

Balance of Care Research Group
University of Toronto

Formal and Informal Care for Older Persons: Assessing the Balance in Ontario

A. Paul Williams, Allie Peckham, Kerry Kuluski, Robin Montgomery, Frances Morton and
Jillian Watkins

Department of Health Policy, Management and Evaluation
University of Toronto

March, 2010

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Acknowledgements

This research was funded by the Ontario Ministry of Health and Long-Term Care, Research Unit, Health System and Planning and Research Branch, Health System Strategy Division, through a grant to the Hospital Management Research Unit, Department of Health Policy, Management and Evaluation, University of Toronto.

The authors gratefully acknowledge the valuable advice and information provided by Steering Committee and Expert Panel members for the Balance of Care Projects conducted in 9 regions of Ontario; findings from these Projects inform this report.

We also wish to acknowledge the valuable assistance of the Central and Toronto Central Community Care Access Centres for providing access to RAI-HC assessment data.

Executive Summary

1.0 Background

Informal caregivers (unpaid care provided by family, friends, and volunteers) play a crucial role in maintaining the health, wellbeing, functional independence and quality of life of community-dwelling older persons otherwise at risk of loss of independence. An emerging body of national and international evidence suggests that in addition to providing a range of direct instrumental and emotional supports, informal carers often serve as the main interface with the formal care system; they access and coordinate services on behalf of older persons who cannot manage on their own due to physical and mental deficits, isolation, and/or barriers related to language and culture (Fast, Eales, & Keating, 2001; Change Foundation., 2008; Change-Ability Inc., 2009; Keefe, Légaré & Carrière, 2009). This research aimed to address the balance between formal (paid care provided by professionals) and informal care for older persons and to determine how the presence or absence of informal caregiver(s) impacts on resource allocation decisions made by home and community care (H&CC) case managers.

In conceptualizing and conducting the analysis, a diagnostic and policy planning tool called Balance of Care (BoC) was used. The BoC was originally developed and applied in the UK and more recently it has been applied in 9 different regions across Ontario (Waterloo, Toronto Central, Central, North West, Central West, North East, Champlain, South West and North Simcoe Muskoka). The aim of the BoC is to determine the most appropriate mix of community-based and institutional resources at the local level (Challis & Hughes, 2002). This approach assumes the likelihood of long-term care (LTC) admission is due to two factors: the demand side which is based on the needs of people; and the supply side which is based on the capacity of the system to meet those needs in a community setting. BoC studies in the U.K. and Ontario have explicitly considered the presence or absence of informal caregivers in the home as a key factor impacting on the formal care needs of older persons and on the design of community-based formal care packages required to support older persons safely and cost-effectively in the community (Challis & Hughes, 2002; Carstairs, 2009). Thus, in addition to considering the balance between community-based and institutional care, the BoC provides a conceptual framework for investigating the balance between formal and informal care.

2.0 Data and Methods

This report used data from three sources:

- findings from the 9 Ontario BoC projects;
- in-depth follow-up interviews with case managers who participated in the Central BoC project, and;
- secondary analysis of home care utilization data from two regions of Ontario (Central and Toronto Central).

In each of the 9 regions where the BoC was conducted, expert panels of care managers from across the care continuum came together to review detailed vignettes (case profiles) based on key variables measuring functional and cognitive capacity as well as access to an informal caregiver in the home drawn from the Resident Assessment Instrument for Home Care (RAI-HC), an assessment tool used by CCAC case managers to assess individuals for home care and LTC placement. The expert panel members

constructed H&CC packages that would appropriately support the profiled individuals in a community setting. In-depth follow-up interviews (n=10) with case managers who participated in the Central BoC project were conducted to better understand why little consensus was reached on ways to support the informal caregiver. The qualitative data specifically set out to identify if ethno-racial variations, location of the caregiver and personal characteristics impacted on the decisions of case managers to allocate formal resources. Secondary analysis was conducted on home care utilization data from two regions of Ontario (Central and Toronto Central). These two jurisdictions were analyzed as they are contiguous, urban and multicultural. This is the first attempt to analyze the information collected concerning seniors and their caregivers by application of the RAI-HC. The secondary data analysis from Toronto Central was used to identify the characteristics of caregivers within this region. The analysis of utilization and costs was completed for the Central CCAC and included all clients who had a RAI-HC assessment. The secondary data analysis from Toronto was used to address how the provision of formal service may change if an informal caregiver is present and how the provision of services may change if the caregiver is living with the specified client, is living outside the home or is unable to continue to provide care.

3.0 Findings

- Among the key findings held during the BoC simulations was consensus among participants around the key role of informal caregivers in maintaining the health, wellbeing and independence of older persons; participants concluded, in fact, that the individual and caregiver should be considered an integral 'unit of care'.
- There was a lesser degree of consensus, however, on the extent to which the presence of an informal caregiver required additional formal services or whether informal caregivers in fact meant that fewer formal services were required. Expert panel members brought different views to the table, provoking vigorous discussion about what needed to be done for older persons and their caregivers.
- Having access to a caregiver was seen to have an impact on whether or not an older person could remain independently living in the community. Caregiver presence varied across all regions in Ontario. For example, in urban areas like Toronto many seniors live alone in apartments and condominiums. However, rural and remote areas are no more likely to have live-in informal caregivers. In part this similarity can be attributed to a large outflow of younger persons leaving remote areas for urban areas. Informal caregivers were most likely to be found in areas with large ethno-cultural communities.

Expert panel members suggested that caregiver contributions vary considerably and are dependent on certain caregiver characteristics, abilities and availability. It was identified through analysis of Toronto Central's data base that spousal caregivers provide more hours of informal caregiving than do adult children or other types of informal caregivers. Spousal caregivers are the most likely to provide personal care compared to adult children who tend to provide mostly IADL care. This difference in care provision was attributed to the functional limits a spousal caregiver may face when attempting to provide such IADL tasks.

Although there was consensus on the importance of assessing and supporting the informal caregivers, there was little agreement about how best to balance the use of formal services and informal care.

Different views and approaches were discussed during BoC simulations when outlining what services should be provided to the 'unit of care'. Care packages that were created revealed different approaches to supporting the whole 'unit of care'. The variation in service provision was evident both within regions and between regions. Some packages provide caregiver specific services such as a caregiver support group, while other packages provide services that ostensibly are aimed at the older person but also benefit the caregiver, such as congregate dining. While both services are mutually beneficial it is evident that the approach to supporting the unit of care can be variable.

Cultural diversity was discussed in detail during the BoC simulations. In regions such as Central and Central West the needs of individuals on the wait list were relatively high in comparison to other regions in Ontario. This difference, according to Steering Committees and Expert Panel participants, was attributed to the presence of large multigenerational and ethno-cultural communities that value aging within the family. The presence of informal caregivers does not however preclude the importance of providing formal supports in these communities. Expert panel members made it clear that failure to connect such populations with appropriate services could lead to crisis situations where older persons are not connected to the formal system until hospitalization or residential LTC is the only option.

Expert panel members viewed home care support as an important element towards preventing distress in caregivers. The analyses of Toronto Central's RAI-HC identified that there is a relationship between caregiver distress and level of home care support. Although this particular research cannot confirm a causal relationship, this analysis shows that distressed caregivers provide more hours of informal care and receive fewer hours of formal support.

The total amount of formal hours did not differ based on the presence of an informal caregiver (in any-capacity). Also, there was no significant difference in the total number of formal hours provided based on the relationship between the caregiver and the care-receiver. There was however significant differences in the mix of services provided; the secondary data analysis provided no clear pattern for service allocation decisions. Overall there were few systematic differences in actual patterns of home care utilization related to informal caregiving.

4.0 Conclusions

This research suggests that identifying the unit of care as including both the individual and their caregiver(s) is crucial for successful aging at home. All 9 of the BoC simulations addressed the importance of supporting informal caregivers and incorporated mutually beneficial services into the care packages.

When developing care packages for the 'unit of care' there was variation in and amongst regions. This variation allows for flexibility. Flexibility in decision making is useful for front-line case managers as one size does not fit all. However, this flexibility without accountability measures can leave room for idiosyncratic and perhaps inequitable decisions.

