Differential impacts of care-giving across three caregiver groups in Canada: end-of-life care, long-term care and short-term care

Allison M. Williams PhD, Li Wang MSc and Peter Kitchen PhD

1School of Geography and Earth Sciences, McMaster University, Hamilton, Ontario, Canada, 2Center of Health Economics and Policy Analysis, McMaster University, Hamilton, Ontario, Canada and 3McMaster Institute of Environment and Health, McMaster University, Hamilton, Ontario, Canada

Accepted for publication 19 August 2013

Correspondence
Allison M. Williams
School of Geography and Earth Sciences
McMaster University
1280 Main Street West, Hamilton, Ontario, Canada L8S 4K1
E-mail: awill@mcmaster.ca

Abstract
Using data from Statistic Canada’s General Social Survey Cycle 21 (GSS 2007), this study explores whether differences exist in the impacts of care-giving among three groups of caregivers providing informal care either in the caregiver’s or recipient’s home, or in other locations within the community: (i) those providing end-of-life (EOL) care (n = 471); (ii) those providing long-term care (more than 2 years) for someone with a chronic condition or long-term illness (n = 2722); and (iii) those providing short-term care (less than 2 years) for someone with a chronic condition or long-term illness (n = 2381). This study lays out the variation in sociodemographic characteristics across the three caregiver groups while also building on our understanding of the differential impacts of care-giving through an analysis of determinants. All three groups of caregivers shared a number of sociodemographic characteristics, including being female, married, employed and living in a Census Metropolitan Area (CMA). With respect to health, EOL caregivers were found to have significantly higher levels of ‘fair or poor’ self-assessed health than the other two groups. Overall, the findings suggest that EOL caregivers are negatively impacted by the often additional role of care-giving, more so than both short-term and long-term caregivers. EOL caregivers experienced a higher proportion of negative impacts on their social and activity patterns. Furthermore, EOL caregivers incurred greater financial costs than the other two types of informal caregivers. The impacts of EOL care-giving also negatively influence employment for caregivers when compared with the other caregiver groups. Consequently, EOL caregivers, overall, experienced greater negative impacts, including negative health outcomes, than did long-term or short-term caregivers. This provides the evidence for the assertion that EOL care-giving is the most intense type of care-giving, potentially causing the greatest caregiver burden; this is shown through the greater negative impacts experienced by the EOL caregivers when compared with the short-term and long-term caregivers.

Keywords: care-giving, carers’ needs, end-of-life care, health, informal care, palliative care

Introduction
The context of care-giving in Canada is changing. As the population continues to age, develops more chronic illness and lives longer, an increasing number of adults will be giving and receiving care (Chappell 2011).
With less funding for home-care and community services, and less acute and palliative hospital beds in an increasingly rationalised healthcare system, informal caregivers have developed a crucial role in sustaining the care of Canadians who need it (Purkis et al. 2008, Williams & Crooks 2008, Chappell 2011). There are currently over 1 million palliative/end-of-life (EOL) caregivers in Canada (Carstairs 2010) and the number of palliative caregivers in Canada will continue to grow. This is a global trend, and a wealth of international research, both qualitative and quantitative, has explored the phenomenon of informal care-giving.

An informal caregiver is defined by Health Canada (2002, p. 6) as:

An individual who provides care and/or support to a family member, friend or neighbour who has a physical or mental disability, is chronically ill or is frail.

Informal caregivers, the majority of whom are family members, are the mainstay of care provision for Canadian people who are elderly, ill and with disability, and are key partners to the healthcare system. Families may not, however, have the time, ability, knowledge or resources to take on the responsibility of caring for those in need while maintaining their own health and quality of life. ‘Caregiver burden’ is the term commonly used to describe the negative physical, mental, emotional, social and economic impacts of providing care (Carretero et al. 2009). Many caregivers are elderly themselves and have their own chronic health conditions. In a variety of research studies, both national and international, the health impacts of care-giving were found to include stress, anxiety, depression, sleep deprivation, fatigue, physical pain and other chronic health conditions (Schulz & Beach 1999, Mangan et al. 2003, Sawatzky & Folwer-Kerry 2003, Rabow et al. 2004, Carretero et al. 2009). There are also social and financial impacts of care-giving that add to the burden, as many informal caregivers incur out-of-pocket costs for prescription drugs and transportation to medical appointments (Donelan et al. 2002, Dumont et al. 2009). In addition, their self-care and social activities are reduced due to the demands of care (Sisk 2000, Proot et al. 2003, Ostwald 2009).

There is an absence of research on the impact of short-term care-giving, and there are few comparative studies between EOL informal caregivers and other informal caregivers. Caregivers providing EOL care are the informal caregivers who may comparatively experience the most burden and negative health impacts from the care-giving experience, as the demands of care-giving especially intensify at the EOL stage (Schulz et al. 2003, Rabow et al. 2004, Zarit 2004) due to the deteriorating health status of the patient (Grunfeld et al. 2004). EOL care-giving is both physically and emotionally demanding, as caregivers have to complete tasks to deal with complex symptoms and emotionally support the dying patient while they are experiencing a great amount of loss and grief themselves (Mangan et al. 2003, Williams et al. 2011). EOL care-giving has been described as a balancing act as caregivers strive to cope and live well in a very vulnerable state (Proot et al. 2003, Stajduhar et al. 2008). Although there is an assertion that EOL is, in fact, the most intense and thereby impacts caregivers most, there is little evidence that supports this argument. This paper aims to fill that gap.

