult and caregiver directly influence the stressors, moderators and outcomes of the caregiving experience (Aneshensel et al., 1995). Most often, the elder and caregiver characteristics included as background and contextual factors are age, gender, marital status, living arrangement, locale of residence, and elder/caregiver relationship. These characteristics are comparable to those included as predisposing variables in studies using the Andersen model. Most studies do not include all of these background factors and there are some differences in where researchers include particular variables within the two main conceptual frameworks. Education, employment status, and income are sometimes included as background factors or considered enabling characteristics within the Andersen model. McKinlay et al. (1995) viewed education and employment status as moderators within the stress process framework because of their influence on one's ability to access services. As such, these factors are discussed when describing other moderators within the stress process model.

Elder and Caregiver's Age

Although age might be interpreted as a moderating variable because of the increased frailty associated with increasing age, it is most often considered a background factor (Miller & McFall, 1991). The majority of studies include either the older adult's or caregiver's age as an independent variable in examining service use. Furthermore, most researchers include the elder's age as an independent variable rather than the caregiver's age. The only exception noted in the studies reviewed was in an analysis of the predictors

of in-home and out-of home service use by family caregivers to older adults with Alzheimer's; age was not included as an independent variable in this study (Biegel et al., 1993).

Across most studies, it is generally observed that increasing age is associated with a greater use of community-based services by older adults and their caregivers (Crowell et al., 1996; Diwan et al., 1997; Murphy & Hepworth, 1996; Shapiro, 1986; Starrett et al., 1988). Specifically, Chappell (1985) observed that individuals aged 75 or over were more likely to be service users. Although some researchers reported conclusively that older age was associated with a greater use of formal services, the influence of age was also observed to vary by service type. Among caregivers of older adults with dementia, McCabe et al. (1995) observed that, with increasing age, more health care aide services were used by caregivers and the likelihood of participation in support groups was diminished. In another study, cognitively intact older adults were more likely to receive formal assistance with heavy housework than their younger counterparts (Denton, 1997).

Despite the trend of increased service use in older age, there are contrary findings. Several researchers reported no significant relationship between the older adult's age and the overall use of community-based health services (Bass & Noelker, 1987; Gill et al., 1998; Penning, 1995b; Strain, 1991). Although these studies examined the use of a variety of formal services, the influence of age was nonsignificant in each stage of regression analysis. The inclusion of other caregiver and elder characteristics or different service types did not influence the significance of age.

Elder and Caregiver's Gender

The majority of studies include the older adult's gender rather than the caregiver's gender as an independent variable. Those studies that included the caregiver's gender focused on the relationships between formal service use and informal care. Overall, the influence of both the caregiver and elder's gender in relation to service use was nonsignificant (Bass & Noelker, 1987; Diwan et al., 1997; Miller & McFall, 1991; Mui & Burnette, 1994; Murphy & Hepworth, 1996; Penning, 1995b; Starrett, 1988; Strain, 1991; Wan & Arling, 1983). Furthermore, exceptions to this finding were inconsistent. Some studies observed that elderly females were more likely to use formal services (Chappell, 1985; Crowell et al., 1996; Johnson & Wolinsky, 1996); others reported that elderly males and male caregivers had higher rates of formal service use (Biegel et al., 1993; Boersma et al., 1997; Chipperfield, 1994). Differences in service use patterns by gender may be related to the influence of the informal support network, or an increasing acceptance of formal services by men. Although Chipperfield accounts for differences in such factors as the presence of informal supporters, further study is required.

Marital Status, Living Arrangement and Elder/Caregiver Relationship

The older adult's marital status, coresidence, and kinship tie to their caregiver are variables that are often interchanged because of their correlation with one another (Biegel et al., 1993; Gill et al., 1998; Penning, 1995a). Situations of spousal caregiving exemplify the difficulty of separating the effects of marital status, living arrangement, and kinship tie. Furthermore, kinship relationship has not been found to be a significant predictor of formal care (Tennstedt et al., 1993). Whether the caregiver is a spouse or an adult child (usually daughter), the influence of the relationship has not been significantly related to

service use (Penning, 1995b; Bass & Noelker, 1997; Miller & McFall). Therefore, the majority of studies analyze the influence of living arrangement on the use of formal services. Usually, the living arrangement describes whether the older adult shared residence with their primary caregiver. Mullan (1993) however, assesses coresidency by the number of people in the same household.

In contrast to findings related to age and gender, the findings on the influence of living arrangement on service use are more consistent. In those studies including living arrangement, coresidence of the older adult with their primary caregiver or with other family members was associated with the use of less services (Bass, Looman, & Ehrlich, 1992; Chappell, 1991; Diwan et al., 1997; Gill et al., 1998; Mullan, 1993; Penning, 1995b; Penrod, Kane, Kane & Finch, 1995; Shapiro & Tate, 1997; Tennstedt et al., 1993). Only one study comparing the use of home care services by older adults in two Canadian provinces reported inconsistent findings. Coresidence was associated with less service use in one province and greater service use in the other (Crowell et al., 1996). Although an explanation for these results was not provided, it may be related to the broad definition of coresidence as the presence of a family member or “other” supporter in the same residence as the older adult.

Locale of Residence

Locale of residence refers to the urban or rural location of the older adult and their caregiver. Few studies include locale of residence as an independent variable influencing service use. Two studies observed that rural dwelling older adults and their caregivers used comparatively more services than their urban counterparts (McCabe et al., 1995; Penning, 1995b). In particular, those living in a less urban setting were more likely to

receive personal care services, when accounting for the influence of caregiver burden (Penning). It should be noted that McCabe et al. defined rural areas as having a population of less than 2500 residents whereas Penning based her findings on CSHA-1 data that included 36 Canadian cities and their surrounding rural areas (CSHA, 1994). It is reported that rural dwelling older adults are under-represented in the CSHA-1.

In contrast to these studies, Coward, Duncan and Freudenberger (1994) reported no residential differences in the kinds of services used by community-dwelling older adults. They do concur with the previous two studies however, in observing that urban areas have significantly more services available. They note that although rural residents tend to indicate that needed services were not available in their community, they effectively use the limited service options available to them. McCabe et al. (1995) concur that rural caregivers' use of services is significantly greater than that of urban caregivers when comparing proportional service utilization.

Summary

A significant variation in the influence of background factors on service use is observed. Since many researchers employed regression analyses and entered the background or predisposing factors first in their analyses, these variations are not likely due to differences in data analysis strategies. Rather, some differences may be attributed to the fact that most studies did not include all the same sociodemographic characteristics as independent variables. It is generally concluded however, that in comparison to other factors, background characteristics contribute little to explaining differences in service use (Penning, 1995b). Despite this, it is suggested that further analysis of these variables

may clarify the observed differences in service use by older adults and their caregivers (Kosloski & Montgomery, 1994; Mullan, 1993).

Stressors

As previously explained in describing the stress process framework, stressors consist of both primary and secondary stressors that diminish a caregiver's ability to respond to the demands of the care recipient. Primary stressors are composed of both objective and subjective characteristics of the care recipient and caregiver. Objective primary stressors outlined by Aneshensel et al. (1995) include the care recipient's cognitive status, functional status, problematic behaviours, and resistance to caregiving. Subjective primary stressors describe the caregiver's sense of role overload, role captivity, and the loss of a meaningful relationship with the care recipient. Secondary stressors indicate the extent to which caregiving intrudes into non-caregiving related activities. Family relations, work conflict, and financial strain are the main secondary stressors identified by Aneshensel et al. in their analysis of the caregiving experience.

Within the literature related to caregiving and service utilization, the focus has been on determining the association between primary stressors and service use. Most studies include variables similar to those primary objective stressors identified by Aneshensel et al. (1995). In addition to cognitive status, functional status, and problematic behaviour, researchers have also included a measure of the caregiver's and elder's physical health status, and the elder's depressive symptomology. Resistance to caregiving was not included as an independent variable in any of the studies reviewed. Caregiver burden and depression were the most commonly included variables similar to the primary subjective stressors studied by Aneshensel et al.. These measures may

provide an indication of the caregiver's role overload, role captivity and the loss of intimate exchange.

With respect to secondary stressors, few studies have included variables comparable to those outlined by Aneshensel et al. (1995). With the exception of one investigation that described the implications of conflicted family relations for caregiving support, none of the studies reviewed considered secondary stressors (Hibbard, Neufeld & Harrison, 1996). This overview therefore, will describe the findings related to the influence of primary objective and subjective stressors on service use.

Objective Stressors

Elder's and Caregiver's Physical Health Status

The elder's and caregiver's physical health status are considered together because few studies include only the caregiver's health as an independent variable (Bass et al., 1992; McCabe et al., 1995). The assessment of health status takes on either a subjective or objective measurement approach. Self ratings of health are more subjective in comparison to determining the number of chronic medical conditions. Self ratings of health are most often described as a global self-rated health assessment or as an elder's self perceived health status compared to age peers (Crowell et al., 1996; Denton, 1997; Gill et al., 1998; Kosloski & Montgomery, 1994; Mullan, 1993; Penning, 1995a; Shapiro & Tate, 1997). These assessments of self-rated health may range on a scale from poor to excellent health status. From a review of 27 community-based studies, Idler and Benyamini (1997) observe that self-rated health is an impressively consistent indicator of mortality.

More objective approaches to the determination of physical health status often include the number of diagnosed chronic conditions or medical problems during a specified time period. These may be reported as a continuous measure or simply a dichotomous variable indicating the presence or absence of disease (Boersma et al., 1997; Diwan et al., 1997; Bass & Noelker, 1987; Johnson & Wolinsky, 1996; Miller & McFall, 1991). Some studies include both subjective and objective indicators of health status by reporting self ratings of health and the number of chronic medical conditions (Penning, 1995b; Strain, 1991).

The association between an elder's physical health status and the use of community-based services by older adults and their caregivers is unclear. Overall however, it is observed that most studies utilizing an older adult's self rated health status reported no significant relationship between the use of various services and health status, whereas those measuring the number of chronic conditions did find a positive association. In contrast, with the exception of one study (Bass et al., 1992), caregiver's health status was found to influence service use either overall or relate to the use of specific services. In particular, poorer caregiver health was positively associated with the use of homemaker, personal care, and supervision services for the older adult (Gill et al., 1998; Penning, 1995b). Although these findings suggest an association between poorer caregiver health status and the increased use of services, it cannot be presumed that the observed declines in health status are a result of the objective conditions of caregiving.

Functional Status

In addition to measures of physical health status, most studies include ratings of functional status defined as limitations in basic activities of daily living (ADLs) and

instrumental activities of daily living (IADLs). Basic ADLs refer to personal care functions such as bathing, dressing, eating, and toileting. Instrumental ADLs describe household tasks such as meal preparation and using the telephone. Relatively few differences are apparent in the basic ADL and IADL tasks included by researchers because of the use of standardized instruments to determine functional status.

Often, functional status is assessed from widely used instruments such as the Older Americans Resources and Services ADL Scale (OARS), the Cambridge Examination for Mental Disorders of the Elderly (CAMDEX), the Functional Dementia Scale, and the Memory and Behaviour Checklist (Boersma, 1997; Caserta et al., 1987; CSHA, 1994; Diwan et al., 1997; Gill et al., 1998; Kashner, Krompholz, McDonnell, Magaziner & Schumann, 1990). Responses may be coded on a scale ranging from independence to total dependence, or summed to indicate the total number of activities for which assistance is required. Most frequently however, researchers report functional status with a dichotomous variable indicating if assistance is required or if ADLs and IADLs can be completed independently. This approach does not describe the amount of assistance required with ADLs or IADLs or specify if the use of assistive devices such as walkers and grab bars is considered as independence in ADLs and IADLs. Of the few studies that consider the use of such devices, levels of disability were reported on a scale (CSHA; Starrett et al., 1988).

The provider of information regarding functional status is also varied. Dependence in ADLs and IADLs may be reported by the older adult, the caregiver, the healthcare provider, or assessed by the researcher. A researcher's report of functional ability may be based on a review of all the available information such as an elder's and/or

caregiver's report, functional assessment, and medical chart review. Furthermore, those studies with cognitively impaired older adults usually include a caregiver's report of functional ability to ensure the accuracy of data (Biegel et al., 1993; Montgomery et al., 1988; Penning, 1995b). Although concordance between a cognitively intact elder's and caregiver's report of functional status is anticipated, older adults with dementia have been observed to report higher levels of functional ability than their caregivers (Kiyak, Teri & Borson, 1994). A general under-reporting of information by elders with dementia was also observed in comparing elder and caregiver responses on questions administered during a psychogeriatric day hospital assessment (Ballard, Chithiramohan, Handy, Bannister, Davis, & Todd, 1991). Agreement between older adults with dementia and their caregivers has been observed to decline with increasing severity of dementia (Ostbye, Tyas, McDowell & Koval, 1997).

Despite different measurement approaches, functional status is consistently found to be an important predictor of service use. With greater dependence in ADLs and/or IADLs, an increased use of services is observed. In describing the use of institutional respite services, Adler et al. (1995) observed that caregivers of more functionally impaired older adults with dementia requested services more quickly and used services more frequently. Furthermore, in a longitudinal analysis of the use of in-home help, a decline in ADLs over time was also associated with a greater likelihood of service use (Miller & McFall, 1991). Several studies demonstrated this association between increasing functional dependency and a greater use of in-home services such as personal care services (Johnson & Wolinsky, 1996; Kashner et al., 1990; Penning, 1995b).

Cognitive Status

Cognitive status is a stressor that has received particular attention in studies of service use by older adults. Research in this area has been based on the assumption that cognitive dysfunction affects both older adults and their caregivers, and is a major determinant of service use (Bergman-Evans, 1994; Penning, 1995b). The impact of cognitive impairment is thought to be significant to the extent that informal caregivers will turn to formal assistance as progressive declines associated with a dementing illness are encountered (CSHA, 1994).

Numerous measurement approaches are used to describe the cognitive status of older adults. Most often, researchers administer a cognitive status exam such as the Modified Mini-Mental State Exam (3MS), Mini-Mental State Examination (MMSE), or Cambridge Examination for Mental Disorders of the Elderly (CAMDEX) (Biegel et al., 1993; Boersma et al., 1997; CSHA, 1994; Crowell et al., 1996; Dellasega, Dansky, King & Stricklin, 1994; Gill et al., 1998; Penning, 1995b). These instruments examine cognitive functioning in several domains including short and long-term memory, orientation, language, and abstraction ability. Results on these tests are either coded by the researchers as a continuous measure or categorized as cognitively impaired versus intact. If possible, some studies determine cognitive status by considering the results of cognitive status tests together with best available information. That is, scores on mental status tests are used together with the diagnosis of a physician or clinical team and a caregiver's report to determine the degree of cognitive impairment (Bass et al., 1992). Other studies rely primarily on diagnosis by physician or clinical team to determine cognitive status (Bass & Noelker, 1987; Caserta et al., 1987; Gill et al., 1998; Shapiro &

Tate, 1997). A few studies describe the cognitive status of the older adult based solely on the primary caregiver's report (Johnson & Wolinsky, 1996; Kosloski & Montgomery, 1994; Montgomery et al., 1988). Although there is no 'gold standard' to measure the accuracy of caregiver's information on mental status, reliance on a caregiver's report has been associated with an increased likelihood of false positive reports of declining cognition (Seltzer & Buswell, 1994). Other studies provide no explanation for how cognitive status was determined (Diwan et al., 1997; McCabe et al., 1995).

In addition to determining cognitive status, an indication of the type and severity of cognitive impairment is sometimes included. McCabe et al. (1995) defined dementia according to first, second, and third stages, but did not explain the differences between these stages. Boersma et al. (1997) described four dementia types including Alzheimer's, multi-infarct dementia, mixed dementia, and an 'other' category. Similarly, the types of dementia in the CSHA-1 were listed as probable Alzheimer's, possible Alzheimer's, vascular dementia, and other dementia. A ranking of mild, moderate, and severe was used to denote the severity of the dementia type (CSHA, 1994).

The expected influence of cognitive impairment on service needs is not clearly demonstrated. Some studies observe an association between cognitive impairment and greater use of community-based services (Caserta et al., 1987; CSHA, 1994; Shapiro & Tate, 1997), whereas others find no significant relationship (Boersma et al., 1997; Gill et al., 1998; Penning, 1995b). Other studies report only significant associations between cognitive impairment, the use of particular services, and service intensity. Kosloski and Montgomery (1994) reported that the use of services such as hospital visits and home health care were best predicted by need factors including cognitive impairment.

Hawranik (1998) found that when other factors such as functional limitations were taken into account, older adults with dementia and their caregivers were more likely to use personal care services than cognitively intact elderly adults; no significant association was found with the use of homemaking, nursing, and meal preparation services. Bass and Noelker (1987) observed that cognitively impaired clients used more service hours per week of in-home personal and health care services. In addition, Dellasega et al. (1994) reported that cognitively impaired clients were readmitted to the care provided by a home health agency more frequently than cognitively intact older adults.

Overall, there appeared to be a trend of greater para-professional service use than professional service use by older adults with dementia. Dellasega et al. (1994) found that cognitively impaired older adults used more home health aide services in comparison to their cognitively intact counterparts who used more skilled nursing care. Similarly, Shapiro and Tate (1997) noted differences in the type and amount of services received by older adults with varying degrees of dementia in a sample of older Manitobans. They observed that older adults diagnosed with dementia were the heaviest users of support services such as adult day care, and used the fewest professional nursing services in comparison to those with no dementia. These findings must be cautiously interpreted however, as Penning (1995b) reported contrasting findings utilizing data from the CSHA-1, which includes a sub-group of the Manitoba respondents studied by Shapiro and Tate. Differences in the findings of these two studies may be related to Penning's consideration of the influence of informal support on service use by cognitively impaired older adults.

Apart from differences in the measure of cognitive status contributing to the lack of consistent findings, the consequences of dementia may in fact be of greater

significance to service use than simply the determination of cognitive status (Penning, 1995b). Hawranik (1998) highlights the need to carefully examine the determination of cognitive status to ensure that the characteristics and behaviours related to cognitive decline are observed. Perhaps evidence of the impact of cognitive impairment on functional independence may better delineate the relationship between service use and cognitive status. That is, cognitive deficits may only relate to service needs when independence in activities of daily living is jeopardized.

Problematic Behaviour

To address some of the limitations of cognitive status as an indicator of service use, researchers have recently begun to include problematic behaviours such as acting out and withdrawal as an independent variable (Gill et al., 1998; McCabe et al., 1995; Mullan, 1993). A measure of behavioural difficulties may provide an indication of the extent to which cognitive status impedes independence and leads to service needs. Most often the assessment of personality changes with cognitive impairment are based on information provided by the caregiver. These ratings have been found to be both reliable and independent of the caregiver's gender, relationship to the care recipient, and living arrangement (Jacomb et al., 1994). Findings related to problematic behaviours and service use are reported in only three of the studies reviewed.

In a study examining barriers to the use of formal community-based services, Mullan (1993) examined the influence of problematic behaviour as a primary stressor related to service use. In addition to cognitive difficulties and functional limitations, problematic behaviours were considered a characteristic of the older adult that may indicate a need for assistance. A 14-item scale was developed to measure the frequency

within a one-week time frame that caregivers reported dealing with challenging behaviours such as agitation and inappropriate sexual behaviour. A Cronbach's alpha of 0.79 is reported. Results from logistic regression analyses did not indicate an association between problematic behaviours and a greater likelihood of service use.

Contrary findings were reported in two studies investigating the factors associated with the use of community based services by older adults with dementia and their caregivers (Gill et al., 1998; McCabe et al., 1995). Data about problematic behaviours was determined using Zarit and Zarit's Memory and Behavioural Problems Checklist (1983) and Neiderehe's Behavioural Problems Checklist (1988). The Memory and Behavioural Problems Checklist determines the frequency of behavioural problems observed by the caregiver in a 6 month period (Zarit and Zarit). The Behavioural Problems Checklist assesses problems observed in six behavioural dimensions including cognitive symptoms (Neiderehe). Results of analyses in both studies demonstrated a significant relationship between increasing severity of behavioural problems and overall service use. In addition, separate regression analyses examining factors related to the use of specific services revealed an increased probability of using out-of-home recreational services and homemaking services with more frequent behavioural problems (Gill et al.).

A lack of information on the specific problematic behaviours assessed in these three studies limits the conclusions that can be drawn. It is notable however, that the positive association between problematic behaviours and service use was only observed when behavioural and cognitive difficulties were measured in the same scale. Further analysis of the role of problematic behaviours related to formal service use is necessary.

Elder's Depressive Symptomology

Few of the studies reviewed included the assessment of the older adult's report of depressive symptoms (Bass et al., 1992; Boersma et al., 1997; Solomon, Wagner, Marenberg, Acampora, Cooney & Inouye, 1993; Wan & Arling, 1983). Bass et al. measured depression with a single-item indicator that determined whether depression was a problem for the older adult. They observed that depression was related to the use of fewer service hours for clients with greater cognitive impairment. Similarly, Solomon et al. and Wan and Arling report that depressive symptoms were significantly associated with the use of community-based services. In contrast, Boersma et al. found no significant relationship between depression, as assessed with the CAMDEX, and the use of community-based or institutional services by older adults. Inconsistent findings preclude the determination of an association between service use and depression, but further analysis of an elder's depressive state may be particularly relevant in relation to service use by cognitively impaired older adults. The under diagnosis of depression in older adults with dementia may confound findings related to service use and cognitive impairment (Bass et al.).

Subjective Stressors

Caregiver Burden

The study of caregiver burden is a well-developed area of research in the gerontological literature. Caregiver burden is understood as a negative affective state resulting from an individual's appraisal of objective role demands (O'Rourke, Haverkamp, Tuokko, Hayden & Beattie, 1996). Caregiver burden arises when the demands of caregiving surpass the perceived available resources (Pearlin et al., 1990).

Caregiving to older adults with dementia is a particular caregiving experience associated with increased levels of caregiver burden. In describing the experiences of family caregivers to older adults with dementia, Chenoweth and Spencer (1986) reported that nearly ¼ of caregivers were exhausted because of the physical and emotional strains of caregiving. Aneshensel et al. (1995) also observed that the progressive declines associated with cognitive impairment are central to the proliferation of stressors, and consequential for a caregiver's well-being. As such, the majority of studies exploring the relationship between caregiver burden and service use were conducted with caregivers of cognitively impaired older adults.

Three studies used the Zarit Burden Interview to evaluate the influence of caregiver burden (Gill et al., 1998; CSHA, 1994; Penning, 1995b). These investigations focused on the use of both in-home and out-of-home services by cognitively impaired older adults. Although the CSHA-1 results indicated that caregiver burden scores were higher with increasing severity of dementia (CSHA, 1994), Penning (1995b) and Gill et al. (1998) found little evidence that as caregiver burden increased, reliance on formal services, as indicated by the use of a greater number of services, increased. There was however, a positive association between specific services (nursing and therapy services), high caregiver burden and additional caregiver or elder factors such as locale of residence (Penning, 1995b).

Interactions between variables were noted by Biegel et al. (1993) and Bass et al. (1992) when analyzing the influence of caregiver burden on service use. Bass et al. reported an interaction between burden, measured as emotional strain and task burden, cognitive impairment, and service use. For example, they observed that greater task

burden was associated with more service use amongst cognitively intact older adults and less service use with increasing cognitive impairment. Biegel et al. observed a positive association between out-of-home service use, minimal functional decline, and lower levels of caregiver strain, as measured on a 4-point Likert scale. It was suggested that either out-of-home services have a beneficial effect on the caregiving situation or that such services were only useful in ideal caregiving circumstances characterized by minimal cognitive impairment, functional decline, and caregiving demands (Biegel et al).

Interestingly, those studies focusing on caregiver burden among caregivers of cognitively intact older adults indicate an association between burden and service use (Bass & Noelker, 1987; Miller & McFall, 1991). A cross-sectional analysis of the influence of family caregivers on older adult's use of in-home nursing and aide services found that a caregiver's reported task burden influenced the receipt of these services. Specifically, contact with the in-home service delivery system was more likely for older adults cared for by stressed caregivers. The amount of formal services received was not however related to caregiver stress once initial use had begun (Bass & Noelker). Rather, the enabling factor of household income contributed most to explaining differences in the amount of service use. Although this may be a reflection of a user fee system, Miller and McFall reported contrasting findings in a national US study. In a longitudinal analysis of the effect of burden on changes in the use of in-home formal assistance, they found that the caregiver's perception of burden was a significant predictor of increased amounts of service use with tasks such as personal care or meal preparation (Miller & McFall).

Caregiver Depression

As with caregiver burden, depression has been thought to be associated with caregiving of persons with dementia and service use. Findings from a secondary analysis of CSHA-1 data indicated that behavioural disturbances related to dementia were one of two elder characteristics associated with higher depressive symptomology (Meshefedjian, McCusker, Bellavance & Baumgarten, 1998). Data from the same study of caregivers across Canada suggested that depressive symptoms were twice as common among caregivers of persons with dementia compared to cognitively intact elders (CSHA, 1994). To alleviate the psychological stress associated with caregiving, some individuals may access formal services. Only one of the studies reviewed investigated this relationship between caregiver depression and formal service use. Herein it was reported that neither caregiver's competence, sense of overload, anger, nor depression directly affected overall service use (Mullan, 1993).

Summary

Similar to background factors, there is much variation in the findings related to the relationship between particular stressors and service use. Unlike background factors however, methodological limitations may significantly contribute to the lack of consistency in findings. Varied approaches to measuring functional ability, cognitive status, problematic behaviours, and caregiver burden all limit comparability and generalizability across studies. O'Rourke et al. (1996) comment for example, that some of the observed differences in the relationship between service use and caregiver burden may be related to a limited understanding of what is precisely measured when assessing caregiver burden. Although this does not negate the findings reported in the literature, it

does underscore the importance of recognizing the variation in measurement across studies, and the subsequent need for a careful analysis of results to limit misinterpretation. Although many studies highlight the significant contribution of stressors in explaining variations in service use, it cannot be concluded that greater needs contribute most to an increased use of services by older adults and their caregivers.