This research provided no clear pattern for service allocation decisions. There are two factors contributing to this finding; first, that decisions made by the Expert Panel Members counteract; and second, that decisions made by the case managers are bound by systemic constraints (e.g. caps on budgets).

There is an obvious gap in provincial frameworks for addressing the unit of care in H&CC packages. A provincially based agenda for developing best practices, innovations and guidelines to better inform resource allocation decisions at the community level is necessary. Currently there is growing consensus around the importance of informal caregivers in sustaining older adults in the community (Keefe, Légaré & Carrière, 2007; Hollander, Guiping & Chappell, 2009). However, there is no clear pattern around resource allocation decisions and what specifically should be done to best support the whole 'unit of care'. Future research will aim to address best practices in supporting the 'unit of care' in the H&CC setting with particular interest on diversity, geography and caregiver characteristics.

Formal and Informal Care for Older Persons in Ontario

1.0 Background

1.1 Goals and Objectives

This research examined the balance between formal and informal care for older persons in Ontario.

It aimed to:

- describe key informal caregiver characteristics;
- analyze how informal caregiver characteristics and needs impact on formal care decisions; and
- analyze how differences in actual utilization of formal home care services are related to the presence or absence, and characteristics of informal caregivers.

1.2 The Balance between Formal and Informal Care

In this report, **formal care** refers to a range of home care and community support services provided to older persons (as well as to other groups such as children with complex continuing care needs) by a mix of providers, some of which are contracted by the Community Care Access Centres (CCACs) including personal support workers, nurses, occupational therapists, physiotherapists, speech pathologists, and dietitians or provided by community support service (CSS) agencies, largely volunteer driven services including meals on wheels, congregate dining, transportation, adult day programs, caregiver respite programs, etc. Such services may be delivered in different settings including the family residence, supportive housing (typically an apartment building with built in services), elderly persons' centres, adult day programs or Alzheimer day programs. In Ontario, a range of formal home and community care (H&CC) services are funded in whole or in part by the Local Health Integration Networks (LHINs). CCAC services are fully publicly funded and free of charge to eligible individuals when available within provincially-set budgets and individual service ceilings. CSS services are partially funded by the province and usually involve user co-payments on a sliding scale geared to income; there is considerable variation in CSS availability particularly outside of urban areas. Formal care services may also be accessed on a pay-as-you-go basis through private commercial providers including retirement homes.

Informal care refers to a range of emotional and instrumental supports provided by social networks, neighbors, friends and family members. Informal care may also involve navigating formal services, linking individuals to services, and coordinating multiple services and providers in the home. Spouses and adult children constitute the main groups of informal caregivers in Ontario as in other jurisdictions. Most informal care is provided by women and for the most part, it is unpaid work (Williams, et al., 2005; Canadian Caregiver Coalition, 2009).

There are important, although not well documented, links between formal and informal care. For example, a recent report commissioned by the Ontario Ministry of Health and Long-Term Care estimates that over 70% of care to older persons is provided by informal caregivers with an economic value of \$21,004,806,165 health care dollars annually (Hollander, Liu, & Chappell, 2009). It also suggests that a continuing decline in informal caregiving, resulting from generalized social trends including a decline in traditional nuclear families and volunteerism, will result in heightened spending on formal H&CC or in greater reliance on residential long-term care (LTC) (Change-Ability inc., 2009).

From a different perspective, other research has noted that informal caregiving continues to be undervalued, and that a decline in such caregiving reflects, in part, a failure of the formal system to provide informal caregivers with sufficient supports. This failure is seen to stem from multiple factors including fiscal constraint, a continuing preoccupation with acute care, and the view that formal care should be provided only when families "fail" (Hollander, et al., 2007).

Two different, but related, perspectives emerge from the literature. On the one hand, formal care may be seen to “fill the gap” created when informal caregivers do not provide adequate care. This suggests a “substitution” effect where formal care may take the place of informal care, or vice versa. It may also suggest that if formal services are too readily available, informal caregivers may withdraw or reduce their efforts, driving up formal care utilization and costs (Stabile, et al, 2006).

On the other hand, formal care to informal caregivers may be seen to produce dividends since it can result in greater informal caregiver capacity. This “additive” effect suggests that by providing needed formal supports to informal caregivers, risk of caregiver burn out and withdrawal is minimized, capacity to support vulnerable persons at home is increased, and demand for formal care, including costly hospital and institutional services is moderated. However, even in this optimistic scenario, there are likely to be limits to an additive effect, a point at which added formal care produces no corresponding increase in informal caregiver capacity even as costs rise (Peckham, 2009).

The importance of understanding and documenting the balance between formal and informal care is highlighted by converging demand and supply side factors.

On the demand side, an aging population, a related increase in the number of older persons with multiple chronic health and social needs, and rising public expectations, combine to generate growing pressures on already strained, and increasingly costly formal care systems.

On the supply side, major policy shifts over the past two decades resulting in fewer hospital beds, shorter lengths of in-patient hospital stays, and greater reliance on out-patient care, have spurred greater demand for limited H&CC resources (Baranek, et al, 2004). Ontario data suggest that one result has been that a larger share of available H&CC resources has been directed toward post-acute care, with a smaller share available for ongoing care needs (Hollander, et al, 2007). While there is little systematic documentation and analysis, it is thought that a greater burden of care for older persons may now rest on informal caregivers even as informal networks experience decline (Carstairs, 2009).

Key questions arise. What care is provided by informal caregivers? What formal services do they receive? What is the optimal balance between formal and informal care for older persons?

1.2 Balance of Care Framework

In conceptualizing and conducting our analysis, we adapt the “Balance of Care” (BoC) model pioneered in the U.K. by Dr. David Challis and his colleagues at the Personal Social Services Research Unit (PSSRU), University of Manchester (Challis & Hughes, 2002).

The Balance of Care (BoC) is a planning tool which seeks to set evidence-based benchmarks for the most appropriate mix of community-based and institutional resources at the local level needed to support an aging population. While conventional projections of care needs often assume that a growing population of older persons will demand a proportionately greater number of residential LTC beds, the BoC emphasizes that the need for such beds will be determined as well by supply-side factors such as the availability of safe, cost-effective formal H&CC. Other things being equal, where adequate H&CC is more accessible, fewer residential LTC beds will be required and a greater proportion of older persons will be able to age successfully in the community.

The BoC also highlights the role of informal caregivers. BoC studies in the U.K. and Ontario have identified caregiver presence or absence as a key factor impacting on the formal care needs of older

persons and their ability to age at home (Clarkson, et al, 2005; Williams, et al, 2009). Where informal caregivers are present, older persons are more likely to avoid or delay institutionalization (Buhr, et al, 2006; Muramatsu, et al, 2007). However, informal caregivers may themselves require formal supports. Thus, in addition to considering the balance of community-based and institutional care, the BoC emphasizes the importance and complexity of the formal/informal care balance.

2.0: Data and Methods

This report draws upon multiple methods and data sources including:

- findings from Ontario BoC projects;
- in-depth follow-up interviews with case managers participating in one region of Ontario (Central Region); and
- secondary analysis of home care utilization data from two regions of Ontario (Central and Toronto Central Regions).

2.1 BoC Projects

To date, BoC projects have been conducted in 9 regions of Ontario:

- Waterloo-Wellington
- Toronto Central
- North West
- Central
- North East
- Central West
- South West
- Champlain
- North Simcoe Muskoka

With some exceptions, these projects have incorporated all of the stages outlined below. Additional details of the methods and findings of the Toronto Central BoC project may be found at <http://www.longwoods.com/home.php?cat=253>.

Stage 1: Steering Committees

BoC projects convene Steering Committees of 14 to 20 senior leaders of local organizations providing a range of health and social services to older persons. These leaders typically represent a broad continuum including hospitals, social services, community supports, home care, housing, mental health and addictions, primary care, and LHINs. Steering Committees provide advice and guidance, nominate individuals for Expert Panels (see below), review and validate project findings, and assist with knowledge transfer.