Using data from Statistics Canada’s General Social Survey Cycle 21 (GSS 2007), this study explores whether differences exist in the impacts of care-giving among three groups of caregivers providing informal care either in the caregiver’s or recipient’s home, or in other locations within the community: (i) those providing EOL care; (ii) those providing long-term care (more than 2 years) for someone with a chronic condition or long-term illness; and (iii) those providing short-term care (less than 2 years) for someone with a chronic condition or long-term illness. Here, the EOL caregivers included two types of respondents: one is the EOL caregiver and the other is one who provided assistance to someone with chronic health or physical limitations who had died within the 12 months immediately preceding the GSS. This study lays out the variation in sociodemographic characteristics across the three caregiver groups while also building on our understanding of the differential impacts of care-giving through an analysis of determinants.

The terms ‘palliative’ and ‘end-of-life’ care are often used interchangeably by researchers and health practitioners. However, the Canadian Hospice Palliative Care Association distinguishes between the two. The Canadian Hospice Palliative Care Association (2013) defines palliative care as:

A special kind of healthcare for individuals and families who are living with a life-limiting illness that is usually at an advanced stage.

The British Columbia Ministry of Health (2006, p. 2) states EOL care as:

The term used for the range of clinical and support services appropriate for dying people and their families.

In the General Social Survey (GSS 2007), Statistics Canada uses the term EOL care and does not refer to palliative care. As a result, to maintain a consistent...
approach in the data analysis and discussion of the findings, this paper refers to EOL care only.

Literature review

There is a wide variety of factors impacting caregiver outcomes, including individual-level factors, organisational/employment factors, as well as societal factors, such as the gendered expectations around care and the growing neo-conservative ideology that families should care for their own. These factors are well summarised in the social determinants of health model (Mikkonen & Raphael 2010), employed by Williams et al. (2011) in reviewing determinants of caregiver burden. Williams et al. (2011) suggest the following health determinants as significant: gender, income and social status, working conditions, health and social services, social support networks, culture, and personal health practices and coping strategies. For example, women continue to make up the majority of primary informal caregivers, and it has been commonly noted that women’s participation in the labour force continues to increase, creating multiple roles and responsibilities in both paid and unpaid work that can exacerbate caregiver burden (Donelan et al. 2001, Clemmer et al. 2008, Williams & Crooks 2008). An American study by Navaie-Waliser et al. (2002a) explored gender differences in informal care-giving; women were more likely to spend more hours care-giving, do more hands-on physical tasks such as direct care of the patient, house work and meal preparation. They also found, similar to Donelan et al. (2001) and Williams et al. (2003), that female caregivers miss more work and report more negative physical and mental health effects as a result of care-giving.

Vulnerability is important to take into account when exploring the impacts of care-giving. Navaie-Waliser et al. (2002b) explored how the effects of care-giving differed among caregivers in the United States, taking into account ethnicity, age, employment status and level of social support. They characterised ‘high-risk’ or ‘vulnerable’ caregivers as those who reported having ‘fair/poor’ health or having a serious health condition. Over one third of their respondents were ‘vulnerable’ and they were more likely than non-vulnerable caregivers to experience negative health impacts from care-giving. A similar study by Gonzalez et al. (2011) found that high-risk/vulnerable caregivers had greater perceived demands and subjective burden than low-risk caregivers, and were more likely to be unemployed and have a low income.

The risk to low-income caregivers is a finding that has been common across various studies exploring different facets of caregivers’ experiences. For example, Williams et al. (2003) compared the impact of eldercare between low-income and higher income family caregivers and found that low-income caregivers presented greater caregiver distress, felt more powerless, lonely and isolated. Low-income caregivers were less likely to access formal support services and transportation was a barrier linked to income. Analysis of the Connecticut Long-Term Care Needs assessment by Robison et al. (2009) found that family caregivers rated their health better than non-caregivers, but that there was a strong relationship between low-income, cohabitation with the patient, unmet needs for community-based services and negative outcomes, including social isolation.

Common health-related impacts of informal care-giving include social isolation, financial stress and loss or reduction in employment (Robison et al. 2009, Funk et al. 2010). It has been noted in several studies that, generally, employed caregivers report better health than unemployed caregivers (Cannuscio et al. 2004, Reid et al. 2010). Reid et al. (2010) assert that it is work interferences – rather than employment status – that play a role in caregiver outcomes. Interferences of employed family caregivers include reduced hours, missing days of work and reduced performance (Koerin et al. 2008, Reid et al. 2010). Caregivers, both long-term and EOL, commonly experience feelings of loneliness even with the existence of a social support network (Levine 1999, Beeson 2003). Clearly, there are a variety of factors impacting caregiver health outcomes, all of which are succinctly captured in the social determinants of health model.

Methods

Data from Statistics Canada’s General Social Survey (GSS Cycle 21: 2007) were employed for the research. This cycle of the GSS collected information, via telephone, on family, social support and retirement for Canadians aged 45 years or over. If called, respondents voluntarily complied to participate in the survey. The GSS 2007 included three modules in which questions were put to the respondents about the unpaid home-care assistance that they had provided in the last 12 months to someone at EOL or with either a long-term health condition or a physical limitation. In the GSS, all respondents are contacted and interviewed over the telephone. Telephone numbers are randomly selected through a technique called Random Digit Dialing based on Statistics Canada’s administrative sources; this produces an unbiased sample. The research team was required to apply to
Statistics Canada for clearance to use the Master file of the GSS that provides disaggregated information on respondents not available in the public file. This process involved a formal application to Statistics Canada, but did not require university ethics approval.