Moderators

Moderators are “comprised of the social, personal, and material resources that help modify or regulate the causal relationship between stressors and outcomes” (Aneshensel et al., 1995, p. 34). They are considered a primary reason for the observed variation in caregivers reactions to similar stressors. When social, personal, and material resources are abundant, it is hypothesized that the effects of stressors are buffered (Pearlin, 1989; Pearlin et al., 1990). Within the stress process model, coping and social support have been considered the two principal moderators (Pearlin et al.), although Aneshensel et al. focused on the moderating influence of social support and caregiving mastery. Social support includes both the instrumental and socioemotional support received by caregivers from informal and formal sources. Coping describes the actions that people take on their own behalf to lessen the impact of stressors, and caregiving mastery indicates the level of caregiving competence (Pearlin).

Although social support has been extensively discussed in the literature related to caregiving and service utilization, there are few studies that include measures of coping and caregiving mastery. Those describing the influence of caregiving mastery have found that a sense of personal competence improves emotional well-being and is associated with the non-use of community services (Aneshensel et al., 1995; Hamilton et al., 1996).

Rather, most studies suggest that additional resources of the older adult and caregiver mediate the effect of stressors and contribute to differences in service use. In addition to measures of social support, the relationship between service use, income, and education has been studied. This review of moderators focuses on these factors.

Social Support

Social support is broadly defined as the informal assistance provided by family, friends, and other individuals such as neighbors. Generally this informal assistance refers to unpaid help from family members (Miller, 1995). Supportive assistance can be instrumental support such as help with bathing or meal preparation, or emotional support such as being available and spending time together. As noted, the analysis of social support in the gerontological literature has been extensive. There is substantial evidence of the widespread involvement of informal caregivers in providing assistance to older adults. Findings from CSHA-I indicated that most community-dwelling older adults have at least one caregiver and the majority have two or more relatives and friends providing assistance (CSHA, 1994). In relation to service use, it has been noted that social support is more relevant to explaining the use of community services than the use of medical services (Penning, 1995a).

Although social support is usually included in the analyses of service utilization, it is measured many different ways. Some studies report the size of the support network (Bass & Noelker, 1987; Penning, 1995b; Solomon et al., 1993), and others indicate the extent to which secondary caregivers are involved in providing assistance (Bass et al., 1992; Biegel et al., 1993; Dellasega et al., 1994). The Lubben Social Network Scale is a

commonly used measure of social support among older populations which describes the quantity and quality of support from family members (Lubben, 1988).

The impact of social support on service use is unclear. A number of studies have found that social support can influence the use of community services. The involvement of informal caregivers has been associated with a lower likelihood of service use (Caserta et al., 1998; Chappell, 1985; Miller & McFall, 1991; Mullan, 1993; Penning, 1995a). Informal support in these studies referred to the size, quantity, and quality of assistance provided by an informal network (Caserta et al.; Chappell; Miller & McFall), or the instrumental and emotional support provided by informal caregivers (Mullan; Penning). Findings indicated an inverse relationship between these measures of informal support and service use. Caserta et al. examined correlates of service use related to respite day-care and in-home respite care. They found that in comparison to caregivers using these services, those caregivers that reported not feeling ready to use these services had larger informal networks, greater contact with their support networks, and higher levels of satisfaction with the social support received. Similarly, Chappell observed that those older adults without social support and greater need, became users of home care services. Miller and McFall also found in their longitudinal analysis of service use that a decrease in the number of informal helpers over time was related to additional formal help. Penning measured both emotional and instrumental support provided by informal caregivers and found that older adults with high levels of instrumental assistance were less likely to use home care services; there was no relationship between emotional support and service use. In contrast, Mullan found that a lack of emotional support for the caregiver was associated with an increased use of formal services.

Other studies report interactions between social support, service use, and additional characteristics of the older adult and caregiver (Bass et al., 1992; Dellasega et al., 1994; Penning, 1995b). Bass et al. observed an interaction between cognitive impairment and the presence of additional informal caregivers. They reported that for cognitively intact older adults, having secondary caregivers predicted the use of more service hours; for cognitively impaired older adults, having additional caregivers predicted the use of fewer service hours. Similarly, Dellasega et al. found that more cognitively impaired older adults had a caregiver and used fewer nursing and health care aide services. It was suggested that the presence of caregivers met the need for supervision that otherwise would be provided by formal caregivers. Penning noted an interaction between formal help, caregiver burden, and informal help, where higher levels of burden and a greater number of informal caregivers was associated with a lower likelihood of the use of nursing services. Overall however, the actual number of caregivers was not significantly related to the use of formal community-based services generally or specific service types.

Despite inconclusive findings, many of the studies demonstrated support for the complementary relationship between informal and formal support (Caserta et al., 1998; Chappell, 1985; Denton, 1997; Penning, 1995a). Findings from these studies indicated that the informal system both supplemented and complemented assistance from formal sources of support. Social support from informal sources is observed to reduce unmet needs and buffer the relationship between health related stressors and service use. Further clarity of the relationship between social support and service use may be achieved with improved measures of this multidimensional concept. Penning (1995a) notes that the type

of support studied is usually categorized along one dimension, yet emotional and instrumental support may have very different effects on service needs.

Income

Findings describing the relationship of income and service use are primarily based on American studies. Consideration to the moderating influence of income in Canadian studies is limited. Havens (1996) notes that variations in the administration of user premiums for community-based services across Canadian provinces may limit comparisons between studies. When included in the literature, income is generally measured as total monthly income of either the caregiver or the older adult, and reported as a continuous or categorical variable. At times, the measurement of monthly income may be complemented or substituted by an indication of the caregiver's employment status (Biegel et al., 1993; Penning, 1995b; Starrett et al., 1988). Missing data is a common occurrence for data on personal incomes. Studies often indicate that estimations for missing income data were necessary (Denton, 1997; Miller & McFall, 1991). In addition, income is not always considered a factor enabling or moderating the use of services. Those studies using the Andersen Newman model sometimes conceptualize income as a predisposing factor rather than an enabling factor as suggested by the model (Penning, 1995b; Starrett et al.). More often however, income is considered an enabling factor that influences the acquisition of services once the decision has been made to seek assistance.

Generally, a paradoxical U-shaped relationship is observed between income and home care service use in the American literature. That is, the more wealthy and the very poor are more likely to access home care services (Grabbe, Demi, Whittington, Jones,

Branch & Lambert, 1995). Those studies reporting a significant effect of higher income on the use of community services attribute their findings to the ability of wealthier individuals to purchase needed services (Bass et al., 1992; Bass & Noelker, 1987; Kosloski & Montgomery, 1994; Mullan, 1993). Bass and Noelker observed that a higher household income was a significant predictor of more service hours per week. Mullan suggested that those with lower incomes were less likely to use services because most services required some out-of-pocket expenses. Interestingly, one Canadian study found similar results related to the use of services provided by ancillary community-based agencies. Snider (1981) commented that the association of income as an enabling factor for greater service use was surprising given that the data was collected from older persons who received fully subsidized health care. The types of services provided by these community-based agencies was not disclosed.

The association between lower income and greater service use may be related to the subsidies provided to those with less income. Gill et al. (1998) observed that lower income, as indicated by receipt of Medicaid, was associated with a greater use of community services overall. It is noted that without Medicaid, many of the families would not have been able to afford or pay for the considerable costs of the community services used. Delisle and Ouellet (1997) also reported that elderly Quebec residents with a relatively low income used community resources such as Meals on Wheels and health information services more frequently. Bass and Noelker (1987) found an interaction between lower income, service contact, and help from family caregivers. They indicated that lower family income and assistance from kin was related to the use of in-home

nursing and aide services. It is suggested that lower income families used more in-home services as a substitute for facility-based care that is less accessible due to high costs.

Contrasting findings are reported in additional studies. Several researchers observe no significant relationship between income and the use of community services (Denton, 1997; Shapiro & Tate, 1997; Tennstedt et al., 1993). In studies based on Canadian data, Denton and Shapiro and Tate both reported that income was not a predictor of formal assistance. Similarly, Tennstedt et al. noted that income was not predictive of the use of formal services, particularly assistance with personal care and housekeeping. All of the studies reviewed that included caregiver employment status as an indicator of income also demonstrated no association with service use (Biegel et al., 1993; Penning, 1995b; Starrett, et al., 1988).

Education

Similar to income, education is conceptualized differently across studies and has demonstrated inconsistent effects on service use. Among those studies using the Andersen Newman model, some have included education as an enabling factor (Bass & Noelker, 1987; Mullan, 1993; Snider, 1981) and others have included education as a predisposing factor in accordance with the model (Miller & McFall, 1991; Gill et al., 1998; Penning, 1995b; Strain, 1991). Within the stress process framework, education has been included as both a background characteristic and moderating factor (McKinlay et al., 1995; Mullan, 1993). Herein education is discussed as a moderating variable related to service use. Bass and Noelker (1987) suggest that educational level is often used as a proxy for knowledge of services and both factors can enable formal service use.

Educational level is considered a resource that may mediate the relationship between stressors and outcomes experienced by older adults and their caregivers.

The analysis of educational level related to service use generally measures educational level as a continuous variable by the number of years of education completed by the older adult or caregiver. Several studies report that education is not significantly associated with service use (Kashner, 1990; Miller & McFall, 1991; Snider, 1981; Strain, 1991). Penning (1995b) observed that an older adult's educational level was not significantly related to service use as a whole, but was positively associated with the receipt of homemaker services. Gill et al. (1998) reported that only the caregiver's educational level was linked to greater formal service use. Specifically, they observed an increased likelihood of the use of personal care, meals, and homemaking services with higher educational levels of caregivers. Similarly, Denton (1997) noted that older adults with higher educational levels received more formal assistance with personal care, yard work, and housework. Conversely, for all caregiving tasks, the fewer the number of years of education completed by the older adult, the greater the likelihood of reliance on informal sources of assistance rather than formal care.

Summary

The role of social support, income, and education as moderators related to service use is varied. Although an association between greater use of services and income has been demonstrated, there are inconclusive findings related to education and social support. Given the predominance of the Andersen Newman model, it is observed that most studies focused on the relationship between these personal and social resources and service utilization. Pearlin et al. (1981) note however, that in addition to acting as an

intervening link between stressors and outcomes, moderators may also influence the stressors experienced. Those caregivers with greater personal and social resources may not be exposed to, or experience hardships in the same way as those with fewer such resources. Further study of the relationship between mediators, stressors, and service use is warranted.

Conclusions of Literature Review

This review of the literature has summarized the findings from research on the use and non-use of community-based services by older adults and their caregivers, with a focus on respite services where possible. Specifically, this discussion has synthesized those findings relating variations in service use to particular characteristics of older adults and their caregivers. It is observed that the Andersen Newman framework and the Stress Process model have been used to conceptualize the study of caregiving and service utilization. Regardless of the conceptual approach used by various researchers however, it is evident that an array of variables have been analyzed in relation to service use, and that conclusions regarding the influence of these factors on service use are inconsistent.

A prevalent finding evidenced in this review of the literature is the low use of all types of services by older adults and their caregivers. Several studies note that a majority of participants were not using any services (Biegel et al., 1993; Crowell et al., 1996; CSHA, 1994; Denton, 1997; George, 1988; Shapiro & Tate, 1997). Furthermore, many of these participants were cognitively impaired older adults for whom greater service needs would be anticipated. The limited use of respite services, which are typically designed for caregivers of older adults with cognitive impairments, is particularly surprising. Gill et al. (1998) comment that the under-utilization of community-based services underscores the

need to further understand the factors that prompt or inhibit service use. By focusing primarily on those factors associated with the use of particular community services, factors related to non-use have been overlooked in the utilization literature. Given the challenge of delivering appropriate services to older adults and their caregivers, further research focusing on service non-use can contribute to our understanding of the caregiving experience.

Chapter Three - Research Methodology

Research Questions

This study describes patterns of respite service utilization by community-dwelling older adults and their informal caregivers. Given that different services respond to different needs, this study focuses on the non-use of four types of respite services and the factors associated with the primary reason for not using these services. The four respite services examined were adult day centre, in-home respite, and institutional respite including personal care home respite, and hospital respite.

Based on the review of the literature and the conceptual approach of the Stress Process Model, the research questions guiding this study were:

1. What is the frequency of use and non-use of adult day centre, in-home respite, hospital respite, and personal care home respite by cognitively impaired older adults and their caregivers?
2. Are there significant differences between users and non-users of respite services in terms of background characteristics, stressors, and moderators?
3. Is there a relationship between cognitive impairment and the use and non-use of respite services when controlling for other variables?
4. What are the reasons given by the informal caregivers for not using adult day centre, in-home respite, hospital respite, and personal care home respite?
5. What factors are associated with the primary reason cited for the non-use of adult day centre, in-home respite, hospital respite, and personal care home respite when controlling for other variables?

Study Design

The Manitoba Study of Health and Aging Data Sets

This thesis is a secondary analysis of cross-sectional data from the MSHA-2¹ completed in 1997. The MSHA-2 followed the completion of the MSHA-1² in 1995, which was an extension of the Canadian Study of Health and Aging-1 involving a larger Manitoba sample (CSHA-1)³. The CSHA-1 was a national study of Canadians aged 65 years and older conducted in 1991-1992 that examined the prevalence of dementia, the risk factors associated with Alzheimer's disease, caregiver burden, and the use of formal services (MSHA Research Group, 1995). The Centre on Aging at the University of Manitoba was one of 18 participating study centers in 10 Canadian provinces. The Centre coordinated the data collection and analysis for the Manitoba component of the study.

The MSHA-2 was also an extension of the Canadian Study of Health and Aging-2 (CSHA-2)⁴. Older adults participating in the MSHA-2 were residents of Manitoba who had previously been randomly selected from provincial health insurance records for the MSHA-1. Stratified quotas by age and geographic location were obtained at the time of initial sampling, with oversampling of the older age groups. In addition to residing in Manitoba, eligibility criteria required that participants speak English and be over the age of 65 at the time of the MSHA-1 (MSHA Research Group, 1995).

¹ The MSHA-2 was funded by Manitoba Health's Healthy Community Development Fund, and the Seniors Independence Research Program through the National Health Research and Development Program of Health Canada.

² The additional data collection undertaken in MSHA-1 was funded by Manitoba Health.

³ CSHA-1 was funded by the Seniors Independence Research Program and administered by the National Health and Research Development Program of Canada.

⁴ The CSHA-2 was funded by the Seniors Independence Research Program and administered by the National Health and Research Development Program of Canada.

Caregivers of the older adults participating in MSHA-2 were also interviewed in both phases of the study. Caregivers initially selected in MSHA-1 included caregivers of older adults diagnosed with cognitive impairment – no dementia (CIND) or dementia, caregivers of older adults with no cognitive impairment and minimal/no functional disability, and caregivers of older adults with no cognitive impairment and some functional disability⁵. In MSHA-2, these caregivers were eligible for follow-up, in addition to caregivers of older adults newly diagnosed with CIND or dementia.

The main objectives of the follow-up study were to: (a) estimate the incidence of dementia; (b) determine the risk factors of dementia; (c) examine changes in cognitive status and functional ability; and (d) examine the use of community-based and institutional long-term care services (MSHA Research Group, 1998). Data collection took place throughout Manitoba during 1996-1997, and involved re-contacting the same older adults and caregivers that had participated in MSHA-1, and also contacting the caregivers of older adults newly diagnosed with dementia in MSHA-2. In-person interviews were conducted in the elderly adult's and/or caregiver's homes or in long-term care institutions; telephone interviews were conducted with family members or friends of participants who had died since 1991-1992. Participants were contacted by telephone or in-person after receiving an introductory brochure explaining the study (Appendix A).

The data collection process in both the MSHA-1 and MSHA-2 included three main phases: a screening interview, a clinical assessment, and a caregiver interview. The screening interview with the elder lasted about one hour and provided a preliminary assessment of health status, self-reported service use, cognitive status, and socio-demographic data. Those participants who scored below the cut-point for cognitive

⁵ See MSHA Research Group Final Report – Technical Section (1995) for more information.

impairment on the basis of scores (≤ 77) obtained on the Modified Mini-Mental State Examination (3MS) (Teng & Chui, 1987) were invited to participate in the clinical assessment. The clinical assessments lasted between two to four hours and focused on the diagnosis of dementia and the classification of its severity. They were conducted by a team of geriatricians, nurses, psychometricians, and a neuropsychologist, and included a medical history, physical examination, and cognitive status testing. Consensual diagnosis was reached among examiners and was based on the Diagnostic and Statistical Manual of Mental Disorders (DSM-III-R) (American Psychiatric Association, 1987) and the National Institute of Neurological and Communicative Disorders and Stroke - Alzheimer's Disease and Related Disorders Association (NINCDS-ADRDA) (McKhann, Drachman, Folstein, Katzman, Price & Stadlan, 1984). Sub-categories of dementia were classified using the International Classification of Diseases (ICD-10) (World Health Organization, 1987).

Of those participants invited to the clinical phase, an interview was also completed with their primary caregiver. Caregivers interviewed in 1991-1992 were eligible for re-contact regardless of clinical diagnosis at follow-up, and caregivers of those older adults diagnosed with CIND or dementia in 1996-1997 were interviewed resulting in a sample of 'old' and 'new' caregivers. The primary caregiver was identified at the time of the screening interview with the elder and was considered the individual most responsible for the "day-to-day decision-making and provision of care to the elder" (MSHA Research Group, 1998, p. 51). The in-person interviews with caregivers lasted about one hour and solicited information on the assistance being provided to elders by family members and formal service providers, as well as information on the caregivers'

health and well-being. Letters of invitation to participate in each phase of the study were sent prior to contacting participants (Appendix B).

Data of Present Study

For this study, a subset of data has been obtained from the screening, clinical, and caregiver phases of the MSHA-2. The sample includes data from both those community-dwelling older adults diagnosed with CIND and dementia in the clinical assessment phase of the study, and whose caregiver completed the caregiver interview. This study includes data from interviews completed with both 'old' and 'new' informal caregivers.

There are 132 pairs of older adults with cognitive deficits and their informal caregivers eligible for inclusion in this study. This sample includes 79 caregivers of older adults diagnosed with CIND, and 53 caregivers of older adults diagnosed with dementia. Of the 132 caregivers, 45 had participated in MSHA-1 and 87 were caregivers of older adults newly diagnosed with CIND or dementia (Appendix C).

Data includes socio-demographic and health characteristics of older adults and their caregivers, and caregivers' reports of formal community-based service use and reasons for non-use. Analysis of this data provides an opportunity to explore the characteristics of non-users of formal community-based services. Secondary analysis is an appropriate research approach given the difficulty of obtaining a sample of community-dwelling cognitively impaired older adults not using formal services.

Definition of Variables

Several variables utilized in this study require definition:

Primary caregiver: as defined in CSHA-2/MSHA-2, refers to the person perceived as the individual "most responsible for day-to-day decision-making and provision of

care to the elder” (MSHA Research Group, 1998, p. 51). This includes caregivers who may not currently be providing care, but were identified by the older adults as the individual most likely to provide assistance if needed. In this study, “primary caregivers” describes informal or unpaid caregivers. This may be a family member, friend, or neighbor.

Formal services: describes community-based services provided by formal caregivers.

This study includes the analysis of four respite services: adult day centre, in-home respite, personal care home respite, and hospital respite. These services may be provided by private health agencies or by the Manitoba Home Care program. For these services, minimal user fees may be applicable. A description of the Manitoba Home Care program is found in Appendix D.

Cognitive Impairment: describes those older adults with evidence of cognitive deficits as established by the clinical assessment and consensual diagnosis of CIND and dementia. The diagnosis of CIND describes older adults with changes in cognitive status that may be attributed to conditions such as depression, delirium, visual and hearing deficits, and social isolation⁶. The diagnosis of dementia includes the sub-categories of Alzheimer’s disease, vascular dementia, other types of dementia related to conditions such as Parkinson’s, Pick’s, and Creutzfeldt-Jacob disease, and unclassifiable dementia. Criteria used to establish cognitive impairment were based on performance on the 3MS, clinical assessment, and results of neuropsychological testing (where available). The criteria applied to establish the

⁶ The diagnostic category of CIND includes 19 sub-categories to indicate possible causes: delirium, chronic alcohol abuse, chronic drug intoxication, depression, psychiatric disease, age-associated memory impairment, stroke, vascular disease, Parkinson’s, brain tumor, multiple sclerosis, epilepsy, socio-cultural, social isolation, blind/deaf, unknown, and other.

diagnosis of dementia where as specified by the DSM-III-R (American Psychiatric Association, 1987) and NINCDS-ADRDA) (McKhann et al., 1984).

Measurement of Variables

The operationalization of variables selected for this study are summarized in Appendix E. The selection and measurement of the variables is based on the review of the literature. The Stress Process Model is used to organize the variables according to background characteristics, stressors, moderators, and outcomes.

Background Characteristics

Background characteristics of both the older adult and caregiver included in the analysis were: age, gender, marital status, living arrangement, locale of residence, and the caregiver's relationship to the elder. Most of these variables were obtained from MSHA-2 with minimal recoding required. The following variables required modification from MSHA-2 and are discussed: marital status, living arrangement, locale of residence, and the caregiver's relationship to the elder.

Marital Status

Both the older adult and their caregiver were asked about their marital status. Categories including never married, married, common-law, divorced, separated, and widowed were recoded into a dichotomous 'married' or 'not married' variable. The category of 'married' (1) included both married and common-law relationships. The category of 'not married' (0) included those participants who were never married or presently divorced, separated, or widowed.

Elder's Living Arrangement

The living arrangement of the elder and caregiver was reported by the caregiver's response to the question, "Do you live in the same house as the elder?" Responses of yes and no were recoded into 'coresiding' (1) and 'living apart' (0) respectively. For those caregivers who reported that they did not co-reside with the elder, they were asked, "Do any people live with the elder?" The response to this question indicated how many elders lived alone or with someone other than the caregiver. Together these two questions were used to determine how many elders lived alone (1) or lived with their caregiver and/or someone else (0).

Locale of Elder's Residence

The geographic location of the elder's residence was based on their location at the time of MSHA-1. To allow for consideration of urban versus rural differences, eight regions across Manitoba were recoded into a dichotomous variable of Winnipeg (1) versus non-Winnipeg (0).

Caregiver's Relationship to the Elder

The caregiver was asked about their relationship to the elder. Thirteen categories of informal caregivers were recoded into three descriptive categories: spouse (0), adult child (1), and other relative/friend (2). The 'other' category included siblings, in-laws, grandchildren, nieces, and friends.

Stressors

As noted in the Stress Process Model, stressors consist of both objective and subjective characteristics of the older adult and caregiver. Objective stressors included from the MSHA-2 were the elder's and caregiver's number of health problems,

caregiver's self-rated health, and the elder's functional status, cognitive status, depressive symptomology, and problematic behaviours. Subjective stressors included from the MSHA-2 were caregiver burden and caregiver depression.

Objective Stressors

Elder's Number of Health Problems

Elder's health status was determined by clinical history and included the identification of a number of diseases such as: cardiac, vascular, respiratory, upper and lower gastrointestinal, hepatic, renal, genitourinary, musculoskeletal, neurologic, psychiatric, endocrine-metabolic, and diseases of the eyes, ears, nose, and throat. Using the best available information based on the elder's report and/or collateral information from the caregiver when cognitive deficits of the elder limited the reliability of reporting, clinicians indicated 'yes' or 'no' for the elder's history of 14 possible health problems. In accordance with approaches used by other researchers, the number of reported health conditions was summed and reported as a continuous variable for this study (Diwan et al., 1997; Penning, 199b).

Caregiver's Number of Health Problems and Self-Rated Health

Caregiver's health status was measured both by identification of the number of health problems experienced in the past year, and a self-rating of health. The health problems for which caregivers indicated 'yes' or 'no' included 24 possible conditions such as: stroke, paralysis, hip or other fractures, Parkinson's disease, thyroid disease, kidney conditions, surgeries, tumors or cancer, heart problems, pacemaker insertions, diabetes, vision and hearing deficits, respiratory problems, arthritis, gastrointestinal conditions, nervousness or being tense, trouble sleeping, and allergies. As with the elder's

health status, the number of reported health problems was summed and reported as a continuous variable.

Caregiver's self-rated health was indicated by a response to the question, "How would you say your health is these days? Would you say your health is very good, pretty good, not too good, poor, or very poor?" Similar to other studies, the measurement of self-rated health was collapsed into 2 categories of pretty good/very good health (1) versus not too good/poor health (0) (Crowell et al., 1996; Hawranik, 1998).

Elder's Functional Status

The elder's functional status was reported by both the elder in the clinical assessment and by the caregiver in the caregiver interview. For this study, the caregiver's report of the older adult's functional status was used as the reliability of the elder's self reported functional ability may be questionable due to the presence of cognitive deficits. Previous research has demonstrated that older adults with dementia rate their functional status as better than reported by their caregivers (Kiyak et al., 1994). Furthermore, with increasing severity of cognitive impairment, agreement between older adults and their caregivers declines (Ostybe et al., 1997).

