



HEALTH OF INFORMAL CAREGIVERS: EFFECTS OF GENDER, EMPLOYMENT, AND USE OF HOME CARE SERVICES

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EXECUTIVE SUMMARY

This report highlights findings from a study on the **health status of informal caregivers** and the impact of **gender, employment status, and home care service use** on their health. Informal caregivers included **family members and friends** who provided assistance to **older individuals** and who received no direct financial reimbursement for this assistance. The research questions were:

- (1) Are there gender differences in the health status of informal caregivers of elders?
- (2) Are employment status and home care service use associated with the health of the informal caregiver, when controlling for gender?
- (3) Do employment status and/or use of home care services predict the subsequent health status of the informal caregiver, when controlling for gender? Are changes in employment status and/or home care service use related to changes in health status?
- (4) What factors do female and male informal caregivers identify as impacting their health? To what extent are there gender differences in these factors?

Several **methods** were used to address these questions. Data from 322 caregiver-elder pairs interviewed for the Manitoba Study of Health and Aging (MSHA) in 1991/92 were extracted to explore the first two questions. The third question drew on information collected from the 155 pairs who were interviewed in 1991/92 and 1996/97 in the community. Three measures of health status were examined, specifically **self-rated health, depression, and caregiver burden**. Caregivers were selected for the MSHA on the basis of the elder's cognitive and physical functioning.

Focus groups/interviews were conducted with 30 informal caregivers to address the fourth research question. These caregivers were identified by service agencies or other caregivers. A workshop with 31 community service providers from 22 agencies/organizations was held to identify existing resources, challenges/barriers, and strategies/solutions to address issues raised by the informal caregivers.

Health of Informal Caregivers and Associated Factors: Findings from the MSHA

The 322 caregivers in the MSHA were relatively healthy in 1991/92. Forty-one percent rated their health as very good and 51% indicated it was pretty good. Only 14% showed signs of possible depression as measured by the well-established Center for Epidemiologic Studies Depression (CES-D) scale (Radloff, 1977). In addition, caregivers had relatively low levels of caregiver burden as measured by the Burden Interview (Zarit & Zarit, 1990).

The relationship of health with gender, employment status, and home care service use in 1991/92 varied depending on the dimension of health under consideration and whether the focus was on the 135 spouses, the 187 adult children, or both spouses and children. No consistent patterns emerged from the regression analyses that considered several factors at the same time. Selected statistically significant findings are highlighted here.

Gender. Husbands were more likely to have poorer self-rated health than wives. Daughters were more likely to have higher levels of burden than sons.

Employment Status. Employed adult children reported higher levels of burden than those not employed, suggesting that caregiving in combination with employment may be related to greater burden.

Home Care Service Use. Adult children who reported the use of at least one home care service such as homemaker/cleaning services, home-help for personal tasks, in-home nursing, home-delivered meals, day centre, day hospital, hospital respite, and nursing home respite tended to have higher levels of burden.

Other Factors Related to Health Status. Other factors that might be important for health status were also examined. The caregiver's provision of assistance with basic activities of daily living (ADLs) such as eating or bathing and with instrumental activities of daily living (IADLs) such as housekeeping or taking medications emerged as particularly important in relation to depression and caregiver burden although the results varied depending on whether spouses and adult children were studied separately or in combination. For example, caregivers who helped with ADLs were more likely to have

possible depression and to report higher levels of burden, when examining all caregivers and spouses but not adult children.

The elder's cognitive status was significantly associated with depression and caregiver burden. Individuals caring for older family members with cognitive impairment had a greater likelihood of depression and higher burden, particularly among spouses.

Subsequent Health Status and Changes in Health. The 155 caregivers interviewed in both 1991/92 and 1996/97 tended to remain healthy in 1996/97. Eighty-eight percent of these caregivers had no change in self-rated health, when considering very good or pretty good self-rated health in comparison to not too good/poor/very poor ratings. Eighty-two percent had no change in the likelihood of depression; 7% had possible depression in 1991/92 only and 11% did so in 1996/97 only. Caregiver burden increased significantly from 1991/92 to 1996/97 although it remained low overall.

Relatively few 1991/92 characteristics emerged as predictors of subsequent health status. Gender and home care service use were not significant for self-rated health, depression, or burden. Among adult children, being employed in 1991/92 was associated with higher burden in 1996/97. Other significant predictors for at least one health measure were the elder's cognitive status, caregivers providing assistance with IADLs, and caring for elders who received help with ADLs/IADLs from other informal caregivers.

Given the small numbers of caregivers with changes in self-rated health or depression, comparisons according to gender, employment status, and home care service use were not made. Female and male caregivers both had significant changes in burden. Among spouses, only wives had increased levels of burden. Among adult children, it was sons who had higher burden levels in 1996/97 than in 1991/92.

These findings from the MSHA should not be interpreted as indicating that there is little impact of caregiving on the health of informal caregivers. Unlike much of the caregiving research, the MSHA did not rely on agencies or organizations to identify caregivers. As a result, these caregivers may or may not have been providing levels of care comparable to individuals who have turned to the formal care system or support groups for assistance.

Discussions with Informal Caregivers on the Impact of Caregiving on Their Health

The focus groups/interviews provided an opportunity to discuss caregiving experiences and whether employment, use of health care services, or other factors influenced health and the ability to manage caregiving and other responsibilities. These caregivers were known to a service agency or voluntarily identified themselves as caregivers. Twelve themes relating to five conceptual areas (**caregiver's health, relationships with family and friends, independence, employment, and service utilization**) emerged. These themes cut across the experiences of female and male caregivers.

Some caregivers described **psychological, emotional, and physical health** changes they had experienced. These changes were not necessarily caused by caregiving but occurred during the time in which caregiving duties had been assumed in addition to usual responsibilities. Several caregivers spoke of a gradual process of social isolation as caregiving took a toll on **friendships** and relationships. The **availability of other family members** was not always viewed as supportive.

The caregivers discussed the frustration that was sometimes caused by the **elder's desire to remain independent**. The elder's perception of being able to function without support or denial of problems led to aggravation and a feeling of futility for some caregivers.

Employment was perceived as a beneficial mental and social activity by several caregivers although effects of caregiving on employment were identified. With regards to **service utilization**, there was a general consensus that resources were limited in availability, were difficult to discover and obtain, and frequently excluded the caregiver.

Strategies to Address Informal Caregivers' Issues

Community service providers were challenged to identify strategies to deal with these issues. Their suggestions related to **raising awareness** about caregiving, **enhancing communication** about available resources, developing innovative **transportation** initiatives, expanding **respite services**, providing **education and psychological/emotional support** to caregivers, and **adjusting bureaucratic systems** to promote collaboration across various systems.

Overall, although the findings cannot be generalized to all caregivers of older adults, the **diversity among informal caregivers** and the **complexity of the issues** they face were readily apparent. Each caregiver has unique situations and circumstances related to the caregiving experience. Family dynamics and history, values and beliefs regarding the role of family and the formal care system in providing assistance, financial circumstances, personalities of both the caregiver and the care receiver, and the nature of the caregiving network appear to influence the caregiving experience.

This study adds to a growing body of literature that calls for the development of policy that better recognizes the critical role of the informal caregiver. Recommendations for health policy and programming¹ include:

- Recommendation 1:** *A deliberate plan for increasing community awareness about resources for informal caregivers and elders needs to be formulated.*
- Recommendation 2:** *Community services must be directed to both the elders' and caregivers' needs.*
- Recommendation 3:** *Informal caregivers should be considered as team members and collaborators in the assessment and planning process with elders and community service providers.*
- Recommendation 4:** *Community resources for informal caregivers need to be more available, accessible, flexible, and responsive to caregivers' needs.*
- Recommendation 5:** *Greater collaboration across systems is needed to enhance understanding of caregiving issues and to initiate innovative strategies to deal with these issues.*

¹ Additional information on these recommendations is provided on pages 61-63.

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HEALTH OF INFORMAL CAREGIVERS: EFFECTS OF GENDER, EMPLOYMENT, AND USE OF HOME CARE SERVICES

Introduction

It is well recognized that labour force participation among women is increasing. At the same time, women are more likely to have the additional responsibility of being an informal caregiver for an older family member. Previous research has suggested that women assume caregiving without relinquishing their other duties and often experience stress and conflict when both employed and caring for their aging spouse or parent.

The **purpose** of this study was to examine the **health status of informal caregivers** and to assess the impact of the caregivers' **gender, employment status**, and use of **home care services** on their health. Of particular interest were differences between female and male caregivers. Informal caregivers included **family members and friends** who provided assistance to **older individuals** and who received no direct financial reimbursement for this assistance. The focus was on caregivers who helped an older family member or friend residing in the community rather than in institutional settings.

This **report** begins with a statement of the four research questions. A brief description of the study components follows. Project findings are then presented.

Research Questions

The study addressed the following research questions:

- (1) Are there **gender differences** in the **health status of informal caregivers** of elders?
- (2) Are **employment status and home care service use** associated with the **health** of the informal caregiver, when controlling for gender?