Of the total sample of 23,404 respondents aged 45 or older, we selected a sub-sample of 7469 individuals who reported that they had provided informal care or EOL care in the last 12 months preceding the survey. From this sub-sample, 1895 observations were dropped because of incomplete records on income, education, marital status, health status and other explanatory variables. A sensitivity analysis (where missing observations are entered in the analyses via a categorical variable) showed that excluding those with missing information did not affect the findings of our study. As a result of our selection criteria, a total of 5574 caregivers were included in the analysis. These respondents were classified into three groups: (i) those providing EOL care; (ii) those providing long-term care (more than 2 years) for someone with a chronic condition or long-term illness; and (iii) those providing short-term care (less than 2 years) for someone with a chronic condition or long-term illness. Here, the EOL caregivers included two types of respondents: one is the EOL caregiver and the other is a caregiver who provided long-term care, but the care receiver had died within the 12 months immediately preceding the GSS. As shown in Box 1, there are 17 questions in the GSS that address the impact on family and social activities, financial situation, employment and health status of care-giving. The GSS 2007 also provides information on the characteristics of caregivers, including gender, age, marital status, education level, income, work status and geography. We also consider a number of health-related variables, such as self-assessed health, self-assessed mental health, activity limitations and chronic conditions. All of these independent variables help us understand which characteristics are implicated in care-giving impacts.

Data analysis was performed in three steps: (i) descriptive statistics were used to report the characteristics across the three types of caregivers; (ii) crosstabulations and the chi-square tests were used to explore the significant differences in the impacts of care-giving across the three types of care-giving; and (iii) a series of logistic regression models estimated the impacts of care-giving (the dependent variable) with the independent variables denoting the type of caregiver, sociodemographic variables and health outcomes.

### Box 1 Questions addressing the impact of care-giving from the General Social Survey (2007)

| Question                                                                 | Response Options                                                                 |
|-------------------------------------------------------------------------|----------------------------------------------------------------------------------|
| In the past 12 months, has assisting someone caused you                  | ilc_q110 reduce the time spent on social activities?                             |
| ilc_q120 to cancel holiday plans?                                        | ilc_q130 to postpone plans to enrol in education or training programme?           |
| ilc_q140 to move in with him or her?                                    | ilc_q160 to turn down a job offer or a promotion?                                |
| ilc_q180 to have extra expenses?                                        |                                                                                  |
| In the past 12 months, to assist someone: ... have you                  | ilc_q210 had access to money from government programme?                           |
| ilc_q220 had access to tax benefit (credits or refunds) for care expenses|                                                                                  |
| ilc_q230 received gifts from the person you/he/she assisted?            | ilc_q240 received financial support from family and friends?                      |
| In the past 12 months, has assisting someone                           | ilc_q310 caused your health to suffer?                                           |
| ilc_q320 caused you to miss full days of work?                          | ilc_q330 caused you to reduce your hours of work?                                |
| ilc_q340 caused you to quit your job?                                   | ilc_q350 caused you to lose your job?                                            |
| ilc_q360 caused you to spend less time with kids?                       | ilc_q370 caused you to spend less time with spouse/partner?                       |

All estimates were weighted to take into account the sampling framework. The GSS is a multistage survey. Statistics Canada provides a final weight (or final design weight) and bootstrap weights, used to generate consistent estimates of population parameters, and sampling variances that account for sample design respectively. The GSS 2007 includes 500 bootstrap weights. We used mean bootstrap weights to estimate the standard error of coefficients in logistic regression, as well as the chi-square test comparing the three groups. The statistical software Stata 11.0 (StataCorp LP, College Station, TX, USA) was used for data analysis.

### Results

**Characteristics of caregivers**

Table 1 presents the characteristics of caregivers in this study. As can be seen in Table 1, 471 respondents aged 45 or over provided EOL care, 2381 respondents provided short-term informal care and 2722 respondents provided long-term informal care in the last 12 months prior to the survey. Caregivers provided informal care either in the caregiver’s or recipient’s home, or in other locations within the community. Consistent with the literature, the majority of caregivers were female (54% in EOL, 57% in short-term and 55% in long-term) and married (70% in EOL, 77% in short-term and 74% in...
Most of the caregivers were employed (59% in EOL, 61% in short-term and 56% in long-term). About one third of caregivers were retired (31% in EOL, 27% in short-term, and 31% in long-term). The majority of caregivers lived in a CMA (78%), with an additional 15% living in a Metropolitan Influence Zone outside the commuting zones of larger urban centres.