The elder's functional status was reported by the caregiver using questions developed by the Older American Resources Study Project (OARS) (Fillenbaum, 1988). The instrument is widely accepted as a valid measure of functional status. The questions cover seven basic ADLs (getting in and out of bed, dressing, eating, bathing, talking care of one's appearance, walking, and toileting), and 15 instrumental ADLs (using the telephone, shopping, doing household tasks – both light and heavy housekeeping, yardwork, preparing meals, doing stairs, getting around the house, getting to places

beyond walking distance, getting outside in any weather, taking medications, managing finances – both day to day banking and long-term financial planning, and doing footcare). Ability to complete these tasks were reported by the caregiver on a scale of 1 (no disability) to 5 (unable to perform activity).

As with previous studies, the reported limitations for each activity of daily living were recoded as ‘no limitations’ (0) and ‘with limitations’ (1). Tasks that the elder could complete without any help were assigned a value of 0 indicating ‘no limitations,’ and tasks for which at least some help from an assistive device or a person was required were recoded to a value of 1 indicating ‘with limitations’. For the basic ADL scale, scores can range from 0-7, and for the instrumental scale scores range from 0-15. The overall scale including both basic and instrumental ADLs has a maximum value of 22. Higher scores indicate that elders require help with a greater number of functional tasks. As with other studies, the total number of limitations in both types of activities of daily living (basic and instrumental) were combined and reported as a continuous variable (Biegel et al., 1993; Johnson & Wolinsky, 1996; Starrett et al., 1988). Missing responses on specific questions were not included in the summed measure.

Elder’s Cognitive Status

Elder’s cognitive status was determined by a process of diagnostic consensus following the clinical assessment by a Registered Nurse and/or Physician. Determination of cognitive status was based on results of the clinical assessment and in part, on scores obtained from the nurse’s administration of the 3MS. The 3MS is a modification of the Folstein Mini-Mental Status Exam (MMSE) and evaluates memory, attention, abstraction, and the ability to carry out commands (Teng & Chui, 1987). The 3MS yields

scores ranging from 0-100 with a lower score indicating greater cognitive impairment. A cut-off score of 77 or below indicates potential cognitive deficits (Teng & Chui). This instrument is widely accepted as a screening instrument for cognitive impairment in elderly non-clinical populations. Previous research has established interrater reliability of the 3MS, indicating its usefulness and validity in comparison to other tests of cognitive function (Abraham, Manning, Boyd & Neese, 1993; Teng & Chui). Teng and Chui report a Pearson's correlation coefficient of 0.98 with the MMSE.

Diagnostic categories included in the MSHA-2 were: no cognitive impairment, CIND, Alzheimer's Disease, Vascular Dementia, Other Specific Dementia (e.g. Parkinson's Disease, Huntington's Disease), and Unclassifiable Dementia. For this analysis, only cognitively impaired older adults were included in the sample and therefore cognitive status was dichotomized as CIND (0) versus dementia (1). That is, the diagnostic category of 'no cognitive impairment' was not applicable and the diagnostic categories of Alzheimer's Disease, Vascular Dementia, Other Specific Dementia, and Unclassifiable Dementia were collapsed into the one diagnostic category of 'dementia'.

Elder's Depression

Depressive symptoms of the elder were assessed based on the clinician's assessment of depression. An overall impression of the presence or absence of depression was indicated using available scores from the short form of the Geriatric Depression Scale (SGDS) and the evaluation of several depressive symptoms based on the elder's and caregiver's report (e.g. loss of appetite, feeling worthless). Possible responses to the determination of depression also included 'questionable,' 'don't know', and 'missing value'. There were no 'missing value' or 'don't know' responses for the clinical

assessment of depression. Overall impression of depression was recoded into three categories: presence of depressive symptoms (0), questionable depressive symptoms (1), and no depressive symptoms (2).

The rating of depression by the clinician was used in this study due to the large number of older adults who did not complete the SGDS (n=26), and the limited reliability of this instrument in the cognitively impaired (Logsdon & Teri, 1995; Mahoney et al., 1994). The SGDS was only administered to those older adults scoring at least 50 on the 3MS as the tool was developed for the screening of depression in non-demented older adults (Logsdon & Teri, 1995). Missing values on the SGDS were anticipated and related to the frequency of 3MS scores <50 among the cognitively impaired sample. Previous research has highlighted the limitations of relying on screening tools for the diagnosis of depression, and emphasized the importance of using clinical judgement to interpret the results of screening tools (Mahoney et al.).

Problematic Behaviour of the Elder

Problematic behaviour of the elder was reported by the caregiver and determined using the Dementia Behaviour Disturbance (DBD) Scale (Baumgarten, Becker & Gauthier, 1990). This 28-item scale, designed for use with caregivers of older adults with dementia, reports the frequency of behavioural problems in the preceding week. The scale was “designed specifically to assess the presence of outwardly manifest problem behaviours likely to distress caregivers” (Baumgarten et al., p. 584). Each behaviour is rated on a Likert scale with 5 possible responses ranging from 0 (never) to 4 (all of the time). Higher scores indicate greater behavioural disturbance. Internal consistency of the

scale has been reported as greater than 0.80 and test-retest reliability moderately high with a Pearson's correlation coefficient of 0.71 (Baumgarten et al.).

Scores on the DBD scale were summed and reported as a continuous variable with a possible maximum score of 112. Several caregivers did not provide responses for all 28 items of the scale. As advised by Baumgarten, preliminary bivariate analysis was conducted in two ways to determine if the means of the completed questions could be assigned to the missing values: (1) excluding all elders with missing values, and (2) including all elders with the mean of the completed questions assigned to missing values (Baumgarten, Personal Communication, June 14, 2000). Both methods of analysis generated similar results. Therefore, for those older adults with missing values on ≤ 4 of the 28 responses, mean values of the remaining items were calculated and then assigned to the missing responses. One respondent had >4 missing responses and as a result, there was one missing value for scores on the DBD scale.

Subjective Stressors

Caregiver Burden

The caregiver's feelings of burden or distress were measured in MSHA-2 using the Zarit Burden Interview (Zarit & Zarit, 1983). This 22-item scale examines a caregiver's perceptions of the burden of caring on their emotional, social, financial and physical well-being (Zarit & Zarit). For each question respondents are asked to indicate to what extent they have felt the impact of caregiving. Responses range from 0 (never) to 4 (nearly always) with higher scores indicating greater burden. The instrument has been used to assess burden reported by caregivers of both cognitively impaired and unimpaired older adults. Internal reliability has been reported at 0.93 using a Cronbach's alpha

(Intrieri & Rapp, 1994). In this study, the scale was scored in a standard manner by summing the responses of the individual items and reporting a continuous variable with a possible range of 0 to 88.

Caregiver Depression

Depressive symptoms of the caregiver were reported using the Center for Epidemiological Studies Depression Index (CES-D) (Radloff, 1977). This 20-item instrument assesses the level of depressive symptoms reported in the previous week. The tool was developed to identify depressive symptoms in non-clinical samples of adults (Logsdon & Teri, 1995). The maximum possible score is 60 with higher scores indicating more severe depressive symptoms. Four questions within the scale that measure positive affect require reverse coding prior to summing scores. Using a cut-off of 16 or greater, sensitivity and specificity has been estimated at 60-90% in community-dwelling populations (Roberts & Vernon, 1983). Cronbach's alpha has been reported at 0.90 (Logsdon & Teri, 1995).

For this study, both a dichotomous and continuous measure of depression were determined. Following reverse coding of questions 4, 8, 12 and 16, an overall summed score was calculated. For those respondents missing on >5 items, a summed score was not calculated and they were not included in further analysis. If ≤ 5 items were missing a mean score was determined from the non-missing responses and assigned to the missing items (McDowell & Newell, 1996). In addition to the continuous measure of summed scores on the CES-D, a dichotomous variable was determined using the cut-off score of 16. Those caregivers with scores of 15 or less were described as reporting no depression

(0), and those with scores of 16 or more were considered as reporting possible depression (1). This dichotomous coding was used for the multivariate analysis.

Moderators

Moderators examined in this study include availability and number of other informal caregivers, elder's and caregiver's income, and caregiver's educational level.

Availability and Number of Other Informal Caregivers

Two indicators of social support in the MSHA-2 used in this study were the availability of other caregivers, and the size of the available support network. As with previous studies, these measures may be used to describe the caregiver's perceived adequacy of informal support for their caregiving role (Denton, 1997; Miller & McFall, 1991; Penning, 1995b). The presence of additional caregivers was determined by the primary caregiver's response to the question, "Does [the elder] have any other caregivers?" Responses of 'yes' were recoded a value of 1 and no were recoded a value of 0.

The size of the available support network was indicated by the primary caregiver's report of the number of additional caregivers identified. The relationship of these additional caregivers of the elder was also reported by the primary caregiver. The types of additional caregivers identified were both informal caregivers such as family members, friends, and neighbors, and formal caregivers such as Home Care workers, doctors, and nurses. For this analysis, only informal caregivers were included as other available caregivers. The total number of other available caregivers was summed and reported as a continuous measure of 0 through 3 or more caregivers.

Elder's and Caregiver's Income

The elder's and caregiver's income were reported in the MSHA-2 as annual income and average monthly household income from all sources respectively. For this study, annual income was calculated for both the older adult and their caregiver and grouped in four categories according to the distribution of values. For both the elder and the caregiver, income categories were: <\$15,000; \$15,000-\$24,999; \$25,000-\$34,999; \$>35,000. In addition, missing responses were tabulated. For the elder's report of income level, 38 or approximately 29% did not provide a response. For the caregiver's report, missing responses increased to 60 or approximately 46%, and are therefore useful only as a descriptor of income level and are excluded from bivariate and multivariate analysis.

Given the anticipated high frequency of missing data, consideration was given to alternate questions describing income levels. To provide some indication of the older adult's income the caregiver was asked, "How well do you think his/her income currently satisfies his/her needs?" Possible responses to this question included a range of 'very well', 'adequately', 'with some difficulty', 'not very well', and 'totally inadequate'. There were no responses of 'not very well' or 'totally inadequate'. As such, the responses to this question were recoded into a dichotomous variable describing the elder's income adequacy as 'with some difficulty' (0) and 'adequately/very well' (1).

For the caregiver, the primary source of income was obtained by the caregiver's response to the question, "What is your primary (largest) source of income?" Income sources considered included Old Age Security and Guaranteed Income Supplement (OAS and GIS), private pension, Canadian Pension Plan (CPP), interest earnings, dividends, family or spouse, and paid employment. The six income sources identified were

categorized and recoded into three groupings: OAS and/or GIS (0), other sources (1), and paid employment (2). The category of 'other sources' included private pensions, interest earnings, dividends, and financial support from spouse or family.

Elder's and Caregiver's Educational Level

The educational level of both the elder and caregiver were indicated by the number of years of education completed and the highest level of schooling completed (e.g. primary or secondary school). For this study, the elder's and caregiver's years of education required no recoding and were considered as continuous variables indicating the number of years of schooling completed.

Outcomes

The respite services in this study were: adult day centre, in-home respite, hospital respite, and personal care home respite. Adult day centre was considered a respite service as its primary purpose is to provide the elder with opportunities for socialization while the caregiver is given time away from the responsibilities associated with caregiving (Manitoba Health, 1975). The dependent variables for this analysis included both the use and non-use of each of the four respite services, and the primary reason reported by the caregiver for the non-use of each of the four respite services. The caregivers' reports of service use rather than the elder's reports were used to improve the reliability of the data.

To determine service use for each respite service, the caregiver was asked to indicate if the elder had used a respite service in the past year. For example, to determine the use of adult day centre, the caregiver responded 'yes' or 'no' to the question "Has [the elder] attended a day centre in the past year?" For each respite service, responses were recoded into 'use' (0) and 'non-use' (1). Responses for each respite service were

then combined to create the dependent variable describing the use of one or more respite services (0) versus the non-use of all respite services (1).

To determine the reasons for non-use, the caregiver was asked to describe for each respite service, “What were your reasons for not using this service?” Reasons for non-use of each respite service were only reported for those services that the caregiver was aware of but had not previously used. There were no interviewer prompts for this question, and the caregiver’s response was recorded verbatim. Responses were analyzed and coded into categories by the MSHA-2 Research group. Response categories included: service not needed, assistance already being provided, elder wouldn’t like it, not sure if service available, not eligible, and difficulty using the service. In addition, being unaware of a service was considered a reason for non-use by those caregivers who had indicated they were unaware of the service in the preceding question (MSHA-2 Research Group, 1999). For this analysis, the most frequently reported reason for non-use of each respite service became one of four additional dependent variables. For each of the respite services studied, the primary reason for non-use reported by the caregiver was ‘unaware of service’. Therefore, for all of the respite services, the reasons for non-use were dichotomized into ‘all other reasons’ (0) versus ‘not aware’ (1).

Data Analysis

Data from the MSHA-2 is housed at the Centre on Aging at the University of Manitoba. Data from the screening, clinical, and caregiver interviews for those community-dwelling older adults diagnosed with CIND or dementia and their caregivers were merged. The requested variables are listed in Appendix F. Data screening and cleaning was conducted by the Centre on Aging staff prior to releasing the data set.

Statistical analysis was done using the Statistical Package for the Social Sciences (SPSS) for Windows. Data analysis included univariate, bivariate, and multivariate techniques.

Univariate Analysis

Univariate analysis included generating frequency distributions with measures of central tendency and variability for all of the variables. These descriptive statistics were examined for outliers, skewness, kurtosis, and missing values. Analysis at this stage focused on the testing of assumptions for further statistical testing and obtaining descriptive information about the sample of elder-caregiver pairs.

Bivariate Analysis

Bivariate analysis facilitated the comparison of users and non-users of the four respite services combined, and the comparison of those caregivers stating they were not aware of each respite service compared to other reasons for non-use. Four sets of bivariate comparisons were completed to examine the reasons for non-use as reasons were reported by the caregiver specific to each service. Cross tabulations with chi-square analysis were used for categorical variables, t-tests were used for normally distributed continuous variables, and Mann Whitney-U tests with mean rank values were used for variables with non-normal distributions. Mean rank values are a non-parametric measure comparable to the mean where results are ranked from smallest to largest, summed, and divided by the number of cases (Hassard, 1991).

To describe the strength of association between variables, correlation statistics including Pearson's and Spearman's Rho were generated, depending on the level of measurement of each variable. These statistics summarize the magnitude and direction of a relationship and range from 0 to ± 1 . A larger absolute value indicates a stronger

association (Polit, 1996). Relationships of $<.50$ describe variables with weak correlations, $.50-.69$ as moderate correlations, and $\geq.70$ as high correlations with very strong relationships between variables (Munro & Page, 1993). For all of the bivariate analyses, a significance level of $p\leq.05$ was utilized as one of the criteria for considering variables for inclusion in the multivariate analysis.

Prior to logistic regression modeling, assessment of multicollinearity was done using a Pearson Product Moment and Spearman's Rho Correlation Matrix. This permits the detection of independent variables that are interrelated (Munro & Page, 1993). A correlation coefficient of $\geq.50$ between variables was used as a cut-off for determining possible multicollinearity.

Multivariate Analysis

Logistic regression modeling was chosen for the multivariate analysis. Logistic regression is used to describe the relationships between a set of independent variables and an outcome variable. Furthermore, it is suited to the analysis of a dichotomous outcome measure (Menard, 1995; Munro & Page, 1993). Due to the limited number of users of the four respite services, multivariate analysis could not be conducted with service use versus non-use as the outcome variable. Rather, to further explore the characteristics associated with non-use, four regression models were developed using the primary reason for non-use of each respite service as the outcome variable. The independent variables included in the regression analysis were those found to have a significant bivariate correlation with the outcome measure ($p\leq.05$). In addition, variables with theoretical support in the literature were included in the regression. Variables were entered into the regression in blocks as suggested in the Stress Process Model; background characteristics were entered

first, followed by stressors - including both objective and subjective stressors, and moderators. To address the possible effects of a relationship between sample size and number of variables in the regression equation, a minimum of 10 subjects per independent variable was allowed.

To describe the results of the logistic regression model overall, the -2 times the log of the likelihood ($-2LL$) and the improvement chi-square were examined. The $-2LL$ is a measure of how well the estimated model fits the data. Smaller values of $-2LL$ indicate a higher likelihood of the observed results, and larger values indicate a poorer fit between the model and the data (Norusis, 1993). The improvement chi-square depicts the change in $-2LL$ between successive steps of the regression equation (Munro & Page, 1993).

To examine the influence of each of the independent variables on the dependent variable, the Beta (B), Wald, and R statistics were reported. The B is the unstandardized regression coefficient that measures the relationship between each of the independent variables and the dependent variable, while the influence of the other independent variables is held constant (Munro & Page, 1993). Positive values indicate an increase in the odds of an event occurring, and negative values a decrease in the odds (Munro & Page; Norusis, 1993). The Wald statistic provides a test of the significance of the logistic coefficient in larger sample sizes (Munro & Page). Lastly, the R statistic is used to examine the partial correlations between the dependent variables and each of the independent variables (Norusis). The R ranges from -1 to $+1$ with positive values indicating that “as the variable increases in value, so does the likelihood of the event

occurring. If R is negative, the opposite is true. Small values indicate small partial correlations” (Munro & Page, p. 240).

Ethical Considerations

Ethical approval for the MSHA-2 was obtained from the Faculty of Medicine Ethics Review at the University of Manitoba (Appendix G). Ethical approval for this thesis was received from the University of Manitoba, Faculty of Nursing Ethics Committee (Appendix H). Written consent for access to the MSHA-2 data set was obtained from the MSHA-2 research group (Appendix I).

This secondary analysis of data from the MSHA-2 uses data for which written consent was obtained from each participant and/or designated proxy in the case of diminished cognitive functioning for each phase of the study (Appendix J). Participants were informed of the study purpose, and assured of confidentiality and their right to withdraw at any time. Access to the data included only subject numbers; names of participants or Manitoba Health numbers were not accessible. Furthermore, there were no responses by which participants could be identified.

Chapter Four - Study Findings

This chapter presents the results of the analysis conducted to address each of the research questions set forth in this study. Findings included are: sample characteristics, bivariate comparisons of the characteristics of respite service users and non-users, reported reasons for non-use of services, and multivariate results of caregiver and elder characteristics associated with the primary reasons for non-use of each respite service.

Sample Characteristics

The sample characteristics are presented according to the Stress Process Model including background characteristics, objective stressors, subjective stressors, and moderators.

Background Characteristics

Background characteristics describe the socio-demographic characteristics of the caregiver and older adult. Characteristics outlined are: ages of the elder and caregiver, gender of the elder and caregiver, marital status of the elder and caregiver, elder and caregiver co-residence, elder's living arrangement, locale of elder's residence, and caregiver's relationship to the elder. Background characteristics are summarized in Table 1.

Ages of the Caregiver and Elder

The elder's ages ranged from 72-101 years, with a mean age of 84.8 years. Nearly half (49.9%) of the elders were 85 years and older suggesting this is a group of primarily "oldest-old" adults.

Table 1**Characteristics of Sample: Background Characteristics (n=132)**

	#	%
Age of Elder		
70-74	8	6.1
75-79	23	17.4
80-84	35	26.5
85-89	32	24.2
90-94	23	17.4
>95	11	8.3
Total	132	99.9
Range 72-101		
Mean 84.8		
Age of Caregiver		
25 - 45	13	9.8
46 - 60	50	37.9
61 - 75	44	33.3
>76	24	18.2
Missing	1	0.8
Total	132	100.0
Range 28-96		
Mean 61.6		
Gender of Elder		
Male	56	42.4
Female	76	57.6
Total	132	100.0
Gender of Caregiver		
Male	37	28.0
Female	95	72.0
Total	132	100.0
Marital Status of Elder		
Married	49	37.1
Never Married/Divorced/Widowed	83	62.9
Total	132	100.0
Marital Status of Caregiver		
Married/Common-law	100	75.8
Never Married/Separated/Divorced/Widowed	32	24.2
Total	132	100.0
Elder and Caregiver Coresidence		
Coreside	51	38.6
Live apart	81	61.4
Total	132	100.0
Elder's Living Arrangement		
Lives alone	65	49.2
Lives with Caregiver or Other	67	50.8
Total	132	100.0
Locale of Elder's Residence		
Winnipeg	62	47.0
Non-Winnipeg	70	53.0
Total	132	100.0
Caregiver's Relationship to Elder		
Spouse	33	25.0
Adult Child	76	57.6
Other Relative	23	17.4
Total	132	100.0

The caregiver's ages ranged from 28-96 years, with a mean age of 61.6 years. One caregiver declined to report their age. Over one-third (38.1%) of the caregivers were between the ages of 65 and 84.

Gender of Elder and Caregiver

Female elders comprised 57.6% of the sample and male elders 42.4%. In contrast, there were nearly three times as many female caregivers (72.0%) as male caregivers (28.0%).

Marital Status of Elder and Caregiver

The majority of older adults were no longer married due to the death of their spouse (56.1%). Married older adults comprised 37.1% of the sample of elders.

Married or common-law caregivers comprised just over three-quarters (75.8%) of the caregiver sample. Only 6.1% of caregivers were widowed.

Elder and Caregiver Co-Residence

Only 38.6% of the caregivers reported that they live in the same residence as the elder. The average length of time the caregiver reported living with the elder was 38.8 years. Of those elders not coresiding with their caregiver, nearly half (49.2%) lived alone.

Locale of the Elder's Residence

The geographic location of the elder's residence was nearly equally distributed between urban (Winnipeg) and rural (non-Winnipeg) locations. Forty seven percent of the elders lived in Winnipeg and 53.0% in other communities throughout the province of Manitoba.

Caregiver's Relationship to the Elder

One quarter (25.0%) of the caregivers were spouses of the older adult and 21.2% of these were wives caring for their husband. The majority (57.6%) of caregivers were adult sons or daughters of the older adult; daughters comprised 36.4% of all caregivers. The remaining caregivers comprised 17.4% of the sample, and included siblings, friends, daughter and sisters-in-law, grandchildren, and nieces.

Objective Stressors

Objective stressors included the elder's and caregiver's number of health problems, caregiver's self-rated health, elder's ADL and IADL limitations, elder's cognitive status, elder's depression, and problematic behaviour of the elder (Table 2).

Elder and Caregiver's Health

The number of chronic conditions of the elder ranged from 0 to 12 of a possible 14, with an average of 5.2 conditions. There was only one elder with no chronic health conditions. Three or more chronic conditions were reported for 82.6% of elders. The most frequently reported conditions were diseases of the eye, ear, nose and throat – EENT (72.0%), vascular conditions (66.7%), and musculo-skeletal and integumentary conditions (62.9%).

The number of chronic conditions identified by the caregiver ranged from 0 to 8 of a possible 24, with an average of 2.6 conditions. The absence of any health problems was reported by 17.4% of all caregivers. Three or more conditions were reported by 41.7% of caregivers. The most commonly identified health problems were surgery such as heart or vascular within the past year (35.6%), nervousness or being tense (31.8%), and trouble sleeping (31.8%).

Table 2		
Characteristics of Sample: Objective Stressors (n=132)		
	#	%
Elder's Health (# of chronic conditions)		
Range 0-12		
Mean 5.2		
Caregiver's Health (# of chronic conditions)		
Range 0-8		
Mean 2.6		
Caregiver's Self Rated Health		
Poor Health/Not too Good	14	10.6
Pretty Good/Very Good Health	118	89.4
Total	132	100.0
Elder's ADL/IADL Limitations		
Range 1-22		
Mean 10.8		
Elder's Basic ADL Limitations		
Range 0-7		
Mean 1.7		
Elder's IADL Limitations		
Range 1-15		
Mean 9.1		
Elder's Cognitive Status		
CIND	79	59.8
Dementia	53	40.2
Total	132	100.0
Elder's Depression		
No depressive symptoms	70	53.0
Questionable depressive symptoms	13	9.8
Presence of depressive symptoms	49	37.1
Total	132	99.9
Problematic Behaviour of Elder		
Range 0-41		
Mean 9.0		

Caregiver's Self-Rated Health

In addition to reporting the number of health problems in the last year, caregivers were asked to rate their own health status. Most caregivers described their own health as pretty good or very good (89.4%). The remaining caregivers (10.6%) described their own health as not too good or poor.

Elder's ADL and IADL Limitations

Elder's overall functional status limitations ranged from requiring assistance with 1 to 22 activities of daily living, with a mean of 10.8 tasks for which assistance was required. There were no elders described as independent on all 22 items measuring basic and instrumental activities of daily living.

Of the seven tasks of basic ADLs, the mean number of limitations was 1.7. Just over one-quarter (27.3%) of the elders were described as having no limitations in getting in and out of bed, bathing, dressing, taking care of their appearance, toileting, eating, and walking. Six elders were described as having limitations in 6 of the 7 basic ADLs. Taking a shower or bath without the help of a person or assistive device was the most frequently identified task for which elders required assistance (72.7%).

The mean number of limitations for the 15 instrumental ADLs was 9.1. In contrast to basic ADLs, there were no elders without limitations on all 15 of the instrumental ADLs. The most frequently identified tasks for which elders required assistance included using the telephone (85.6%), doing yardwork (84.8%), and going up and down stairs (77.3%). There was no information reported for one elder's ability to manage long-term financial planning (e.g. investments), day-to-day spending, medications, and stairs. There were 6 missing responses for the elder's ability to provide their own footcare. The mean number of IADL limitations for these respondents was based on a maximum possible summed score of 11 and 25 limitations respectively.

Elder's Cognitive Status

Elders with cognitive impairment – no dementia comprised 59.8% of the sample. The remaining 40.2% of elders were diagnosed with dementia. Of these, 62.3% were

described as having moderate to severe cognitive limitations such that independent living was hazardous, and partial or continual supervision for activities of daily living was likely required. The remaining 37.7% of elders with dementia were described as having mild cognitive changes affecting work and/or social activities, but not limiting the capacity for independent living (DSM-III-R) (American Psychiatric Association, 1987).