- (3) Do **employment status and/or use of home care services** predict the **subsequent health status** of the informal caregiver, when controlling for gender? Are changes in employment status and/or home care service use related to changes in health status?
- (4) What factors do female and male informal caregivers identify as **impacting their health**? To what extent are there gender differences in these factors?

Study Components

The project consisted of the following components: (1) an examination of the health of informal caregivers and associated factors; (2) discussions with informal caregivers regarding the impact of caregiving on their health; and, (3) the development of strategies to address issues raised by informal caregivers. Each component is briefly described here; additional information is provided in the Appendices. The study was approved by the Ethical Review Committee of the Faculty of Nursing, University of Manitoba (Appendix A).

Health of Informal Caregivers and Associated Factors

The first study component involved analysis of data from the **Manitoba Study of Health and Aging** (MSHA). Conducted by researchers at the University of Manitoba's Centre on Aging¹, this study began in 1991. Data were collected in 1991/92 and 1996/97 from interviews with older adults and their caregivers, clinical assessments, and extraction of Provincial Home Care data and Manitoba Health administrative data. The **inclusion** of caregivers for the MSHA was based on the **elders' cognitive and physical functioning**. In other words, caregivers in the MSHA cannot be considered as constituting a random sample of caregivers.

This report draws primarily on the information collected in 1991/92 and 1996/97 during in-person interviews conducted separately with elders and their caregivers (see Appendix B for details). Data from the 1991/92 study were used to examine gender

¹ Detailed information on the methodology is available for the 1991/92 study in a report entitled Manitoba Study of Health and Aging Final Report: Technical Section (MSHA Research Group, 1995) and for the 1996/97 study in a report entitled Follow-up to the Manitoba Study of Health and Aging (MSHA-2): Methodology (MSHA-2 Research Group, 1998).

differences in the 1991/92 health status of informal caregivers, and whether employment status and home care service use were associated with health, when gender was taken into account. Information from caregivers who participated in both 1991/92 and 1996/97 (referred to hereafter as the follow-up sample) was used to study whether gender, employment status, and/or the use of home care services were related to health status in 1996/97.

Three **criteria** were used to select the pairs of elders and caregivers for the analyses in this report. Specifically, caregiver-elder pairs were included in the analysis if, in 1991/92:

- (1) The elder was residing in the community;
- (2) The caregiver answered the questions related to their health and use of services; and,
- (3) The caregiver was a spouse or adult child.

The **final 1991/92 sample** consisted of **322 caregiver-elder pairs** (212 female caregivers, 110 male caregivers).

The **follow-up sample** was limited to caregiver-elder pairs where:

- (1) The elder lived in the community in 1991/92 and 1996/97;
- (2) The same caregiver completed an in-person interview in 1991/92 and 1996/97;
- (3) The cognitive status of the elder was known in 1996/97;
- (4) The caregiver answered the questions regarding their health and use of services in 1991/92 and 1996/97; and,
- (5) The caregiver was a spouse or adult child.

A total of **155 caregiver-elder pairs** were in the follow-up sample (97 female caregivers, 58 male caregivers).

The MSHA included a number of questions regarding caregivers' health status, employment status, use of home care services, and other factors that may be related to

the caregivers' health. The key measures of interest are briefly described below; Appendix B contains information on other factors.

Health Status. Self-rated health, the presence of depressive symptoms as measured by the Center for Epidemiologic Studies Depression (CES-D) scale (Radloff, 1977), and caregiver burden as measured by the Burden Interview (Zarit & Zarit, 1990) were examined (see Appendix C for details).

Employment Status. Comparisons were made between caregivers who were employed and those who were not employed. Distinctions between full-time and part-time employment were explored as appropriate.

Home Care Service Use. Use of home care services in the prior year included use of **homemaker/cleaning services** (e.g., cleaning, laundry, meal preparation); **home help with personal tasks** (e.g., bathing, dressing, grooming, toileting); **in-home nursing** (e.g., changing dressings, checking blood pressure, medications); **home-delivered meals** (e.g., Meals on Wheels); **day centre; day hospital; hospital respite**; and, **nursing home respite**. These services may have been obtained privately or through the publically-funded, province-wide Home Care program.

Discussions with Informal Caregivers

The second study component involved **focus groups** with **informal caregivers** (see Appendix D for details). The **purpose** was to encourage discussion about their caregiving experience and whether employment, use of home care services, or other factors influenced their health and the ability to manage caregiving and other responsibilities (Research Question #4).

The study team's community members were asked to identify caregivers who used their services. Caregivers themselves could provide the names of family or friends who were caring for older individuals. A **convenience sample** of caregivers was recruited, based on the following **selection criteria**:

- (1) Elders must be living in the community and not in institutional settings; and,
- (2) Caregivers must be friends or family members who were caring for an older adult and who considered themselves as caregivers.

Thirty caregivers participated in this component of the study. Twenty-six individuals (20 females, 6 males) attended one of eight focus groups between November 1999 and February 2000. Four caregivers (all female) were unable to attend a focus group and were interviewed separately in-person.

Open-ended **questions** were used to guide the discussions. In addition, caregivers were asked to complete a short self-administered questionnaire regarding selected demographic characteristics, self-rated health, the presence of depressive symptoms (Radloff, 1977), and caregiver burden (Zarit & Zarit, 1990) (see Appendix C for specific measures). This questionnaire was added after the first focus group session to ensure that consistent information on these topics was obtained.

Each session/interview was tape-recorded and the tapes were then transcribed verbatim. Several themes emerged from an analysis of the transcripts and are discussed in this report.

Strategies to Address Issues Raised by Informal Caregivers

The intent of the third study component was to inform **community service providers** of the study findings and to facilitate discussion about, and the development of, strategies that could address the issues facing caregivers (see Appendix E for details). The study team identified several agencies that serve well and frail seniors in the community. A letter inviting participation and asking for two representatives to attend the workshop was sent to each agency.

A half-day **workshop** was held on April 19, 2000 with 31 representatives from 22 agencies/organizations. It began with a presentation of selected study findings by the researchers and was followed by small-group discussions to identify **existing resources**, **challenges/barriers**, and **creative strategies/solutions** to deal with the issues. The

workshop concluded with a wrap-up session during which the groups shared highlights from their discussions.

The information from the workshop was summarized and distributed to each participant. A synthesis of the workshop discussions forms the basis for an examination of possible strategies to address issues raised by informal caregivers.

Remainder of the Report

Attention now turns to selected study findings. Factors associated with the health of informal caregivers are examined first, followed by a discussion of the issues raised by caregivers, and the strategies identified by representatives from health and social service agencies to address these issues.

**HEALTH OF INFORMAL CAREGIVERS
AND ASSOCIATED FACTORS**

HEALTH OF INFORMAL CAREGIVERS AND ASSOCIATED FACTORS

The first three research questions relate to the health of informal caregivers and factors associated with their health. These questions are:

- (1) Are there **gender differences** in the **health status of informal caregivers** of elders?
- (2) Are **employment status and home care service use** associated with the **health** of the informal caregiver, when controlling for gender?
- (3) Do **employment status and/or use of home care services** predict the **subsequent health status** of the informal caregiver, when controlling for gender? Are changes in employment status and/or home care service use related to changes in health status?

Data from the Manitoba Study of Health and Aging (MSHA) were used to address these questions. A brief description of **selected characteristics** of the caregivers and the elders for whom they provided care is first presented. Attention then turns to the health of the caregiver and factors associated with their health.

Characteristics of Caregivers and Elders

The **1991/92 MSHA sample** consisted of **322 caregiver-elder pairs**. An examination of the caregivers' and elders' characteristics reveals the diversity in these pairs. Selected characteristics are summarized in Table 1. Additional information, including a comparison according to the caregiver's gender, is available in Appendix B.

About two-thirds of the caregivers were **female**. There were 187 pairs where the caregiver was the elder's **adult child** (58%) (hereafter referred to as **adult children**) and 135 pairs where the caregiver was the elder's **spouse** (42%) (hereafter referred to as **spouses**).

Table 1

PROFILE OF THE 322 CAREGIVER-ELDER PAIRS: 1991/92 SAMPLE¹

Caregivers' Characteristics

- ◆ 66% of the caregivers were **female**.
- ◆ 58% were the elders' **children** and 42% were their **spouses**.
- ◆ Their **ages** ranged from 26 to 86 years, with an average age of 58.
- ◆ 44% were **employed**.
- ◆ 29% had more than 12 years of **education**.
- ◆ 85% were **married**.
- ◆ 16% provided assistance with at least one **basic activity of daily living** (ADL) such as eating or bathing.
- ◆ 75% assisted with at least one **instrumental activity of daily living** (IADL) such as housekeeping or taking medications.
- ◆ 40% reported the use of at least one **home care service** such as homemaker/cleaning services or home-delivered meals.