As shown in the last column of Table 1, significant differences with respect to sociodemographic characteristics existed across the three types of care-giving (EOL, short-term and long-term). These include most age categories as well as marital status, higher levels of education, income categories below $40,000 and working status (particularly retired). With respect to caregiver health, approximately half of the caregivers had one or more chronic conditions. Long-term informal caregivers (48%) had a high proportion of activity limitations when compared with EOL (44%) and short-term caregivers (41%). There was a significant difference in the health of caregivers across the three groups, with EOL caregivers having a significantly

**Table 1** Percentage of characteristics of caregivers by care types

| Variables                        | EOL   | Short-term | Long-term | Chi-square test |
|----------------------------------|-------|------------|-----------|-----------------|
| **N**                            | 471   | 2381       | 2722      |                 |
| **Gender**                       |       |            |           |                 |
| Male                             | 45.6  | 43.3       | 46.5      | 5.3912***       |
| **Age**                          |       |            |           |                 |
| 45–54                            | 40.8  | 53.2       | 45.9      | 43.15***        |
| 55–65                            | 35.7  | 29.6       | 32.3      |                 |
| >65                              | 23.5  | 17.2       | 21.8      |                 |
| **Marital status**               |       |            |           |                 |
| Married/common law               | 70.0  | 76.9       | 74.0      | 13.51***        |
| Widowed/separated/divorced       | 21.2  | 17.0       | 18.4      |                 |
| Single, never married            | 8.8   | 6.1        | 7.6       |                 |
| **Education**                    |       |            |           |                 |
| Post-graduate/professional       | 34.5  | 27.4       | 29.4      | 12.13***        |
| Secondary education              | 35.4  | 40.9       | 38.1      |                 |
| Less than secondary education    | 30.1  | 31.7       | 32.4      |                 |
| **Income**                       |       |            |           |                 |
| Under $20,000                    | 7.6   | 6.4        | 8.8       | 29.38***        |
| $20,000–$29,999                  | 6.0   | 7.3        | 9.4       |                 |
| $30,000–$39,999                  | 11.7  | 9.1        | 9.5       |                 |
| $40,000–$49,999                  | 8.0   | 9.4        | 9.6       |                 |
| $50,000–$59,999                  | 10.4  | 11.2       | 10.0      |                 |
| $60,000–$69,999                  | 14.6  | 15.5       | 14.6      |                 |
| $70,000–$79,999                  | 13.7  | 13.0       | 12.5      |                 |
| $80,000+                         | 27.9  | 28.2       | 25.7      |                 |
| **Work status**                  |       |            |           |                 |
| Working                          | 59.1  | 61.1       | 56.0      | 16.98***        |
| Retired                          | 31.0  | 27.1       | 30.5      |                 |
| Other                            | 9.9   | 11.8       | 13.5      |                 |
| **Self-assessed health**         |       |            |           |                 |
| Excellent/very good              | 60.9  | 64.4       | 59.9      | 19.07***        |
| Good                             | 25.7  | 25.9       | 26.9      |                 |
| Fair/poor                        | 13.4  | 9.7        | 13.2      |                 |
| **Self-assessed mental health**  |       |            |           |                 |
| Excellent/very good              | 78.0  | 76.8       | 75.3      | 2.87            |
| Good                             | 18.3  | 19.5       | 20.4      |                 |
| Fair/poor                        | 3.6   | 3.7        | 4.3       |                 |
| Activity limitation (yes/no)     | 43.5  | 40.6       | 48.0      | 28.72***        |
| Chronic condition (yes/no)       | 57.1  | 51.6       | 57.7      | 20.50***        |
| Geography                        |       |            |           |                 |
| Census Metropolitan Area         | 78.3  | 78.9       | 78.4      | 1.134           |
| Metropolitan Influence Zone      | 14.7  | 14.7       | 14.6      |                 |
| Rural                            | 7.0   | 6.3        | 7.1       |                 |

*P < 5%, **P < 1%, ***P < 0.1% (Plackett 1983).

EOL, end of life.
higher proportion in ‘fair/poor’ self-assessed health than the other two caregiver groups.

**Impacts of care-giving across caregiver groups**

Table 2 presents the results of impacts of care-giving across the three caregiver groups, with EOL caregivers being affected most.

Overall, a high proportion of caregivers incurred social and activity impacts (48% in EOL care, 30% in short-term care and 32% in long-term care). Not surprisingly, the social impacts significantly differ across the three caregiver types. For example, EOL caregivers were more likely to reduce the time spent on social activities, cancel holiday plans and spend less time with their children or a spouse/partner than the short-/long-term caregivers. Long-term caregivers were more likely to reduce the time spent on social activity when compared with the short-term caregivers. This suggests that all three groups of caregivers, and particularly the EOL caregivers, are compromising two determinants of health, social support networks, and, indirectly, personal health practices and coping strategies, in that they are not fully engaged in social and related activities.

When considering income as a health determinant, the EOL caregivers were found to incur greater financial and employment costs than the other two groups of caregivers, although this was partially balanced by government payments. We can see that a greater number of EOL caregivers (44%) were incurring extra expenses than short-term caregivers (30%) and long-term caregivers (33%). Roughly half as many short-term caregivers had access to money from government (2.4%) or had access to tax benefits (2.7%) than EOL caregivers (5.1% and 5.8%) or long-term caregivers (4.4% and 6.0%). The long-term caregivers had greater success getting money from government or receiving a tax benefit than did short-term caregivers, a difference of 2.0% and 3.4% respectively. There were no significant differences in receiving gifts or financial support from family and friends across the three types of care-giving assistance. With respect to working conditions, the impact of EOL care-giving was greater on employment than that of the other two types of care-giving; 6.6% and 4.8% more EOL caregivers missed full days of work and reduced the hours of work respectively. Also, slightly more EOL caregivers (about 2%) postponed plans to enrol in education training when compared with the two other caregiver types, potentially compromising their ability to be promoted at work. With respect to quitting or losing a job, no substantial differences exist across the three types of care-giving. Interestingly, employment impacts of short-term and long-term care-giving are identical.