Stage 2: Stratification of LTC Wait Lists

Key multi-measure measures from RAI-HC (Resident Assessment Instrument – Home Care) assessments are used to stratify individuals on CCAC LTC wait lists into 36 relatively homogenous sub-groups. These measures are:

- cognitive performance including short term memory, cognitive skills for decision-making, expressive communication and eating self-performance (coded into 2 categories: intact, not intact);
- level of difficulty with ADLs (activities of daily living) including eating, personal hygiene, locomotion, and toilet use (coded into 3 categories: no difficulty, some difficulty, great difficulty);

- level of difficulty with IADLs (instrumental activities of daily living) including meal preparation, housekeeping, phone use, and medication management (coded into 3 categories: no difficulty, some difficulty, great difficulty); and
- presence of an informal/family caregiver in the home (coded into 2 categories: present, not present).

Stage 3: Analysis

Each of the 36 sub-groups defined is assigned a name, and the number of wait-listed individuals in each sub-group is determined. For example, the first, relatively low needs sub-group, containing individuals who are cognitively intact, experience no difficulty performing ADL or IADL tasks, and have a caregiver living with them, is named “Appleton.” In contrast, the 36th sub-group, named “J. Johns,” contains individuals who are not cognitively intact, cannot perform ADL and IADL tasks independently, and do not have a caregiver living with them.

Stage 4: Vignettes

“Vignettes” (detailed profiles based on the RAI-HC data) are developed for typical individuals in sub-groups populated with sufficient numbers of individuals to warrant analysis; this minimum is set at 2.5% or more of those wait listed. In Ontario projects, between 13 and 15 sub-groups have met this numbers threshold, accounting for 87% or more of wait-listed individuals.

Stage 5: Expert Panels

Expert Panels are convened including 15 to 20 experienced front-line case managers from local provider organizations across the health and social care continuum (including health care services, social services, hospitals, community support services, CCAC, seniors’ homes, community mental health, and primary care). Expert panels review vignettes and construct H&CC care packages needed to support typical individuals in each vignette safely and appropriately in the community.

Stage 6: Costing and Divert Rates

Costs are estimated for each H&CC package constructed. “Divert” rates are calculated by comparing costs for each H&CC package for a 13 week period against the costs of a residential LTC bed for the same period. To ensure “apples-to-apples” comparisons, only direct LHIN costs are included in these calculations; user fees and co-payments are excluded. Where the direct LHIN cost for an H&CC package for a sub-group is less than or equal to the direct LHIN cost of a residential LTC bed, individuals in this sub-group are considered as potentially H&CC “diverts.” Overall divert rates are estimated by summing up the total number of individuals in divertible sub-groups, and dividing by the total number of individuals in all sub-groups retained in the analysis.

2.2. In-Depth Follow-Up Interviews with Case Managers

In-depth follow up interviews were conducted with 10 case managers who had participated in the Central LHIN BoC project conducted in the summer of 2008. These case managers represented a continuum including community support services agencies, CCAC, and supportive housing. These interviews aimed to develop a “richer” understanding of the logic underlying the allocation decisions made by BoC expert panels, and particularly, how informal caregiver needs were taken into account. The following in-depth interview questions asked:

- What role do informal caregivers typically play in caring for frail older adults in the community? What role should they be expected to play?
- What are the characteristics of informal caregivers?

- How do caregiver roles, characteristics and needs differ across ethno-racial communities? How should differences be taken into account when making decisions about care packages for older adults?
- Would the [formal] services provided change if the informal caregiver was a:
 - Live in caregiver- spouse
 - Live in caregiver- adult child or children
 - Out-of-house caregiver- adult child or children
 - Out-of-house caregiver- friend, neighbour
 - Long-distance caregiver

Interviews were conducted in the fall of 2008. With the written permission of the interviewees, they were audio recorded and transcribed, and then analyzed using Nvivo software.

2.3. CCAC Home Care Utilization Analysis

We also conducted descriptive analysis of home care utilization data from two regions in which BoC projects had been conducted and where utilization data were accessible: Central and Toronto Central. The aim was to determine how the presence or absence, and characteristics, of informal caregivers, impacted on patterns of formal home care utilization.

The Toronto Central analysis included 9,143 individuals who had received RAI-HC assessments; were waiting for residential LTC, or were classified as long-stay clients; and were receiving or had received CCAC home care services. The Central analysis included 12,857 individuals meeting the same criteria.

Where available, data from two sections of the RAI-HC were analyzed:

- “Section G: Informal Support Services” which identifies individuals receiving home care services, those with informal caregivers, and key caregiver characteristics (e.g. relationship to client and caregiver living arrangements); and
- “Section P: Service Utilization” which records the mix and volume of home care services provided.

2.4 Analysis of Overall Health Care System Utilization and Costs

A more thorough analysis of home and health care utilization was conducted as part of a related project (see Appendix A). This project, conducted at the Institute for Clinical Evaluative Sciences (ICES), was lead by one of our team members (Wodchis). It linked CCAC RAI-HC assessment data with CCAC home care utilization data, OHIP data, and data on hospital and rehabilitation services, to document and analyze overall patterns of health care utilization and costs for older persons currently on LTC waiting lists.

This analysis included three cohorts of Central CCAC clients who had a RAI-HC assessment. The cohorts were defined as of March 31, 2007 and all health care utilization was tracked for one year from April 1, 2007 until March 31, 2008. The analyses included 13,223 clients in the first cohort; 637 in the second, and 681 in the third.

3.0 Findings

3.1 Unit of Care

While representing different regions of Ontario with different population and health system characteristics, BoC expert panel and steering committee participants unanimously agreed that within home and community, the unit of care includes both the individual and caregiver. They also identified

the presence or absence of a caregiver as a crucial determinant of whether or not older person, particularly those with cognitive deficits, can remain at home.

In contrast to acute care, where individual patients, or body parts (e.g., hips and knees, eyes, heart), are treated apart from their social context, in H&CC, older persons often have multiple social and health needs, and care from multiple sources and providers must be accessed and coordinated. Here context matters and informal carers are at the centre of this context. The unit of care extends beyond the individual to include family members, neighbors and friends. In addition to providing direct instrumental and emotional support, informal caregivers may also access and coordinate formal services, particularly for individuals experiencing limitations due to factors including cognitive decline, dementia, poverty, isolation, lack of education, culture, and language.

Also, in contrast to acute care, where the focus is on the time-limited treatment and cure of episodic illness, in home and community care (H&CC) the emphasis is more often on managing chronic conditions, maintaining the highest level of functional capacity and well-being possible, and assisting older persons to adapt to changes that are part of the normal aging process.

Although there was considerable variation in the mix and volume of H&CC services recommended by expert panels in different regions of Ontario (see sections below), virtually all BoC care packages included formal supports for caregivers when they were present. While increasing the total costs of H&CC packages, it was felt that failing to include them would send the wrong message. Informal caregiver needs and supports were seen to be inseparable from the needs of older persons.

Expert panel and steering committee participants also emphasized that because of this both needs assessments and care planning should be done jointly, not separately. It was noted in this connection that while widely used as a guide for resource allocation, MAPLe (Method of Assigning Priority Levels) scores specifically do not take into account informal caregiver characteristics and needs.

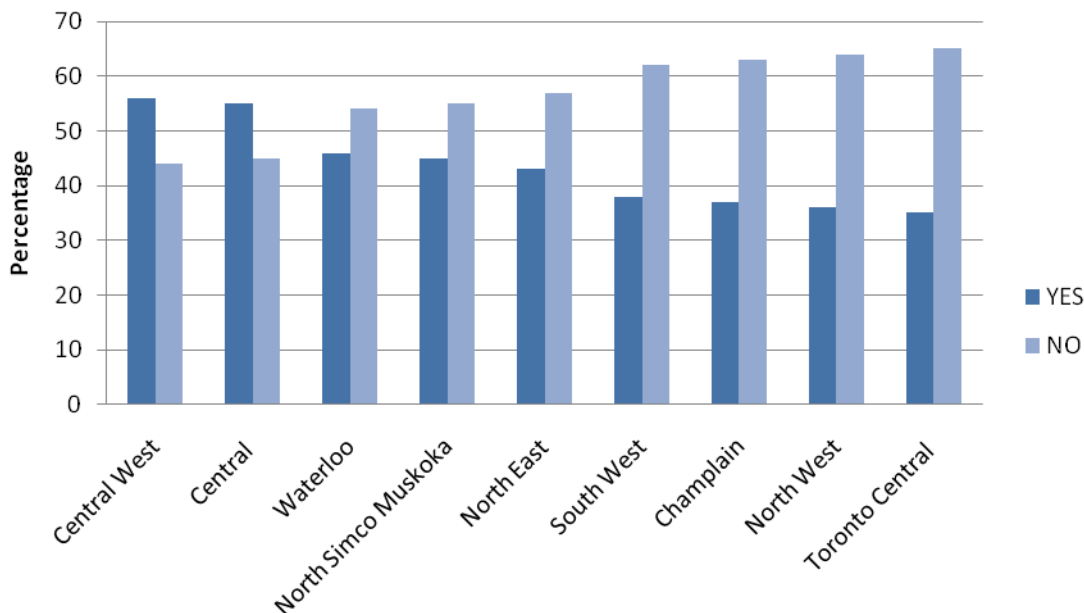
3.2 Caregiver Presence

A second key finding is that caregiver presence varies considerably across regions of Ontario.