Elders' Characteristics

- ◆ 59% of the elders were **female**.
- ◆ Their **ages** ranged from 65 to 97 years, with an average age of 77.
- ◆ 52% lived in **Winnipeg**.
- ◆ 41% **lived alone**.
- ◆ 31% were **cognitively impaired**.
- ◆ 23% required in-person assistance with at least one **basic activity of daily living** (ADL).
- ◆ 75% required in-person assistance with at least one **instrumental activity of daily living** (IADL).

¹ Additional information is available in Appendix B. Tables B-7 to B-9 focus on the caregivers' characteristics; Tables B-10 and B-11 provide details on the elders' characteristics. Statistically significant differences according to gender are reported in the Appendix.

1991/92 Health Status

In this study, **self-rated health**, **depression**, and **caregiver burden** were examined. The findings are highlighted here; additional information is found in Appendix F for self-rated health, Appendix G for depression, and Appendix H for caregiver burden.

In 1991/92, 41% of the caregivers rated their health as **very good** while 51% indicated that their health was pretty good.² Less frequent were responses of not too good (7%), poor (<1%), or very poor (<1%). Only 14% of the 322 caregivers showed signs of **possible depression** as measured by the Center for Epidemiologic Studies Depression (CES-D) scale (Radloff, 1977).³

The caregiver's feelings of **burden** were assessed using the Burden Interview (Zarit & Zarit, 1990).⁴ Scores on the Burden Interview ranged from 0 to 62 out of a possible 88, with a mean of 11. This indicates relatively low levels of burden among this sample of caregivers. Norms or cut-off points have not been established for this scale and thus it is not possible to identify a group of caregivers who can be considered as severely burdened. Fifty-five percent of the caregivers indicated that they at least sometimes felt that the elder was dependent upon them; 37% noted that at least sometimes they felt that the elder seemed to expect them to take care of him/her as if the caregiver was the only one upon whom s/he could depend. Only 8% felt that at least sometimes their health had suffered because of their involvement with the elder.

² In the MSHA, caregivers were asked "How would you rate your health these days? Would you say your health is very good, pretty good, not too good, poor, or very poor?"

³ The presence of depressive symptomatology was measured in the MSHA by the Center for Epidemiologic Studies Depression (CES-D) scale (Radloff, 1977). Respondents are asked how frequently 20 different statements describe their feelings and behaviours in the past week (rarely or none of the time, some or a little of the time, occasionally or a moderate amount of the time, most or all of the time). Examples of statements are: "I was happy"; "I talked less than usual"; "I felt lonely"; and "I enjoyed life". Item scores are summed to obtain an overall depression score ranging from 0 to 60. Scores of 16 or more are commonly used to indicate possible depression (McDowell & Newell, 1996). Appendix C provides additional information on this measure.

⁴ The Burden Interview consists of 22 statements to which respondents are asked to indicate the frequency of their feelings about caring for another person (Zarit & Zarit, 1990). Examples are: "Do you feel that because of the time you spend with (name of care receiver) that you don't have enough time for yourself?"; "Do you feel your health has suffered because of your involvement with (name of care receiver)?"; and, "Do you feel you should be doing more for (name of care receiver)?". An overall burden score was obtained by summing the responses of all 22 items. Possible scores range from 0 to 88. Appendix C provides additional information on this measure.

Factors Associated with 1991/92 Health Status

Several factors that may be associated with health status were examined. Attention focuses first on gender differences as well as differences according to employment status and home care service use. Consideration is then given to these characteristics in combination with other factors that may be related to the health of informal caregivers. Comparisons were made for all caregivers, spouses only, and adult children only. The findings are highlighted here; more detailed information appears in the appendices (Appendix F - self-rated health; Appendix G - depression; Appendix H - caregiver burden).

Gender Differences

When examining only gender and health status, gender differences were evident for self-rated health and caregiver burden. As highlighted in Table 2, husbands were more likely to have poorer self-rated health than wives who were caring for their spouses. Female caregivers reported higher levels of caregiver burden than their male counterparts but this was evident only when considering all caregivers or adult children only. There were no gender differences in depression.

Employment Status

Comparisons according to employment status were limited to the 187 adult children as only 14 spouses were employed. Among these 187 caregivers, 126 (67%) were employed. There were no statistically significant differences in self-rated health, depression, or caregiver burden between employed and unemployed adult children.

Table 2			
1991/92 HEALTH STATUS WITH GENDER, EMPLOYMENT STATUS, AND HOME CARE SERVICE USE			
Characteristic and Sample	Poorer Self-rated Health	More Likely to Have Depression	Higher Caregiver Burden
Gender			
All caregivers	---	---	Females
Spouses only	Males	---	---
Adult children only	---	---	Females
Employment Status			
All caregivers	N/A	N/A	N/A
Spouses only	N/A	N/A	N/A
Adult children only	---	---	---
Home Care Service Use			
All caregivers	---	---	Users
Spouses only	---	---	Users
Adult children only	---	---	Users

--- Not statistically significant at $p < .05$.

N/A Characteristic was not examined for the specific sample of caregivers.

Note: Additional information is available in Appendix F for self-rated health, Appendix G for depression and Appendix H for caregiver burden.

Home Care Service Use

Caregivers who reported the use of at least one home care service did not differ from those who did not use services in terms of their self-rated health or the likelihood of depression. However, service users reported higher levels of caregiver burden than those not using these services. This was evident when considering all caregivers, spouses only, and adult children only.

Gender, Employment Status, Home Care Service Use, and Other Factors

In addition to considering gender, employment status, and home care service use separately, it is important to examine these characteristics in combination with other factors that may be related to the health of informal caregivers. These other characteristics included the relationship of the caregiver and elder, the elders' cognitive status (cognitively intact vs. cognitively impaired), the caregivers' provision of assistance with ADLs and IADLs, and the provision of assistance with ADLs/IADLs from other informal caregivers.⁵ In addition, self-rated health was considered when examining depression and caregiver burden. Regression analyses allowed for these characteristics to be studied together.⁶ The results are discussed separately for all caregivers, spouses only, and adult children only as it was not possible to include all characteristics for each group.

Self-rated Health. Considering first all 322 caregivers, spouses tended to have poorer ratings of their health than did adult children (Table 3). None of the other characteristics emerged as significant. Among the **spouses**, only gender was significant; males tended to report poorer self-rated health than females. Among the **adult children**, no characteristics were statistically significant.

Depression. Gender, employment status, and home care service use were not associated with the likelihood of depression, irrespective of whether the sample consisted of all caregivers, spouses only, or adult children only (Table 3). When examining all caregivers, caregivers with poorer self-rated health, those assisting with ADLs, and those caring for elders with cognitive impairment were more likely to have possible depression.

Among the **spouses**, caregivers who had poorer self-rated health, those who provided assistance with at least one ADL, those who had not provided assistance with at least one IADL, and those caring for elders who did not receive assistance with ADLs/IADLs from other informal caregivers were more likely to have possible depression. Once again, caregivers caring for elders with cognitive impairment were more likely to experience possible depression.

⁵ See Appendix B for information on the measurement of these characteristics.

⁶ Statistical tables are presented in Appendix F (Tables F-4 to F-6) for self-rated health, Appendix G (Tables G-4 to G-6) for depression and Appendix H (Tables H-7 to H-9) for caregiver burden.

Table 3

CHARACTERISTICS ASSOCIATED WITH 1991/92 HEALTH STATUS

Characteristic	Poorer Self-rated Health			More Likely to Have Depression			Higher Caregiver Burden		
	All Caregivers	Spouses Only	Adult Children Only	All Caregivers	Spouses Only	Adult Children Only	All Caregivers	Spouses Only	Adult Children Only
Caregiver's Gender	---	Males	---	---	---	---	---	---	Females
Employment status	N/A	N/A	---	N/A	N/A	---	N/A	N/A	Employed
Use of home care services	---	---	---	---	---	---	Users	---	Users
Spouses vs. adult children	Spouses	N/A	N/A	---	N/A	N/A	Children	N/A	N/A
Self-rated health	N/A	N/A	N/A	Poorer	Poorer	Poorer	---	---	---
Caregiver assistance with ADLs	---	---	---	Provides help	Provides help	---	Provides help	Provides help	---
Caregiver assistance with IADLs	---	---	---	---	Does not provide	---	Provides help	---	Provides help
Other informal caregivers' assistance with ADLs/IADLs	---	---	---	---	Does not provide	---	---	---	---
Elder's cognitive status	---	---	---	Impaired	Impaired	---	Impaired	Impaired	---

--- Not statistically significant at $p < .05$.

N/A Characteristic was not examined for the specific sample of caregivers.

Note: Based on regression analyses. Statistical tables are presented in Appendix F (Tables F-4 to F-6) for self-rated health, Appendix G (Tables G-4 to G-6) for depression and Appendix H (Tables H-7 to H-9) for caregiver burden.

Among the **adult children**, the caregivers' self-rated health was the only characteristic that emerged as significant. Adult children with poorer self-rated health were more likely to have possible depression than those with better ratings of their health.