**Table 2** Differences in the impacts of care-giving (%) by care types

| Impact of care-giving | EOL | Short-term | Long-term | Pairwise comparison |
|-----------------------|-----|------------|-----------|---------------------|
| ilc_q110: Did you reduce the time spent on social activities? | 48.3 | 30.3 | 32.4 | <0.001 <0.001 0.032 |
| ilc_q120: Did you cancel holiday plans? | 33.9 | 16.6 | 16.8 | <0.001 <0.001 0.812 |
| ilc_q130: Did you postpone plans to enrol in education training? | 6.0 | 3.9 | 4.4 | 0.013 0.047 0.270 |
| ilc_q140: Did you move in with him or her? | 6.3 | 3.3 | 2.7 | 0.002 <0.001 0.041 |
| ilc_q160: Did you turn down a job offer or a promotion? | 2.9 | 2.6 | 2.8 | 0.491 0.826 0.381 |
| ilc_q180: Did it cause extra expenses? | 43.8 | 30.1 | 33.2 | <0.001 <0.001 0.002 |
| ilc_q210: Did you have access to money from government programme? | 5.1 | 2.4 | 4.4 | <0.001 0.371 <0.001 |
| ilc_q220: Did you have access to tax benefit for care expenses? | 5.8 | 2.7 | 6.0 | <0.001 0.782 <0.001 |
| ilc_q230: Did you receive the gift from the person you assisted? | 14.8 | 17.3 | 18.7 | 0.046 0.002 0.088 |
| ilc_q240: Did you receive financial support from family and friends? | 5.5 | 4.2 | 4.5 | 0.081 0.193 0.439 |
| ilc_q310: Did you cause your health to suffer? | 20.1 | 10.6 | 14.1 | <0.001 <0.001 <0.001 |
| ilc_q320: Did the care cause to miss full days of work? | 22.0 | 15.4 | 14.6 | <0.001 <0.001 0.263 |
| ilc_q330: Did you reduce your hours of work? | 14.0 | 9.2 | 9.0 | 0.001 0.001 0.778 |
| ilc_q340: Did you quit your job? | 1.0 | 0.5 | 0.3 | 0.146 0.035 0.097 |
| ilc_q350: Did you lose your job? | 0.3 | 0.2 | 0.4 | 0.726 0.438 0.146 |
| ilc_q360: Did you spend less time with kids? | 21.9 | 15.4 | 16.1 | <0.001 <0.001 0.339 |
| ilc_q370: Did you spend less time with spouse/partner? | 26.2 | 18.6 | 18.4 | <0.001 <0.001 0.845 |

EOL, end of life.
Given the impacts on the various social determinants of health, it is not surprising that EOL caregivers were almost twice as likely to have experienced negative health impacts as short-term caregivers (20.1% vs. 10.6%). Long-term caregivers (14.1%) were also more likely to have been affected than short-term caregivers. Overall, the general pattern suggests that EOL caregivers experienced a greater impact on social activities, employment and health than either short-term caregivers or long-term caregivers. However, the differences between short-term caregivers and long-term caregivers were smaller.

Determinants of the impacts of care-giving

A series of 17 logistic regressions were carried out to assess the most significant determinants of the impacts of care-giving. Table 3 shows an abbreviated version of the results of the logistic regression where the dependent variables denote the impact of care-giving such as cancelling holiday plans, missing full days of work or reducing hours of work or spending less time with a partner. However, long-term caregivers were more likely to have access to financial support from government, including tax benefits, when compared with short-term caregivers (the reference group), when controlling for socioeconomic factors. EOL caregivers were more likely to have a health problem when compared with the short-term caregivers (OR = 2.30). There was no difference between long-term and short-term caregivers in impacts of care-giving such as cancelling holiday plans, missing full days or reducing hours of work or spending less time with a partner. However, long-term caregivers were more likely to have access to a tax benefit (OR = 2.32) or to receive government support (OR = 1.76) and less likely to move in with the care recipient (OR = 0.77). In addition, long-term caregivers were more likely to have extra expenses, receive gifts from the care recipient and have a health problem than short-term caregivers.

With respect to the impacts on social and family activities, younger female caregivers were more likely to incur costs than younger men (the reference group). Married caregivers were less likely to have access to financial support from government, including tax benefits, when compared with short-term caregivers (the reference group), when controlling for socioeconomic factors. EOL caregivers were more likely to have a health problem when compared with the short-term caregivers (OR = 2.30). There was no difference between long-term and short-term caregivers in impacts of care-giving such as cancelling holiday plans, missing full days or reducing hours of work or spending less time with a partner. However, long-term caregivers were more likely to have access to a tax benefit (OR = 2.32) or to receive government support (OR = 1.76) and less likely to move in with the care recipient (OR = 0.77). In addition, long-term caregivers were more likely to have extra expenses, receive gifts from the care recipient and have a health problem than short-term caregivers.

