Defining disability: Recognizing the heterogeneity of care receivers and its consequences for projecting future care needs of Canadians

Authors:
***Janice Keefe**, Mount Saint Vincent University; **Patrick Charbonneau**, Université de Montréal; **Yann Décarie**, Université de Sherbrooke ; **Jacques Légaré**, Université de Montréal*

Introduction

There are approximately 900,000 individuals receiving home care services in Canada at any given time (Canadian Home Care Association, 2008). In this country and elsewhere, there is a growing shift towards support services that allow seniors with chronic care needs to remain in their homes (Carrière, Keefe, Légaré, Lin, & Rowe, 2007). Population aging and consumer wishes fuel the increased need for the provision of chronic care for older Canadians in their homes for as long as possible. These trends have implications for the future availability of both family/friend (informal) and formal supports. The authors' previous research has focused on projecting the increased need for support over the next thirty years (Carrière, Keefe & Légaré, 2007) and as well exploring the costs of possible policy options for family/friend caregivers (Keefe, Légaré, & Carrière, 2007). While we know that family/friend sources of support will remain the most significant contributor of home support in the future, recent research by the authors indicates a rapid increase in formal supports required to meet home support needs up to 2031. The thrust of our current research is to investigate factors contributing to the amount of care provision by analyzing what services are being provided by whom. This analysis will help to understand the types of activities that are driving projected human resource needs.

Recently, efforts to engage policy makers in our research have led to insightful contributions from both government and non-governmental organization partners. As a consequence, the definition of activities that are included in our calculations of projected need has expanded. This research examines multiple factors that contribute to projecting the numbers of the population who will have

care needs when taking into account the heterogeneity of the care receiver population. Canadians 65 years and over who need assistance constitute the population at interest.

Research question

How are projections of human resources needs affected by changes in definitions of need for assistance by increasing the number and the type of activities included?

Methods

Using Statistics Canada 2002 General Social Survey, logistics regressions estimated levels of disability for those with long term health problems. Seven activities **1)** personal care; **2)** house cleaning; **3)** meal preparation; **4)** grocery shopping; **5)** transportation; **6)** banking/bill paying; and **7)** household maintenance/outside work were analyzed in 3 groups. Group A included those receiving help for only one of 1-4 and none of 5-7; Group B received help for at least both one of 1-4 and one of 5-7 OR at least two of 1-4 and none of 5-7; and Group C received help for at least 1 of 5-7 and none of 1-4. The amount of assistance is stated in terms of hours per week while the source of assistance can be broken down in formal, informal (family/friends) and mixed sources.

The parameters will be applied at five-year intervals in Statistics Canada LifePaths microsimulation model (Wolfson & Rowe, 2004) to project future demand. The LifePaths modelling allows us to incorporate contextual variables that impact on the availability of informal caregivers and rates of disability among the older population and to take into account the changing nature of family structure as new cohorts enter old age. Furthermore, this paper advances our previous research (Carriére et al., 2007) by using more recent data (2002 GSS), and expanding the number of activities of daily living considered.

Results

In order to obtain the hours of time spent, we apply the median amount of hours of assistance per week by age, sex and source of assistance to the projected population who will receive assistance. Moving from Scenario 1 to Scenario 2 however, produced results that were far than what we

expected, as the median number of hours per week is lower for 7 activities (3 hours) than for 4 activities (4.4 hours). This is because the new included activities require much less time than the four original activities. In order to improve our projections, this issue warrants further investigation.