Caregiver Burden. Turning first to all 322 caregivers, caregivers who reported the use of at least one home care service, adult children, those who provided assistance with at least one ADL, those who provided assistance with at least one IADL, and those caring for an elder with cognitive impairment reported significantly higher levels of caregiver burden (Table 3).

Among the 135 **spouses**, provision of assistance with ADLs and cognitive status of the elder were the only two factors that emerged as significant. Among the 187 **adult children**, daughters, those using at least one home care service, those who were currently employed, and those who provided assistance with at least one IADL reported significantly higher levels of caregiver burden.

1996/97 Health Status and Changes from 1991/92 to 1996/97

Attention now turns to 1996/97 health status and changes in health status between 1991/92 and 1996/97. Of interest was whether **employment status and/or use of home care services** predicted **subsequent health status** of the informal caregiver, when controlling for gender, and whether changes in employment status and/or home care service use were related to changes in health.

Of the 322 caregiver-elder pairs in the 1991/92 sample, **155 pairs** comprised the follow-up sample. A comparison of the characteristics of these 155 caregivers and the 167 who were not in the follow-up sample is included in Appendix B. A brief description of the 1991/92 characteristics of the follow-up sample is presented here, followed by a discussion of self-rated health, depression, and caregiver burden in 1996/97.

Selected 1991/92 Characteristics of the Follow-up Sample

A summary of selected 1991/92 characteristics is presented in Table 4; additional information appears in Appendix B.

Table 4	
PROFILE OF THE 155 CAREGIVER-ELDER PAIRS: FOLLOW-UP SAMPLE¹	
1991/92 Caregivers' Characteristics	
◆	63% of the caregivers were female .
◆	59% were the elders' children and 41% were their spouses .
◆	Their ages ranged from 27 to 81 years, with an average age of 56.
◆	51% were employed .
◆	31% had more than 12 years of education .
◆	86% were married .
◆	12% provided assistance with at least one basic activity of daily living (ADL) such as eating or bathing.
◆	68% assisted with at least one instrumental activity of daily living (IADL) such as housekeeping or taking medications.
◆	32% reported the use of at least one home care service such as homemaker/cleaning services or home-delivered meals.
1991/92 Elders' Characteristics	
◆	61% of the elders were female .
◆	Their ages ranged from 65 to 94 years, with an average age of 75.
◆	56% lived in Winnipeg .
◆	39% lived alone .
◆	17% were cognitively impaired .
◆	14% required in-person assistance with at least one basic activity of daily living (ADL).
◆	68% required in-person assistance with at least one instrumental activity of daily living (IADL).

¹ Additional information is available in Appendix B. Tables B-12 to B-14 focus on the caregivers' characteristics; Tables B-15 and B-16 provide details on the elders' characteristics. Statistically significant differences according to gender are reported in the Appendix.

Health Status of the Follow-up Sample

In 1996/97, 47% of the 155 caregivers in the follow-up sample rated their health as **very good** while 44% indicated that their health was pretty good. Less frequent were responses of not too good (8%) or poor (2%). Only 15% of the 155 caregivers showed signs of **possible depression** as measured by the Center for Epidemiologic Studies Depression (CES-D) scale (Radloff, 1977). The caregiver's feelings of **burden** once again were assessed using the Burden Interview (Zarit & Zarit, 1990). Scores on the Burden Interview ranged from 0 to 52 out of a possible 88, with a mean of 12.

Factors Predicting 1996/97 Health Status

The possibility that gender, employment status, home care service use, and other characteristics such as the relationship of the caregiver and elder, elders' cognitive status (cognitively intact vs. cognitively impaired), the caregivers' provision of assistance with ADLs and IADLs, and the provision of assistance with ADLs/IADLs from other informal caregivers in 1991/92 predicted health status in 1996/97 was explored.⁷ In addition, self-rated health was considered when examining depression and caregiver burden. Regression analyses allowed for these characteristics to be studied together.⁸

Self-rated Health. Considering first all 155 caregivers, spouses tended to have poorer ratings of their health in 1996/97 than did adult children. None of the other characteristics emerged as significant predictors. Among the **spouses**, only the elders' cognitive status in 1991/92 was significant; caring for an elder with cognitive impairment in 1991/92 was predictive of poorer self-rated health in 1996/97. Among the **adult children**, no characteristics were statistically significant.

⁷ See Appendix B for information on the measurement of these characteristics.

⁸ Statistical tables are presented in Appendix F (Tables F-8 to F-10) for self-rated health, Appendix G (Tables G-8 to G-10) for depression and Appendix H (Tables H-11 to H-13) for caregiver burden.

Depression. When examining all caregivers, only poorer self-rated health in 1991/92 was related to subsequent possible depression. None of the 1991/92 characteristics were significant when considering the spouses only or the adult children only.

Caregiver Burden. Turning first to all 155 caregivers, adult children, caregivers who were providing IADL assistance, those whose elder had help with ADLs/IADLs from other informal caregivers, and those caring for cognitively impaired elders in 1991/92 were significantly more likely to report higher levels of burden in 1996/97. Among the **spouses**, caring for a cognitively impaired elder in 1991/92 was predictive of higher levels of burden in 1996/97. Among **adult children**, being employed, providing assistance with IADLs, and caring for an elder with cognitive impairment in 1991/92 was associated with higher burden in 1996/97.

Change in Health Status from 1991/92 to 1996/97

Relatively little **change** in health status as measured by self-rated health, depression, and caregiver burden was evident among this follow-up sample of caregivers. When considering very good or pretty good self-rated health in comparison to not too good/poor/very poor ratings, 88% of the 155 caregivers had no change in their self-rated health. There was no change in the likelihood of depression for 82% of the caregivers; 7% had possible depression in 1991/92 only and 11% did so in 1996/97 only.

Caregiver burden levels increased significantly from 1991/92 to 1996/97 although burden remained relatively low overall. There were significant differences in the 1991/92 and 1996/97 levels among both female and male caregivers when considering all caregivers. Among the **spouses**, only wives had increased levels of burden. Among **adult children**, it was sons who had higher burden levels in 1996/97 than in 1991/92.

Given the small number of caregivers who had changes in self-rated health or depression, comparisons according to changes in employment status and home care service use were not made. In terms of burden, caregivers who were employed in both

1991/92 and 1996/97 and those who were unemployed at both times had significantly higher burden levels in 1996/97 than they did in 1991/92. There were no differences in the burden of caregivers with a change in employment status. Caregivers who reported no change or a decreased number of services had significantly higher levels of caregiver burden in 1996/97 than they did in 1991/92. The burden levels of caregivers who increased the number of services did not change significantly from 1991/92 to 1996/97.

Summary

The importance of exploring various dimensions of health and studying different groups of caregivers is evident from these findings. The relationship between gender, employment status, and home care service use and the health of individuals caring for older family members varies depending on whether one is considering self-rated health, depression, or caregiver burden and whether the focus is on spouses, adult children, or both spouses and children.

In answer to the first research question, “*Are there gender differences in the health status of informal caregivers of elders?*”, husbands were more likely to have poorer self-rated health than wives. Daughters were more likely to have higher levels of burden than sons. No differences in depression were evident.

With regard to the second research question, “*Are employment status and home care service use associated with the health of the informal caregiver, when controlling for gender?*”, employment status and home care service use emerged as important only when considering caregiver burden. Employed adult children reported higher levels of burden than those not employed when a number of characteristics were taken into account. This suggests that caregiving in combination with employment may result in greater burden. However, caregivers in the MSHA had relatively low levels of burden overall.

Home care service use was associated with burden for adult children but not for spouses. Adult children who reported using at least one home care service tended to have higher burden levels. This does not mean that service use has led to either increased or decreased levels of burden, that high levels of burden have resulted in the

use of services, or that services are only used when the burden of caregiving gets heavier. It may be that the care needs of the elder are such that even with formal services use, the burden levels are higher. Alternatively, as discussed in the next section, negotiating the health care system can be a challenge and a source of frustration for some caregivers. Adult children, particular daughters, are more likely to find themselves with multiple demands associated with their own family and caring for older parents which may translate into higher levels of burden.

In addition to gender, employment status, and home care service use, several other factors were examined in relation to the health of these informal caregivers. The provision of assistance with either ADLs or IADLs emerged as particularly important in relation to the likelihood of depression and caregiver burden although the results varied depending on whether spouses and adult children were studied separately or in combination. For example, caregivers who helped with ADLs were more likely to have possible depression and to report higher levels of caregiver burden, when considering all caregivers and spouses only.

Individuals caring for an older family member with cognitive impairment had a greater likelihood of possible depression and caregiver burden, particularly among spouses. Cognitively impaired family members place demands on these caregivers that may not be experienced by those assisting elders who are physically frail but cognitively intact. Further research regarding the differences in the caregiving situations according to the cognitive status of older family members is needed.