Table 3 Adjusted odds ratios [95% confidence intervals] for care type for impact of care-giving questions (n = 5574)

| Impact of care-giving | Care type          |
|----------------------|--------------------|
|                      | EOL                | Long-term        |
| ilc_q110             | 2.374 [2.030, 2.775] | 1.162 [1.057, 1.276] |
| ilc_q120             | 2.777 [2.369, 3.256] | 1.051 [0.939, 1.177] |
| ilc_q130             | 1.798 [1.285, 2.514] | 1.173 [0.948, 1.451] |
| ilc_q140             | 1.976 [1.399, 2.790] | 0.772 [0.614, 0.970] |
| ilc_q160             | 1.283 [0.809, 2.037] | 1.125 [0.864, 1.465] |
| ilc_q180             | 1.869 [1.590, 2.197] | 1.164 [1.061, 1.277] |
| ilc_q210             | 2.086 [1.455, 2.989] | 1.760 [1.381, 2.244] |
| ilc_q220             | 2.197 [1.567, 3.079] | 2.324 [1.828, 2.955] |
| ilc_q230             | 0.863 [0.709, 1.051] | 1.132 [0.917, 1.384] |
| ilc_q240             | 1.408 [1.025, 1.933] | 1.063 [0.864, 1.308] |
| ilc_q310             | 2.304 [1.893, 2.803] | 1.339 [1.175, 1.527] |
| ilc_q320             | 1.876 [1.528, 2.304] | 1.043 [0.920, 1.182] |
| ilc_q330             | 1.839 [1.434, 2.357] | 1.078 [0.917, 1.266] |
| ilc_q340             | 2.275 [1.040, 4.976] | 0.598 [0.287, 1.248] |
| ilc_q350             | 1.042 [0.285, 3.807] | 1.567 [0.570, 4.308] |
| ilc_q360             | 1.740 [1.436, 2.108] | 1.110 [0.986, 1.249] |
| ilc_q370             | 2.042 [1.680, 2.480] | 1.105 [0.983, 1.241] |

EOL, end of life; Short-term care is the reference group. The other control variables are age and gender, marital status, education, income, work status, self-access health, self-assess mental health, activity limitation, the number of chronic conditions and geography.
(OR = 0.39) to move in with the patient and were more likely to spend less time with their children than those who were single. People with higher education experienced a greater impact on social and family activities. Compared with the caregivers in the lowest income households (under $20,000), all other caregivers were more likely to reduce the time spent on social activities. Caregivers with higher incomes were less likely to reduce the time spent with their children. Employed caregivers were less likely to move in with the patient and more likely to spend less time with their spouse/partner. Caregivers with poor self-assessed mental health or activity limitations were more likely to reduce the time spent on social activities, cancel holiday plans and move in with the patient. Caregivers who had chronic conditions were less likely to cancel holiday plans or move in with the patient. Geography was not a significant factor, with the exception of residents living in a CMA being more likely to cancel holiday plans.

With respect to the financial impacts, younger female caregivers were more likely to incur extra expenses or receive gifts compared with younger males (the reference group). In addition, older men were less likely to incur extra expenses or receive gifts compared with the reference group. However, older male and older female caregivers were more likely to access financial support from government or to receive a tax benefit. People who were married or who had higher education were also more likely to have extra expenses. Caregivers with a higher household income were more often able to access tax benefits for care expenses, but less likely to receive financial support from family and friends. Not surprisingly, retired caregivers were less likely to have access to financial support from government or to access tax benefits.

Our findings also suggest a number of significant effects that care-giving has on employment, a key determinant of health. First, compared with males under the age of 55 (the reference group), female caregivers of the same age, as well as females between the ages of 55 and 65 were more likely to quit their jobs. Older male caregivers were less likely to experience employment-related costs. Second, married caregivers were more likely to reduce the hours of work, but less likely to turn down a job offer or a promotion. Higher educated caregivers were more likely to postpone plans to enrol in educational training or turn down a job offer or promotion. Third, people who have higher household incomes were more likely to miss full days of work while care-giving. Caregivers residing in middle-income households were more likely to quit their job than were caregivers residing in a lower income household. Fourth, employed caregivers were more likely to miss full days of work (OR = 11.6) and more likely to reduce the hours of work (OR = 5.0) than unemployed caregivers. Fourth, caregivers who had fair/poor self-assessed mental health (OR = 10.5) or who had activity limitations (OR = 4.45) were more likely to lose their job than were healthy caregivers. Activity limitations were also significant in caregivers quitting their job. Fifth, caregivers living in a CMA (OR = 1.86) were more likely to turn down a job offer or a promotion than those living in a rural area.

Female caregivers were more likely to experience poor health, especially younger females. Caregivers with higher incomes, together with retired caregivers, were less likely to incur health costs. Caregivers with poor self-assessed health or mental health, as well as with chronic conditions or activity limitations, were more likely to experience decreased health.

**Discussion**

There are two obvious limitations to the analysis. The first is not examining the caregiver’s relationship with the care recipient, which is a key variable in caregiver burden. The GSS does collect these data, but were inadvertently not used in this analysis. The second is that the GSS did not collect data specific to the actual setting in which the care was provided (i.e. caregiver/care recipients home or other settings within the community). Recognising these limitations, the results of this research are useful for informing the provision of caregiver supports generally, specific to health and social care in the community.