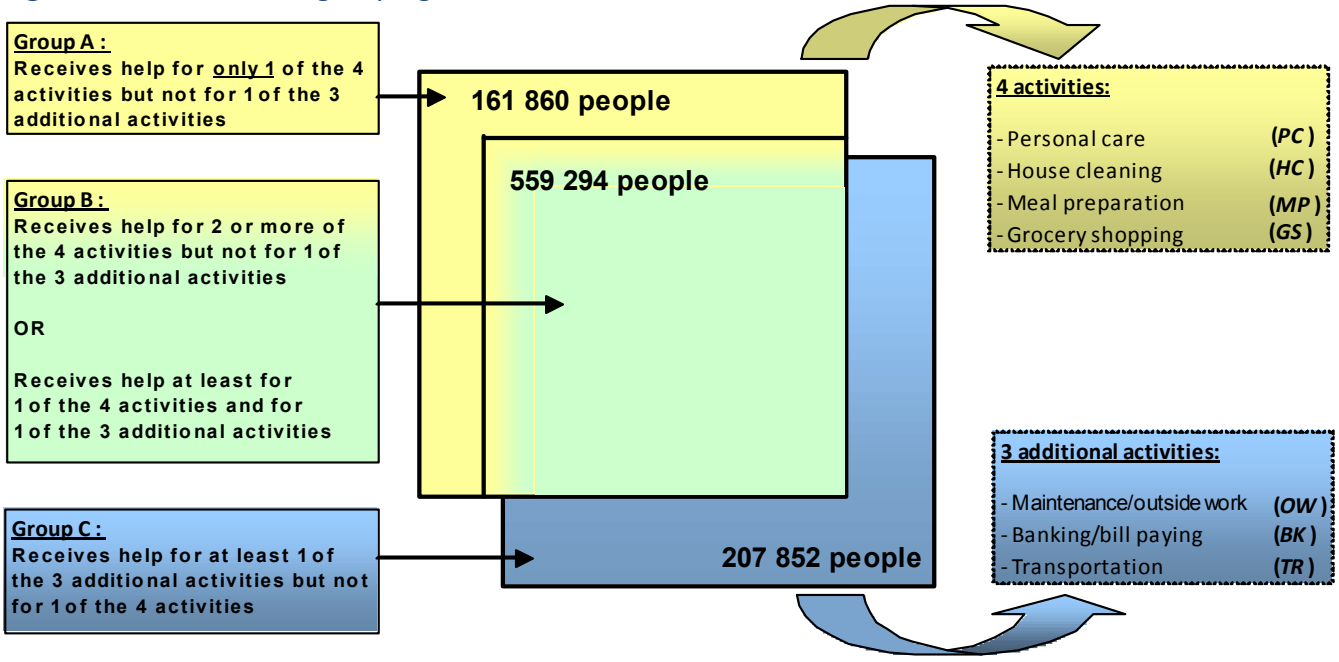
Table 1. Canadian Population aged 65 years and over needing assistance

Year	***Scenario 1**: Activities 1-4*	***Scenario 2**: Activities 1-7*
2006	***746 465***	***896 896***
2031	***1 504 218***	***1 865 761***

Source: Statistics Canada LifePaths projections

Moving from Scenario 1 (activities 1-4) to Scenario 2 (activities 1-7) increases the number of older persons being defined as needing assistance by 20% in 2006 and 24% in 2031. In both cases, the number of persons needing assistance more than doubles.

Figure 1. Care receivers groupings, Canada, 2002



Accordingly, we have established three distinct groups that may better represent those at risk (Figure 1). Descriptive results indicate that Group B is very different than the two other groups and likely the group on which subsidized home care programs will want to focus their efforts. For example, compared to Groups A and C, Group B members are more frequently females, less educated, older, more often widowed, with a higher degree of severity and far more likely to be receiving both formal and informal (mixed) help.

Table 2. Median and mean hours of time spent per week, males and females 65 years and over, for each group, according to the **number of activities** for which help was received

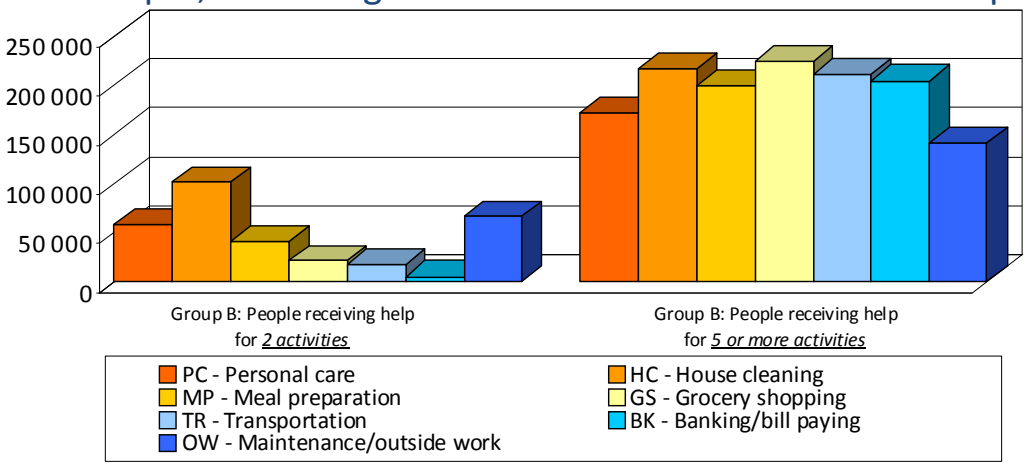
	N	% (among each group)	Median	Mean
Group A	**161 860**		**1,0**	**5,3**
Group B	**559 294**		**9,5**	**18,7**
2 activities	153 577	27 %	2,6	6,7
3-4 activities	176 126	31 %	8,0	15,6
5-7 activities	229 591	**41 %**	**18,5**	29,1
Group C	**207 852**		**1,0**	**3,9**
1 activity	199 955	**96 %**	1,0	3,5
2-3 activities	7 897	4 %	7,9	14,6