The third research question was *“Do employment status and/or use of home care services predict the subsequent health status of the informal caregiver, when controlling for gender? Are changes in employment status and/or home care service use related to changes in health status?”* Neither gender nor home care service use in 1991/92 emerged as significant predictors of health status in 1996/97. Employment status predicted subsequent levels of caregiver burden only among the adult children. The 1991/92 cognitive status of the older family members was much more likely to be a predictor, particularly for caregiver burden. Changes in health status as measured here were infrequent among the caregivers who were interviewed in both 1991/92 and 1996/97, thereby making it difficult to assess whether changes in employment status and/or home care service use were related to changes in health status.

Overall, the findings from this component of the study illustrate the diversity among caregivers. Gender differences in the health of informal caregivers exist but there is no consistent pattern across the various dimensions of health or the various types of caregivers. Employment status was not a particularly strong factor and home care service use was associated primarily with higher levels of caregiver burden. The extent to which these findings are generalizable to all individuals caring for an older family member is difficult to assess. Unlike much of the caregiving research, the MSHA did not rely on agencies or organizations to identify caregivers. Rather caregivers were selected based on the cognitive and physical functioning of a random sample of older adults. As a result, these caregivers may or may not be providing levels of care comparable to individuals who have turned to the formal care system or support groups for assistance.

**DISCUSSIONS WITH
INFORMAL CAREGIVERS
ON THE IMPACT OF CAREGIVING
ON THEIR HEALTH**

DISCUSSIONS WITH INFORMAL CAREGIVERS ON THE IMPACT OF CAREGIVING ON THEIR HEALTH

The second component of the project involved **discussions with informal caregivers** about their caregiving experience and whether employment, use of home care services or other factors influenced their health and their ability to manage caregiving and other responsibilities. This addresses the fourth research question which was:

- (4) What factors do female and male informal caregivers identify as **impacting their health**? To what extent are there gender differences in these factors?

The data are from focus groups/interviews with 30 informal caregivers (see Appendix D for details). A total of 12 themes emerged from the data. These themes corresponded to five conceptual areas: **caregiver's health; relationships with family and friends; independence; employment;** and, **service utilization**. Prior to discussing these themes, a brief description of the characteristics of the caregivers and the elders for whom they provided care is presented.⁹

Characteristics of Caregivers and Elders

Selected characteristics of the 30 caregivers (24 females, 6 males) and the elders are highlighted in Table 5. Additional information is provided in Appendix D.

Male caregivers tended to be older than female caregivers, with median ages of 71 and 57 respectively. Nine of the 11 employed caregivers were female. The length of time spent caregiving ranged from one to 240 months for female caregivers and from 11 to 168 months for male caregivers. In terms of health status, gender differences were not apparent for self-rated health or depression. Female caregivers did, however, tend to have higher levels of caregiver burden.

⁹ Selected highlights from this component of the study have been prepared and distributed to the 30 informal caregivers (see Appendix I).

Table 5

PROFILE OF THE 30 FOCUS GROUP/INTERVIEW PARTICIPANTS¹

- ◆ 24 of the 30 caregivers were **female**.
- ◆ 14 caregivers were **spouses**, 13 were the **older adults' children**, two were **other family members**, and one was a **friend**.
- ◆ Their **ages** ranged from 38 to 88 years, with a median age of 59.
- ◆ 11 were **employed**.
- ◆ 18 **lived with** the elder.
- ◆ 19 reported the use of at least one service from the provincially-funded Home Care program; 6 noted the use of **private services**.
- ◆ 8 of 25 caregivers rated their **health** as very good.
- ◆ 9 out of 23 caregivers reported possible **depression**.
- ◆ 23 caregivers answered the questions on **caregiver burden**. Their average score was 32 out of a possible 88.
- ◆ 25 caregivers were **providing assistance** to one older adult; 5 were caring for two older individuals.
- ◆ 19 of the 35 older adults they assisted were **female**.
- ◆ The older adults' **ages** ranged from 60 to 94 years, with a median age of 78.
- ◆ Based on the caregivers' reports, 13 of the older adults had some form of **cognitive impairment**.

¹ Additional information is available in Appendix D. Tables D-1, D-3, D-4, and D-5 focus on the caregivers' characteristics. Table D-2 provides details on the elders' characteristics. Differences according to gender are reported in the Appendix.

Caregiver's Health

The first conceptual area related to the **caregiver's health**. Some caregivers described psychological, emotional, and physical changes they experienced over the duration of the caregiving period. The changes were not necessarily caused by caregiving but occurred during the time in which they had assumed caregiving duties in addition to their usual responsibilities.

The following three **themes** were identified in relation to the caregiver's health:

- *The health of the caregiver deteriorated during the caregiving experience;*
- *Caregiving places a psychological toll on the caregiver, and,*
- *Never able to forget about caregiving responsibilities: Constantly in the back of their minds.*

Each theme is briefly discussed here.

The Health of the Caregiver Deteriorated During the Caregiving Experience

Fourteen of the 30 caregivers stated that their health worsened during the caregiving period. Of these, eight were caring for an elder with cognitive impairment. Two caregivers did not think caregiving affected their health. The remaining 14 did not explicitly discuss the effect of caregiving on their health.

Caregivers identified both physical and emotional symptoms as responses to the elder's behaviour or care needs, such as sleeplessness, crying episodes, and feeling fatigued. Physical symptoms such as weight gain as a means of coping with the stress, exacerbation of arthritis symptoms, gastric ulcer pain, and sore joints/muscles from the physical care they provided were also described. A wife caring for her husband who has difficulty sleeping explained:

He has problems at night sleeping and, of course, that keeps me awake. I tried sleeping in the other room and forgot that I couldn't sleep because I wasn't in that room; I was worried that I wouldn't hear him.

A caregiver whose husband has cognitive impairment said:

I got these crying jags and that's why I thought maybe things were getting a little hard for me.

The fatigue from caregiving and other responsibilities were described by several caregivers. A daughter who had been caring for her mother and father for less than one year commented:

I've only been doing this for a short while. But I'm already tired, so who knows how long.

A daughter employed part-time and caring for her mother with Alzheimer's disease revealed:

And I was so exhausted for a couple of years that I would come home and go to bed at 6:00 at night and get up in the morning at 6:00 --- twelve hours.

A spouse described her fatigue when caring for her husband with dementia as follows:

Some days I've been so tired, I just sit in my lazyboy and read and doze all day almost.

Caregiving Places a Psychological Toll on the Caregiver

Some caregivers identified psychological problems they experienced. Some were on anti-depressants but were unsure whether the caregiving situation specifically resulted in their depression. They did, however, view caregiving as a contributing factor in conjunction with other life events, such as a change of employment, financial troubles, personal health problems, or marital difficulties. A caregiver who was caring for her cognitively impaired husband confessed:

I got up in the morning and I said, 'Why not take it all? I've got the pills and why not just take them all?'

She began to see a psychiatrist shortly after this critical point.

Another caregiver described how caring for her parents coupled with other responsibilities led to a crisis point, stating:

Sometimes it gets to me. Like, I would say five years ago, I can honestly say and I admit it, I was close to a nervous breakdown.

This caregiver dealt with this by discussing her feelings with her physician every month for an extended period.

Other caregivers spoke of obtaining prescriptions for depression/anxiety or taking more prescription medications during the caregiving period. They were unsure whether their medication practices were solely related to the caregiving but identified caregiving as an issue affecting their ability to manage.

Never Able to Forget About Caregiving Responsibilities: Constantly in the Back of Their Minds

A feeling commonly expressed by caregivers was the constant responsibility they felt for their family member or friend. This sense of responsibility never left them, even when a hired worker was with the elder while the caregiver was at work or taking a break. Caregivers spoke about how mentally they were not able to obtain relief and were always feeling anxious or concerned about safety or health. One caregiver who was providing care for her mother with cognitive impairment described this as follows:

*You always have this thing hanging over your head. How is it today?
What's going to happen today?*

Another caregiver described her caregiving situation with her parents as:

*I feel responsible for them that I can never quite get them out of my mind.
I'm always kind of on-call for them.*

A wife caring for her husband who was not cognitively impaired stated "I don't think there is a break."

This emotional tension generally persisted no matter what the caregivers were doing. It sometimes led to actions initiated by the caregiver out of an emotional exaggeration or anxiety. A daughter who provided care to her cognitively impaired mother had a second home outside Winnipeg. She commented:

I can't tell you how many times we had to drive back the 60 miles, either she didn't put the phone right on the cradle so the line is busy all the time and '... did she fall? Or did she pull the phone off the hook? Or what was happening?'

Overall, caregivers performed multiple roles while caring for a family member or friend. The multiple demands had psychological, physical, and emotional health consequences for several caregivers. Caregivers frequently expressed experiencing a constant state of tension, whether or not they were physically with the elder.