Elder's Depression

Depressive symptoms of the elder were determined by the clinical team and described as the presence or absence of depressive symptoms, or questionable depressive symptoms. Just over one-third (37.1%) of the elders were described as having symptoms of depression. Over half (53.0%) presented with no symptoms of depression and 9.8% reported some symptoms of depression but the diagnosis of depression was questionable.

Problematic Behaviour of Elder

Scores on the Dementia Behaviour Disturbance Scale (Baumgarten et al., 1990) ranged from 0 to 41 from a possible maximum score of 112; higher scores indicate an increasing frequency of behavioural problems. The mean score was 9.0 suggesting few elders demonstrated the behavioural problems measured by this scale. The most frequently reported behavioural problems were the elder's lack of interest in daily activities (55.4%) and the elder misplacing or hiding things (48.5%).

Subjective Stressors

Subjective stressors measured were caregiver burden and the caregiver's report of depressive symptoms (Table 3).

Table 3

Characteristics of Sample: Subjective Stressors (n=132)		
	#	%
Caregiver Burden		
Range 0-52		
Mean 16.3		
Caregiver Depression		
Minimal Depressive Symptoms	112	84.8
High Depressive Symptoms	20	15.2
Total	132	100.0

Caregiver Burden

Caregiver's scores on the Zarit Burden instrument (Zarit & Zarit, 1983) ranged from 0-52 from a possible 80. The mean score of 16.3 indicates that the caregivers did not report high levels of burden. The questions to which caregivers most frequently reported some degree of burden (responded 'sometimes', 'frequently', or 'nearly always') were fears about the elder's future (58.4%) and feeling that the elder was dependent on them (69.7%). One caregiver did not complete the Zarit Burden instrument.

Caregiver's Depression

The CES-D was used to measure the caregiver's report of depression and scores ranged from 0-42 from a possible maximum score of 60. The mean score of 7.8 suggests most caregivers reported few symptoms of depression. Using the cut-off score of 16, the majority of caregivers (84.8%) reported minimal signs of depression.

Moderators

The moderators measured in this study include: availability of other informal caregivers, number of other informal caregivers, elder's and caregiver's income, and elder's and caregiver's educational level (Table 4).

Table 4**Characteristics of Sample: Moderators (n=132)**

	#	%
Availability of Other Informal Caregivers		
Yes	76	57.6
No	56	42.4
Total	132	100.0
# of Other Informal Caregivers		
0	56	42.4
1	36	28.8
2	17	12.1
≥3	23	16.7
Total	132	100.0
Elder's Annual Income		
<\$15,000	64	48.5
\$15,000-\$24,999	23	17.4
\$25,000-\$34,999	4	3.8
≥\$35,000	2	1.5
Missing	38	28.8
Total	132	100.0
Adequacy of Elder's Income		
With Some Difficulty	14	10.6
Adequately/Very Well	114	86.4
Missing	4	3.0
Total	132	100.0
Caregiver's Annual Income		
<\$15,000	11	8.3
\$15,000-\$24,999	27	20.5
\$25,000-\$34,999	5	3.8
≥\$35,000	29	22.0
Missing	60	45.5
Total	132	100.1
Caregiver's Primary Income Source		
OAS and/or GIS	31	23.5
Private Pension	24	18.2
Paid Employment	44	33.3
Other Sources	29	22.0
Missing	4	3.0
Total	132	100.0
Elder's Educational Level (years completed)		
0-6	53	40.2
7-9	45	34.1
10-12	24	18.2
≥13	6	4.5
Missing	4	3.0
Total	132	100.0
Range 0-16		
Mean 7.2		
Caregiver's Educational Level (years completed)		
0-6	10	7.6
7-9	29	22.0
10-12	57	43.2
≥13	36	27.3
Total	132	100.1
Range 0-18		
Mean 11.0		

Availability and Number of Other Informal Caregivers

Nearly half of the caregivers (57.6%) indicated that other individuals were available to provide assistance to the elder. At least one other available caregiver was identified by 28.8% of all caregivers. Adult children of the elder were the most commonly identified additional caregivers. Just over 40% of caregivers reported that there were no other available caregivers.

Elder's and Caregiver's Income

Average annual household income of the elder was reported by the caregiver and ranged from less than \$9,999 to greater than \$70,000. A large proportion of elders (48.5%) had incomes of less than \$15,000 per year. Despite this, 86.4% of caregivers indicated that the elder's income adequately or very well satisfied the elder's needs. Elder's annual income was not reported by 28.8% of all caregivers, and there were four missing responses pertaining to the adequacy of the elder's income.

Average annual household income of the caregiver ranged from \$7,200 to \$72,000. In contrast to elder's income, only 8.3% of caregivers reported incomes of less than \$15,000 per year. Nearly half of all caregivers (45.4%) declined to report their annual household income. Most caregivers did however, indicate their primary source of income. Approximately one-third (33.3%) of caregivers reported that their income was from paid employment. Nearly one-quarter (23.5%) indicated that old age security and/or the guaranteed income supplement comprised the majority of their income. The remaining caregivers identified private pensions and other sources including interest earnings, dividends, and family as their primary income source (40.2%). Data on income source was not available for 3% of all caregivers. There were four missing respondents

on this question; these were not the same four caregivers who did not report the elder's income adequacy.

Elder's and Caregiver's Educational Level

Years of education completed by the elder ranged from 0-16 years with a mean of 7.2 years of schooling completed. A proportion of elders (40.2%) had completed only six or fewer years of schooling. There was no data for four elders.

The years of education completed by the caregiver ranged from 0-18 years with a mean of 11.0 years. Over one-quarter of caregivers (27.3%) had completed more than 12 years of education.

Summary of Sample Characteristics

Although the MSHA-2 was a follow-up study of individuals who were aged 65 and older at the time of the 1990 study, close to one-half of the older adults participating in this study were over the age of 85 years. Given that the rates of dementia increase with age and that this study included only older adults with cognitive impairments, it is not surprising that the older age groups were well represented (NACA, 1996). Most elders were widowed and living alone. In comparison, one-third of the caregivers were married, and over the age of 65 years. Although many of the caregivers were married, most were not coresiding with the elder. Rather, over one-third of the caregivers were daughters caring for their parent.

Most elders and caregivers identified at least one chronic health condition. Symptoms of depression were not reported by most of the elders and caregivers, and behavioural problems of the elder were uncommon. Most older adults, however, did have significant functional limitations. Despite this, caregivers did not report high levels of

burden. Over one-half of the caregivers indicated that other caregivers were also available to provide assistance to the elder.

Use of Respite Services

The patterns of respite service use are summarized in Table 5. The majority of caregiver-elder pairs (87.9%) were not using any of the four respite services. Only 16 caregivers (12.1%) reported using one or more of the four respite services in the previous year. These caregivers tended to be female (75.0%), married (62.5%), daughters of their care recipients (62.5%), and residing in Winnipeg (68.8%). The majority described their own health as pretty good or very good (87.5%), and most were caregivers of elders with dementia (62.5%). They reported an average of 12.9 years of completed schooling.

Table 5

Use of Respite Services (n=132)

	#	%
Adult Day Centre		
Use	12	9.1
Non-Use	<u>120</u>	<u>90.9</u>
Total	132	100.0
Hospital Respite		
Use	2	1.5
Non-Use	<u>130</u>	<u>98.5</u>
Total	132	100.0
PCH Respite		
Use	2	1.5
Non-Use	<u>130</u>	<u>98.5</u>
Total	132	100.0
In-Home Respite		
Use	5	3.8
Non-Use	<u>127</u>	<u>96.2</u>
Total	132	100.0
Respite Services Combined		
Use of 1+ Respite Services	16	12.1
Non-Use of All Respite Services	<u>116</u>	<u>87.9</u>
Total	132	100.0

Of the 16 caregivers using respite services, 11 caregivers used only one respite service, and five caregivers reported using two of the respite services. Three caregivers used adult day centre and in-home respite, and two caregivers used adult day centre and institutional respite. No caregivers used more than two of the four respite services. Hospital and personal care home respite were the most infrequently used services (both 98.5%), followed by in-home respite (96.2%). Adult day centre was the most frequently used respite service (9.1%). Overall, the elder-caregiver pairs used very few respite services. Nearly 90% of caregivers indicated that none of the respite services had been used in the previous year.

Comparison of Service Users and Non-Users

Comparisons of users and non-users are presented in Tables 6 through 10 using the framework of the Stress Process Model. The analysis of elder-caregiver pairs using and not using at least one of the four respite services revealed significant differences between users and non-users. The results are based on 16 users (12.1%) and 116 non-users (87.9%) of the four respite services. Only those characteristics that were significant at $p \leq .05$ are discussed. However, conclusions cannot be drawn from these comparisons as there is minimal variance across the two groups, and the number of users is very small.

Background Characteristics

No significant differences were observed in terms of background characteristics (Table 6). The geographic location of the elder's residence approached significance ($p = .063$). Users of respite services tended to reside in Winnipeg and non-users tended to reside outside of Winnipeg.

Table 6**Comparison of Users and Non-Users of Respite Services Combined
Background Characteristics**

	Users	Non-Users	p
Age of Elder			
Mean	83.4	85.0	.371
n=132			
Age of Caregiver			
Mean	57.9	62.1	.255
Mean Rank	55.9	67.4	
n=131*			
Gender of Elder			
Male (n=56)	7.1%	92.9%	.132
Female (n=76)	15.8%	84.2%	
n=132			
Gender of Caregiver			
Male (n=37)	10.8%	89.2%	.773
Female (n=95)	12.6%	87.4%	
n=132			
Marital Status of Elder			
Married (n=49)	8.2%	91.8%	.284
Not Married (n=71)	14.5%	85.5%	
n=132			
Marital Status of Caregiver			
Married (n=100)	10.0%	90.0%	.187
Not Married (n=32)	18.8%	81.2%	
n=132			
Elder and Caregiver Coresidence			
Coresiding (n=51)	13.7%	86.3%	.654
Residing Apart (n=81)	11.1%	88.9%	
n=132			
Elder's Living Arrangement			
Lives Alone (n=65)	10.8%	89.2%	.639
Lives With Caregiver or Other (n=67)	13.4%	86.6%	
n=132			
Locale of Elder's Residence			
Winnipeg (n=62)	17.7%	82.3%	.063
Non-Winnipeg (n=70)	7.1%	92.9%	
n=132			
Caregiver's Relationship to Elder			
Spouse (n=33)	9.1%	90.9%	.827
Adult Child (n=76)	13.2%	86.8%	
Other Relative (n=23)	13.0%	87.0%	
n=132			

* Age of caregiver was not available for one respondent.

Objective Stressors

Comparisons of users and non-users in terms of objective stressors found significant differences in the elder's functional limitations (Table 7). Elder's cognitive status only approached significance ($p=.052$) with a greater proportion of elders diagnosed with CIND not using services and a greater proportion of elders diagnosed with dementia using services.

	Users	Non-Users	p
Elder's Health (# of chronic conditions)			
Mean n=132	5.7	5.1	.367
Caregiver's Health (# of chronic conditions)			
Mean	3.2	2.5	
Mean Rank n=132	75.8	65.2	.294
Caregiver's Self Rated Health			
Poor Health/Not too Good (n=14)	14.3%	85.7%	
Pretty Good/Very Good Health (n=118) n=132	11.9%	88.1%	.793
Elder's # of ADL/IADL Limitations			
Mean	2.6	1.6	
Mean Rank n=132	85.2	63.9	.032
Elder's # of Basic ADL Limitations			
Mean	2.6	1.6	
Mean Rank n=132	85.2	63.9	.032
Elder's # of IADL Limitations			
Mean	12.0	8.7	
Mean Rank n=132	90.5	63.2	.007
Elder's Cognitive Status			
CIND (n=79)	7.6%	92.4%	
Dementia (n=53) n=132	18.9%	81.1%	.052
Elder's Depression			
No depressive symptoms (n=70)	11.4%	88.6%	
Questionable depressive symptoms (n=13)	15.4%	84.6%	
Presence of depressive symptoms (n=49) n=132	12.2%	87.8%	.922
Problematic Behaviour of Elder			
Mean	13.3	8.4	
Mean Rank n=131*	82.2	63.8	.068

* One respondent excluded due to >4 missing responses on DBD Scale.

Functional Limitations

There were significant differences between users and non-users in the number of ADL/IADL limitations overall, basic ADL limitations, and IADL limitations. Elders with more limitations in the combined measure of activities of daily living were more likely to use respite services than elders with fewer limitations. Similarly, a relationship between limitations in basic and instrumental ADLs and use of respite services was observed. The mean number of limitations in basic ADLs was higher for users than non-users, and the mean number of IADL limitations was higher for users than non-users of respite services.

Elder's Cognitive Status

Although the elder's cognitive status only approached significance, it is discussed here as it was a primary variable of interest related to the use and non-use of respite services. Descriptive statistics of users and non-users of each respite service by the type of cognitive impairment are summarized in Table 8; results of significance testing are not reported due to small group sizes. All of the respite services appeared to be used more

Table 8

Comparison of Users and Non-Users by Type of Cognitive Impairment		
	CIND (n=79)	Dementia (n=53)
Adult Day Centre		
Use	6.3%	13.2%
Non-Use	93.7%	86.8%
Hospital Respite		
Use	0.0%	3.8%
Non-Use	100.0%	96.2%
PCH Respite		
Use	1.3%	1.9%
Non-Use	98.7%	98.1%
In-Home Respite		
Use	2.5%	5.7%
Non-Use	97.5%	94.3%

frequently by elders with dementia in comparison to elders with CIND. Generally, elders diagnosed with CIND comprised the majority of non-users of all four respite services. In particular, hospital respite was not used by any elders with CIND.

Subjective Stressors

Caregivers of elders who were using respite services had a mean burden score that was significantly higher than elders not using respite services (Table 9). Caregivers of elders using services had a mean burden score of 26.7 compared to 14.9 for non-users of respite services.

Table 9

Comparison of Users and Non-Users of Respite Services Combined Subjective Stressors

	Users	Non-Users	p
Caregiver Burden*			
Mean	26.7	14.9	
Mean Rank	94.3	62.1	.001
n=131			
Caregiver Depression			
Minimal Depressive Symptoms (n=112)	12.5%	87.5%	
High Depressive Symptoms (n=20)	10.0%	90.0%	.440
Mean Rank	73.4	65.6	
n=132			

* One caregiver did not complete the Zarit Burden Instrument

Moderators

Both the elder's and caregiver's educational level was significantly associated with service use (Table 10). Elders and caregivers with a higher mean number of years of completed schooling tended to be users of respite services. In terms of elder's and caregiver's annual income, the large proportion of missing values limited comparisons between users and non-users. Annual income of the elder and caregiver was excluded from further analysis due to the large proportion of missing values.

Table 10

Comparison of Users and Non-Users of Respite Services Combined
Moderators

	Users	Non-Users	p
Availability of Other Informal Caregivers			
Yes (n=76)	13.2%	86.8%	.671
No (n=56)	10.7%	89.3%	
n=132			
# of Other Informal Caregivers			
0 (n=56)	10.7%	89.3%	
1 (n=38)	18.4%	81.6%	.439
2 (n=16)	12.5%	87.5%	
3 + (n=22)	4.5%	95.5%	
n=132			
Elder's Annual Income			
<\$15,000 (n=64)	10.9%	89.1%	
\$15,000-\$24,999 (n=23)	17.4%	82.6%	
\$25,000-\$34,999 (n=5)	20.0%	80.0%	***
>\$35,000 (n=2)	0.0%	100.0%	
Missing (n=38)	10.5%	89.5%	
n=94			
Adequacy of Elder's Income*			
With Some Difficulty (n=14)	0.0%	100.0%	
Adequately/Very Well (n=114)	14.0%	86.0%	***
n=128			
Caregiver's Annual Income			
<\$15,000 (n=11)	0.0%	100.0%	
\$15,000-\$24,999 (n=27)	11.1%	88.9%	
\$25,000-\$34,999 (n=5)	40.0%	60.0%	***
>\$35,000 (n=29)	24.0%	75.9%	
Missing (n=60)	16.7%	83.3%	
n=72			
Caregiver's Primary Income Source**			
OAS and/or GIS (n=31)	6.5%	93.5%	
Other Sources (n=53)	13.2%	86.8%	.466
Paid Employment (n=44)	15.9%	84.1%	
n=128			
Caregiver's Educational Level (years completed)			
Mean	12.9	10.7	.009
n=132			
Elder's Educational Level (years completed)			
Mean	9.8	6.8	.001
n=132			

*There were 4 missing responses on adequacy of elder's income.

** There were 4 missing responses on caregiver's primary income source.

*** Not calculated due to large proportion of missing responses.

Summary

The comparison of the characteristics of users and non-users of one or more respite services revealed some differences between these elder-caregiver pairs. Elders who were not using respite services tended to have fewer functional limitations, were diagnosed with CIND, and have lower levels of education. Caregivers of elders not using respite services reported less caregiver burden and had completed fewer years of schooling than caregivers of elders using services. Overall, respite services were infrequently utilized. Of the four respite services examined, adult day centre was the most commonly used, and personal care home respite and hospital respite were both the most under-utilized services.

Reasons for Non-use of Respite Services

The caregivers' reasons for non-use are presented in Table 11. For those caregivers who were aware of, but had not previously used respite services, reasons for non-use were recorded verbatim and subsequently coded by MSHA researchers into categories to facilitate analysis. For those caregivers that had indicated they were unaware of each respite service, being unaware was also categorized as a reason for non-use. Caregivers using services were not asked to report possible reasons for non-use. Therefore, a possible 120 caregivers reported reasons for non-use of adult day centre, 127 caregivers for in-home respite, and 130 caregivers for both personal care home and hospital respite.

The most frequently stated reason for not using each of the respite services was not being aware of the service. Nearly half of all caregivers (48.8%) reported that they were unaware of in-home respite services, and more than half of the caregivers reported

that they were unaware of PCH respite (53.1%) and hospital respite (53.8%). On the contrary, it appeared that more caregivers were familiar with adult day centres as only 40.8% indicated that they were unaware of this service. Other frequently identified reasons for non-use of respite services were that the service was not needed, and that the elder did not want the service. Difficulty using the respite services and service ineligibility were not commonly stated reasons for non-use.

Table 11

Reasons Reported by Caregiver for the Non-Use of Respite Services

	Adult Day Centre		In-home Respite		PCH Respite		Hospital Respite	
	n	%	n	%	n	%	n	%
Not aware of service	49	40.8	62	48.8	69	53.1	70	53.8
Not Needed	35	29.2	57	44.9	52	40.0	53	40.8
Assistance already provided	2	1.7	3	2.4	-	-	1	0.8
Elder doesn't want service	25	20.8	3	2.4	7	5.4	4	3.1
Not eligible	3	2.5	-	-	-	-	-	-
Difficulty using service	1	0.8	-	-	-	-	-	-
Missing	5	4.2	2	1.6	2	1.5	2	1.5
Total	120	100.0	127	100.1	130	100.0	130	100.0

Results of Bivariate Analysis of Reasons for Non-Use

The characteristics associated with the primary reason for not using each respite service were examined prior to conducting the multivariate analysis. Given that the reasons for non-use were reported for each respite service separately, bivariate analysis was completed for each respite service. In so doing, the significant characteristics associated with the caregiver reporting an unawareness of each respite service could be considered for inclusion in the multivariate analysis. Characteristics that were significant at $p \leq .05$ for each respite service were considered for introduction into the multivariate

analysis and are described here. Complete results of the analysis for each respite service are presented in Appendix K according to the Stress Process Framework.

Adult Day Centre

The bivariate analysis focusing on adult day centre non-use was conducted with 115 non-users including 49 caregivers who reported not being aware of adult day centre and 66 caregivers who reported other reasons for non-use. The caregiver's gender, elder's marital status, and the locale of the elder's residence were found to be statistically significant (Table 12). Male caregivers were more likely to report not being aware of adult day centres (65.6%) compared to female caregivers (33.7%). Female caregivers more frequently reported other reasons for not using day centres (66.3%). Caregivers of married elders were also more likely to report not being aware of adult day centres (55.6%) than elders who were widowed or had never been married (34.3%). Finally, caregivers of elders residing outside of Winnipeg were less aware of adult day centres than those caring for Winnipeg residents. The majority of caregivers of Winnipeg residents reported other reasons for not using adult day centres.

Table 12

**Bivariate Results
Characteristics of Caregivers Not Aware of Adult Day Centre Compared to Other Reasons
(n=115 non-users)**

	Not Aware n=49	Other Reasons n=66	p
Gender of Caregiver			
Male	65.6%	34.4%	
Female	33.7%	66.3%	.002
n=115			
Marital Status of Elder			
Married	55.6%	44.4%	
Not Married	34.3%	65.7%	.024
n=115			
Locale of Elder's Residence			
Winnipeg	26.0%	74.0%	
Non-Winnipeg	55.4%	44.6%	.002
n=115			

In-Home Respite

The bivariate analysis of in-home respite was conducted with 125 non-users including 62 caregivers who reported not being aware of in-home respite and 63 caregivers who reported other reasons for non-use. The elder's marital status and caregiver's educational level were found to be statistically significant (Table 13). Caregivers of married elders more often reported not being aware of in-home respite (55.3%) compared to caregivers of elders who were not married (46.2%). Caregivers of elders who were not married more commonly reported other reasons for not using in-home respite (53.8%). Not being aware of in-home respite was also significantly associated with the caregiver's educational level. Caregivers who had completed fewer years of education more frequently reported not being aware of in-home respite.

Table 13

Bivariate Results
Characteristics of Caregivers Not Aware of In-Home Respite Compared to Other Reasons
(n=125 non-users)

	Not Aware n=62	Other Reasons n=63	p
Marital Status of Elder			
Married	55.3%	44.7%	
Not Married	46.2%	53.8%	.050
n=125			
Caregiver's Educational Level (years completed)			
Mean	9.9	11.8	.001
n=125			

Hospital Respite

The bivariate analysis of hospital respite was conducted with 128 non-users including 70 caregivers who reported not being aware of hospital respite and 58 caregivers who reported other reasons for non-use. The caregiver's gender, elder's marital status, locale of the elder's residence, and caregiver's education were found to be

statistically significant (Table 14). Caregivers of male elders (69.4%), unmarried elders (70.0%), and those elders living outside of Winnipeg (64.7%) more frequently reported not being aware of hospital respite. As with in-home respite, the caregiver's educational level was also associated with the primary reason for non-use. Caregivers reporting other reasons for non-use had a mean of 12.1 completed years of schooling compared to a mean of 10.0 completed years for those reporting they were not aware of hospital respite.

Table 14

**Bivariate Results
Characteristics of Caregivers Not Aware of Hospital Respite Compared to Other Reasons
(n=128 non-users)**

	Not Aware n=58	Other Reasons n=70	p
Gender of Caregiver			
Male	69.4%	30.6%	.036
Female	48.9%	51.1%	
n=128			
Marital Status of Caregiver			
Married	50.0%	50.0%	.054
Not Married	70.0%	30.0%	
n=128			
Locale of Elder's Residence			
Winnipeg	43.3%	56.7%	.015
Non-Winnipeg	64.7%	35.3%	
n=128			
Caregiver's Educational Level (years completed)			
Mean	10.0	12.1	.001
n=128			

Personal Care Home Respite

The bivariate analysis of personal care home respite was conducted with 128 non-users including 58 caregivers who reported not being aware of hospital respite and 70 caregivers who reported other reasons for non-use. Only the locale of the elder's residence and the caregiver's education were found to be statistically significant (Table 15). As with the other respite services, caring for elders residing outside of Winnipeg was associated with not being aware of personal care home respite. In terms of the caregiver's

educational level, more years of completed schooling was again associated with stating a reason other than not being aware of personal care home respite. Those caregivers reporting other reasons for not using personal care home respite had a higher mean number of years of education (12.1) compared to those caregivers stating they were not aware of personal care home respite (9.9).

Table 15

**Bivariate Results
Characteristics of Caregivers Not Aware of PCH Respite Compared to Other Reasons
(n=128 non-users)**

	Not Aware n=58	Other Reasons n=70	p
Locale of Elder's Residence			
Winnipeg	42.4%	57.6%	.015
Non-Winnipeg n=128	63.8%	36.2%	
Caregiver's Educational Level (years completed)			
Mean n=128	9.9	12.1	.001

Summary

The comparison of the characteristics of caregivers stating they were not aware of each respite service with caregivers stating other reasons revealed that four characteristics were significant at the bivariate analysis: caregiver's gender, caregiver's marital status, locale of elder's residence, and caregiver's educational level. Not being aware of adult day centre was associated with caregivers who were male, married, and providing care to elder's living in non-Winnipeg locations. Not being aware of in-home respite was associated with male caregivers with less education. Not being aware of hospital respite was associated with caregivers who were married, male, with less education, and providing care to elders residing in non-Winnipeg locations. Not being aware of personal

care home respite was associated with caregivers with less education providing care to elders residing in non-Winnipeg locations.

Results of Testing for Multicollinearity

Prior to conducting multivariate analysis to further examine the characteristics associated with not being aware of respite services, a Pearson Product Moment and Spearman's Rho Correlation Matrix tests were used to identify correlations between the independent variables being considered for inclusion in the regression modeling. Results of this testing contributed to determining which independent variables were included in the multivariate analysis. Correlation coefficients of $\geq .50$ indicate moderate to strong intercorrelations such that the variables should not be entered into analysis together (Munro & Page, 1993). No strong correlations between the independent variables were observed. A Pearson Product Moment Correlation Matrix is included in Appendix L as the Spearman's rank-order correlation yielded similar results and is considered a less accurate variant of the Pearson Product Moment tests (Polit, 1996).