Groups A and C are less likely to be candidates for home care programs since almost all received assistance with only one activity, 100% for Group A and 96% for Group C, both for one hour per week (Table 2). The median hours increase significantly when assistance is received for more than one activity. Group B stands out as unique – both because of the definition (at least 2 activities had to have been received) and because of the 41% of members that receive assistance with 5 to 7 activities of daily living for an average of 18.5 hours per week.

Among those who receive assistance with two activities, house cleaning, household maintenance and personal care are most common (Figure 2). The group who receive help with 5-7 are noticeably distinct. Between 125,000-200,000 people receive help with each of seven activities resulting in less

variation among the type of assistance. This "high need" group will be of particular interest as they need a sustained network of support either formal and/or informal to enable them to remain in the community.

Figure 2. Activities* for which people received help among Group B, according to the number of activities with help



* Activities are not mutually exclusive

Further analysis of Group A and C reveal three key activities – personal care, house cleaning (96% of Group A) and, for Group C, household maintenance and outside work (96%) (Tables 3 and 4). Group A in particular may be of interest to agencies providing community-based supportive services since fully 70% of the care receivers are being helped through formal sources of assistance (Figure 3). In contrast, only 8% of care receivers in Group 3 were requiring help from a formal network. It is suggested that the 3 additional activities (TR, BK, OW) are important to our projections in terms of obtaining an overall amount of hours but they are less critical to the projection of human resources needs for chronic home care providers.

Table 3. Activities for which people received help among Group A

Type of activity	N	Percentage*
PC - Personal care	83 029	51,3%
HC - House cleaning	72 663	44,9%
MP - Meal preparation	3 354	2,1%
GS - Grocery shopping	2 814	1,7%

* Percentage of people (among the group) that received help for a particular activity

Table 4. Activities for which people received help among Group C

Type of activity	N	Percentage*
TR - Transportation	16 581	8,0%
BK - Banking/bill paying	3 377	1,6%
OW - Maintenance/outside work	195 998	94,3%

Within Group B, as the number of activities increase, the proportion of people who receive mixed help increases and the proportion who receive from formal only declines from 33% to 3%. This reinforces the importance of informal sources of support to community dwellers (Figure 3). Our other work demonstrated that the proportion of hours in the mixed is primarily from informal sources of support. Based on these results it is recommended that we emphasize Group B membership in our projections and analyze by number of activities, age, sex and source of assistance.

Figure 3. Source of assistance of the care receivers, according to their activity group