Relationships with Family and Friends

*The second conceptual area was **relationships with family and friends**. The majority of caregivers spoke of different ways caregiving took a toll on their friendships and their relationships with others. Some spoke of a gradual process of losing ties with other people because of the time caregiving took and the energy it demanded. The availability of other family members was not necessarily seen as supportive of the caregiver.*

Two themes pertaining to relationships with family and friends were identified:

- Insidious loss of social ties for the caregiver; and,*
- Availability of support is not always synonymous with supportiveness.*

Insidious Loss of Social Ties for the Caregiver

Most caregivers spoke of different ways in which caregiving hindered them from maintaining ties with friends. The actual provision of care as well as the time and energy that caregiving consumed were mentioned as causes for this insidious process. A spouse who was employed part-time described it as follows:

It's a gradual isolation. Your life and part of your activities and part of who you are, get dropped one by one. And it's because it's too much of an effort...It's something in the back of your head, you're very aware of it at some level. And then one day you wake up and realize it's happening to me, you know, even when you think that you're ahead of it.

A married caregiver caring for her parents stated:

We must arrange our lives to ensure someone who can be trusted is with my parents. Sometimes it is hard, like, my husband and I, we are never able to get away. We never went on a holiday for three years.

Another caregiver providing care to her parents referred to the changes in her friendships:

It's causing a lot of other problems too. I would say my personal relationships. I don't have time for my friends....I'm so tired when I have a moment to myself, the last thing I want to do is be on the phone talking and I'm just really starting to ignore people.

The loss of social ties was also influenced by the planning and amount of energy that had to be expended in order to go anywhere.

Your friends go to the ball game but you don't because of how far it is, you don't know where to park and where you're going to walk and what you're going to do.

A recently retired female caregiver caring for her cognitively impaired husband referred to the advanced planning that is needed in order to obtain respite services:

You have to arrange it [to go out] quite a long ways ahead. So I had this November booked back in September.

The caregivers also remarked on how former friends of their family member slowly refrained from visiting or telephoning them. A daughter caring for her mother used the analogy of a divorce:

It's like when people divorce. When people are that age, they get frightened, '... that could happen to me.' And they don't know how to handle it, so they don't come.

Availability of Support Is Not Always Synonymous with Supportiveness

Having family members available did not necessarily mean they assisted the caregiver in the provision of care nor did it mean their 'assistance' was considered helpful by the caregiver. All focus groups discussed the types of assistance caregivers received from family members or friends. In most cases, the caregivers had at least one family member who lived nearby or could be reached by telephone for advice or assistance.

'Assistance' could take different forms, including listening to the caregiver about their concerns, actual assistance in problem-solving, helping with tasks or visiting the elder.

Caregivers perceived the role and responsibilities of other family members or friends in the caregiving situation in several different ways. Some caregivers had mutually arrived at a sharing of caregiving tasks with other family members or friends. An adult son spoke positively about the caregiving situation and how the family worked together in keeping his mother at home.

So we would just do her shopping for her and things like that. And I have a sister and brother. We all take her out once in awhile, take her home for a day. We [son and his wife] are doing, I would say, close to half of it. My sister does a lot too.

A daughter-in-law who provided support to her husband's parents also spoke about the sharing of responsibility, stating:

There is a really good rapport amongst the children, like the sons and daughters-in-law, so I don't feel that I'm alone in the situation. There is a sharing of responsibility that makes it a lot easier.

In other caregiving situations, caregivers expressed frustration and fatigue at being the sole caregiver while other family members remained uninvolved. The caregiver may or may not have requested assistance from other family members. These family members may not have offered their help or may not have provided assistance when asked. A daughter explained the lack of assistance she received from her brother in the care of their parents:

[Redacted text]

I have a brother but you would never know he was available or around. He doesn't even phone them to see how they're doing. It's a rare occurrence. He's wrapped up with his own family and there's always an excuse.

In another situation, a daughter providing care to her mother felt overwhelmed by the situation but had not asked for help. Unexpectedly, her own daughter spontaneously assumed the task of cleaning her grandmother's house. The caregiver discussed how she felt emotionally relieved by this assistance and indicated that she told her daughter:

You're making me feel so good. You've taken such a weight off my shoulders.

A third perspective on the role of other family members in caregiving was also evident in the discussions. Some caregivers did not expect other family members, such as grandchildren or their spouse, to assist them in caregiving. They explained that these family members had their own lives and responsibilities and therefore should not be called upon for assistance. Any assistance they could provide was perceived to be thoughtful and considerate. Socialization or visiting with the older adult were seen as appropriate activities rather than providing transportation to appointments, personal care, or cleaning. A female caregiver caring for her husband spoke of the perceived role her children should play:

My daughter and her husband, they work, they've got their house to run. And I don't think you put that onto your kids.

Overall, the relationships between the caregivers and their family and friends were frequently identified as key sources of strength that influenced their ability to manage their caregiving and other responsibilities. Caregivers spoke of the loss of social contacts and friendships that took place over time due to the progressive amount of time caregiving

consumed and the energy it expended. Caregivers had varying opinions of the roles family members should or do play in assisting them with caregiving.

Independence

The third conceptual area related to **independence**. The theme focused on the elder's desire for independence, despite their cognitive and functional limitations.

Elder's Desire for Independence Influences Caregiver Stress

Caregivers caring for elders with and without cognitive impairment described situations in which the elder insisted upon maintaining their independence despite safety concerns or the caregiver's protests. Several caregivers of elders who were not cognitively impaired spoke of ways in which the elder resisted using safety equipment or refused to use services that would assist themselves or the caregiver in managing in the home. A daughter described her mother as fiercely independent, commenting:

So, under protest, she got a walker. It's sitting folded up behind her T.V. covered with a blanket. She also refuses to use a cane. She's very wobbly and for a long time, I would grab her arm when we were walking, and she would grab it away.

A daughter who was caring for her mother and father spoke of her mother's reluctance to receive her help or advice. The daughter was afraid that her mother would hurt herself when lifting her husband who was totally dependent upon others for his care. She stated:

But old people say, 'Don't teach me, I know what I'm doing.' But mom, we know how hard it is to lift people.

In one focus group, two participants discussed their parents' insistence that everything was fine, despite the caregivers' perceptions of the failing cognitive and physical processes. One explained:

They do this nebulous kind of talking. I came to the conclusion they were so terrified of being separated that they would cover up for each other.

The elders' desire to remain independent was a source of frustration to several caregivers. Particularly, perceptions of being able to function without support or denial of problems led to aggravation and a feeling of futility for some caregivers.

Employment

Employment not only provided income but was perceived as a beneficial mental and social activity by several caregivers. However, caregiving responsibilities often affected employment. Two themes relating to employment were:

- Being employed was perceived as a resource by some caregivers; and,*
- Caregiving and employment: A double bind.*

Being Employed was Perceived as a Resource by Some Caregivers

Nine of the eleven caregivers who were employed described work as important in preserving their mental health. They enjoyed their work and found it provided relief from their caregiving responsibilities. Being employed part-time or full-time served as a form of socialization, contact with the rest of the world, and an emotional release. Two caregivers explained:

Work is my sanity, that's my relief. I have to have something that is for me. And my job is me, and that's my outlet.

I think if I didn't go to work, I would climb the wall.

For one caregiver, work not only provided relief or diversion from the caregiving situation but provided renewed energy. She stated "Work is sort of invigorating."

Work was seen as a form of relief from caregiving even for caregivers whose jobs did not have flexible hours. A caregiver who was caring for her mother linked her physical health to being employed, stating:

I don't have colitis when I am at work. It 'definitely' does not add extra stress.

Five caregivers were employed in positions with flexible hours that enabled them to take time during the day to conduct certain caregiving tasks. Two caregivers spoke of their work as being very demanding, with no flexibility for dealing with caregiving issues during work hours. Even those caregivers who were unable to modify their hours or needed to

work full-time because of finances described work as an important resource to their mental health.

Caregiving and Employment: A Double Bind

Three caregivers perceived their primary role as providing care to their family member and modified their employment in order to accommodate caregiving. A daughter deliberately selected a specific job that enabled her to continue caring for her parents. She explained:

I took a cut in pay but my piece of mind and having my folks, it was the best thing that could have happened to us.

Another caregiver decided to accept a position with fewer hours in order to provide care to her parents, stating:

I chose to take the lesser job [a part-time rather than a full-time position] because I realized I was going to be spending a lot of time with my parents. And I'm so glad I did that.

An employed daughter providing care to her mother with Alzheimer's disease found caregiving was consuming the majority of her time. She adjusted her employment situation by eventually reducing to half-time.

Some caregivers were affected financially because of employment limitations due to caregiving. In particular, two caregivers worked part-time because of the time spent caregiving although financially they felt a need to be employed full-time.

Service Utilization

*There was a general consensus across the focus groups that resources for caregivers were limited in availability, were difficult to discover and obtain, and frequently excluded the caregiver. Five themes relating to **service utilization** emerged from the discussions:*

- *Reluctance to use services;*
- *Lack of knowledge of available community services;*
- *Obtaining the best fit of services can be a struggle initially;*
- *A good match leads to contentment; and,*
- *Being part of the team.*

Reluctance to Use Services

There was a reluctance to use services by both the elders and the caregivers. Some caregivers were frustrated by the elder's reluctance to access services that may increase safety and provide short-term relief for the caregiver. They found it energy-consuming to try to convince the elder of the merits of the resource or ensure their safety. Caregivers discussed the need to orchestrate other arrangements which frequently resulted in the supervision or care being conducted by themselves. It appeared some elders did not consider the consequences of their decisions on their family member or friend.