All three groups of caregivers (EOL, short-term and long-term) shared a number of sociodemographic characteristics, including being female, married, employed and living in a CMA. With respect to health, EOL caregivers were found to have significantly higher levels of poorer self-assessed health than the other two groups. Overall, the findings specific to the various social determinants of health suggest that EOL caregivers are negatively impacted by the often additional role of care-giving, and more so than both short-term and long-term caregivers. EOL caregivers experience a higher proportion of negative impacts on their social and activity patterns. Furthermore, EOL caregivers incur greater financial costs than the other two types of informal caregivers. EOL care-giving also negatively influence employment when compared with the other caregiver groups. Consequently, EOL caregivers, overall, experience greater negative impacts, including negative health outcomes, than do long-term or short-term caregivers. This provides the evidence for the assertion that EOL
care-giving is the most intense type of care-giving, potentially causing the greatest caregiver burden.

The research findings suggest a number of policy directions, many of which point to better supporting EOL caregivers and the need to account for gender variations. To minimise negative health impacts, addressing health determinants early in the caregiver trajectory is necessary for all three care types, and especially for EOL caregivers. For example, the provision of improved financial support to assist with healthcare/out-of-pocket costs would better sustain caregivers in providing care in the community. Furthermore, enhanced employment accommodations for caregiver-employees, such as availability of flexi-time or work-from-home options, would enable caregivers to better manage both roles more effectively; this is particularly the case for female caregivers who were found to more likely leave the workforce due to care-giving responsibilities. In addition, access to available respite and social support opportunities (i.e. caregiver support groups), whether available through public programmes or non-governmental organisations, would enable caregivers to better meet their social support needs through positive personal health and coping strategies while managing the demands of care-giving.

It is important to recognise that the impact of care-giving varies, as the population of informal caregivers in Canada is a very diverse group. In their commentary on the geographies of care, Milligan et al. (2007) critique the tendency in research to homogenise caregivers and the care-giving experience. They call for more attention in care research to be paid to differences within and among social groups, such as culture, socioeconomic status and social norms and expectations of care. Certainly, the analysis presented herein has provided some further insights into these differences.

Building on the suggestion of Milligan et al. (2007), researchers are beginning to call for an intersectional analysis of the experience of informal care-giving; this type of analysis would address the role of social location, which encompasses the various categories of identity and features of peoples’ lives, including gender, age, race, culture, income, education, health/disability, sexuality (sexual orientation) and geography (Hankivsky et al. 2010, Chappell & Funk 2011). This is certainly a plausible next step in the work presented herein, as qualitative intersectionality analysis may shed light on the inequities among caregiver experiences and explore ways to reduce those inequities; it also may help researchers tease out how various social determinants of health interact and impact caregivers. Care-giving is a complex phenomenon and researchers must consciously work to deconstruct the homogenisation of family caregivers and/or essentialisation of their experience, to validate varying experiences and support the unique caregiver needs. A qualitative approach would allow for the role of social location to be better captured, particularly given the opportunity that a qualitative approach facilitates documenting caregiver histories beyond the last 12 months, while also permitting an in-depth exploration of the numerous impacts of care-giving, as implicated by social location.

Acknowledgements

The primary author is supported by a Canadian Institute of Health Research/Ontario Women’s Health Council Mid-Career Award in Women’s Health.

References

Beeson R.A. (2003) Loneliness and depression in spousal caregivers of those with Alzheimer’s disease versus non-caregiving spouses. Archives of Psychiatric Nursing 17 (3), 135–143.

British Columbia Ministry of Health (2006) A provincial framework for end-of-life care. Available at: http://www. health.gov.bc.ca/library/publications/year/2006/frame work.pdf (accessed on 22/6/2013).

Health Canada (2002) National Profile of Family Caregivers in Canada – 2002: Final Report. Health Canada, Ottawa.

Cannuscio C.C., Colditz G.A., Rimm E.B., Berkman L.F., Jones C.P. & Kawachi I. (2004) Employment status, social ties and caregivers’ mental health. Social Science and Medicine 58, 1247–1256.

Carretero S., Garcés J., Ródenas F. & Sanjose V. (2009) The informal caregiver’s burden of dependent people: theory and empirical review. Archives of Gerontology and Geriatrics 49 (1), 74–79.

Carstairs S. (2010) Raising the Bar: A Roadmap of Future Palliative Care in Canada. Senate of Canada, Ottawa.

Chappell N. (2011) Population aging and the evolving care needs of older Canadians: an overview of the policy challenges. Available at: http://www.irpp.org/pubs/irppstudy/ irpp_study_no21.pdf (accessed on 28/5/2010).

Chappell N.L. & Funk L.M. (2011) Social support, caregiving, and aging. Canadian Journal on Aging 30 (3), 355–370.

Clemmer S.J., Ward-Griffin C. & Forbes D. (2008) Family members providing home-based palliative care to older adults: the enactment of multiple roles. Canadian Journal on Aging 27 (3), 267–283.

Donelan K., Falik M. & DesRoches C.M. (2001) Caregiving: challenges and implications for women’s health. Women’s Health Issues 11 (3), 185–200.

Donelan K., Hill C.A., Hoffman C., Scoles K., Feldman P.H., Levine C. & Gould D. (2002) Challenged to care: informal caregivers in a changing health system. Health Affairs 21 (4), 222–231.