As noted earlier, the presence or absence of an informal caregiver in the home was one of four key measures used to stratify LTC wait-listed individuals in Ontario BoC projects. This is a relatively conservative measure in that it does not take into consideration others, including friends, neighbors and family members living outside the home, who might also provide some level of informal care. Nevertheless, steering committee and expert panel members agreed that having a live-in caregiver, particularly for older persons requiring 24/7 monitoring, was critical for one's ability to age at home.

The following table illustrates this variability. Wait listed individuals in Toronto Central were least likely to have caregivers living with them; only about a third reported a live-in caregiver. Live-in caregivers were most likely to be present in Central West where close to two thirds of those waiting for LTC had caregivers at home. Arrayed between Toronto Central and Central West were regions like Champlain, where less than 40% of wait listed individuals had caregivers, and Central, where those with live-in caregivers outnumbered those without.

Caregiver Living with Client?



Such variations were seen by steering committee and expert panel members to stem from different factors. In urban areas like Toronto, an increasing number of older persons live alone in apartments or condominiums. Interestingly, a growing number of older persons in rural and remote areas now also live apart from informal caregivers likely due to an outflow of younger persons following jobs and education to cities, and an inflow of older persons wishing to retire in cottage country.

Higher proportions of live-in caregivers in regions like Central and Central West were thought to reflect a combination of the availability of larger homes and the presence of new immigrant communities, particularly those from Asia (in Central) and South East Asia (in Central West). One result was a large number of multi-generational extended families including caregivers living together in single households. It was also noted that these communities typically place great emphasis on maintaining individuals in the home, even those at high levels of need. Further research will look at caregiver trends in urban and rural areas and areas with large ethno-cultural populations.

3.3 Caregiver Characteristics and Contributions

Access to an informal caregiver was seen to play a key role in determining whether or not older persons could remain independent, particularly at higher levels of need. However, it was emphasized that even when living in the same home, the characteristics and contributions of informal caregivers varied considerably.

Case managers distinguished between caregivers who are adult children and spouses. While adult children are generally more able to provide needed (IADL) care (as they may be more physically able), they are less likely to live in the same household, and they may have families of their own to care for. Moreover, they may be less likely to wish to participate in intimate personal activities such as toileting and bathing. In this connection, concerns were raised about the stresses confronted by a growing number of caregivers in the “sandwich generation” who were primary caregivers both to children and parents.

By contrast, although spouses were more likely to live in the same dwelling and to be available on a 24 hour basis, their caregiving capacity, due to age and ability, tended to be more limited, with many

requiring formal supports themselves. Typically, this was the story of the 85 year old wife caring for her 86 year old husband.

Friends and neighbors who did not live in the home also made important contributions, although usually on a more casual basis. It was observed that friends and neighbors often limited their role to providing emotional and instrumental support (e.g., housekeeping, grounds keeping, transportation, shopping).

It was also noted that whether an adult child, spouse, relative or friend, most informal caregivers were women providing care as unpaid work. Although often treated as “free,” such work directly impacted on a women’s ability to participate in the paid workforce, and to build up employment-based pensions, increasing the burden as they age, particularly if their spouse dies and they have to live on a single income (Armstrong, et al, 2002).

The RAI-HC data from Central Region revealed the following caregiver characteristics:

- more than half of informal caregivers (56%) were adult children, followed by spouses (30%) other relatives (10%) and friends/neighbors (5%);
- 70% of spouses provided support for ADLs including such “heavier care” tasks as bathing and toileting. Just over a third of children (37%) and a quarter of relatives (28%), friends and neighbors (24%) also provided supports for ADLs;
- nine in ten spouses (91%), and similar numbers of children (86%), provided supports for IADLs including such “lighter care” tasks as transportation and meals. Almost three quarters (73%) of relatives and friends/neighbors also helped with IADL tasks; and
- more than 90% of all informal caregivers provided advice and emotional support.

Type of Care Provided by Each Type of Informal Caregiver (Central)

Type of Support Provided	Spouse (N=1883)	Adult Child (N=4419)	Other Relative (N=1294)	Friend /Neighbor (N=812)
IADL*	91%	86%	73%	72%
ADL*	70%	37%	28%	24%
Advice & Emotional Support*	98%	98%	94%	93%

*p<0.05

* Note: The RAI-HC data does not provide information on the age, sex or ethnicity of caregivers.

While they tended to provide different types of supports, few differences were observed in the actual hours spent caregiving by adult children and spouses. In Toronto Central, both averaged more than two full working days per week caring for older persons on wait lists for LTC -- while spouses said they provided just less than 19 hours of care per week, adult children provided almost 18 hours.

Comparison of Total Hours Spent by Informal Caregivers (Toronto Central)

Type of Informal Caregiver	Mean Hours Per Week	Number of Cases (%)
Spouse	18.9	1648 (23%)
Adult Child	17.7	3809 (52%)
Other Relative	17.5	1120 (15%)
Friend/Neighbour	6.2	715 (10%)

Not Statistically Significant

Total Missing Cases = 1116

Case managers flagged the negative consequences of caregiver distress and burn-out for caregivers, who often themselves required care as a result; for care recipients, who often experienced a decline in support; and finally for the formal system, since both the caregiver and the care recipient often required additional care, including hospital and institutional care. However, thresholds for experiencing distress and burn-out were seen to be highly variable. Key considerations, in this respect, were the physical and mental capacity of the caregiver, as well as cultural attitudes about the role of women and the obligations of families to support their members.

The table below presents results from analysis of Toronto Central RAI-HC data. Caregiver distress was defined as stating they are unable to continue in caregiving activities. Accordingly, 9% of caregivers indicated that they experienced distress; these individuals averaged significantly more hours of informal caregiving (20 hours per week) than those caregivers who were not distressed (7 hours per week). This suggests a threshold of just above 2 working days per week beyond which some caregivers may experience burn out. Note that many caregivers in Toronto Central were close to or had already exceeded this threshold.

Comparison of Total Hours Spent by Distressed and Not Distressed Caregivers (Toronto Central)

Distressed?	Mean Hours Per Week	Number of Cases (%)
Yes: cannot continue providing care	19.7	99 (9%)
No: can continue to provide care	7.4	7234 (91%)

Total Missing Cases = 1210

*p<0.05

3.4 Balancing Formal and Informal Care

As noted, BoC steering committee and expert panel members consistently emphasized the importance of assessing and supporting the needs of informal caregivers and at risk older persons as a single unit.

Case managers agreed on the following:

- In addition to directly providing supports for ADLs and IADLs, caregivers often also function as case managers and “air traffic controllers.” This role is particularly vital when older persons experience cognitive decline, coupled with increased IADL and ADL needs, decreased capacity to communicate needs, and increased resistance to dealing with unfamiliar faces. As such, informal caregivers may serve as the link to the formal system, and coordinate formal services and providers in the home.
- The capacity of and needs of informal caregivers, as well as older persons, must be considered simultaneously when constructing formal care packages. For example, if an older person has a live-in caregiver who is capable of providing instrumental support, services such as meals on wheels and meal preparation may be less crucial, while other services, such as caregiver counseling and respite may be more crucial.
- Caregivers may benefit directly from a range of caregiver-specific supports including: caregiver counseling, education, support groups, in-home respite, and LTC short stay respite. However, they may also benefit from services provided to the older person, so that considerable economies can be achieved when formal supports for older persons and informal caregivers are integrated into a single package. This is because H&CC services can often be substituted one for another, and because they can serve more than one individual’s needs. For example, in addition to providing older persons access to nutrition, socialization, and instrumental supports such as medications checks, adult day programs can also provide the caregiver with respite, emotional support, and connections to additional services as required. Services such as housekeeping and home maintenance can reduce the burden on both the older person and the caregiver, a particularly important objective when caregivers are themselves older persons.