Some elders could be convinced or encouraged to use a service while others adamantly refused to attend an out-of-home program or have someone come into their home. A daughter-in-law who had tried to convince her father-in-law to accept day hospital or night respite explained:

We've tried a lot of these things and he's objected. Once he's there, he's okay, but to get him there is a problem.



Some caregivers themselves expressed hesitation to use community services. For some, there had to be a personal crisis before formal assistance was sought. A daughter providing care to both parents described her experience as follows:

I had to be there every day. I was running over there every day and I started to think, 'Wait a minute, I'm working full-time, ... Oh, my gosh, how much more can I take.' I arranged for her to go through the Home Care system.

Another daughter spoke of her personal crises while providing personal care, meal preparation, and housekeeping activities for her mother who still lived in her own home. She felt guilty that she was not able to handle her life and her mother's care. She spoke of working through feelings of guilt when she decided to request Home Care assistance for her mother, stating:

And so I have peace of mind saying she's okay, she's looked after. And that's important. But you have to work through that.

One wife cared for her husband with progressive cognitive impairment for over ten years before requesting Home Care. She finally sought assistance when she became exhausted and found that she could no longer manage working full-time and leaving him at a friend's house during the day.

Lack of Knowledge of Available Community Services

Caregivers discussed their lack of knowledge about available home care services, particularly when they began caregiving. For several caregivers, this struggle to find out about resources continued even after they had used some services.

Examples of their experiences illustrate this lack of knowledge. A caregiver whose husband had urinary incontinence for a year was doing laundry every day. She was unaware that incontinent pads could be provided through the Home Care program. A daughter thought she was not eligible for publically-funded Home Care because she did not reside with her mother. A granddaughter expressed interest in attending a support group but did not know whether there were support groups for family caregivers. A caregiver who had worked within a long-term care facility told of her encounters with other informal caregivers and their minimal knowledge about available resources. She suggested that there was an unawareness of the Manitoba Senior Citizens' Handbook¹⁰ and the services for caregivers in the community. A caregiver caring for her husband summarized her experiences as "Things seem to be like little secrets."

Obtaining the Best Fit of Services Can Be a Struggle Initially

Over half of the 19 caregivers who were using the publically-funded Home Care program spoke of difficulties they experienced with the provision of services. Their frustrations centred around the frequent change of staff, lack of knowledge by staff about the client's health, inadequately trained staff, and inconsistent performance by individual workers and across workers.

¹⁰ The Manitoba Senior Citizens' Handbook is now published as the Manitoba Seniors' Guide.

Caregivers spoke of how initially they needed to advocate for consistency in the workers providing care. A daughter providing care to both her parents explained:

My biggest problem with my folks has not been my folks, it has been Home Care. They used to send me six different people in a week.

A husband caring for his wife with Alzheimer's disease described his experience with Home Care as follows:

Home Care is the hardest thing to manage to get. It all depends on the resource coordinator you get assigned to, because they can make or break you. And they did break me at one point. The only thing you can do is keep on their tail. That's what I used to do.

Coupled with the abovementioned problems was absenteeism of staff with no replacement. This experience was echoed by other caregivers who found the frequent change in staff frustrating to themselves and disturbing to their family member or friend. For some, it meant being late for work because they needed to orient each new staff member. Other caregivers identified increased anxiety and agitation in the family member. The staffing arrangement did not change until they persistently insisted upon continuity with only one or two different staff per week. After advocating for this change, these caregivers were satisfied with the stability of the direct care staff and the development of a trusting relationship with the Home Care personnel.

A related concern involved the lack of preparation of Home Care staff for the client's care. According to some caregivers, staff did not know the nature of the care required nor the elder's cognitive status. This concern was particularly emphasized by the caregivers of individuals with cognitive impairment. A wife caring for her husband with dementia stated:

This girl we have now didn't know he had dementia when she came in. I had to tell her. And she doesn't know really how to handle it yet.

Another caregiver also caring for a husband with dementia said,

I think it would be good if the Home Care workers really knew a little more about Alzheimer's and who were able to interact with them a little bit. The people who have come so far are just people who have sat there [rather than interacting with her husband].

A Good Match Leads to Contentment

Caregivers frequently saw themselves as the gatekeeper, mediator, and advocate for their family member. If they felt the services did not address the needs of the elder, or if the elder did not like the worker or services, the caregivers tended to be dissatisfied with the care situation. The caregivers were content with the care situation when they perceived that the services adequately met the needs of the elder and there was a 'good match' between their perceptions of these needs and the 'best' array of services they were able to negotiate.

Several caregivers spoke of experiencing relief when they knew there was a capable Home Care worker in their home. A daughter caring for her mother who was cognitively intact commented:

...when [name of worker] was there and I came home I felt so relaxed, because everything... there wasn't a thing I could see that I had to do and it was so good.

Caregivers also experienced relief when they knew their family member enjoyed or was content with the workers. A caregiver whose spouse had Alzheimer's disease said,

My husband likes those staff who do things with him, 'they do things'. He accepts them so well.

Being Part of the Team

Caregivers frequently saw themselves as the advocate and communicator of the elder's needs and as a vital link between the elder and the health care system. They knew the elder's needs and wanted to ensure the health care professionals were aware of, and addressed, these needs. Some caregivers spoke of how they wanted to be included in the decision-making about their family member's care. Some described themselves as assertive and knowledgeable about the system, and had taken deliberate steps to get involved. A male caregiver providing care to his mother stated:

...when VON and Home Care assessed my mother, we, my wife and I, went over together. She understands the service provision,... I understand it more from a political level and she understands it from a service delivery level, but that's a fair bit of empowerment put together. We feel quite comfortable talking to somebody coming over to assess my mother, and we know the questions to ask.

A caregiver employed full-time and caring for her mother insisted on being included in the planning. She explained:

I always made sure we had a family meeting. We need an understanding from the health care team. And maybe it's the system all in all that we talk about family care whatever it may be but nobody is walking the talk right now. It's all individualized care.

Being acknowledged as a legitimate team member with insight into and knowledge about the elder's needs was very important to some caregivers. These caregivers felt they knew

the elder better than the health professionals and wanted to ensure the elder's best interests were considered.

Overall, a number of themes related to service use emerged from these discussions. Caregivers spoke of a reluctance to use formal services. A lack of knowledge of existing services was expressed and various problems were encountered when using formal services. Some caregivers assumed the role of advocate until the appropriate services from their perspective had been obtained. Inclusion in the assessment and planning process with the health care providers was important to several caregivers.

Summary

The discussions with these informal caregivers focused on the caregiving experience and the issues faced by individuals caring for older family members or friends. Caregiving was viewed by several caregivers as a contributing factor to their psychological, emotional, and to a lesser extent, physical health. Generally, the health of the caregiver appears to be at risk when caregiving duties are added to other responsibilities.

Gender differences were difficult to detect. Only six males participated in the focus groups. They described their experiences in ways similar to at least some of the female caregivers. Both females and males had positive and negative encounters with the health care system; some caregivers, irrespective of gender, spoke of social isolation. It may be that males and females who agree to participate in focus groups are more similar in their caregiving experiences than different. At the same time, the diversity among females and among males must be recognized.

Despite the emergence of common themes, each caregiver had unique situations and circumstances related to caregiving. Family dynamics and history, values and beliefs regarding the role of family and the formal care system in providing assistance, financial circumstances, personalities of both the caregiver and the elder, and the nature of the caregiving network appear to influence the caregiving experience. Further attention to these factors is needed in order to better understand the issues faced by individuals providing and receiving assistance.

***STRATEGIES TO ADDRESS
INFORMAL CAREGIVERS' ISSUES***

STRATEGIES TO ADDRESS INFORMAL CAREGIVERS' ISSUES

*In addition to gathering information from informal caregivers, a critical component of this study was the sharing of identified issues with **community service providers**. The intent was to facilitate discussion regarding the issues raised by informal caregivers and to identify creative strategies to address these concerns (see Appendix E for details).¹¹*

*A half-day **workshop** was held on April 19, 2000 with 31 representatives from 22 agencies/organizations. The focus was on **existing resources, challenges/barriers, and creative strategies/solutions**. Five issues were discussed, including **psychological/emotional effects of caregiving, social isolation, the need for a responsive work environment, lack of knowledge of available community resources, and caregivers' and older adults' reluctance to use services**.*

Existing Resources

Several existing resources were identified as potentially addressing some of the issues raised by caregivers (see Appendix J for details). Workshop participants themselves learned about new resources for their clients.

Challenges/Barriers

*While identifying existing resources, the workshop participants acknowledged the existence of various challenges/barriers that interfere with the resolution of the issues. The challenges/barriers can be grouped as follows: a **knowledge/information gap; consumers' reluctance to seek help; gaps in the formal support system; and system***

¹¹ The discussion presented here draws on a summary prepared by Elsie Regehr, Age & Opportunity, in her role as a community member of the study team.

barriers to service. Each challenge/barrier is discussed briefly here; additional information is provided in Appendix J.