Multivariable Findings

Stepwise logistic regression analysis was conducted to examine the characteristics of caregivers stating they were not aware of each of the respite services. The selection of variables for inclusion in each of the models was based upon the results of the bivariate analysis, multicollinearity testing, and evidence of theoretical support in the literature (Table 16). The variables found to be significant at the bivariate level and included in the regression analysis were: caregiver's gender, caregiver's marital status, locale of elder's residence, and caregiver's education. Variables included in the regression analysis based on theoretical support noted in the literature review were: elder's age, elder's living

arrangement, caregiver's self-rated health, elder's number of ADL/IADL limitations, elder's cognitive status, caregiver burden, and availability of other informal caregivers. Although the elder's education was found to be significant at the bivariate level when comparing users and non-users, it was excluded from the regression analysis as there is limited theoretical support linking an elder's education to service use (Denton, 1997; Penning, 1995b; Strain, 1991). Rather, the caregiver's educational level was included as it has been related to the use of some services, and may influence the decision to use services that are providing relief to the caregiver (Gill et al., 1998; Mullan, 1993). The same variables were included in each of the regression models. For each of the regression models, the variables were entered in three blocks according to the Stress Process framework; background characteristics were entered first, followed by stressors and moderators.

Table 16

Variables Selected for Inclusion in Stepwise Logistic Regression Models

Background Characteristics	Stressors	Moderators
Age of Elder	Elders # of ADL/IADL Limitations	Availability of Other Caregivers
Gender of Caregiver	Caregiver's Self-Rated Health	Caregiver's Educational Level
Marital Status of Caregiver	Elder's Cognitive Status	
Elder's Living Arrangement	Caregiver Burden	
Locale of Elder's Residence		

Not Aware of Adult Day Centre

The results of the logistic regression model for the caregiver reporting not being aware of adult day centres are presented in Table 17. The model Chi-square of the first block of variables is significant suggesting that the background characteristics contributed to the goodness-of-fit of the model to the data. In particular, the negative and significant *B* and *R* statistics for the caregiver's gender ($p < .05$) and the elder's locale of

Table 17

Stepwise Logistic Regression Model for Adult Day Centre

Independent Variables	Step 1			Step 2			Step 3		
	B	Wald	R	B	Wald	R	B	Wald	R
Background Characteristics									
elder's age	0.01	0.06	0.00	0.03	0.61	0.00	0.03	0.70	0.00
gender of caregiver	-1.11	5.58*	-0.15	-1.30	6.86**	-0.19	-1.50	8.11**	-0.21
marital status of caregiver	0.51	0.70	0.00	0.67	1.50	0.00	0.66	1.46	0.00
locale of elder's residence	-1.07	6.03**	-0.16	-1.01	5.00*	-0.15	-0.89	3.53	-0.11
elder's living arrangement	-0.36	0.70	0.00	-0.39	0.77	0.00	-0.29	0.40	0.00
Stressors									
caregiver's self-rated health				-1.04	2.07	-0.02	-0.89	1.45	0.00
elder's # of ADL/IADL limitations				-0.20	1.95	0.00	-0.24	2.48	-0.06
elder's cognitive status				0.14	0.10	0.00	0.34	0.49	0.00
caregiver burden				0.00	0.00	0.00	0.00	0.00	0.00
Moderators									
availability of other caregivers							0.25	0.31	0.00
caregiver's educational level							-0.12	2.48	-0.06
	-2LL=138.7 Model $\chi^2=16.5$ Improvement $\chi^2=16.51$ df=5 p<.01			-2LL=135.0 Model $\chi^2=20.2$ Improvement $\chi^2=3.7$ df=4 p=ns			-2LL=132.3 Model $\chi^2=22.8$ Improvement $\chi^2=2.7$ df=2 p=ns		

* p<.05

** p<.01

residence ($p=.01$) indicated that female caregivers and elders who reside in Winnipeg were less likely to report not being aware of adult day centres than male caregivers and elders who reside in non-Winnipeg locations.

The entry of the second block of variables into the regression resulted in an Improvement Chi-square value indicating that the addition of stressors did not contribute significantly to the model. However, the association of the caregiver's gender and the elder's locale of residence with not being aware of adult day centres remained significant ($p<.05$). The overall model Chi-Square at Step 2 was significant ($p<.05$) although the Improvement Chi-Square was not.

Lastly, the moderating variables were entered into the regression equation (Step 3). The Improvement Chi-Square remained non-significant at this stage suggesting that the moderators also did not contribute significantly to the model. However, the negative and significant B and R statistics for the caregiver's gender remained significant ($p=.01$), as did the overall model Chi-Square ($p<.05$), when taking into account the remaining background characteristics, stressors, and moderators. The caregiver's gender (male) was the only significant variable in the full model; the locale of the elder's living arrangement became non-significant with the addition of the moderating variables.

Not Aware of In-Home Respite

The results of the regression model for caregivers reporting not being aware of in-home respite are summarized in Table 18. The first block of variables resulted in a non-significant model Chi-Square indicating that the background characteristics did not contribute to the goodness-of-fit of the model to the data. The caregiver's marital status however, demonstrated a weak association with not being aware of in-home respite. The

Table 18

Stepwise Logistic Regression Model for In-Home Respite

Independent Variables	Step 1			Step 2			Step 3		
	B	Wald	R	B	Wald	R	B	Wald	R
Background Characteristics									
elder's age	0.03	1.08	0.00	-0.05	1.82	0.00	-0.06	2.44	-0.05
gender of caregiver	-0.23	0.30	0.00	-0.32	0.53	0.00	-0.61	1.72	0.00
marital status of caregiver	-0.94	3.90*	-0.11	-1.00	4.05*	-0.11	-1.24	5.21*	-0.14
elder's living arrangement	0.04	0.01	0.00	0.14	0.12	0.00	0.53	1.32	0.00
locale of elder's residence	0.43	1.30	0.00	-0.31	0.62	0.00	0.11	0.06	0.00
Stressors									
caregiver's self-rated health				-1.17	2.61	-0.06	-0.68	0.82	0.00
elder's # of ADL/IADL limitations				0.04	0.08	0.00	0.01	0.00	0.00
elder's cognitive status				0.07	0.03	0.00	0.33	0.51	0.00
caregiver burden				-0.03	2.38	-0.05	-0.03	2.44	-0.05
Moderators									
availability of other caregivers							0.03	0.01	0.00
caregiver's educational level							-0.25	9.51**	-0.22
-2LL=164.3 Model $\chi^2=7.5$ Improvement $\chi^2=7.5$ df=5 p=ns									
-2LL=160.0 Model $\chi^2=11.9$ Improvement $\chi^2=4.3$ df=5 p=ns									
-2LL=148.7 Model $\chi^2=23.2$ Improvement $\chi^2=11.3$ df=2 p<.01									

* p<.05
** p<.01

negative and significant B and R ($p=.05$) revealed that married caregivers were less likely to be aware of in-home respite than caregivers who were not married. Similarly, the entry of the second block of variables did not result in a significant Improvement Chi-Square or model Chi-Square. Caregiver's marital status remained weakly associated ($p<.05$) with not being aware of in-home respite.

The third step of the regression equation resulted in a significant Improvement Chi-Square ($p<.01$) demonstrating a contribution of the moderators to the model overall. In this full model both the caregiver's marital status remained significant ($p<.05$), and the caregiver's educational level became significant ($p<.01$). The negative and significant B and R statistics for the caregiver's educational level indicated that caregivers with more years of education were less likely to report they were not using in-home respite because they were not aware of the service.

Not Aware of Hospital Respite

The results of the regression model comparing the characteristics of caregivers reporting they were not using hospital respite because they were not aware of the service are presented in Table 19. The entry of the background characteristics resulted in a significant model Chi-square ($p<.05$) suggesting that the variables did contribute to the goodness-of-fit of the model to the data. Although none of the variables independently demonstrated a significant association with the dependent variable. With the entry of the stressors into the regression equation, the Improvement Chi-Square remained non-significant and there were no significant variables.

The third step of the regression equation included the moderating variables. The significant model Chi-Square ($p<.01$) and the Improvement Chi-Square illustrated that

Table 19

Stepwise Logistic Regression Model for Hospital Respite

Independent Variables	Step 1			Step 2			Step 3		
	<i>B</i>	Wald	R	<i>B</i>	Wald	R	<i>B</i>	Wald	R
Background Characteristics									
elder's age	0.01	0.03	0.00	-0.01	0.11	0.00	0.01	0.17	0.00
gender of caregiver	-0.66	2.26	-0.04	-0.76	2.79	-0.07	-1.15	5.29*	-0.14
caregiver's marital status	-0.76	2.49	-0.05	-0.80	2.56	-0.06	-1.06	3.84*	-0.11
elder's living arrangement	-0.34	0.79	0.00	-0.28	0.47	0.00	0.01	0.00	0.00
locale of elder's residence	-0.68	3.27	-0.09	-0.51	1.68	0.00	-0.07	0.03	0.00
Stressors									
caregiver's self-rated health				-0.80	1.37	0.00	-0.32	0.21	0.00
elder's # of ADL/IADL limitations				0.05	0.15	0.00	0.05	0.00	0.00
elder's cognitive status				-0.34	0.69	0.00	-0.11	0.07	0.00
caregiver burden				0.01	0.55	0.00	-0.01	0.32	0.00
Moderators									
availability of other caregivers							0.09	0.04	0.00
caregiver's educational level							-0.25	9.55**	-0.22
	-2LL=163.2 Model $\chi^2=11.9$ Improvement $\chi^2= 11.9$ df=5 p<.05			-2LL= 160.4 Model $\chi^2=14.7$ Improvement $\chi^2=2.8$ df=4 p=ns			-2LL=149.1 Model $\chi^2=26.0$ Improvement $\chi^2=11.3$ df=2 p<.01		

* p<.05

** p<.01

the moderators contributed significantly ($p < .01$), after taking into account the background characteristics and stressors. With the full model, the caregiver's marital status, gender, and educational level were all significant ($p < .05$). The negative B and R statistics for these variables demonstrated that married, female caregivers, and caregivers with higher level of education were less likely to state they were not aware of hospital respite. In other words, they were more likely to be aware of hospital respite.

Not Aware of Personal Care Home Respite

Finally, the regression model comparing the characteristics of caregivers reporting they were not aware of personal care home respite to those caregivers reporting other reasons for non-use are presented in Table 20. The first block of variables entered into the regression equation were again the background characteristics. Consideration of the model Chi-Square suggested that the background characteristics did not significantly contribute to the goodness-of-fit of the model to the data. Similarly, the second block of variables resulted in a non-significant model Chi-Square and Improvement Chi-Square with none of the background characteristics or stressors significantly contributing to the model.

The third stage of the regression equation included the moderating variables. At this last stage, the full model resulted in a significant Improvement Chi-Square ($p < .01$) suggesting that the moderator variables contributed to the goodness-of-fit of the model to the data after taking into account background characteristics and stressors. The negative and significant B and R statistic for the caregiver's education indicated that caregivers with higher levels of education were less likely to report that they did not use personal

Table 20

Stepwise Logistic Regression Model for Personal Care Home Respite

Independent Variables	Step 1			Step 2			Step 3		
	B	Wald	R	B	Wald	R	B	Wald	R
Background characteristics									
elder's age	0.03	0.73	0.00	-0.04	1.37	0.00	-0.04	1.49	0.00
gender of caregiver	-0.27	0.43	0.00	-0.35	0.64	0.00	-0.71	2.27	-0.04
caregiver's marital status	-0.49	1.17	0.00	-0.57	1.43	0.00	-0.81	2.42	-0.05
elder's living arrangement	-0.11	0.09	0.00	0.00	0.00	0.00	0.32	0.50	0.00
locale of elder's residence	-0.73	3.82	-0.10	-0.56	2.03	-0.01	-0.12	0.07	0.00
Stressors									
elder's # of ADL/IADL limitations				0.04	0.09	0.00	-0.02	0.03	0.00
caregiver's self-rated health				-1.01	2.21	-0.04	-0.52	0.55	0.00
elder's cognitive status				-0.05	0.02	0.00	0.24	0.29	0.00
caregiver burden				-0.03	2.67	-0.06	-0.02	1.83	0.00
Moderators									
availability of other caregivers							0.04	0.01	0.00
caregiver's educational level							-0.26	9.67	0.22**
	-2LL=167.5 Model $\chi^2=7.9$ Improvement $\chi^2=7.9$ df=5 p=ns			-2LL= 162.9 Model $\chi^2=12.5$ Improvement $\chi^2=4.6$ df=4 p=ns			-2LL=151.5 Model $\chi^2=23.9$ Improvement $\chi^2=11.4$ df=2 p<.01		

** p<.01

care home respite because they were not aware of the service. This is the only variable that is significant in the full model ($p < .01$).

Summary of Multivariate Analysis

The overall results of the logistic regression analysis are summarized in Table 21 across the four respite services. Although the results were not consistent across service types, it is noted that the background characteristics, namely caregiver's gender and marital status, and one moderator variable, namely caregiver's education, were most frequently associated with the caregiver not being aware of respite services. Male caregivers were less likely to be aware of adult day centres and hospital respite. Married caregivers were less likely to be aware of in-home respite and hospital respite, and caregivers with fewer years of education were less likely to be aware of in-home respite and institutional respite. None of the variables included as stressors in the regression equations were associated with caregivers stating they were not aware of the respite services. In particular, cognitive status was not a significant factor associated with caregivers reporting they were not aware of each of the four respite services.

Table 21

Summary of Multivariate Analysis

Characteristics Associated with Caregivers Reporting They were 'Not Aware' of Services

Variables	Adult Day Centre	In-Home Respite	Hospital Respite	Personal Care Home Respite
Background Characteristics				
elder's age	-	-	-	-
caregiver's gender	male caregivers	-	male caregivers	-
caregiver's marital status	-	married	married	-
elder's living arrangement	-	-	-	-
elder's locale of residence	-	-	-	-
Stressors				
caregiver self-rated health	-	-	-	-
# of ADL/IADL limitations	-	-	-	-
cognitive status	-	-	-	-
caregiver burden	-	-	-	-
Moderators				
availability of other caregivers	-	-	-	-
caregiver's educational level	-	fewer years of education	fewer years of education	fewer years of education

Chapter Five – Summary and Discussion

The purpose of this final chapter is to review the objectives of this study and highlight the major findings with reference to the existing literature. The summary of findings is presented in five subsections addressing each of the five research questions that directed this analysis. In addition, the limitations of this study are considered with directions for future research suggested. In closing, the implications for clinical practice are presented.

Overview of Study

The intent of this study was to examine those factors associated with the non-use of respite services by community-dwelling older adults with cognitive impairment. Past research has focused on those caregiver-care receiver pairs using community-based services, highlighting the need for a greater understanding of those not using services, and in particular those not using respite services. Few studies have explored caregivers' apparent reluctance to use services despite the burden associated with supporting older adults with cognitive impairment.

This study of service non-use was a secondary analysis of data from the follow-up to the Manitoba Study of Health and Aging (MSHA-2) completed in 1996-97. This study used a sub-sample of older adults with cognitive impairment and their caregivers to describe characteristics associated with the non-use of four respite services: adult day centre, in-home respite, hospital respite, and personal care home respite. The Stress Process Model was used as an organizing framework to understand the experience of caregiving. Within this model, the use of services was considered an outcome of the caregiving experience; service use is a strategy used by caregivers to maintain their role

despite the presence of stressors. Based on a review of the literature and the conceptual approach of the Stress Process Model, the research questions addressed in this study were:

1. What is the frequency of use and non-use of adult day centre, in-home respite, hospital respite, and personal care home respite, by cognitively impaired older adults and their caregivers?
2. Are there significant differences between users and non-users of respite services in terms of background characteristics, stressors, and moderators?
3. Is there a relationship between cognitive impairment and the use and non-use of respite services when controlling for other variables?
4. What are the reasons given by the informal caregivers for not using adult day centre, in-home respite, hospital respite, and personal care home respite?
5. What factors are associated with the primary reason cited for the non-use of adult day centre, in-home respite, hospital respite, and personal care home respite when controlling for other variables?

Summary of Findings

Research Question #1: Patterns of Respite Service Use

The analysis of service use focused on the use and non-use of four respite services. These services are intended to provide a period of respite or relief to the caregiver with possible additional benefits of socialization and companionship for the older adult.

The use of services was dichotomized as the use of one or more respite services, and the non-use of all respite services. As with previous studies of service utilization

(Biegel et al., 1993; Birkel & Jones, 1989; Crowell et al., 1996; CSHA, 1994; Denton, 1997; Noelker & Bass, 1989), the rates of service use were low with 12.1% of caregivers reporting the use of one or more respite services and 87.9% reporting the non-use of all four respite services. Adult day centre was the most frequently used service (n=12 or 9.1%) and institutional respite (both hospital and personal care home) were equally under-utilized (n=2 or 1.5%). In-home respite was also infrequently used (n=5 or 3.8%). This finding is in contrast to a prospective study by Lawton et al. (1989a) where in-home respite was more frequently used than nursing home respite or adult day care programs. It is noted however, that the profiles of service use did not include all of the services that participants were using prior to the study period; a “relatively large number” were reportedly already using services such as adult day care (p. 17).

Research Question #2: Comparison of Users and Non-Users

Bivariate analysis including contingency tables, parametric tests, and non-parametric tests were used to compare the users of one or more respite services and the non-users of respite services. Due to the small proportion of users, multivariate analysis could not be conducted. The bivariate results are based on comparisons of 16 users and 116 non-users and are discussed in relation to the only article reviewed that reported bivariate results comparing users and non-users of respite services (Adler et al., 1995).

In terms of background characteristics, there were no significant differences between users and non-users of respite services. The majority of elders using and not using respite services were in the oldest-old age group, female, widowed, and living alone. Most caregivers were female, married, adult children of the elder, and not co-residing with the elder. This profile of respite users and non-users is not unique but rather

comparable to a sample of older adults and their informal caregivers participating in a recent Canadian survey of respite programs (Canadian Association for Community Care, 1998).

In terms of stressors, significant differences between users and non-users were found in comparisons of functional status and caregiver burden. Functional status of the older adult was measured by limitations in activities of daily living. A summative measure of the caregiver's report of limitations in functional status was used. Significant differences between users and non-users were found in terms of basic ADLs ($p < .05$) and instrumental ADLs ($p < .01$), as well as the overall number of limitations ($p < .05$). Older adults using respite services had a greater number of limitations in their activities of daily living than those not using respite services. Adler et al. (1995) report similar bivariate findings in their analysis comparing 23 respite users and 35 respite non-users with dementia. They observed that respite users were more limited in activities of daily living than respite non-users. It is unclear whether the significance of functional limitations to service non-use may be related to the process of eligibility for services. Within the Manitoba Home Care program, access to respite services is managed by Case Coordinators who assess the need for services based in part, on a functional needs assessment of the older adult (Havens, 1996).

Caregiver burden was measured using the Zarit Burden Interview. Those caregivers reporting less burden tended not to use respite services in comparison to those reporting greater levels of burden. Again, Adler et al. (1995) also found significant differences in caregiver burden between respite users and non-users at the bivariate level. Those caregivers using respite services had significantly higher mean scores on the Zarit

Burden Interview than respite non-users. It may be that caregivers do not access respite services because the potential benefits are out-weighed by the possible disruptive and negative consequences for elders with cognitive impairments. Until such time that the need for assistance and periods of rest are imperative to continue in the caregiving role, the use of respite services may be minimized.

Finally, in terms of moderators, both the elder's and the caregiver's educational level, as indicated by the number of completed years of education, were significant. Elders and caregivers with fewer years of completed schooling used respite services less often than those with higher levels of education. In contrast, although Adler et al. (1995) only measured caregiver's education, they found no significant differences between users and non-users of respite services. Differences in findings may be related to the categorical measurement of caregiver's education used by these researchers. Reporting of completed education in five categories including some schooling, high school graduate, some college, college graduate, and post-graduate training is more general and may be less sensitive to the measurement of mean differences between groups.

Research Question #3: Cognitive Impairment and Service Use

The participants in this study were all diagnosed by the MSHA-2 research team with cognitive impairments described as CIND or dementia. Again, due to the small sample size and the skewed distribution of users and non-users, multivariate analysis exploring the relationship between cognitive impairment and service use could not be conducted. However, bivariate comparisons provided an opportunity to describe the relationship between the type of cognitive impairment and the use and non-use of respite services.

The differences between users of one or more respite services and non-users in terms of cognitive status approached significance ($p=.052$). Older adults with dementia comprised 18.9% of users of one or more respite services compared to older adults diagnosed with CIND who comprised 7.6% of users. These results are contradictory to previous findings suggesting that respite care is of greatest relevance to caregivers of older adults who are not extremely impaired (Kosloski & Montgomery, 1993). Adult day centres were the most commonly used service by older adults with cognitive impairments and were found to be used by both elders with CIND and dementia. Adult Day Centres may be designating program days for participants with cognitive deficits.

One of the most striking findings with respect to cognitive impairment and service use was the significant proportion of older adults and their caregivers not using services. In terms of all four respite services combined, 92.4% of the caregivers of older adults diagnosed with CIND were not using any services, and 81.1% of the caregivers of older adults diagnosed with dementia were not using any services. These results are similar to that found in previous studies documenting the limited use of respite services by older adults with cognitive impairment and their caregivers (Adler et al., 1995; Canadian Association for Community Care, 1998; Chappell 1993a; Strang & Haughey, 1998).

Attention to the lack of service use is warranted given the reported effectiveness of respite services in assisting caregivers of older adults with dementia (Cotrell, 1996; Deimling, 1992; Lawton et al., 1989a). However, studies exploring caregivers' reluctance to access respite services despite the perceived burden of caregiving are few. Recommendations from a Canadian survey of respite programs suggest that respite use is limited by a lack of awareness of services, a lack government support for respite care,

and barriers related to seniors' perceptions of respite programs (Canadian Association for Community Care, 1998). In a recent review of a night respite program available to Winnipeg residents, it was found that caregivers and older adults were reluctant to use out-of-home respite services (Hawranik, 1999). Similarly, in a demonstration project of respite services, Lawton et al. (1989b) found that in-home respite was preferred "because it permits flexibility in the amounts and timing of the service, it is useful for [clients] with all levels of disability, and because a familiar environment is maintained for the [client]" (p. 29). These factors are particularly relevant to those with cognitive impairments and may act as barriers to the use of out-of-home respite services such as adult day centres. In addition, the use of institutional respite services may be limited due to the costs incurred by the use of these services.

Research Question #4: Reasons for Non-Use

With the intention of further exploring the non-use of respite services, reasons given by caregivers for not using services were examined. For those caregivers that were aware of, but had not previously used respite services, reasons for non-use were recorded verbatim and coded into descriptive categories. For those caregivers that had indicated they were unaware of each respite service, being unaware was also categorized as a reason for non-use. Across all four respite services, the most frequent reason for non-use was the caregiver indicating they were not aware of the service. These findings are supported by previous research that found that "a relatively large amount of variance in service use can be explained by the extent of older persons' awareness of available services and their perception of those services as sources of assistance for their own current or potential needs" (McCaslin, 1988, p. 597). Others extend the importance of

service awareness to include health professionals' and caregivers' service knowledge. In a study of the need for adult day programs, Barber, Paton and Wishnia (1993) note that while there is knowledge and enthusiasm on the part of providers, there is also a lack of awareness by potential clients. The role of professionals in creating awareness and facilitating access to respite services was not explored in this study, but may influence the use and non-use of services by older adults and their caregivers.

Interestingly, in this study the reasons given by caregivers for not using respite services did not appear to be related to program barriers or the ineffectiveness of respite. In contrast, a study of caregivers' perceptions of respite services found that the quality of care, convenience of the services, and overall usefulness directly affected the use of services (Kosloski & Montgomery, 1993). In this study, only four caregivers mentioned difficulties with using the respite services (e.g. transportation problems) and ineligibility for services as reasons for non-use; these reasons were reported only in relation to the non-use of Adult Day Centres.

Research Question #5: Factors Associated with Unawareness of Respite Services

The comparison of caregivers stating they were unaware of respite services with those reporting other reasons for non-use allowed the exploration of differences between users and non-users while controlling for other variables. Using the caregiver's reason for non-use (not aware of services) as the dependent variable in logistic regression modeling, comparisons were conducted for each respite service according to the Stress Process Model. Background characteristics were entered first into the regression equations, followed by stressors and moderators.

Although differences between the respite services emerged, three factors were significantly associated with being unaware of particular services, two background characteristics - caregiver's gender and caregiver's marital status, and one moderator variable, caregiver's education. Male caregivers were more likely to not be aware of adult day centres, married caregivers were less likely to be aware of in-home respite and hospital respite, and caregivers with less education were more likely to not be aware of in-home respite and institutional respite. These findings are similar to those reported by the MSHA-2 Research Group in an analysis of respite service use by cognitively impaired and cognitively intact older adults and their caregivers. They observe that caregivers who were not aware of certain types of respite services were more likely to be male caregivers, caregivers with less education, caregivers of elder's living outside Winnipeg, and caregivers with poorer self-rated health (MSHA Research Group, 1999). Unlike this study, Day Hospitals were also included as a respite service in the analysis of reasons for service non-use.