However, there was less agreement on exactly what should be done.

There were two general lines of thought paralleling those in the literature. The first was that by supporting caregivers, their capacity to provide informal care increased, and the risk of caregiver distress and withdrawal was minimized. This was seen to be particularly true for spouses, who tended to be older, and often experienced limits to their functional capacity. However, it also applied to other caregivers, including adult children, who often cared for their own families as well.

In contrast, the second line of thought, while still advocating for caregiver support, cautioned against anything more than a minimum, particularly when caregivers were not experiencing distress. The logic was that as formal services increased beyond a basic level, informal caregivers tended to withdraw, leaving a vacuum to be filled by additional formal services. Instead of contributing to independence, and system sustainability, the wrong mix and volume of formal services could instead create greater dependence both for caregivers and for older persons, and generate additional system costs.

These different lines of thought were evident when constructing BoC H&CC packages in different regions of the province. Case managers brought different views to the table, provoking vigorous discussion about what needed to be done for informal caregivers. While differences were always resolved, it was observed that on a day-to-day basis, there were few opportunities for such discussion, and few best practices or guidelines to inform case managers as they made allocation decisions. Case managers

noted that while there are regulations, service limits and protocols pertaining to care recipients, there is little advice on how the needs of informal caregivers should be addressed. While leaving room for flexibility and innovation, this could also produce inconsistent or inequitable decisions.

3.5 Case Studies: Copper and C. Cameron

As examples of how approaches to care for caregivers varied, we present care packages for two different BoC subgroups (Copper and C. Cameron) constructed in two different regions of the province (Toronto Central and North Simcoe Muskoka).

The first pair of H&CC packages presented below is for “Copper,” one of the lightest needs BoC subgroups. Copper has a live-in caregiver, is cognitively intact, has low ADL needs, and moderate difficulty with IADLs.

Reflecting the experience of other Ontario BoC projects, both of these packages include care for Copper and Copper’s informal caregiver. They also reflect different approaches to providing this care. For example, a “Caregiver Support Group” is included in the Toronto Central package. In addition to providing advice and emotional support, such groups give Copper’s caregiver an opportunity to engage with people experiencing similar challenges. Of course, Copper’s caregiver also benefits indirectly from other services such as congregate dining which get the older person out of the home for a predictable period, thus allowing the caregiver some time off, and reducing effort spent in meal preparation. Likewise, home maintenance, home help, and in-home support benefit the older person and the caregiver, as both require a safe, livable environment.

The North Simcoe Muskoka package also includes direct and indirect supports for caregivers. For example, caregiver respite is embedded in a generic category titled “personal care and support;” additional supports may be derived from other categories including “care coordination,” “programs and services” and “home maintenance.”

Care Packages for Copper: Toronto Central and North Simcoe Muskoka

Toronto Central		North Simcoe Muskoka	
Service	Frequency	Service	Frequency
Meals on Wheels	3 times per week	Care Coordination (LTC, financial, future planning, screening and prevention)	2 hours initial visit + 1 hour per month ongoing
Caregiver Support Group	Once per month	Caregiver Support	Nil
Personal Care and Support (provided by PSW)	2 hours per week	Personal Care and Support – bathing, meal preparation, laundry, housekeeping, caregiver relief, grocery shopping, medication monitoring (provided by PSW)	2 hrs per week
Programs and Services Congregate Dining	Once per month	Programs and Services Seniors centre (social recreation)	1 half day per week
In-Home Help/Homemaking	2 hours every other week	Professional Health Care Services (OT, Nursing, PT, Social Work, Dietician, Speech Therapist)	\$80/13 weeks envelope
Home Maintenance Snow removal, yard work, home maintenance	Once per month	Home Maintenance Snow removal, yard work, home maintenance	2 hrs per week
Transportation	1 round trip per week	Transportation	2 round trips per week
Occupational Therapist	Assessment once a week (total 2 visits)	Blister Pack for medication management, including home delivery	
		Physical and Mental Wellness (may include SMART program visit, SIM training, Gym membership, yoga etc.)	\$60 per month

The second set of care packages (see below) is for “C. Cameron.” Individuals in this sub-group have considerably higher needs than those in “Copper:” they are not cognitively intact, have moderate difficulty with ADLs, and high difficulty with IADLs. Like Copper, C. Cameron has a live-in caregiver.

Reflecting the relatively high needs of individuals in the “C. Cameron” sub-group, H&CC packages for Toronto Central and North Simcoe Muskoka are much “busier”: they include a greater range and volume of services.

In the Toronto Central package, caregiver supports are again both direct and indirect. For example, the category titled “caregiver support” includes a mix of services such as in-home respite, caregiver support groups, counseling, education, and social work support. Likewise, “LTC (long-term care) respite” refers to the program which allows older persons to occupy a residential LTC bed for a limited period of time (in this case two weeks per year) without formally being admitted to LTC; the aim is to give caregivers a scheduled period of time off. In addition, caregivers receive indirect support through CCAC in-home PSW services, home maintenance, and client case management.

In the North Simcoe Muskoka package, indirect caregiver supports derive from services including personal care to the older person, home maintenance, day programs which provide a form of respite to the caregiver, case management, and home maintenance. However, this package also contains a budget of \$250.00 per month to cover some combination of direct caregiver supports including, but not limited to, PSW help, counseling, support group, neighbor visit, respite (short stay), and First Link (Alzheimer’s Society support program).

Care Packages for “C. Cameron”: Toronto Central and North Simcoe Muskoka

Toronto Central		North Simcoe Muskoka	
Service	Frequency	Service	Frequency
In-Home Support (Provided by PSW)	2 hours per day	Care Coordination (LTC, financial, future planning, screening and prevention)	6 hours initial visit + 1 hour per month .
Caregiver Respite (paid)	10 hours per week	Caregiver Support [PSW, counseling, support group, respite (short stay), First Link (Alzheimer’s Society support program)]	\$250 per month
Caregiver Support/Educational Group	Once per month	Personal Care and Support – bathing, meal preparation, laundry, housekeeping, caregiver relief, grocery shopping, medication monitoring	10 hrs per week
Programs and Services Adult day service	2 days per week	Programs and Services 5 day program visits (social recreation)	\$500 per week
In-Home Help/Homemaking	2 hours every other week	Professional Health Care Services (OT, Nursing, PT, Social Work, Dietician, Speech Therapist)	\$480 (6 visits)
Home Maintenance Snow removal, yard work, home maintenance	Once per month	Home Maintenance Snow removal, yard work, home maintenance	2 hrs per week
Transportation	10 round trips per month	Transportation	6 round trips per week
Occupational Therapist	1 visit per week (total 4 visits)	Blister Pack for medication management, including home delivery	
Meals on wheels	6 per week		
CCAC Nursing- Medication Management	Once per month		
LTC Respite	Once every 6 months		
Blister Pack	Once per week		

In summary, these packages emphasize that care for caregivers is seen by front-line case managers across the province as an integral element of H&CC packages. They also demonstrate different approaches to supporting caregivers: H&CC packages include direct supports such as caregiver respite, as well as indirect supports through services such as congregate dining, which provide nutrition and social connection for the older person, but also respite and a reduction of meals preparation for the caregiver. By assessing and responding to the needs of older persons and their caregivers as a unit, there is considerable potential to provide appropriate care and achieve efficiencies.

3.6 Cultural Diversity

Expert Panels and follow-up interviews consistently identified diversity as a key factor impacting on the balance between formal and informal care for older persons. Cultural diversity was defined broadly to include ethno-cultural differences as well as differences in sexual orientation. In addition to impacting on what and how formal services are delivered, cultural diversity was specifically seen to impact on the “tipping point” for residential LTC.

It is worth noting that while there is a vast literature pointing toward the importance of diversity in health and social care, and in services for older persons, neither CCAC administrative data nor RAI-HC assessment data record ethno-cultural background or sexual orientation. Although language may be used as a proxy for ethno-cultural diversity, it can miss important ethno-cultural differences (e.g., individuals identifying as Caribbean often speak English as a first language), and no proxies were suggested for sexual orientation. Nevertheless, our qualitative data provided a number of key observations.