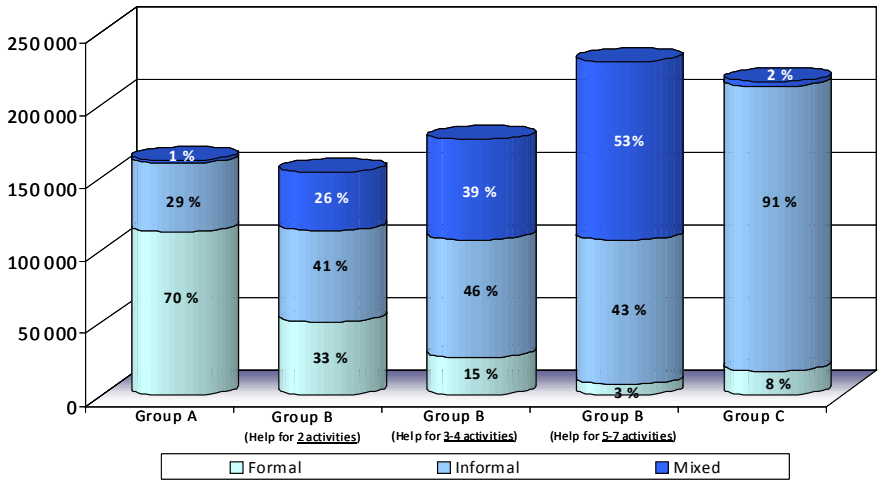
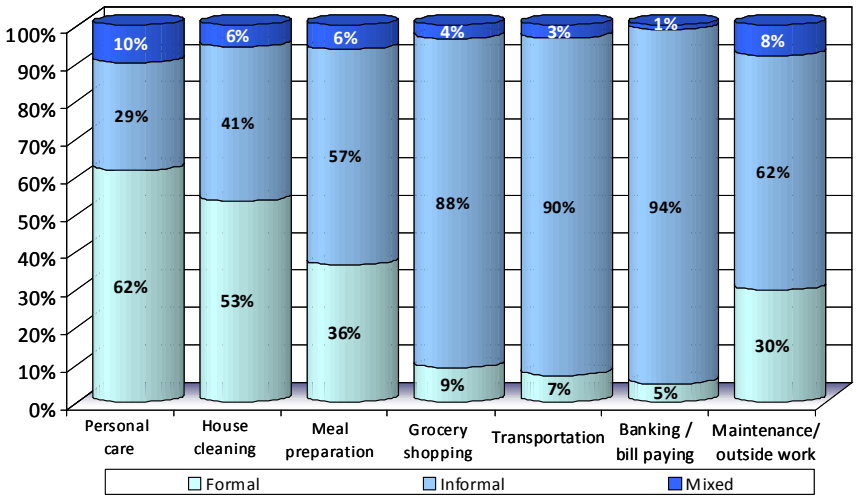


Figure 4. Distribution of the care receivers' source of assistance, for each individual activity



Findings confirm that certain types of activities such as banking/bill paying, grocery shopping, and transportation are in the domain of informal support with 11% or less receiving any formal support on these activities (Figure 4). Personal care and housecleaning, and to lesser extent, meal preparation, are activities where formal support are significant. These analyses represent source of assistance at one point in time (2002). Whether this portrait will continue with the upcoming baby boom cohort will need to be tracked.

Conclusion

Attempts to improve projections of future home care needs revealed the sensitivity of measures and the diversity within groups of care receivers. Specifically, increasing the number of activities taken into account has created a problem when using the median number of hours to calculate the future total number of hours of assistance per week. Our analysis demonstrates three distinct Groups within the 7 activities and reinforces the heterogeneity of the population aged 65 and older receiving assistance in the community.

Table 2 shows that there is a strong correlation between the median and the mean number of hours per week when our population is subdivided into 3 groups, the within group membership being more homogeneous than the two original scenarios (using either 4 or 7 activities). For example, the mean for Group B at 18.7 hours per week is close to the median for those who require assistance for 5-7 activities. Other analysts (for example, Linda Pikard and her colleagues from LSE) also focus on the supply of intense care provided for 20 or more hours a week for disabled older people.

These results provide us with the necessary evidence to support our approach to projecting human resource needs for chronic home care. While hours of help received by Groups A and C are important to our projections in terms of obtaining an overall amount of hours, we believe they are less critical to the projection of human resources needs for chronic home care providers. It is recommended that we emphasize Group B membership in our projections and analyze by number of activities, age, sex and source of assistance.

Understanding the characteristics of older persons in Groups A, B and C further demonstrates the continuum of services provided and the need to have multiple policies to meet the needs of the aging population. Source of assistance varies significantly depending on the type of activity. Subsidized home care may fit the needs of Group B but increased civic engagement both in terms of private enterprise (Group A) and informal support (Group C) will also be necessary.

References

Canadian Home Care Association. (2008). *Portraits of home care in Canada, 2008. Executive Summary*. Ottawa, ON: The Canadian Home Care Association.

Carrière, Y., Keefe, J., Légaré, J., Lin, X., & Rowe, G. (2007). Population aging and immediate family composition: Implications for future home care services. *Genus, LXIII* (1-2), 11-31.

Keefe, J., Légaré, J., & Carrière, Y. (2007). Developing new strategies to support future caregivers of the aged in Canada: Projections of need and their policy implications. *Canadian Public Policy*, *33*, S65-S80.

Wolfson, M & Rowe, G. (2004), "Disability and informal support: Prospects for Canada" in Cohen, S.B., Lepkowski, J.M. (eds.), *Eighth Conference on Health Survey Research Methods,* Hyattsville, MD; National Center for Health Statistics, 15-22.