Dumont S., Jacobs P., Fassbender K., Anderson D., Turcotte V. & Harel F. (2009) Costs associated with resource utili-
ization during the palliative phase of care: a Canadian perspective. Palliative Medicine 23 (8), 708–717.
Funk L., Stajduhar K.I., Toy C., Aoun S., Grande G. & Todd C. (2010) Part 2: home-based family caregiving at the end of life: a comprehensive review of published qualitative research (1998–2008). Palliative Medicine 24 (6), 594–607.
Gonzalez E.W., Polansky M., Lippa C.F., Walker D. & Feng D. (2011) Family caregivers at risk: who are they? Issues in Mental Health Nursing 32 (8), 528–536.
Grunfeld E., Coyle D., Whelan T. et al. (2004) Family caregiver burden: results of a longitudinal study of breast cancer patients and their principal caregivers. Canadian Medical Association Journal 170 (12), 1795–1801.
Hankivsky O., Reid C., Cormier R., Varcoe C., Clark N., Benoit C. & Brotman S. (2010) Exploring the promises of intersectionality for advancing women’s health research. International Journal for Equity in Health 9, 5.
Koerin B.B., Harrigan M.P. & Secret M. (2008) Eldercare and employed caregivers: a public/private responsibility? Journal of Gerontological Social Work 51 (1–2), 143–161.
Levine C. (1999) The loneliness of the long-term caregiver. The New England Journal of Medicine 340, 20.
Mangan P.A., Taylor K.L., Yabroff R., Fleming D.A. & Ing-Mikkonen J. & Raphael D. (2010) Part 2: home-based family caregiving at the end of life: balancing between burden and capacity. Palliative and Supportive Care 1 (3), 247–259.
Mikkonen J. & Raphael D. (2010) Social determinants of health: the Canadian facts. Available at: http://www.thecaadianfacts.ca (accessed on 12/5/2010).
Milligan C., Atkinson S., Skinner M. & Wiles J. (2007) Geographies of care: a commentary. New Zealand Geographer 63, 135–140.
Navaie-Waliser M., Spriggs A. & Feldman P.H. (2002a) Informal caregiving – differential experiences by gender. Medical Care 40 (12), 1249–1259.
Navaie-Waliser M., Feldman P.H., Gould D.A., Levine C., Kuerbis A.N. & Donelan K. (2002b) When the caregiver needs care: the plight of vulnerable caregivers. American Journal of Public Health 92 (3), 409–413.
Ostwald S.K. (2009) Who is caring for the caregiver? Promoting spousal caregiver’s health. Family and Community Health 32 (S1), S5–S14.
Plackett R.L. (1983) Karl Pearson and the chi-squared test. International Statistical Review 51 (1), 59–72.
Proot I.M., Abu-Saad H.H., Crebolder H.F.J.M., Goldsteen M., Luker K.A. & Widdershoven G.A. (2003) Vulnerability of family caregivers in terminal palliative care at home; balancing between burden and capacity. Scandinavian Journal of Caring Sciences 17, 113–121.
Purkis M.E., Ceci C. & Bironsdottir K. (2008) Patching up the holes: analyzing the work of home care. Canadian Journal of Public Health 99 (S2), S27–S32.
Rabow M., Hauser J.M. & Adams J. (2004) Supporting family caregivers at the end of life: “they don’t know what they don’t know”. Journal of the American Medical Association 291 (4), 483–491.
Reid R.C., Stajduhar K.I. & Chappell N.L. (2010) The impact of work interferences of family caregiver outcomes. Journal of Applied Gerontology 29 (3), 267–289.
Robison J., Fortinsky R., Kleppinger A., Shugrue N. & Porter M. (2009) A broader view of family caregiving: effects of caregiving and caregiver conditions on depressive symptoms, health, work, and social isolation. Journal of Gerontological: Social Sciences 64B (6), 788–798.
Sawatzky J.E. & Folwer-Kerry S. (2003) Impact of caregiving: listening to the voice of informal caregivers. Journal of Psychiatric and Mental Health Nursing 10 (3), 277–286.
Schulz R., Mendelsohn A.B., Haley W.E. et al. (2003) End-of-life care and the effects of bereavement on family caregivers of persons with dementia. New England Journal of Medicine 349 (20), 1936–1942.
Schulz R. & Beach S. (1999) Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. Journal of the American Medical Association 282 (23), 2215–2219.
Sisk R.J. (2000) Caregiver burden and health promotion. International Journal of Nursing Studies 37, 37–43.
Stajduhar K., Martin W.L., Barwich D. & Fyles G. (2008) Factors influencing family caregivers’ ability to cope providing end-of-life cancer care at home. Cancer Nursing 31 (1), 77–85.
Statistics Canada (2007) General Social Survey Cycle 21: Family, Social Support and Retirement. Ottawa, Ontario.
The Canadian Hospice Palliative Care Association (2013) FAQ: what is palliative care? Available at: http://www.chpca.net/family-caregivers/faqs.aspx (accessed on 22/6/2013).
Williams A. & Crooks V.A. (2008) Introduction: space, place, and the geographies of women’s caregiving work. Gender, Place and Culture 15 (3), 243–247.
Williams A., Forbes D.A., Mitchell J., Esser M. & Corbett B. (2003) The influence of income on the experience of informal caregiving: policy implications. Health Care for Women International 24, 280–291.
Williams A.M., Eby J., Crooks V.A. et al. (2011) Canada’s Compassionate Care Benefit: is it an adequate public health response to addressing the issue of caregiver burden in end-of-life care? BMC Public Health 11 (1), 335.
Zarit S.H. (2004) Family care and burden at the end of life. Canadian Medical Association Journal 170 (12), 1811–1812.