A first observation is that cultural diversity impacts on the design and delivery of formal H&CC at all levels. “Culturally competent” or “culturally appropriate” services and programs were seen to be provided, whenever possible, in the language of the recipient and caregiver; these programs built-in ongoing education and support for staff around issues of cultural sensitivity and differences; where possible, they recruited workers from the communities being served and engaged community representatives in program design and delivery; they provided familiar foods; and they pro-actively identified and addressed barriers to access to needed care experienced by diverse communities.

As a result, culturally competent and appropriate programs and services were seen to come with a cost. For instance, it was noted that training staff takes time and resources which have to be budgeted. Food preparation, particularly where specific combinations of food products may not be combined (e.g., meat and dairy), can require separate preparation facilities. However, such costs will vary depending on existing infrastructure and capacity. For example, costs may be lower where communities already have well-established service infrastructures and where trained workers are more readily available (such as the Chinese community in Toronto), as compared to communities with less well established infrastructures and human resources pools (such as the Somali community in Toronto). Instead of attempting to estimate exact costs, the approach taken in three BoC projects, in regions characterized by newly established and growing ethno-racial communities, was to add a “diversity overhead” to H&CC packages. For example:

- In Central West, the Expert Panel added 5% of the total package cost to each H&CC package to cover system navigation for individuals from diverse communities
- In Central, 2% of the total package cost was added for interpretation and translation
- Similarly in South West, 2% of the total package cost was added for interpretation, translation and cultural competence

Steering Committee and Expert Panel participants also emphasized that cultural diversity impacts on the balance between formal and informal care, and on the ability of older persons to age at home. As noted, case managers observed that large, multi-generational households tend to be prevalent in some ethno-racial communities, in some areas of the province. For example, an emerging East Asian community in Central West tends to be concentrated in urban and sub-urban areas where there are large houses, supporting extended families. In such households, which often include multiple informal caregivers, older persons with relatively high levels of need may be supported at home, in a culturally appropriate environment, with relatively few formal services. However, it was also observed that in

some instances, such households attempted to support older persons beyond a safe point, leading to hospitalization or emergency placement in residential LTC.

Case managers also observed that:

- Some cultural communities (e.g., Italian, South East Asian and Caribbean) are less likely to wish to accept formal services. In such communities, the need for formal services may be seen as a reflection of the family's failure to support their aging relative, resulting in feelings of guilt and shame.
- Emerging ethno-racial communities are more likely to live in multigenerational households, facilitating financial stability and providing built-in support for children and older persons. However, such households may also "mask" individual needs from the formal system, and act as a barrier to formal services, so that when informal capacity is exceeded, few community care options remain and the tipping point for residential LTC is high.

It is important to note, that in Central West and Central, both characterized by large emerging ethno-racial communities, but relatively underdeveloped formal H&CC service infrastructures, the threshold or "tipping" point for residential LTC was relatively high; those on LTC wait lists in these regions tended to have higher levels of need than individuals elsewhere. Although the RAI-HC data are insufficient to demonstrate a direct link, steering committee and expert panel participants concluded that this was due to the presence of relatively dense informal social networks; as a result, many older persons continued to age at home at relatively high levels of need, but without formal services. On the downside, when informal networks did fail, crisis often ensued for the older persons who often required emergency placements, accompanied by considerable anxiety and distress for families.

3.7 What Do Caregivers Actually Receive?

We conducted descriptive analysis of Toronto Central RAI-HC data to examine:

- differences in home care hours related to caregiver characteristics (e.g. spouse vs. child; distressed vs. not distressed); and
- differences in the mix of home care services provided to caregivers.

For the purpose of this analysis, we included all individuals on the CCAC LTC wait list, as well as those classified as long-stay clients.

The following table summarizes the total formal service utilization hours provided to informal caregivers. Although spouses tend to be older and less able than children, and more likely to provide "heavier care," there was no significant difference in total hours of formal home care received.

Total Formal Hours Received by Informal Caregivers (Toronto Central)

Relationship of Informal Caregiver	Mean Hours Formal Care Per Week	Number of Cases (%)
Spouse	6.1	1871 (22%)
Adult Child	6.3	4379 (52%)
Other Relative	6.6	1282 (15%)
Friend/Neighbour	6.4	804 (10%)

Not Statistically Significant
Total Missing Cases = 72

However, we did observe significant differences in the mean number of home care hours provided to informal caregivers who we categorized as “distressed” (unable to continue to provide care) and “not distressed” (able to continue).

Total Formal Hours Provided to Distressed and Not Distressed Caregivers (Toronto Central)

Distressed?	Mean Hours Formal Care Per Week**	Number of Cases
Yes: cannot continue providing care	4.9	823 (9%)
No: can continue providing care	6.3	8237 (91%)

Total Missing Cases = 735

**p<0.01

Interestingly, these data show that “distressed” caregivers averaged fewer hours of formal care than their counterparts: 4.9 hours per week as compared to 6.3 hours. While initially counter-intuitive, since we expected to see distressed caregivers receive more formal hours, it could also be that fewer formal supports may contribute to distress. Further research is necessary to clarify the relationship between caregiver distress and hours of formal care.

We also observed statistically significant differences in the mix of formal services provided, although it is not clear what these differences reflect. For example:

- If a caregiver was present, CCAC clients averaged more hours of Home Health Aides.
- If a caregiver was not present, clients averaged more hours of care from Visiting Nurses.

Formal Care Hours for Persons with a Caregiver in Any Capacity Compared to No Caregiver (Toronto Central)

Service		Mean Hours Per Week (M)	Number of Cases (%)
Home Health Aide	Caregiver In any capacity	2.75**	8315 (92%)
	No Caregiver	2.01	747 (8%)
Visiting Nurses	Caregiver In any capacity	.40	8314 (92%)
	No Caregiver	.55*	749 (8%)
Speech Language Pathology	Caregiver In any capacity	.00	8316 (92%)
	No Caregiver	.00	749 (8%)
Homemaking	Caregiver In any capacity	1.73	8315 (92%)
	No Caregiver	1.42	747 (8%)
Meals	Caregiver In any capacity	.85	8316 (92%)
	No Caregiver	.79	749 (8%)
Volunteer	Caregiver In any capacity	.02	8316 (92%)
	No Caregiver	.02	749 (8%)
Occupational Therapy	Caregiver In any capacity	.06	8316 (92%)
	No Caregiver	.07	749 (8%)
Day Center	Caregiver In any capacity	.37	8316 (92%)
	No Caregiver	.19	749 (8%)
Social Worker	Caregiver In any capacity	.03	8316 (92%)
	No Caregiver	.25	749 (8%)

Total Missing Cases = 4
 (* $p < 0.05$, ** $p < 0.001$)

Overall, we observed few systematic differences in patterns of home care for informal caregivers. Although the data analyzed do not allow us to determine why this is the case, case managers on BoC expert panels observed that:

- While case managers have considerable discretion in the mix and volume of services they provide to caregivers and older persons, they work within a variety of external constraints including budgets and provincial service ceilings which reduce variation particularly among individuals at higher levels of assessed need who have reached or are close to their service maximum (note that CCAC service ceilings were recently lifted for individuals on LTC wait lists although not for long-stay clients). Moreover, some services may be more or less accessible, particularly outside of major urban areas.
- While collectively emphasizing the needs of caregivers, individual case managers may respond in different, and sometimes countervailing ways, in effect, washing out patterns. For example, while some case managers said they would provide additional support for caregivers who also

had paid employment, others suggested that fewer supports might be warranted since such individuals were likely to be more capable and would likely have more access to social outlets. Case managers noted that a range of additional factors such as sex, age, family composition, economic status, and of course, individual preferences, also impact on their resource allocation decisions, producing considerable variation.

4.0 Conclusions

In this report we have used the Balance of Care framework, and multiple data sources, to examine the balance between formal and informal caregiving for older persons in Ontario.

Our findings suggest a number of key conclusions.