Possible explanations for these findings are varied. Gender differences in the awareness of respite services may suggest differences in social networks. Male caregivers may be less inclined than female caregivers to seek emotional support and information from friends and colleagues about caregiving and available support services. Or, perhaps male caregivers who were named by the older adults in this study as the primary caregiver did not in actuality provide the hands on care, but rather relied on their spouses or siblings for assistance and knowledge of services. Married caregivers may have also been less aware of services and used services less often because of a reliance on their spouse to provide informal respite care. The eligibility structure of home care services in

Manitoba considers the availability of family caregivers to provide services prior to implementing formal care (Manitoba Health, 1975). Both the preference for, and obligation to rely on family for caregiving relief may contribute to an overall lack of awareness of respite services. In terms of the relationship of educational level and service awareness, Mullan (1993) suggests that “education is an omnibus variable that may be a surrogate for a set of interconnected characteristics such as knowledge, attitudes, beliefs, and norms about using formal services” (p. 251). Educational level may be an indicator of one’s reliance on others for information versus one’s ability to independently seek out information about services. Caregivers with fewer years of education may rely on traditional formal care providers such as family physicians for knowledge of respite services more than caregivers with higher levels of education who may know the ‘right’ questions to ask and have the experience and ‘know-how’ to seek out the help needed.

Unlike the findings in the general service utilization literature that focus on the use of services, need factors or stressors such as functional ability and cognitive status of the elder did not emerge as significantly associated with caregivers not using respite services because they were unaware of services. Rather, characteristics of the caregiver were the primary factors associated with not using services due to a lack of awareness. These differing results may support the notion that caregivers have a significant role in the decision to access respite services. The influence of caregivers on service use has been previously described in a study of discretionary and non-discretionary services. Discretionary services such as respite services entail greater discernment on the part of the service user and reflect self-initiated service use in comparison to non-discretionary services that tend to be initiated by service providers (Kosloski & Montgomery, 1994;

Penning, 1995a). Caregiver characteristics influenced the use of discretionary services and underscored the significance of considering who is defining the need for service (Kosloski & Montgomery). The results of this analysis of respite service non-use describe a profile of potentially high-risk caregivers who are not using respite services due to a lack of awareness of their availability. Considering the caregiver as the client of respite services may facilitate the use of these services by caregivers and assist in maintaining the caregiving role.

Study Limitations

A number of limitations relate to this study. First, this research was limited by sampling procedures and sample size. The sample selection used to identify eligible caregivers in MSHA-1 and MSHA-2 may not comprise a representative sample of informal caregivers. The small sample size also restricted the analyses that were conducted, therefore limiting the generalizability of the results. Although the sample was intentionally limited to those older adults with cognitive impairment and their caregivers, the findings may not be representative of all older adults with cognitive loss supported in the community by informal caregivers. Black (1995) notes that when using secondary data sets, “the ability to study sub-populations may be limited sometimes because sample size is not adequate to support the analyses of interest to the researcher” (p. 143).

There are also limitations related to the use of the Stress Process Model as the theoretical framework used to guide this study. Although the model attempts to describe outcomes of the caregiving experience, it has not been well developed. Rather, it appears that the use of this model has evolved to include service use as one outcome of the caregiving experience (Mullan, 1993; Pearlin et al., 1996). Differing interpretations of

factors to be included at various stages of the model limit the utility of the model and comparisons across studies. Although the model acknowledges that caregiving may be stressful, it assumes that service use is an adaptation by caregivers to reduce stress. It may however, be a limited perspective to assume that the ability of caregivers to cope is demonstrated by management strategies such as service use. Rather than exploring the domains and relationship articulated within the model, the Stress Process model served primarily used as an organizing framework from which to examine characteristics associated with the non-use of respite services.

The focus on only four respite services may also limit the findings of this study. Other forms of respite such as night-respite may have been available to caregivers. As well, caregivers may not have known the services by the labels used to describe them in this study. For example, a caregiver may have an in-home sitter or companion for their elder and not have identified this as in-home respite.

Finally, there are limitations that relate specifically to the use of a secondary data set. Although the identification of service non-users was possible through the use of an existing data set, disadvantages to the use of secondary data related to a “. . . lack of control over the content of the data” (Black, 1995, p. 142). The most significant drawback of this secondary data set related to the structuring of the interview questions posed to caregivers to explore reasons for the non-use of services. The use of a screening question to determine whether caregivers were aware or unaware of each service resulted in only those caregivers who were aware of the service being asked to identify reasons for non-use. For the caregivers who were unaware of the service, the reason for non-use was considered their unawareness of the service. Furthermore, for those caregivers who

were asked to identify reasons for non-use, verbatim responses were recorded but no probes were provided to clarify caregivers' responses. For example, there was no supporting information detailing why a caregiver reported that a service was not used because it was "not needed". It could not be determined that needs did not exist because others provided the care or because the older adult or caregiver did not require the services. It could also not be determined if services were not used because they were unavailable to older adults and caregivers in their own communities. Further qualitative analysis of caregivers' reasons for non-use was not possible due to the limited data.

Issues of missing data were also problematic in terms of income reporting by elders and their caregivers. Despite the possible association between income level and the use of respite services for which fees are charged, income levels could not be included in the statistical analysis due to the large proportion of missing values. It may have been useful to review the data set and substitute measures of employment status rather than income levels where available. Although previous research has not demonstrated a significant difference between employed and unemployed caregivers in levels of caregiving stress (Dellasega, 1990), employment status may have been an alternative indicator of one's need for respite services and the ability to access services.

Recommendations for Future Research

In many ways, this study has contributed to an understanding of the low rates of respite service use by raising additional questions for future study. An understanding of the caregiving process and factors associated with the non-use of services may best be addressed in a longitudinal study. In this way, older adults and their caregivers can be followed over time so that the effects of declines in cognitive status and changes in

moderating resources can be detected. Lawton et al. (1989) conclude that caregiving situations are dynamic in that caregivers who at one time may decline respite, may at a later time have needs that result in service use. Moreover, it may be useful to conduct in-depth interviews with caregivers of older adults with dementia focusing on their descriptions of reasons for both use and non-use. Despite the extensive body of literature examining service utilization, there is a notable absence of a qualitative analysis of caregivers' reasons for service use and non-use. Conducting interviews with caregivers who have been offered and declined services may provide unique information about attitudes toward service use.

Although there are potential difficulties with small sample sizes when studying sub-groups of older adults and their caregivers, it may be useful to focus on particular types of caregivers. The significant relationship between the caregiver's marital status and a lack of awareness about respite services raises questions about the influence of caregiver-elder relationships. Differences between adult children and spousal caregivers may be particularly relevant to the decision to use services directed at providing relief to the caregiver. For example, out-of-home respite such as Adult Day Centres may be preferred by spousal caregivers so that they are able to have periods of rest in their own home.

Finally, further research could consider additional variables related to caregiving of older adults with dementia. Behavioural difficulties were measured in this study, but the relationship between problematic behaviours such as wandering and the non-use of services were not well established. In part, the Dementia Behaviour Disturbance Scale that tends to assess extreme behavioural problems, may not be an appropriate measure of

behavioural problems demonstrated by community-dwelling older adults. As such, it remains unclear if services are infrequently used due to troublesome behaviours that mitigate the anticipated benefits of respite care.

Employment status and work conflict also requires further study. Aneshensel et al. (1995) describe both positive and negative consequences of employment and highlight the need to understand “the extent to which work and caregiving complement or collide with one another” (p. 87). The use of respite services may be less beneficial for employed caregivers who already have opportunities to spend time away from caregiving. Conversely, unemployed caregivers may not have the financial resources to access respite care. Exploration of work conflict may be of increasing interest, as costs of providing and using respite services are likely to increase.

Implications for Nursing

The findings of this thesis highlight the importance of creating an awareness of respite services among caregivers and reviewing our definition of respite care. The findings of this study overwhelmingly demonstrated that caregivers to older adults with cognitive impairments did not use respite services due to a lack of awareness of such services. Given the burden and potential health risks of caring for older adults with cognitive loss, it is unclear why awareness of these services is not promoted among these high-risk caregivers by health care providers. To date, fears about induced demand – that is, caregivers using formal services because they are readily available – are not supported in practice. Rather, caregivers continue to prefer and rely on informal sources of assistance rather than formal respite services (Havens, 1996; Lawton et al., 1989). As health professionals assisting older adults to remain in the community, it is essential to

include the most isolated caregivers that may have never sought formal assistance when creating an awareness of the availability and effectiveness of respite care.

Approaches to disseminating awareness of respite services can occur on various levels. Within nursing education programs, courses in gerontological nursing need to sensitize students to the contribution of informal caregivers and the possible need for respite from the responsibilities of caregiving. Student practicums could include sessions between students and informal caregivers where caregivers describe their caregiving experiences and students provide information on relevant services. Within clinical practice, the assumption that caregivers are not aware of respite services because they are not needed must be challenged. Nurses need to proactively educate older clients and their caregivers about the availability and benefits of respite programs. Given that many older adults and their caregivers receive health care only from a family physician, information brochures in medical clinics may increase the awareness of services. For employed caregivers, information could also be made available through Employee Assistance Programs. For many caregivers with multiple demands on their time, more traditional approaches such as health education sessions may not be well attended. Rather, low-key approaches such as information brochures or informative e-mail notices for those caregivers on-line may be more effective. Collaborating with other health professionals to support informal caregivers and create an awareness of respite services would be essential to the success of any educational strategy.

The findings of this study also reflect the importance of informal caregiving and suggest the need to re-consider our definition of respite care on a policy level. Although it is widely accepted that respite care is targeted to the caregiver to provide relief from

caregiving responsibilities, the criteria for eligibility are based on the assessed needs of the older adult (Canadian Association for Community Care, 1998). In so doing, the caregiver is not considered the recipient of services and respite is viewed not as an outcome but as a service. The need for respite should be determined on the basis of the caregiver's need, including an assessment of other available support mechanisms and consideration of the best way to provide relief. As such, our understanding of services that provide respite may broaden to include services not typically considered as respite care. For example, a caregiver may identify that meal services provide relief or time away by replacing the responsibility of providing meals to the care recipient with a formal service. Flexibility within the system of service delivery will be increasingly necessary in response to the needs of informal caregivers providing care to our aging population.

Summary

In summary, this chapter has highlighted the major findings of the five research questions guiding this study with reference to previous studies on service utilization. Limitations of this study and directions for future research were outlined. Finally, the relevance of this study's findings for health professionals assisting older adult with dementia and their caregivers was explored. A heightened awareness of the significant proportion of non-users of respite services may promote further research and facilitate the identification of high-risk caregivers by health care providers. This study has contributed to an understanding of caregivers that are not aware of and not using services by describing a profile of caregiver characteristics. Encouraging the timely use of respite care is essential for caregivers who have taken on the responsibility of caregiving to older adults with cognitive impairment.

References

Abraham, I.L., Manning, C.A., Boyd, M.R., & Neese, J.B. (1993). Cognitive screening of nursing home residents: Factor structures of the Modified Mini-Mental State (3MS) Examination. International Journal of Geriatric Psychiatry, 8, 133-138.

Adler, G., Kuskowski, M., & Mortimer, J. (1995). Respite use in dementia patients. Clinical Gerontologist, 15(3), 17-30.

American Psychiatric Association, Committee on Nomenclature and Statistics (1987). Diagnostic and Statistical Manual of Mental Disorders, Revised Third Edition. Washington, DC: American Psychiatric Association, 97-163.

Andersen, R. (1968). A behavioural model of families' use of health services. Chicago: Center for Health Administration Studies Research.

Andersen, R., & Newman, J.F. (1973). Societal and individual determinants of medical care utilization in the United States. Milbank Memorial Fund Quarterly, 51, 95-124.

Aneshensel, C.S., Pearlin, L.I., Mullan, J.T., Zarit, S.H., & Whitlatch, C.J. (1995). Profiles in caregiving: The unexpected career. New York: Academic Press.

Ballard, C.G., Chithiramohan, R.N., Handy, S., Bannister, C., Davis, R., & Todd, N.B. (1991). Information reliability in dementia sufferers. International Journal of Geriatric Psychiatry, 6, 313-316.

Barber, G.M., Paton, R.N., & Wishnia, G.C. (1993). Public's perceived need for adult day care versus actual use. Home Health Care Services Quarterly, 14, (2/3), 53-71.

Bass, D.M., & Noelker, L.S. (1987). The influence of family caregivers on elder's use of in-home services: An expanded conceptual framework. Journal of Health and Social Behaviour, 28, 184-196.

Bass, D.M., Looman, W.J., & Ehrlich, P. (1992). Predicting the volume of health and social services: Integrating cognitive impairment into the Modified Andersen framework. The Gerontologist, 32(1), 33-43.

Baumgarten, M., Becker, R., & Gauthier, S. (1990). Validity and reliability of the Dementia Behavior Disturbance Scale. Journal of the American Geriatrics Society, 38(3), 221-226.

Bergman-Evans, B.F. (1994). Alzheimer's and related disorders: Loneliness, depression, and social support of spousal caregivers. Journal of Gerontological Nursing, 20(3), 6-16.

Biegel, D.E., Bass, D.M., Schulz, R., & Morycz, R. (1993). Predictors of in-home and out-of home service use by family caregivers of Alzheimer's Disease patients. Journal of Aging and Health, 5(4), 419-438.

Birkel, R.C. & Jones, C.J. (1989). A comparison of the caregiving networks of dependent elderly individuals who are lucid and those who are demented. The Gerontologist, 29(1), 114-119.

Black, C. (1995). Using existing data sets to study aging and the elderly: An introduction. Canadian Journal on Aging, 14(1), 135-150.

Boersma, F., Eefsting, J.A., VandenBrink, W., VanTilburg, W. (1997). Care services for dementia patients: Predictors for service utilization. International Journal of Geriatric Psychiatry, 12, 1119-1126.

Burdz, M.P., Eaton, W.O. & Bond, J.B. (1988). Effect of respite care on dementia and nondementia patients and their caregivers. Psychology and Aging, 3, 38-42.

Canadian Association for Community Care (1998). National Respite Care Project: Final Report. Canadian Association for Community Care.

Caserta, M.S., Lund, D.A., Wright, S.D., & Redburn, D.E. (1987). Caregivers to dementia patients: The utilization of community services. The Gerontologist, 27(2), 209-214.

Chappell, N.L. (1985). Social support and the receipt of home care services. The Gerontologist, 25(1), 47-54.

Chappell, N.L. (1991). Living arrangements and sources of caregiving. Journal of Gerontology: Social Sciences, 46, S1-S8.

Chappell N.L. (1993a). Implications of shifting health care policy for caregiving in Canada. Journal of Aging and Social Policy, 5(1/2), 39-55.

Chappell, N.L. (1993b, June). Informal social support. Paper presented at the annual meeting of the Canadian Long Term Care Association, Vancouver, BC.

Chenoweth, B., & Spencer, B. (1986). Dementia: The experience of family caregivers. The Gerontologist, 26(3), 267-272.

Chipperfield, J.G. (1994). The support source mix: A comparison of elderly men and women from two decades. Canadian Journal on Aging, 13(4), 434-453.

Chui, T. (1996). Canada's population: Charting into the 21st century. Canadian Social Trends, Autumn, 3-7.

Cotrell, V. (1996). Respite use by dementia caregivers: Preferences and reasons for initial use. Journal of Gerontological Social Work, 26(3/4), 35-55.

Coward, R.T., Duncan, P., & Freudenberger, K.M. (1994). Residential differences in the use of formal services prior to entering a nursing home. The Gerontologist, 34(1), 44-49.

Crowell, S.J., Rockwood, K., Stolee, P., Buehler, S.K., James, B.M., Kozma, A., & Gray, J.M. (1996). Use of home care services among the elderly in Eastern Canada. Canadian Journal on Aging, 15(3), 413-426.

CSHA (1994). Patterns of caring for people with dementia in Canada. Canadian Journal on Aging, 13(4), 470-487.

Deimling, G.T. (1992). Respite use and caregiver well-being in families caring for stable and declining AD patients. Journal of Gerontological Social Work, 18(1/2), 117-134.

Delisle, M.A., & Ouellet, H. (October, 1997). Social participation and use of services in groups of elders. Paper presented at the 26th Annual Scientific and Educational Meeting of the Canadian Association on Gerontology.

Dellasega, C. (1990). The relationship between caregiving and employment. AAOHN Journal, 38(4), 154-159.

Dellasega, C., Dansky, K., King, L. & Stricklin, M.L. (1994). Use of home health services by elderly persons with cognitive impairment. Journal of Nursing Administration, 24(6), 20-25.

Denton, M. (1997). The linkages between informal and formal care of the elderly. Canadian Journal on Aging, 16(7), 31-50.

Diwan, S., Berger, C., & Kelley, E. (1997). Composition of the home care service package: Predictors of type, volume, and mix of services provided to poor and frail older people. The Gerontologist, *37*(2), 169-181.

Fillenbaum, G. G. (1988). Multidimensional functional assessment of older adults: The Duke Older Americans Resources and Services Procedures. Hillsdale, NJ: Lawrence Erlbaum Associates.

Flint, A.J. (1995). Effects of respite care on patients with dementia and their caregivers. International Psychogeriatrics, *7*(4), 505-517.

Fortinsky, R.H., & Hathoway, T.J. (1990). Information and service needs among active and former family caregivers of persons with Alzheimer's disease. The Gerontologist, *30*, 604-609.

George, L.K. (1988, November). Why won't caregivers use community services? Unexpected findings from a respite care demonstration/evaluation. Paper presented at the Annual Meeting of the Gerontological Society of America.

Gill, C.E., Hinrichsen, G.A., & DiGiuseppe, R. (1998). Factors associated with formal service use by family members of patients with dementia. The Journal of Applied Gerontology, *17*(1), 38-52.

Grabbe, L., Demi, A., Whittington, F., Jones, J.M., Branch, L., & Lambert, R. (1995). Functional status and the use of formal home care in the year before death. Journal of Aging and Health, *7*(3), 339-364.

Hamilton, E.M., Braun, J.W., Kerber, P., Thurlow, C., & Schwieterman, I. (1996). Factors associated with family caregivers' choice not to use services. American Journal of Alzheimer's Disease, July/August, 29-38.

Hassard, T. (1991). Understanding biostatistics. St. Louis, MO: Mosby.

Havens, B. (1996). Canadian health care systems and aging: The Manitoba experience. The Southwest Journal on Aging, 11(2), 63-76.

Hawranik, P. (1998). The role of cognitive status in the use of inhome services: Implications for nursing assessment. Canadian Journal of Nursing Research, 30(2), 45-65.

Hawranik, P. (1999). Evaluation of the Riverview Health Centre Night Respite Program. Riverview Health Centre: Winnipeg, MB.

Hibbard, J., Neufeld, A., & Harrison, M.J. (1996). Gender differences in the support networks of caregivers. Journal of Gerontological Nursing, 22(9), 15-23.

Homer, A.C., & Gilleard, C.J. (1994). The effect of inpatient respite care on elderly patients and their carers. Age and Ageing, 23, 274-276.

Idler, E.L., & Benyamini, Y. (1997). Self-rated health and mortality: A review of twenty-seven community studies. Journal of Health and Social Behaviour, 38, 21-37.

Intrieri, R.C., & Rapp, S.R. (1994). Self control skillfulness and caregiver burden among help-seeking elders. Journal of Gerontology: Psychological Sciences, 49(1), 19-23.

Jacomb, P., Jorm, A., Christensen, H., MacKinnon, A., Henderson, S., Scott, R., & Korten, A. (1994). Personality changes in normal and cognitively impaired elderly: Informant reports in a community sample. International Journal of Geriatric Psychiatry, 9, 313-320.

Johnson, R.J., & Wolinsky, F.D. (1996). Use of community-based long-term care services by older adults. Journal of Aging and Health, 8(4), 512-537.

- Kashner, T.M., Krompholz, B., McDonnell, C., Magaziner, J., & Schumann, B. (1990). Acute and custodial care among impaired aged. Journal of Aging and Health, 2(1), 28-41.
- Kiyak, H.A., Teri, L., & Borson, S. (1994). Physical and functional health assessment in normal aging and in AD: Self reports vs family reports. The Gerontologist, 34(3), 324-330.
- Kosloski, K. & Montgomery, R.J.V. (1993). Perceptions of respite services as predictors of utilization. Research on Aging, 15(4), 399-413.
- Kosloski, K., & Montgomery, R.J.V. (1994). Investigating patterns of service use by families providing care for dependent elders. Journal of Aging and Health, 6(1), 17-37.
- Lawton, M., Brody, E., & Saperstein, A. (1989a). Respite services for caregivers: Research findings for service planning. Home Health Services Quarterly, 8(4), 103-130.
- Lawton, M., Brody, E., & Saperstein, A. (1989b). A controlled study of respite service for caregivers of Alzheimer's patients. Gerontologist, 29(1), 8-16.
- Lawton, M., Brody, E., & Saperstein, A. (1991). Respite care for caregivers of Alzheimer's patients: Research and practice. New York, NY: Springer Publishing Co.
- Logsdon, R.G., & Teri, L. (1995). Depression in Alzheimer's disease patients: Caregivers as surrogate reporters. Journal of the American Geriatrics Society, 43, 150-155.
- Lubben, J.E. (1988). Assessing social networks among elderly populations. Family and Community Health, 11, 42-52.

Mahoney, J., Drinka, T.J.K., Abler, R., Gunter-Hunt, G., Matthews, C., Gravenstein, S., & Carnes, M. (1994). Screening for Depression: Single question versus GDS. Journal of the American Geriatrics Society, 42(9), 1006-1008.

Manitoba Health (1975). Policy Guidelines: Continuing Care, Province of Manitoba. Winnipeg, MB: Province of Manitoba.

McCabe, B.W., Sand, B.J., Yeaworth, R.C., & Nieveen, J.L. (1995). Availability and utilization of services by Alzheimer's disease caregivers. Journal of Gerontological Nursing, 21(1), 14-22.

McCaslin, R. (1988). Reframing research on service use among the elderly: An analysis of recent findings. The Gerontologist, 28(5), 592-599.

McDowell, I. & Newell, C. (1996). Measuring health: A guide to rating scales and questionnaires (2nd ed.). New York: Oxford University Press.

McKhann, G., Drachman, D., Folstein, M., Katzman, R., Price, D., & Stadlan, E.M. (1984). Clinical diagnosis of Alzheimer's disease: Report of the NINCDS-ADRDA Work Group under the Auspices of Department of Health and Human Services Task Force on Alzheimer's disease. Neurology, 34, 939-944.

McKinlay, J.B., Crawford, S.L., & Tennstedt, S.L. (1995). The everyday impacts of providing informal care to dependent elders and their consequences for the care recipients. Journal of Aging and Health, 7(4), 497-528.

Menard, S. (1995). Applied logistic regression analysis. Thousand Oaks, CA: Sage.

Meshefedjian, G., McCusker, J., Bellavance, F., & Baumgarten, M. (1998).

Factors associated with symptoms of depression among informal caregivers of demented elders in the community. The Gerontologist, 38(2), 247-253.

Miller, C.A. (1995). Nursing care of older adults: Theory and practice (2nd ed.).

Philadelphia: JB Lippincott.

Miller, B., & McFall, S. (1991). The effect of caregiver's burden on change in

frail older persons' use of formal helpers. Journal of Health and Social Behavior, 32, June, 165-179.

Mohide, E.A., Pringle, D.M., Streiner, D.L., Gilbert, J.R., Muir, G. & Tew, M.

(1990). A randomized trial of family caregiver support in the home management of dementia. Journal of American Geriatrics Society, 38, 446-454.

Montgomery, R.J.V., Kosloski, K., & Borgatta, E. (1988). The influence of

cognitive impairment on service use and caregiver response. The Journal of Applied Social Sciences, 13(1), 142-169.

MSHA Research Group (1995). Executive Summary, Winnipeg, Canada: Centre

on Aging, University of Manitoba.

MSHA Research Group (1995). Final Report – Technical Section, Winnipeg,

Canada: Centre on Aging, University of Manitoba.

MSHA Research Group (1998). Methodology Report, Winnipeg, Canada: Centre

on Aging, University of Manitoba.

MSHA Research Group (Feb. 1999). Community-based Service Use in Manitoba

by Older Adults and their Caregivers, Winnipeg, Canada: Centre on Aging, University of Manitoba

Mui, A.C., & Burnette, D. (1994). Long-term care service use by frail elders: Is ethnicity a factor? The Gerontologist, 34(2), 190-198.

Munro, B.H. & Page, E.B. (1993). Statistical methods for health care professionals (2nd ed.). Philadelphia: JB Lippincott.

Mullan, J.T. (1993). Barriers to the use of formal services among Alzheimer's caregivers. In S.H. Zarit, L.I. Pearlin, & K.W. Schaie (Eds.), Caregiving systems: Formal and informal helpers (pp. 241-259). Hillsdale, NJ: Erlbaum.

Munro, B.H., & Page, E.B. (1986). Statistical methods for health care research (2nd ed.). Philadelphia: JB Lippincott.

Murphy, J.F., & Hepworth, J.T. (1996). Age and gender differences in health services utilization. Research in Nursing and Health, 19, 323-329.

National Advisory Council on Aging (1996). Aging Vignettes #37 and #45.

Neiderhe, G. (1988). TRIMS Behavioural problem checklist. Pharmacology Bulletin, 24(4), 771-773.

Noelker, L.S. & Bass, D.M. (1989). Home care for elderly persons: Linkages between formal and informal caregivers. Journals of Gerontology: Social Sciences, 44, S63-70.

Norusis, M.J. (1993). SPSS for Windows: Advanced statistics users's guide release 6.0. Chicago: SPSS Inc..

O'Rourke, N., Haverkamp, B.E., Tuokko, H., Hayden, S., & Beattie, B.L. (1996). The relative contribution of subjective factors to expressed burden among spousal caregivers of suspected dementia patients. Canadian Journal on Aging, 15(4), 583-596.

Ory, M.G., Hoffman, R.R., Yee, J.L., Tennstedt, S. & Schulz, R. (1999). Prevalence and impact of caregiving: A detailed comparison between dementia and nondementia caregivers. The Gerontologist, 39 (2), 177-185.

Ostbye, T., Tyas, S., McDowell, I., & Koval, J. (1997). Reported activities of daily living: Agreement between elderly subjects with and without dementia and their caregivers. Age and Ageing, 26, 99-106.