Knowledge/Information Gap

Workshop participants discussed the lack of recognition of caregiver issues, concerns, and needs by caregivers themselves, the general public, and formal service providers. It was suggested that some individuals do not view themselves as caregivers even though they would be identified as such by service providers. In addition, information was seen as not easily accessible to the consumer and service providers. Innovative case-finding approaches were viewed as needed in order to identify caregivers early and before a crisis.

Consumers' Reluctance to Seek Help

The reluctance of both caregivers and elders to seek help was identified as a challenge/barrier. This reluctance was perceived to be related to a number of factors. Some caregivers were thought to have unrealistic perceptions of their own emotional/physical strength or to have a distrust of the bureaucratic system. Workshop participants spoke of caregivers feeling intimidated when raising concerns or requesting services for fear of a withdrawal of, or decrease in, their current services. Professional jargon, automated telephone answering services, and an overwhelming amount of information were viewed as increasing feelings of intimidation. Feelings of stigmatization associated with asking for help were seen as contributing to a reluctance to use formal services. Lack of financial resources, a reluctance to pay for private services, difficulties with transportation, language/cultural barriers, and inadequate time to attend information sessions due to caregiving responsibilities were also identified as possible contributors to a hesitation to seek services.

Gaps in the Formal Support System

Workshop participants identified various gaps in the formal support system. Underfunding and workplace deficits were noted as potential barriers. There was a perceived lack of awareness by employers regarding employees' responsibilities to care for older family members. Leaves of absences were seen as rarely available for individuals caring for older adults, and employee assistance programs in the workplace were thought to generally give minimal attention to elder care issues.

System Barriers to Services

Several participants spoke about system barriers that interfere with service delivery. The question of "whose job is it anyway?" was raised as no designation has been given for primary responsibility for support, education, and information dissemination for caregivers. The health care system is complex with policy differences between hospitals, long-term care, and the community, across community agencies, and within agencies or programs. Service providers themselves are frequently unaware of other agencies' services. Programs were viewed as often inflexible and addressing specific eligibility criteria with an unwillingness or inability to deal with situation-specific needs or circumstances.

Creative Strategies/Solutions

*The major emphasis of the workshop was on the development of creative strategies/solutions to address the issues raised by informal caregivers. These strategies can be grouped into six broad areas, including: **raising awareness** about caregiving; **enhanced communication** about available resources; **innovative transportation initiatives**; **expanded respite services**; provision of **education and psychological/emotional support**; and **adjustments in bureaucratic systems** (see Appendix J for details).*

Raising Awareness About Caregiving

There was an identified need to raise awareness about caregiving with the general public, the medical community, the workplace, and educational settings. Suggestions

included mall displays, television or radio spots about caregiving, public statements on caregiving in newspapers, employee assistance programs offering training and education regarding elder care issues, and community placements for students.

Enhanced Communication About Available Resources

Workshop participants suggested that easier access to information for formal and informal caregivers was needed. Possibilities included a checklist of resources at hospital discharge, a caregiver hotline, and listings under “caregiver” in telephone directories. There was a need for improved information exchanges between disciplines/departments/agencies. As well, workshop participants called for a greater sensitivity to cultural beliefs and practices.

Innovative Transportation Initiatives

Transportation was viewed as a critical issue for caregivers and elders. There was a call for innovative transportation initiatives such as community shuttle services for appointments and groceries, and multiple pick-ups/cab-sharing for individuals in close geographical proximity with the same destination.

Expanded Respite Services

Workshop participants expressed a need for expanded respite services. Increased flexibility in services was seen as a means to facilitate greater use. Suggested actions were increased funding, the inclusion of the caregiver in respite planning, and the involvement of trained workers who could implement constructive and appropriate activities. Longer term in-home respite, weekend respite, more flexible institutional options, and increased use of day and night programs were identified as workable options.

Provision of Education and Psychological/Emotional Support

Offering both educational programs and psychological/emotional support to caregivers was identified as a strategy to be implemented both in the community and at the workplace. Strategies such as mediation to address conflict arising within families and between formal and informal providers, self-help and support groups, volunteer support, a caregiver website, and a caregiver phone-in help line were mentioned as were grief/loss counselling and daily reassurance programs.

Adjustments in Bureaucratic Systems

*Adjustments in the health care system and in employment/financial services were requested by workshop participants. Increased collaboration and communication between the caregiver and the **health care system** were seen as a means to address various issues. Examples included client-centred rather than system-centred care plans, consideration of the strengths/limitations of the informal support system in care planning, the inclusion of the family as a team member and collaboration in the planning process, and the recognition of the natural helper role of the 'friendly neighbour'. Orientation of home support and respite workers to the specific needs of the client was viewed as beneficial.*

*With regard to **employment/financial services**, employers, unions, and the government were seen as needing to take increased action to support informal caregivers. Strategies included the provision of flexible work hours to accommodate caregivers' predictable and unpredictable demands, the availability of employee assistance programs to deliver educational workshops and personal counselling on elder care issues, negotiation of family sick days to include time caring for a dependent parent or spouse, the provision of taxation benefits and reimbursement for caregiving expenses, and the ability of the Canada Pension Plan (CPP) to take caregiving years for a dependent parent or spouse into account when calculating the contributory period.*

Overall, the workshop served as a vehicle to facilitate deliberation among service providers. Participants increased their own awareness of services and were provided with a forum to discuss strategies to address issues common to their agencies.

SUMMARY AND RECOMMENDATIONS

SUMMARY AND RECOMMENDATIONS

This study has focused on the health of informal caregivers. The diversity among caregivers and the complexity of issues they face is evident. At the same time, it must be recognized that neither the MSHA or the focus groups/interviews relied upon a random sample of caregivers thereby limiting the generalizability of results.

Gender differences in the health of informal caregivers exist but there are not consistent patterns across various dimensions of health. In addition, there are differences depending on whether the focus is on spouses or adult children who are providing care for an older family member.

The results from the focus groups/interviews with the informal caregivers suggest that caregiving is viewed by some caregivers as a contributing factor to their psychological, emotional, and to a lesser extent, physical health. Generally, the health of the caregiver appeared to be at risk when the caregiver assumed a number of other responsibilities in addition to caregiving. There was a general lack of awareness of the resources available in the community. The caregivers expressed a lack of recognition of their contribution in maintaining the elder in the community and desired participation in the planning process.

The following recommendations for health policy and programming have been formulated from the project findings and the workshop with community service providers.

Recommendation 1. A deliberate plan for increasing community awareness about resources for informal caregivers and elders needs to be formulated.

- ▶ *Organization of a multi-pronged approach that would include involvement of physicians, community service providers, hospitals and families in the dissemination of information.*
- ▶ *Availability of information on resources at the time of hospital discharge for hospital staff and patients and their families.*
- ▶ *Initiation of a caregiver 'phone-in' line that would provide information on resources to informal caregivers, elders and others.*
- ▶ *Implementation of strategies for agencies to become more aware of the services each offers.*

Recommendation 2. Community services must be directed to both the elders' and caregivers' needs.

- ▶ *Awareness that informal caregivers may have multiple responsibilities in addition to the caregiving they provide.*
- ▶ *Consideration of the amount and type of care the informal caregiver may be providing.*
- ▶ *Assessment of the caregiver's ability to manage their caregiving and other responsibilities.*

Recommendation 3. Informal caregivers should be considered as team members and collaborators in the assessment and planning process with elders and community service providers.

- ▶ *Acknowledgement that informal caregivers may have valuable information about the elder that community services providers may be unable to obtain from other sources and may find useful.*

Recommendation 4. Community resources for informal caregivers need to be more available, accessible, flexible, and responsive to caregivers' needs.

- ▶ *Greater funding for respite services.*
- ▶ *Inclusion of the informal caregiver in respite planning to ensure the service provides "respite".*
- ▶ *Provision of longer-term in-home respite.*
- ▶ *Weekend respite.*
- ▶ *Initiation of more flexible institutional options.*
- ▶ *Increases in referrals to day and night respite programs.*
- ▶ *Availability of mediation services to address conflict arising within families and between community service providers and informal caregivers.*

- ▶ *Provision of support groups and self-help groups to foster exchange of information and mutual aid.*
- ▶ *Provision of volunteer support to provide respite, reassurance, or assistance with problem-solving.*

Recommendation 5. Greater collaboration across systems is needed to enhance understanding of caregiving issues and to initiate innovative strategies to deal with these issues.

- ▶ *Provision of counselling and educational programming related to elder care through employee assistance programs in the workplace.*
- ▶ *Consideration of elder care leave and flexible hours in negotiations between unions and employers.*

Overall, this project has added to a growing body of literature that calls for the development of policy that better recognizes the critical role of the informal caregiver.¹²

¹² Several actions are planned in order to disseminate the information from this study. These plans are outlined in Appendix K.

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