First, in H&CC sector, the older person and the informal caregiver together define the unit of care. In acute care where individuals (or body parts) are treated on a short-term episodic basis apart from their social environment, caregivers may play important, although more limited roles. By contrast, in H&CC, where care is often complex and ongoing, informal caregivers play more central and demanding roles over extended time periods, often to end-of-life. In addition to providing direct instrumental and emotional supports, informal caregivers make links to needed formal care and they coordinate multiple formal services and service providers in the home.

Second, the presence of informal caregivers varies considerably across Ontario. In urban areas like Toronto where many older persons live alone in apartments and condominiums, only a minority of LTC wait listed individuals live with a caregiver; however, older persons in rural and remote areas of the province such as the North West, may be no more likely to have a live-in caregiver due to an outflow of younger persons following employment to urban areas. Interestingly, informal caregivers are most likely to be present in Central, Central West and South West, with the former two regions characterized by large emerging ethno-cultural communities, and the latter characterized by a relatively stable, mostly rural, population.

Third, even when informal caregivers are present in the home, they may contribute in different ways and have different needs. Spouses, for instance, are more likely to spend considerable time (about two working days per week) providing “heavier” personal care such as bathing and toileting. However, compared to adult children who tend to provide “lighter care” IADLs, they are older and more likely to face functional limits related to aging.

Fourth, there appears to be a relationship between caregiver distress and the level of home care support. While the data cannot show a causal relationship, “distressed” caregivers provided more hours of informal care but received fewer hours of formal care than those who were not distressed. Since it doesn’t seem likely that formal home care hours would be cut when an informal caregiver indicated that they could not continue to care for an older person, this finding may reflect the consequences of too few formal supports leading to increased burden.

Fifth, H&CC care packages for individuals at similar levels of need revealed considerable variation by region. In some regions, direct supports were emphasized; in others, there was more emphasis on indirect supports. Such variations clearly reflect regional variation in service availability, and well as different approaches to caring for caregivers. They also demonstrate the value of addressing the needs of both the caregiver and the care recipient as an integrated whole since services can benefit both, and since different services can be substituted for the same purpose. For example, adult day programs provide a range of benefits to older persons including ongoing assessment, emotional support,

medications management, nutrition, personal care and social activation; they also benefit informal caregivers by providing respite, as well as help with the older person's ADLs and IADLs.

Sixth, although Balance of Care projects have focused primarily on establishing evidence-based benchmarks for the optimal mix of community-based and institutional resources within the formal system, it seems clear from the data presented in this report, that the formal/informal balance is equally as important. Recall that a main hypothesis of BoC projects is that access to community-based services is critical in determining need for residential LTC; where fewer such services are available, the needs threshold or tipping point for residential LTC will be lower and it will appear that more beds will be needed. However, our data suggest that even in regions like Central and Central West where home and community service infrastructures are relatively underdeveloped compared to population size and growth, the tipping point for LTC is relatively high; individuals on LTC wait lists in these regions have high needs compared to other regions. The missing link, according to steering committee and expert panel participants, is related to the presence of large houses and emerging ethno-cultural communities which value extended families and aging within the family; older persons even at high levels of need are often maintained at home. More research is necessary to explore this trend.

However, expert panel members cautioned that this should not be seen as evidence that formal supports for caregivers and older persons are any less important in such communities. Indeed, they contended that a failure to connect with formal care at lower levels of need could mean that older persons presented to the formal system only after they and their families were in crisis and when the only viable options were hospitalization or residential LTC.

Finally, we come to a fundamental policy question: how best to balance formal and informal care for older persons? One current approach is to rely on the demonstrated professionalism, commitment and insight of front-line expert panel members to strike the best possible balance taking into consideration complex factors including the preferences and needs of older persons and their caregivers, and services and resources available at the local level. However, this poses the risk of "street level bureaucracy" where some individuals may make idiosyncratic or inequitable decisions based on their own personal preferences or beliefs. An alternative approach might be to regulate centrally what formal care informal caregivers should receive. While promoting equity in the sense of more uniform treatment, this poses the risk of constraining flexibility and innovation, knowing that regions have widely different formal service capacity, and that responses to established and emerging communities, including communities defined by ethno-racial and sexual orientation diversity, may require culturally appropriate approaches. A "middle option," suggested by participants in BoC projects across the province, may be to establish regional or provincial frameworks for broadly-based discussion around approaches to caring for caregivers, leading to the identification of best practices and innovations, and the development of guidelines to inform resource allocation decisions. Such discussion might include experience from other jurisdictions where older persons and informal caregivers, as well as professional case managers, and multi-disciplinary teams, participate in decisions about the best use of available resources, and take co-responsibility for those decisions.

In summary, our findings are consistent with those of other recent reports in Ontario and elsewhere, which have emphasized the crucial role played by informal caregivers in supporting older persons to age at home, and the need for the formal system to support caregivers. They go further to describe the diverse characteristics and contributions of informal caregivers in different regions of Ontario. They also suggest that although there is broad consensus about the importance of caring for caregivers, there is yet no clear pattern of resource allocation, or consensus at the front line about what should be done.

March, 2010

Future research should address the 'unit of care'. More specifically, the resources that care-receivers, caregivers and care providers need (from their points of view) to sustain the informal caregiving role. Findings should assist in developing best practices, innovations and guidelines to better inform resource allocation decisions made in the H&CC sector.

Appendix A: Analysis of Overall Health Care System Utilization and Costs

Wodchis, Walter P, PhD (Michigan), MAE (Michigan), MA (Waterloo)
Associate Professor, Full SGS Member
Health Policy, Management and Evaluation
Faculty of Medicine, University of Toronto
Health Sciences Building, 4th Floor
155 College Street, Suite 425
Toronto, ON M5T 3M5

The analyses aimed to encompass a wider perspective of care use by individuals receiving home care and those who have applied to Long Term Care. Patterns of care utilization and costs more broadly throughout the health system are examined, including acute care, prescription drugs (Ontario Drug Benefit Plan), doctor services (OHIP), rehabilitation, and complex continuing care.

The results are useful to help to evaluate and target interventions aiming to reduce pressures in institutional care settings (e.g. Emergency Department (ED) and acute care patients identified as being suitable for an Alternate Level of Care (ALC)). Previous research has emphasized the links between access to appropriate H&CC packages and rates of utilization of other, often more costly medical, hospital and institutional care services such as hospital emergency room (ER) visits, hospital ALC beds, and LTC beds. Such links have sparked innovations such as CREMS (Community Referrals by EMS) in Toronto, in which paramedics stabilize older persons and make direct referrals to CCACs, thereby avoiding unnecessary hospitalizations. Similarly, Geriatric Emergency Medicine (GEM) nurses used in Ottawa, Toronto and other centres, appear to have had success at “diverting” older persons presenting as social admissions to appropriate H&CC services. In other Canadian jurisdictions such as Vancouver Coastal Health, ALC bed rates have reportedly been halved through the use of a mix of initiatives including GEM nurses, transitional housing, and formal home care.

This project aims to link CCAC RAI-HC assessment data with CCAC home care utilization data, Canadian Institute for Health Information (CIHI) hospital utilization data, and OHIP data to document and analyze overall patterns of health care utilization and costs for older persons currently on LTC wait lists in their own homes; in hospitals; and in LTC facilities. A key objective is to estimate utilization patterns and costs for older persons at different levels of assessed care, in different parts of the system, as the basis for understanding current uses patterns, factors driving them, and the extent to which integrated care models can potentially impact on utilization and system costs.

Methods

Population

The analyses of utilization and costs were completed for the Central CCAC. All clients having a RAI-HC assessment by the Central CCAC were included.

Cohort Definitions

The populations of clients with a RAI-HC assessment were classified into 3 cohorts for comparative analyses:

1. Clients receiving long-stay home care and not on a LTC waiting list
2. Clients receiving long-stay home care who are on a LTC waiting list
3. Clients not receiving home care who are on a LTC waiting list

The cohorts were defined as at March 31, 2007 and all health care utilization was tracked for one year from April 1, 2007 until March 31, 2008. Our analyses included 13,223 clients in the first cohort; 637 in the second, and 681 in the third.

Data Sources and Linkage

RAI-HC data were used to measure the health status and care needs for clients receiving home care and those who had applied for LTC. The latter clients are tracked in Ontario using the MOHLTC Client Profile (CPRO) database. The CPRO tracks client location and applications for up to 3 LTC homes. Health service utilization was measured using data housed at the Institute for Clinical Evaluative Sciences (ICES).