Patterson, C.J.S. (1999). The recognition, assessment and management of dementing disorders: Conclusions from the Canadian Consensus Conference on Dementia. Canadian Medical Association Journal, 160 (12 Suppl), S1-S15.

Pearlin, L.I. (1989). The sociological study of stress. Journal of Health and Social Behaviour, 30, 241-256.

Pearlin, L.I., Lieberman, M.A., Menaghan, E.G., & Mullan, J.T. (1981). The stress process. Journal of Health and Social Behaviour, 22, 337-356.

Pearlin, L.I., Mullan, J.T., Semple, S.J., & Skaff, M.M. (1990). Caregiving and the stress process: An overview of concepts and their measures. The Gerontologist, 30(5), 583-594.

Pearlin, L.I., Aneshensel, C.S., Mullan, J.T., & Whitlatch, C.J. (1996). Caregiving and its social support. In R.H. Binstock, & L.K. George (Eds.), Handbook of aging and the social sciences (4th ed.) (pp. 283-302). San Diego: Academic Press.

Penning, M. (1995a). Health, social support, and the utilization of health services among older adults. Journal of Gerontology: Social Sciences, 50B, S330-S339.

Penning, M. (1995b). Cognitive impairment, caregiver burden, and the utilization of home health services. Journal of Aging and Health, 7(2), 233-253.

Penrod, J.D., Kane, R.A., Kane, R.L., & Finch, M.D. (1995). Who Cares? The size, scope, and composition of the caregiver support system. The Gerontologist, *35*(4), 480-497.

Polit, D.F. (1996). Data analysis and statistics for nursing research. Stamford, NY: Appleton & Lange.

Radloff, L. (1977). The CES-D scale: A self-report depression scale for research in the general population. Applied Psychological Measurement, *1*, 385-401.

Rudin, D.J. (1994). Caregiver attitudes regarding utilization and usefulness of respite services for people with Alzheimer's disease. Journal of Gerontological Social Work, *23*(1/2), 85-107.

Seltzer, B., & Buswell, A. (1994). Psychiatric symptoms in Alzheimer's Disease: Mental status examination versus caregiver report. The Gerontologist, *34*(1), 103-109.

Shapiro, E. (1986). Patterns and predictors of home care use by elderly when need is the sole basis for admission. Home Health Care Services Quarterly, *7*(1), 29-44.

Shapiro, E., & Roos, N.P. (1989). Predictors and patterns of nursing home and home care use. In M.D. Petersen & D.L. White (Eds.), Health care of the elderly: An information sourcebook (pp. 127-166). Newbury Park: Sage.

Shapiro, E., & Tate, R. (1997). The use and cost of community care services by elders with unimpaired cognitive function, with cognitive impairment/no dementia, and with no dementia. Canadian Journal on Aging, *16*(4), 665-681.

Silverstein, N.M. (1984). Informing the elderly about public services: The relationship between sources of knowledge and service utilization. The Gerontologist, *24*(1), 37-40.

Snider, E.L. (1981). Young-old versus old-old and the use of services. Does the difference make the difference? Journal of the American Geriatrics Society, 29, 354-358.

Strang, V.R., & Haughey, M. (1998). Factors influencing the caregivers' ability to experience respite. Journal of Family Nursing, 4(3), 231-254.

Solomon, D., Wagner, R., Marenberg, M., Acampora, D., Cooney, L., & Inouye, K. (1993). Predictors of formal home health care use in elderly patients after hospitalization. Journal of the American Geriatrics Society, 41, 961-966.

Starrett, R.A., Rogers, D., & Walters, G. (1989). Home health care utilization: A causal model. Home Health Care Services Quarterly, 9(4), 125-140.

Stephens, M.P. (1993). Understanding barriers to caregivers' use of formal services: The caregiver's perspective. In S.H. Zarit, L.I. Pearlin, & K.W. Schaie (Eds.), Caregiving systems: Formal and informal helpers (pp. 261-272). Hillsdale, NJ: Erlbaum.

Strain, L. (1991). Use of health services in later life: The influence of health beliefs. Journal of Gerontology: Social Sciences, 46(3), S143-S150.

Strang, V. & Haughey, M. (1998). Factors influencing the caregivers' ability to experience respite. Journal of Family Nursing, 4(3), 231-254.

Swan, J.H., & Estes, C.L. (1990). Changes in aged populations served by home health agencies. Journal of Aging and Health, 2, 373-394.

Teng, E.L., & Chui, H.C. (1987). The Modified Mini-Mental State (3MS). Journal of Clinical Psychiatry, 48, 314-318.

Tennstedt, S.L., Crawford, S., & McKinlay, J.B. (1993). Determining the pattern of community care: Is coresidence more important than caregiver relationship? Journal of Gerontology: Social Sciences, 48(2), S74-S83.

Townsend, A.L. (1993). In S.H. Zarit, L.I. Pearlin, & K.W. Schaie (Eds.), Caregiving systems: Formal and informal helpers (pp. 293-301). Hillsdale, NJ: Erlbaum.

Wan, T.T.H., & Arling, G. (1983). Differential use of health services among disabled elderly. Research on Aging, 5(3), 411-431.

Wan, T., & Odell, B. (1981). Factors affecting the use of social and health services among the elderly. Cambridge, NY: Cambridge University Press.

Warren, R. & Cohen, S. (1985). Respite Care. Rehabilitation Literature, 46(3/4), 66-71.

Wolinsky, F.D., & Arnold, C.L. (1988). A different perspective on health and health services utilization. In G.L. Maddox & M.P. Lawton (Eds.), Annual Review of Gerontology and Geriatrics, Volume 8 (pp. 71-101). New York: Springer.

World Health Organization (1987). Tenth Revision of the International Classification of Diseases, 1987 Draft of Chapter V, Categories F009-F99, Mental, Behavioural and Development Disorders. In: Clinical Descriptions and Diagnostic Guidelines, MNH/MEP.87.1 Rev.1. Geneva: WHO.

Zarit, S.H., & Zarit, J.M. (1983). The memory and behaviour problems checklist and the burden interview. Unpublished manuscript, University of Southern California, Department of Psychology, Los Angeles.

CANADIAN STUDY OF HEALTH AND AGING

Canadians are now living longer. Of those currently reaching retirement age, two thirds of the women and half of the men will live to be 80 years of age or older. As part of a national effort to plan services for these people, the Canadian Study of Health and Aging (CSHA-1) was undertaken in 1991. Over 10,000 Canadians above the age of 65, in 36 communities across Canada, participated in the study - the largest study of its kind ever undertaken.

This study included surveys and clinical examinations, and recorded details of health, disability and memory problems. It also identified what factors were associated with these problems and the effect of the health problems on other family members.

FOLOW-UP TO THE CANADIAN STUDY OF HEALTH AND AGING (CSHA-2)

The study also created a basis from which to study changes in health over time. To build on this valuable information we will be returning to the same people for the follow-up to the Canadian Study of Health and Aging (CSHA-2). This will help us to find answers to such questions as

- why do some people experience fewer health problems than others?
- which people have now developed physical disabilities and memory problems?
- what are the reasons for this?
- why do people decide to move to a seniors' residence?

PARTICIPATION IS VITAL

All who participated in the first study will be included in CSHA-2. Most will be interviewed in their homes; some will be asked to have a medical examination; and, for some, a relative will be asked to provide additional information. Participation of all those who took part in the first phase of the study is vital to the success of CSHA-2.

GLOBAL IMPLICATIONS

The Canadian Study of Health and Aging has achieved international recognition as a major contributor to the understanding of seniors' health issues. This study forms part of a World Health Organization survey being conducted in several countries throughout the world.

BENEFITS OF THE STUDY

When the study is finished, we will be able to add to the picture of seniors' health in Canada. We will then better understand details of changes in health as people age. This will, in turn, help governments to plan health care and supportive services.

For more information about the Canadian Study of Health and Aging in your area, please contact

Centre on Aging
University of Manitoba
338 Isbister Building
Winnipeg, MB R3T 2N2

Appendix B



INTRODUCTORY LETTER TO ELDERS



140

THE UNIVERSITY OF MANITOBA

CENTRE ON AGING

338 Isbister Building
Winnipeg, Manitoba
Canada R3T 2N2

Tel: (204) 474-8754
Fax: (204) 474-7576

February 1, 1996

Mary Jones
14 Any St.
Winnipeg, MB
HOH HOH

Dear Mrs. Jones:

Approximately five years ago, you participated in the Manitoba Study of Health and Aging conducted by the Centre on Aging, University of Manitoba. The project focused on health and the use of services among Manitobans aged 65 and over. The information we received from this project was extremely important.

We are now reinterviewing the same people who participated in the earlier study. We are interested in understanding changes in health and the need for services over time. This interview will take approximately an hour. Your answers will be completely confidential.

One of our staff will be calling you soon to arrange a convenient time and day to meet. Please feel free to ask any questions which you may have. We are truly interested in your opinions and value your participation in our project.

If you have any immediate questions, do not hesitate to call us at the University of Manitoba, Centre on Aging, 474-6547.

Thank you once again for your participation. We look forward to talking to you.

Sincerely,

Laurel A. Strain, Ph.D.
Director

Jackie Sweiden, M.A.
Project Coordinator





INTRODUCTORY LETTER TO ELDER



141

THE UNIVERSITY OF MANITOBA

CENTRE ON AGING

338 Isbister Building
Winnipeg, Manitoba
Canada R3T 2N2

Tel: (204) 474-8754
Fax: (204) 474-7576

Jane Doe
234 Any Street
Winnipeg, MB
HOH HOH

Dear Mrs. Doe:

Recently you took the time to talk with one of our interviewers as part of the Follow-up to the Manitoba Study on Health and Aging. We would like to thank you very much for your participation in this study so far.

At that time we mentioned the possibility of your further participation involving a medical check-up. This is an important second stage of the study where you will provide additional information for health professionals regarding the health of seniors. You have been one of the few chosen for this aspect of the study. Nina Labun, the Research Nurse, will call you soon to tell you more about it.

We do need everyone's help to make this a successful study!

We look forward to discussing this with you and if you have any questions please call Nina Labun at 474-6587.

Sincerely,

Dr. P. Montgomery, M.D., F.R.C.P.C.
Associate Head
Section of Geriatric Medicine
University of Manitoba

Nina Labun, R.N., B.N.
Research Nurse





**LETTER OF INVITATION - ELDER SCREENED
AND CLINICAL ASSESSMENT**



THE UNIVERSITY OF MANITOBA

CENTRE ON AGING

338 Isbister Building
Winnipeg, Manitoba
Canada R3T 2N2

Tel: (204) 474-8754
Fax: (204) 474-7576

August 27, 1996

Mary Jones
123 Any Street
Winnipeg, MB
R3T 2N2

Dear Mrs. Jones:

MANITOBA STUDY OF HEALTH AND AGING - FINAL PHASE

In the past few months, you and Mr. Jones have been participating in the Follow-up to the Manitoba Study of Health and Aging conducted by the Centre on Aging, University of Manitoba. As a final part of this study, we are interested in finding out about the services that you and Mr. Jones might use or need and the support and care you provide.

We would like to talk to you for approximately an hour at your convenience. Your answers will be completely confidential. One of our staff will be calling you soon to arrange a time and day to meet. Please feel free to ask any questions which you may have. We are truly interested in this information and value your participation in our project.

If you have any immediate questions, do not hesitate to call us at the Centre on Aging, University of Manitoba, at 474-6547.

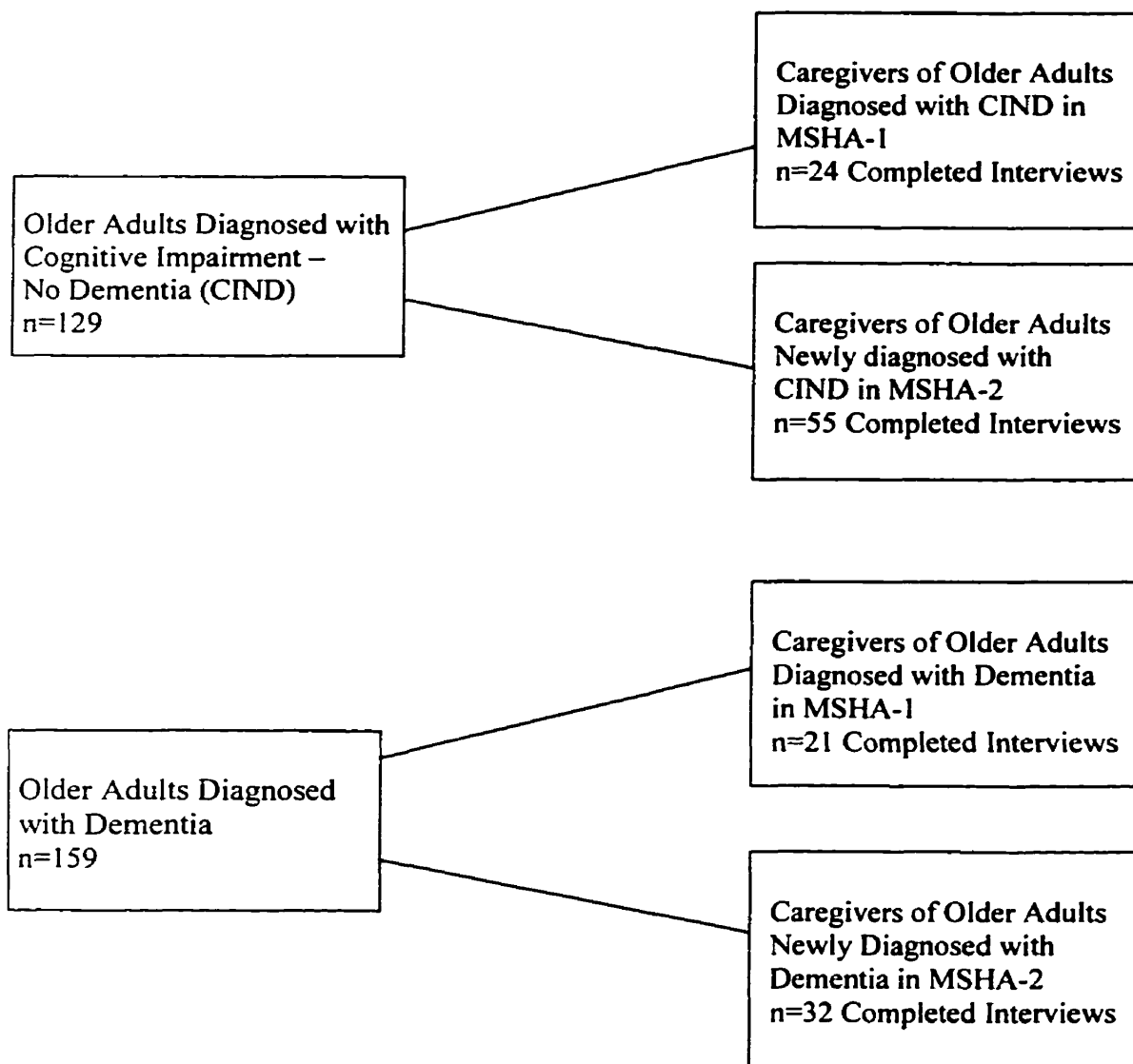
Thank you once again for your participation. We look forward to talking to you.

Sincerely,

Laurel A. Strain, Ph.D.
Director

Jackie Sweiden, M.A.
Project Coordinator



Caregiver Sample – MSHA-2**Total n=288****Total n=132**

Appendix D

Community-based Services in Manitoba

The community services examined in the MSHA-2 are services delivered either by private agencies or by the publicly funded Manitoba Home Care program, and include personal care services, nursing services, therapy services, respite services, and support services such as meal and transportation. The Manitoba Home Care program provides “the coordinated delivery of a broad range of health and social services to meet the needs of the persons who require assistance or support in order to remain at home, or whose functioning without Home Care is likely to deteriorate making it impossible for the person to stay at home in the community” (Manitoba Health, April 1975, p. 1). Unlike other provinces, Manitoba’s Home Care program is a province-wide system of health and social services delivered with minimal user premiums. In terms of respite services, adult day centres frequently charge a minimal fee to cover costs for lunch and transportation. Institutional-based respite services charge a small daily user fee and require a minimum of a 2-week time period of respite care. More recently, night respite has also been available in Winnipeg through a pilot project subsidized by a long-term care institution in Winnipeg for a cost of \$6/night to cover transportation costs.

Services accessed through Home Care are provided on the basis of professionally assessed need including the consideration of those activities which family, friends, or neighbors could perform. Service delivery is coordinated by professional case coordinators and provided by paid professional and/or paraprofessional staff as well as volunteers. A proportion of services are provided by private agencies who have been awarded service contracts by Manitoba Health (Havens, 1995).

Operationalization, Source and Measurement of Variables

Description	Question Source	Measurement
Background Characteristics		
Age of Elder	rn1-rn3; ¹ dobd,dobm,doby	<i>continuous</i>
Age of Caregiver	cg16-cg18; ² cg2-cg4	<i>continuous</i>
Gender of Elder	sex	0=male;1=female
Gender of Caregiver	cg10	0=male;1=female
Marital Status of Elder	rn11	0=not married; 1=married
Marital Status of Caregiver	cg19	0=not married; 1=married
Elder and Caregiver Co-Residence	cg26	0=live apart; 1=coreside
Elder's Living Arrangement	cg87	0=coresides with cg or other; 1=lives alone
Locale of Elder's Residence	region2	0=non-Wpg; 1=Wpg
Caregiver's Relationship to Elder	cg13	0=spouse 1=adult child 2=other relation
Stressors		
<u>Objective Stressors</u>		
# of Health Problems - Elder	md261-md274 ³	<i>continuous</i>
# of Health Problems - Caregiver	cg983-cg1006	<i>continuous</i>
Caregiver's Self Rated Health	cg1008	0=not too good/poor health 1=pretty good/very good health
Elder's # of ADL/IADL Limitations	cg167-cg420	<i>continuous</i>
Elder's # of Basic ADL Limitations	cg167-cg420	<i>continuous</i>
Elder's # of Instrumental ADL Limitations	cg167-cg420	<i>continuous</i>
Elder's Cognitive Status	clstat2 ⁴	0=CIND; 1=dementia
Elder's Depression	md91 ⁴	0=presence of depressive symptoms; 1=questionable depressive symptoms; 2=no depression
Problematic Behaviour of Elder	cg869-cg923	<i>continuous</i>
<u>Subjective Stressors</u>		
Caregiver Burden	cg935-cg956	<i>continuous</i>
Caregiver Depression	cg1069-cg1088	0=no depression (0-15) 1=possible depression (16+)
Moderators		
Availability of other Informal Caregivers	cg137	0=no; 1=yes
# of other Informal Caregivers	cg138	0-3+
Elder's Annual Income	cam154 ⁵	0=<\$15,000; 1=\$15,000-24,999 2=\$25,000-34,999; 3=>\$35,000; 4=mv
Adequacy of Elder's Income	cam153 ⁵	0=with some difficulty 1=adequately/very well
Caregiver's Annual Household Income	cg1097	0=<\$15,000; 1=\$15,000-24,999 2=\$25,000-34,999; 3=>\$35,000; 4=mv
Caregiver's Primary Income Source	cg1098	0=OAS&/or GIS; 1= other sources; 2=paid employment

Operationalization, Source and Measurement of Variables

Description	Question Source	Measurement
Caregiver's Educational Level	cg24	<i>continuous</i>
Elder's Educational Level	eldedu	continuous
Outcomes		
Respite Services Combined	cg714, cg736,cg758 cg670	0=use; 1=non-use
Adult Day Centre Use	cg670	0=use; 1=non-use
In-Home Respite Use	cg758	0=use; 1=non-use
Hospital Respite Use	cg714	0=use; 1=non-use
PCH Respite Use	cg736	0=use; 1=non-use
Adult Day Centre Reason for Non-Use	nouse5	<i>0=all other reasons; 1=not aware</i>
In-Home Respite Reason for Non-Use	nouse9	<i>0=all other reasons; 1=not aware</i>
Hospital Respite Reason for Non-Use	nouse7	<i>0=all other reasons; 1=not aware</i>
PCH Respite Reason for Non-Use	nouse8	<i>0=all other reasons; 1=not aware</i>

¹ RN refers to interview questions in Interview Schedule 'Clinical Assessment'

² CG refers to interview questions in Interview Schedule 'Caregiver Interview'

³ MD refers to interview questions in Interview Schedule 'Clinical Assessment'

⁴ Refers to interview questions in Interview Schedules 'C2' and 'E1'

⁵ Refers to interview questions in Interview Schedule 'CAMDEX'

Italicized measurement values indicate the coding of variables for multivariate analysis
Interview Schedules available from the Centre on Aging, University of Manitoba

Appendix F

Requested Datasets and Variables from MSHA-2

Screening Interview

elder's age elder's gender elder's education
--

Clinical Assessment: Physical examination

Variable Label	Variable Description
RN11	elder's marital status
RN96-109B	ADL/IADL
RN116-127	HRCA
RN187-192	service use
MD78-91	depressive symptoms
MD33	emotional incontinence
MD22,24	speech/communications deficits
MD21,21	STM/LTM deficits
MD25	personality problems
MD26	mood
MD101	judgment failure/change
MD48	way-finding difficulties
MD42	difficulty going out alone
MD1000	difficulty driving car
MD27-MD32	dysfunctional behaviour
MD37	nocturnal confusion
MD1001	verbal/emotional agitation
MD34	hallucinations
MD36	delusions
RN35	3MS total score
RN143	GDS score

Clinical Assessment: Interview Schedule B4

Variable Label	Variable Description
CAM153,154	elder's income

Clinical Assessment: Interview Schedule E1

Variable Label	Variable Description
Incdiag	diagnosis
con1	severity of dementia

Clinical Assessment: Interview Schedule C1

Variable Label	Variable Description
MD260	presence of coexisting disease
MD261-MD274	type of coexisting disease

Requested Datasets and Variables from MSHA-2

Caregiver Interview Schedule: Version 1 - Informal Caregiver, Elder subject in community

Variable Label	Variable Description
CG10	cg gender
CG13	cg relationship to elder
CG14	cg age
CG19	cg's marital status
CG23A-D	cultural background of caregiver
CG24,25	education of cg
CG26	coresidence of cg
CG27	length of coresidence
CG28,29	others in coresidence/number of others
CG40,41	children in coresidence/number of children
CG52,53	close relatives within 1 hour drive/number
CG54,55	people in coresidence
CG80,81,82	children not in coresidence
CG84-86,86A	number of brothers/sisters
CG87,88	people in coresidence with elder/relationship
CG117-119	children not in coresidence with elder
CG120,121	close relatives to elder
CG122	friends within 1 hour drive
CG143,144,158	cg employment status
CG167-431	cg report of ADL/IADL
CG432-433	cg report of elder's ability to be alone
CG452-459	cg involvement
CG478-485	MD visit/hospital room visit
CG486,487	hospital admission/length
CG488-511	homemaker service
CG512-533	home delivered meals
CG534-555	personal care services
CG556-577	in-home nursing care
CG670-691	day centre
CG692-713	day hospital
CG714-779	respite care
CG869-934	Baumgarten Dementia Behaviour Scale
CG935-956	Zarit Burden
CG962-971	cg's report of caregiving
CG983-1007A	cg's health problems
CG1008	cg self reported health
CG1009	cg self reported change in health
CG1010	cg's impact of health status on caregiving
CG1069-1088	CES-D
CG1097	cg average monthly household income
CG1098	cg source of income

Appendix G

UNIVERSITY OF MANITOBAFACULTY COMMITTEE ON THE USE OF HUMAN SUBJECTS IN RESEARCH

NAME: Dr. Laurel Strain

OUR REFERENCE: E94:119

DATE: January 23, 1996

YOUR PROJECT ENTITLED:

Follow-up to the Canadian Study of Health and Aging. (CSHA-2)
Revised Proposal.

HAS BEEN APPROVED BY THE COMMITTEE AT THEIR MEETING OF:

Approved by Dr. Gordon Grahame on behalf of the Committee on
January 16, 1996.

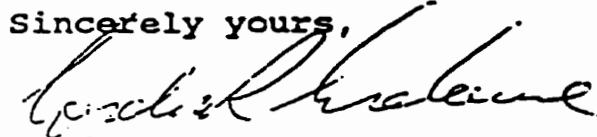
COMMITTEE PROVISOS OR LIMITATIONS:

Revised proposal approved as per your letter dated November 23,
1996.

Any significant changes of the protocol should be reported to the
Chairman for the Committee's consideration, in advance of
implementation of such changes.

****THIS IS FOR THE ETHICS OF HUMAN USE ONLY. FOR THE LOGISTICS OF
PERFORMING THE STUDY, APPROVAL SHOULD BE SOUGHT FROM THE RELEVANT
INSTITUTION, IF REQUIRED.**

Sincerely yours,



Gordon R. Grahame, M.D.,
Chairman,
Faculty Committee on the Use of
Human Subjects in Research.

GRG/11

TELEPHONE INQUIRIES:

789-3255 - Lorraine Lester

The University of Manitoba
FACULTY OF NURSING
ETHICAL REVIEW COMMITTEE

APPROVAL FORM

Proposal Number #99/16

Proposal Title: "Factors Associated With the Non-Use of Community Health Services
By Cognitively Impaired Older Adults and Their Informal Caregivers"


Name and Title of
Researcher(s): Nina Labun

Date of Review: April 7, 1999

APPROVED BY THE COMMITTEE: April 8, 1999

Comments:

Date: April 8, 1999


Susan McClement, Associate Chair

NOTE:

Any significant changes in the proposal should be reported to the Chairperson for the Ethical Review Committee's consideration, in advance of implementation of such changes.



THE UNIVERSITY OF MANITOBA

CENTRE ON AGING

158



338 Isbister Building
Winnipeg, Manitoba
Canada R3T 2N2

Tel: (204) 474-8754
Fax: (204) ~~261-9999~~
474-7576

September 22, 1998

Nina Labun
115 Henderson Hwy.
Winnipeg, MB
R2L 1L3

Dear Nina:

Your request for access to the Follow-up to the Manitoba Study of Health and Aging data has been approved by the MSHA-2 Research Group. Please contact Audrey (474-6698) to arrange an appointment to discuss the specifics of your request and the time frame for provision of these data to you.

Best wishes with your research.

Sincerely,

A handwritten signature in cursive script that reads 'Laurel'.

Laurel Strain, Ph.D.
Director



Appendix J

CONSENT TO SCREENING INTERVIEW

MANITOBA STUDY OF HEALTH AND AGING

I understand that a research team from the Centre on Aging, University of Manitoba is conducting the Follow-up to the Manitoba Study of Health and Aging in which I participated in 1991-92. All study participants are being re-interviewed about changes in their health, in their need for services and in memory changes over time.

I understand that I have been asked to participate in the study. The interview should take approximately an hour. I may also be invited to participate in a further study component, along with a close relative who is well-informed about my health.

I have been promised that all information will be confidential. No results will be released in any way that could identify me personally.

I agree to participate in this study and know that I have the right to withdraw at any time.

NAME: _____
(please print)

SIGNATURE: _____

INTERVIEWER: _____
Name Number

DATE: _____

ID # _____

PROXY CONSENT TO SCREENING INTERVIEW

MANITOBA STUDY OF HEALTH AND AGING

I understand that a research team from the Centre on Aging, University of Manitoba is conducting the Follow-up to the Manitoba Study of Health and Aging in which _____ participated in 1991-92. All study participants are being re-interviewed about changes in their health, in their need for services and in memory changes over time.

I understand that _____ has agreed to participate in this follow-up study and I also agree to his/her participation.

All information will be confidential. No results will be released in any way that could identify _____ or me personally.

NAME: _____
(please print)

RELATIONSHIP TO PARTICIPANT: _____

SIGNATURE: _____

INTERVIEWER: _____
Name Number

DATE: _____

ID # _____



INTRODUCTORY LETTER TO ELDER



THE UNIVERSITY OF MANITOBA

CENTRE ON AGING

338 Isbister Building
Winnipeg, Manitoba
Canada R3T 2N2

Tel: (204) 474-8754
Fax: (204) 474-7576

Jane Doe
234 Any Street
Winnipeg, MB
HOH HOH

Dear Mrs. Doe:

Recently you took the time to talk with one of our interviewers as part of the Follow-up to the Manitoba Study on Health and Aging. We would like to thank you very much for your participation in this study so far.

At that time we mentioned the possibility of your further participation involving a medical check-up. This is an important second stage of the study where you will provide additional information for health professionals regarding the health of seniors. You have been one of the few chosen for this aspect of the study. Nina Labun, the Research Nurse, will call you soon to tell you more about it.

We do need everyone's help to make this a successful study!

We look forward to discussing this with you and if you have any questions please call Nina Labun at 474-6587.

Sincerely,

Dr. P. Montgomery, M.D., F.R.C.P.C.
Associate Head
Section of Geriatric Medicine
University of Manitoba

Nina Labun, R.N., B.N.
Research Nurse



CONSENT FOR CLINICAL ASSESSMENT

MANITOBA STUDY OF HEALTH AND AGING-2

I understand that as a participant of the Manitoba Study of Health and Aging-2, I have been requested to take part in a clinical assessment. The purpose of this assessment is to study certain aspects of memory.

The assessment will take place either at the clinic or in my home. I will be reimbursed for travel expenses to and from the clinic and the cost of lunch in the cafeteria for me and a companion.

I understand that this clinical assessment will involve:

- Interviews with me and a relative or friend. The interviews will be about my activities, and details of my family and medical history.
- A physical examination.
- Further tests related to memory.

I understand that the assessment may last approximately 5 hours, including breaks. No painful procedures will be involved.

I agree to take part in the clinical assessment described above and understand that I may withdraw at any time. I have been promised that all information will be confidential.

NAME _____
(please print)

SIGNATURE _____

Interviewer _____

or

Name

_____ Number

Research Nurse
(Witness)

DATE _____

ID# _____

PROXY CONSENT FOR CLINICAL ASSESSMENT

MANITOBA STUDY OF HEALTH AND AGING-2

I understand that _____ has agreed to participate in a clinical assessment, as part of the Manitoba Study of Health and Aging-2. The purpose of this assessment is to study certain aspects of memory.

I understand that this clinical assessment will involve:

- Interviews with _____ and a relative or friend of _____. The interviews will be about his/her activities, and details of his/her family and medical history.
- A physical examination.
- Further tests related to memory.

I agree to _____ taking part in the clinical assessment described above and understand that _____ may withdraw at any time. I have been promised that all information will be confidential.

NAME: _____
(please print)

RELATIONSHIP TO PARTICIPANT: _____
(please print)

SIGNATURE _____

Interviewer	_____	_____
or	Name	Number
Research Nurse		
(Witness)		

DATE _____

ID# _____



LETTER OF INVITATION - ELDER SCREENED AND CLINICAL ASSESSMENT



165

THE UNIVERSITY OF MANITOBA

CENTRE ON AGING

338 Isbister Building
Winnipeg, Manitoba
Canada R3T 2N2

Tel: (204) 474-8754
Fax: (204) 474-7576

August 27, 1996

Mary Jones
123 Any Street
Winnipeg, MB
R3T 2N2

Dear Mrs. Jones:

MANITOBA STUDY OF HEALTH AND AGING - FINAL PHASE

In the past few months, you and Mr. Jones have been participating in the Follow-up to the Manitoba Study of Health and Aging conducted by the Centre on Aging, University of Manitoba. As a final part of this study, we are interested in finding out about the services that you and Mr. Jones might use or need and the support and care you provide.

We would like to talk to you for approximately an hour at your convenience. Your answers will be completely confidential. One of our staff will be calling you soon to arrange a time and day to meet. Please feel free to ask any questions which you may have. We are truly interested in this information and value your participation in our project.

If you have any immediate questions, do not hesitate to call us at the Centre on Aging, University of Manitoba, at 474-6547.

Thank you once again for your participation. We look forward to talking to you.

Sincerely,

Laurel A. Strain, Ph.D.
Director

Jackie Sweiden, M.A.
Project Coordinator



CONSENT TO CAREGIVER INTERVIEW FOLLOW-UP SAMPLE

MANITOBA STUDY OF HEALTH AND AGING

I understand that a research team from the Centre on Aging, University of Manitoba is conducting the Follow-up to the Manitoba Study of Health and Aging in which I participated in 1991/92. All study participants are being re-interviewed about changes in their health, the impact of caregiving and their need for support and services.

I understand that I have been asked to participate in the study. The interview should take approximately an hour.

I have been promised that all information will be confidential. No results will be released in any way that could identify me personally.

I agree to participate in this study and know that I have the right to withdraw at any time.

NAME: _____
(please print)

SIGNATURE: _____

INTERVIEWER: _____
(name) (number)

DATE: _____

ID#: _____

CONSENT TO CAREGIVER INTERVIEW NEW CAREGIVER SAMPLE

MANITOBA STUDY OF HEALTH AND AGING

I understand that a research team from the Centre on Aging, University of Manitoba is conducting the Follow-up to the Manitoba Study of Health and Aging. All study participants are being interviewed about changes in their health, the impact of caregiving and their need for support and services.

I understand that I have been asked to participate in the study. The interview should take approximately an hour.

I have been promised that all information will be confidential. No results will be released in any way that could identify me personally.

I agree to participate in this study and know that I have the right to withdraw at any time.

NAME: _____
(please print)

SIGNATURE: _____

INTERVIEWER: _____
(name) (number)

DATE: _____

ID#: _____

Bivariate Results
Characteristics of Caregivers Not Aware of Adult Day Centre Compared to Other Reasons
Background Characteristics

	Not Aware	Other Reasons	p
Age of Elder			
Mean	84.5	85.2	.619
n=115			
Age of Caregiver			
Mean	63.5	61.3	
Mean Rank	59.9	55.7	.497
n=114			
Gender of Elder			
Male	42.3%	57.7%	.953
Female	42.9%	57.1%	
n=115			
Gender of Caregiver			
Male	65.6%	34.4%	.002
Female	33.7%	66.3%	
n=115			
Marital Status of Elder			
Married	55.6%	44.4%	.024
Not Married	34.3%	65.7%	
n=115			
Marital Status of Caregiver			
Married	43.2%	56.8%	.822
Not Married	40.7%	59.3%	
n=115			
Elder and Caregiver Coresidence			
Coresiding	53.3%	46.7%	.062
Residing Apart	35.7%	64.3%	
n=115			
Elder's Living Arrangement			
Lives Alone	62.5%	37.5%	.280
Lives With Caregiver or Other	47.5%	52.5%	
n=115			
Locale of Elder's Residence			
Winnipeg	26.0%	74.0%	.002
Non-Winnipeg	55.4%	44.6%	
n=115			
Caregiver's Relationship to Elder			
Spouse	58.1%	41.9%	
Adult Child	36.4%	63.6%	.124
Other Relative	38.9%	61.1%	
n=115			

Bivariate Results
Characteristics of Caregivers Not Aware of Adult Day Centre Compared to Other Reasons
Objective Stressors

	Not Aware	Other Reasons	p
Elder's Health (# of chronic conditions)			
Mean	5.1	5.1	.999
n=115			
Caregiver's Health (# of chronic conditions)			
Mean	2.6	2.4	
Mean Rank	58.8	57.4	.823
n=115			
Caregiver's Self Rated Health			
Poor Health/Not too Good	58.3%	41.7%	
Pretty Good/Very Good Health	40.8%	59.2%	.244
n=115			
Elder's # of ADL/IADL Limitations			
Mean	1.4	1.7	
Mean Rank	54.6	60.5	.333
n=115			
Elder's # of Basic ADL Limitations			
Mean	1.4	1.7	
Mean Rank	54.6	60.5	.333
n=115			
Elder's # of IADL Limitations			
Mean	8.7	8.7	
Mean Rank	58.0	58.0	.995
n=115			
Elder's Cognitive Status			
CIND	44.4%	55.6%	
Dementia	39.5%	60.5%	.606
n=115			
Elder's Depression			
No depressive symptoms	41.0%	59.0%	
Questionable depressive symptoms	58.3%	41.7%	.507
Presence of depressive symptoms	40.5%	59.5%	
n=115			
Problematic Behaviour of Elder			
Mean	7.4	8.6	
Mean Rank	54.1	60.1	.337
n=114			

Bivariate Results
Characteristics of Caregivers Not Aware of Adult Day Centre Compared to Other Reasons
Subjective Stressors

	Not Aware	Other Reasons	p
Caregiver Burden			
Mean	14.3	15.2	
Mean Rank	55.5	59.0	.557
n=114			
Caregiver Depression			
Minimal Depressive Symptoms	43.4%	56.6%	
High Depressive Symptoms	37.5%	62.5%	.657
Mean Rank	57.04	58.71	
n=115			

Bivariate Results
Characteristics of Caregivers Not Aware of Adult Day Centre Compared to Other Reasons
Moderators

	Not Aware	Other Reasons	p
Availability of Other Informal Caregivers			
Yes	40.9%	59.1%	.669
No	44.9%	55.1%	
n=115			
# of Other Informal Caregivers			
0	55.1%	44.9%	.761
1	62.5%	37.5%	
2	64.3%	35.7%	
≥3	50.0%	50.0%	
n=115			
Adequacy of Elder's Income			
With Some Difficulty	61.5%	38.5%	.101
Adequately/Very Well	37.8%	62.2%	
n=111			
Caregiver's Primary Income Source			
OAS and/or GIS	54.8%	45.2%	.078
Other Sources	30.2%	69.8%	
Paid Employment	48.6%	51.4%	
n=111			
Caregiver's Educational Level (years completed)			
Mean	10.1	11.2	.067
n=115			
Elder's Educational Level (years completed)			
Mean	6.7	7.3	.328
n=111			

Bivariate Results
Characteristics of Caregivers Not Aware of In-Home Respite Compared to Other Reasons
Background Characteristics

	Not Aware	Other Reasons	p
Age of Elder			
Mean	84.5	85.4	.449
n=125			
Age of Caregiver			
Mean	63.3	60.1	
Mean Rank	66.4	58.8	.237
n=124			
Gender of Elder			
Male	50.0%	50.0%	
Female	49.3%	50.7%	.938
n=125			
Gender of Caregiver			
Male	57.1%	42.9%	
Female	46.7%	53.3%	.293
n=125			
Marital Status of Elder			
Married	55.3%	44.7%	
Not Married	46.2%	53.8%	.050
n=125			
Marital Status of Caregiver			
Married	44.8%	55.2%	
Not Married	65.5%	34.5%	.238
n=125			
Elder and Caregiver Coresidence			
Coresiding	56.5%	43.5%	
Residing Apart	45.6%	54.4%	.238
n=125			
Elder's Living Arrangement			
Lives Alone	46.9%	53.1%	
Lives With Caregiver or Other	52.5%	47.5%	.533
n=125			
Locale of Elder's Residence			
Winnipeg	41.4%	58.6%	
Non-Winnipeg	56.7%	43.3%	.087
n=125			
Caregiver's Relationship to Elder			
Spouse	58.1%	41.9%	
Adult Child	44.4%	55.6%	.393
Other Relative	54.5%	45.5%	
n=125			

Bivariate Results
Characteristics of Caregivers Not Aware of In-Home Respite Compared to Other Reasons
Objective Stressors

	Not Aware	Other Reasons	p
Elder's Health (# of chronic conditions)			
Mean n=125	5.2	5.0	.600
Caregiver's Health (# of chronic conditions)			
Mean	2.7	2.3	
Mean Rank n=125	66.3	59.8	.311
Caregiver's Self Rated Health			
Poor Health/Not too Good	66.7%	33.3%	
Pretty Good/Very Good Health n=125	47.8%	52.2%	.214
Elder's # of ADL/IADL Limitations			
Mean	1.7	1.8	
Mean Rank n=125	63.0	63.0	.990
Elder's # of Basic ADL Limitations			
Mean	1.7	1.8	
Mean Rank n=125	63.0	63.0	.990
Elder's # of IADL Limitations			
Mean	9.4	8.5	
Mean Rank n=125	66.4	59.7	.299
Elder's Cognitive Status			
CIND	51.9%	48.1%	
Dementia n=125	45.8%	54.2%	.506
Elder's Depression			
No depressive symptoms	44.9%	55.1%	
Questionable depressive symptoms	63.6%	36.4%	
Presence of depressive symptoms n=125	53.3%	46.7%	.423
Problematic Behaviour of Elder			
Mean	7.3	10.1	
Mean Rank n=124	56.8	68.0	.084

Bivariate Results
Characteristics of Caregivers Not Aware of In-Home Respite Compared to Other Reasons
Subjective Stressors

	Not Aware	Other Reasons	p
Caregiver Burden			
Mean	14.0	16.8	
Mean Rank	58.7	66.2	.248
n=124			
Caregiver Depression			
Minimal Depressive Symptoms	51.4%	48.6%	
High Depressive Symptoms	38.9%	61.1%	.326
Mean Rank			
n=125			

Bivariate Results
Characteristics of Caregivers Not Aware of In-Home Respite Compared to Other Reasons
Moderators

	Not Aware	Other Reasons	p
Availability of Other Informal Caregivers			
Yes	46.6%	53.4%	.268
No	53.8%	46.2%	
n=125			
# of Other Informal Caregivers			
0	53.8%	46.2%	.871
1	47.2%	52.8%	
2	43.8%	56.2%	
≥3	47.6%	52.4%	
n=125			
Adequacy of Elder's Income			
With Some Difficulty	64.3%	35.7%	.217
Adequately/Very Well	46.7%	53.3%	
n=121			
Caregiver's Primary Income Source			
OAS and/or GIS	60.0%	40.0%	.360
Other Sources	45.8%	54.2%	
Paid Employment	44.2%	55.8%	
n=121			
Caregiver's Educational Level (years completed)			
Mean	9.9	11.8	.001
n=125			
Elder's Educational Level (years completed)			
Mean	6.9	7.2	.700
n=121			

Bivariate Results
Characteristics of Caregivers Not Aware of Hospital Respite Compared to Other Reasons
Background Characteristics

	Not Aware	Other Reasons	p
Age of Elder			
Mean	84.7	84.9	.849
n=128			
Age of Caregiver			
Mean	62.7	60.5	
Mean Rank	66.5	61.1	.413
n=127			
Gender of Elder			
Male	50.9%	49.1%	
Female	57.5%	42.5%	.456
n=128			
Gender of Caregiver			
Male	69.4%	30.6%	
Female	48.9%	51.1%	.036
n=128			
Marital Status of Elder			
Married	58.3%	41.7%	
Not Married	52.5%	47.5%	.521
n=128			
Marital Status of Caregiver			
Married	50.0%	50.0%	
Not Married	70.0%	30.0%	.054
n=128			
Elder and Caregiver Coresidence			
Coresiding	63.3%	36.7%	
Residing Apart	49.4%	50.6%	.125
n=128			
Elder's Living Arrangement			
Lives Alone	49.2%	50.8%	
Lives With Caregiver or Other	60.0%	40.0%	.220
n=128			
Locale of Elder's Residence			
Winnipeg	43.3%	56.7%	
Non-Winnipeg	64.7%	35.3%	.015
n=128			
Caregiver's Relationship to Elder			
Spouse	59.4%	40.6%	
Adult Child	52.1%	47.9%	
Other Relative	56.5%	43.5%	.771
n=128			

Bivariate Results
Characteristics of Caregivers Not Aware of Hospital Respite Compared to Other Reasons
Objective Stressors

	Not Aware	Other Reasons	p
Elder's Health (# of chronic conditions)			
Mean n=128	5.4	5.0	.389
Caregiver's Health (# of chronic conditions)			
Mean	2.8	2.3	
Mean Rank n=128	68.2	60.1	.215
Caregiver's Self Rated Health			
Poor Health/Not too Good	69.2%	30.8%	
Pretty Good/Very Good Health n=128	53.0%	47.0%	.266
Elder's # of ADL/IADL Limitations			
Mean	1.7	1.7	
Mean Rank n=128	64.4	64.6	.982
Elder's # of Basic ADL Limitations			
Mean	1.7	1.7	
Mean Rank n=128	64.4	64.6	.982
Elder's # of IADL Limitations			
Mean	9.3	8.6	
Mean Rank n=128	66.6	61.9	.473
Elder's Cognitive Status			
CIND	59.5%	40.5%	
Dementia n=128	46.9%	53.1%	.165
Elder's Depression			
No depressive symptoms	51.5%	48.5%	
Questionable depressive symptoms	69.2%	30.8%	
Presence of depressive symptoms n=128	55.3%	44.7%	.496
Problematic Behaviour of Elder			
Mean	7.4	10.6	
Mean Rank n=127	58.6	70.4	.073

Bivariate Results
Characteristics of Caregivers Not Aware of Hospital Respite Compared to Other Reasons
Subjective Stressors

	Not Aware	Other Reasons	p
Caregiver Burden			
Mean	15.1	17.5	
Mean Rank	62.3	66.0	.574
n=127			
Caregiver Depression			
Minimal Depressive Symptoms	42.6%	57.4%	
High Depressive Symptoms	60.0%	40.0%	.075
Mean Rank	69.8	58.2	
n=128			

Bivariate Results**Characteristics of Caregivers Not Aware of Hospital Respite Compared to Other Reasons****Moderators**

	Not Aware	Other Reasons	p
Availability of Other Informal Caregivers			
Yes	51.4%	48.6%	.375
No	59.3%	40.7%	
n=128			
# of Other Informal Caregivers			
0	45.7%	37.9%	.734
1	27.1%	29.3%	
2	12.9%	12.1%	
≥3	14.3%	20.7%	
n=128			
Adequacy of Elder's Income			
With Some Difficulty	71.4%	28.6%	.166
Adequately/Very Well	51.8%	48.2%	
n=124			
Caregiver's Primary Income Source			
OAS and/or GIS	60.0%	40.0%	.731
Other Sources	51.0%	49.0%	
Paid Employment	53.5%	46.5%	
n=124			
Caregiver's Educational Level (years completed)			
Mean	10.0	12.1	.001
n=128			
Elder's Educational Level (years completed)			
Mean	7.2	7.1	.953
n=124			

Bivariate Results
Characteristics of Caregivers Not Aware of PCH Respite Compared to All Other Reasons
Background Characteristics

	Not Aware	Other Reasons	p
Age of Elder			
Mean	84.5	85.5	.336
n=128			
Age of Caregiver			
Mean	62.8	60.6	
Mean Rank	66.4	61.3	.436
n=127			
Gender of Elder			
Male	52.7%	47.3%	.816
Female	54.8%	45.2%	
n=128			
Gender of Caregiver			
Male	62.2%	37.8%	.232
Female	50.5%	49.5%	
n=128			
Marital Status of Elder			
Married	60.4%	39.6%	.252
Not Married	50.0%	50.0%	
n=128			
Marital Status of Caregiver			
Married	51.0%	49.0%	.260
Not Married	62.5%	37.5%	
n=128			
Elder and Caregiver Coresidence			
Coresiding	60.0%	40.0%	.268
Residing Apart	50.0%	50.0%	
n=128			
Elder's Living Arrangement			
Lives Alone	50.0%	50.0%	.390
Lives With Caregiver or Other	42.4%	57.6%	
n=128			
Locale of Elder's Residence			
Winnipeg	42.4%	57.6%	.015
Non-Winnipeg	63.8%	36.2%	
n=128			
Caregiver's Relationship to Elder			
Spouse	62.5%	37.5%	
Adult Child	49.3%	50.7%	.442
Other Relative	56.5%	43.5%	
n=128			

Bivariate Results
Characteristics of Caregivers Not Aware of PCH Respite Compared to All Other Reasons
Objective Stressors

	Not Aware	Other Reasons	p
Elder's Health (# of chronic conditions)			
Mean n=128	5.3	5.0	.411
Caregiver's Health (# of chronic conditions)			
Mean	2.8	2.2	
Mean Rank n=128	62.2	59.0	.116
Caregiver's Self Rated Health			
Poor Health/Not too Good	71.4%	28.6%	
Pretty Good/Very Good Health n=128	51.8%	48.2%	.163
Elder's # of ADL/IADL Limitations			
Mean	1.6	1.7	
Mean Rank n=128	64.6	64.4	.972
Elder's # of Basic ADL Limitations			
Mean	1.6	1.7	
Mean Rank n=128	64.6	64.4	.972
Elder's # of IADL Limitations			
Mean	9.4	8.5	
Mean Rank n=128	67.2	61.3	.370
Elder's Cognitive Status			
CIND	57.1%	42.9%	
Dementia n=128	49.0%	51.0%	.367
Elder's Depression			
No depressive symptoms	53.2%	46.8%	
Questionable depressive symptoms	69.2%	30.8%	
Presence of depressive symptoms n=128	51.5%	48.5%	.496
Problematic Behaviour of Elder			
Mean	7.5	10.1	
Mean Rank n=127	58.7	70.1	.078

Bivariate Results
Characteristics of Caregivers Not Aware of PCH Respite Compared to All Other Reasons
Subjective Stressors

	Not Aware	Other Reasons	p
Caregiver Burden			
Mean	14.6	17.8	
Mean Rank	61.1	67.4	.336
n=127			
Caregiver Depression			
Minimal Depressive Symptoms	56.0%	44.0%	
High Depressive Symptoms	42.1%	57.9%	.263
Mean Rank	69.8	58.2	
n=128			

Bivariate Results
Characteristics of Caregivers Not Aware of PCH Respite Compared to All Other Reasons
Moderators

	Not Aware	Other Reasons	p
Availability of Other Informal Caregivers			
Yes	50.7%	49.3%	
No	58.2%	41.8%	.400
n=128			
# of Other Informal Caregivers			
0	58.2%	41.8%	
1	51.4%	48.6%	
2	56.3%	43.8%	.763
≥3	45.5%	54.5%	
n=128			
Adequacy of Elder's Income			
With Some Difficulty	76.9%	23.1%	
Adequately/Very Well	50.5%	49.5%	.070
n=124			
Caregiver's Primary Income Source			
OAS and/or GIS	63.3%	36.7%	
Other Sources	50.0%	50.0%	.444
Paid Employment	50.0%	50.0%	
n=124			
Caregiver's Educational Level (years completed)			
Mean	9.9	12.1	.001
n=128			
Elder's Educational Level (years completed)			
Mean	7.3	7.1	.715
n=124			

Appendix L

Pearson Product Moment Correlation Matrix

	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.
1. elder's age	-											
2. cg's gender	-.029	-										
3. cg's marital status	-.280	.119	-									
4. living arrangement	.260	.007	.062	-								
5. locale of residence	.106	.182	.107	.105	-							
6. cg's self-rated health	.081	-.160	-.023	.142	.127	-						
7. # of ADL limitations	.252	-.027	.046	-.051	.057	-.096	-					
8. cognitive status	.131	-.005	.031	-.003	.220	-.019	.251	-				
9. caregiver burden	-.212	.099	.075	.000	.154	-.168	.134	.203	-			
10. availability of other cgs	.008	.010	.087	.263	.163	.152	-.087	.015	.081	-		
11. cg's education	.102	-.148	-.046	-.232	.329	.281	-.056	.234	.085	.190	-	
12. elder's education	-.029	-.127	-.060	-.128	.213	.259	.154	.128	.015	.034	.321	-