RAI-HC and CPRO data were transferred to ICES under conditions of a data use agreement between Central CCAC and ICES. Patient identifiers were encrypted at ICES in accordance with PHIPPA and ICES privacy policy. Encrypted health card numbers were used to link the RAI and CPRO data together and with all other health care utilization data including acute and other institutional care, physician, Ontario Drug Benefit program, home care and LTC.

Measures and Comparisons

Population characteristics for the 3 cohorts were described based on measures obtained from the RAI-HC. These include measures of cognition (Cognitive Performance Scale), functional dependence (Activities of Daily Living and Instrumental Activities of Daily Living), health instability (Changes in Health and End Stage Scale). Patients were categorized using the Balance of Care (BoC) groups used in the related research projects. Health system use and costs were compared across the 3 cohorts, stratified by BoC groups. Similar to the other related projects, 14 BoC groups were sufficiently common to enable analyses. Demographic information was obtained from the Ontario Registered Persons Database and neighborhood income from Statistics Canada Census data.

Results

Baseline Age, Sex and Income

Nearly half of all clients who have applied to LTC are age 85 or over. Home care clients who have not applied for LTC include younger patients and are also most likely to live in the lowest income neighborhoods. Clients who are not using formal services and have applied to LTC are less likely to live in the lowest income neighborhoods. Otherwise there was little difference in wealth with the highest income quintile equally common for all cohorts.

Functional Dependence

Individuals who had applied to LTC were most likely to have great difficulty in IADLs as measured using the BoC group categorizations. In actual performance/involvement, clients who received home care and had applied to LTC were most likely to be in the highest dependency category. The involvement measure includes both the activities the client performed themselves, and what would be impacted by the degree of assistance provided by home care services (e.g. assistance with baths and meal preparation).

In ADL dependence and cognition (CPS), home care clients who had applied to LTC were the most likely to have great impairment and were least likely to have no or low impairment. CHES scores indicated that the home care only population had the fewest indications of health instability.

Summary

Overall, the clients receiving home care were younger and have the highest level of function. Those receiving home care who has applied to LTC are oldest and have the highest degree of impairment and

dependency. Those who have applied to LTC but were not receiving home care at the start of the study period (March 31, 2007) had similar levels of difficulty as the LTC applicants who were receiving home care. However, among LTC applicants, those receiving home care had a greater degree of dependency. Because the measure of dependency includes service provision/assistance, the difference may represent lower or unmet need among the clients not receiving home care. It suggests though that clients on the wait list not receiving formal home care are not filling the gap entirely with private-pay support (if they did the dependency and involvement results would look more similar between both groups on the LTC waitlist).

Informal Care and Caregiver Distress

Clients receiving home care and who applied to LTC are receiving the highest level of informal supportive care; 53% receive more than the median of 15 hours per week. Clients who are only receiving home care or who do not receive formal home care and applied to LTC receive similar levels of informal support with 42% and 44% of clients receiving more than 15 hours of support per week. The prevalence of signs of distress * [add footnote] was 22% and 24% among caregivers of LTC applicants (with and without home care services respectively) whereas it was only 16% among the population that had not applied to LTC.

Balance of Care Groups

The most prevalent groups were Copper, Davis, C Cameron and I Innis. In addition, the Wong group constituted 13% of the LTC applicant population not receiving home care. Both Copper and Davis are cognitively intact, have no ADL impairment and only some IADL impairments, Copper does and Davis does not have an informal caregiver. Copper has home care costs that are approximately 10% higher than Davis and formal care costs approximately 20% higher.

Individuals in the C Cameron group are cognitively impaired, have some ADL and great IADL difficulty, but are supported by a live-in caregiver. Still, C Cameron's home care costs are on average less than 10% higher than those of Davis with approximately equal formal care services. It may be that the informal caregiver is able to counter-act the increased impairment in cognition, ADL and IADLs (comparing Davis to C Cameron).

I Innis has the highest level of functional impairment in cognition, ADL and IADL domains but also has a live-in caregiver. I Innis clients have the second highest home care and non-home care service costs. While still supported in the community, I Innis clients are most likely to be admitted to LTC. Still, a substantial proportion of individuals in the community (10% of the home-care only cohort) are supported in the community and had not yet applied to LTC. At the same time I Innis was the largest group among home care clients who had applied for LTC. I Innis likely represents the highest end of the spectrum that can be safely maintained in the community. That is, once one has reached full dependency, they can only be maintained in the community with the support of a live-in caregiver. If this can be done safely, the home care costs for half of this population are less than \$9,000 per year suggesting that home care is cost-effective from the health system perspective. The higher formal system costs are higher, but are primarily attributable to the I Innis clients who were admitted to LTC during the year.

The Wong grouping comprised the second most prevalent group of residents in the LTC-only cohort. These individuals are cognitively impaired and have great difficulty in IADL performance, though no ADL dependency. They have a live-in caregiver. The median annual home care costs were lowest for Wong compared to all other represented BoC groups. They also had among the lowest formal health care system costs. As a comparison point, Xavier clients are the same as Wong except that they have no live-

in caregiver and they have 25% higher home care and non-home care costs. The live-in caregiver may account for part of this difference.

Service Utilization

Utilization is consistent with the observations made above. The home care only group are the least impaired and the most likely to receive ambulatory services including same-day surgeries. They are least likely to be admitted to LTC within a 12 month period (our observation period). Clients who have applied to LTC are slightly more likely to be admitted to home care if they are not receiving formal home care services (41% admitted) compared to those receiving formal home care services (35% admitted). Remarkably, on average, more than 50% of all clients visited the ED at least once during the year. Of these the home-care only population had a median of 2 visits while the LTC applicant populations had a median of 1 visit.

Income Equity

We examined the levels of service utilization and costs by neighborhood income quintile and found that there was no systematic variation in the level of home care according to income, and the highest level of formal care services were found (generally) in the lowest and the highest income quintiles.

Among all populations, clients received more formal home care when caregivers also provided more informal care. In contrast, clients received less formal non-home care services when informal caregivers provided 15 hours or fewer hours of care per week.

Clients with caregivers who provided more than 15 hours of informal care per week received substantially more formal care services than clients whose caregivers provided 15 hours or less (in all 3 cohorts). Notably, among clients receiving home care, there was little difference in the amount of formal care among clients whose caregivers showed signs of distress, but among clients who did not receive home care and had applied to LTC, clients with distressed caregivers received substantially more home care services (formal home care services would have been initiated throughout the year at some point after the cohort was defined (March 31, 2007)).

Transitions

We also examined the location of clients after one year. The most notable result in the transition analyses is that clients in each cohort were most likely to be in the same cohort after one year. This was true for 63% of the home-care only cohort, 52% of the cohort with home care and an LTC application and 57% of the clients with no formal home care at the start of the observation period but who had applied to LTC. Over 15% of the population died within the year with differences in outcomes associated with health status indicators at the start of the year.

Summary

A few key findings of this analysis include:

1. There is considerable overlap among clients in the three cohorts: home care clients who have not applied to LTC and LTC applicants who do and do not receive home care services.
2. Live-in informal care providers play an important role in maintaining clients in the community and are associated with lower home care and total system costs for comparable clients (stratified by BoC groups).
3. Informal care appears to be a complement (rather than a substitute) to formal care services, particularly for clients who receive home care and have applied to LTC. These clients all appear to be near to the home-care service maximums.

4. Informal care is negatively related to non-home care formal care services and costs, but analyses conducted to date do not clarify whether formal care results from less informal care or whether informal care is not impacted by formal care because the type of support available informally is different than that provided in non-home care settings.

Next Steps

We are in the process of adding two more CCACs/LHINs to the analytical cohort and will be using combinations of the various measures described in this analysis to identify and characterize high cost cohorts. This will include more in depth understanding of the health care costs associated with managing complex individuals, in particular finding ways to best identify clients at a point in time, who have high ED and ALC use throughout the year. Analyses are also being conducted to develop a longitudinal, temporal view of health services use to examine whether the provision of informal care impacts on current and subsequent formal home care and whether either or both of these impact on subsequent formal health care service utilization.

Reference List:

- Armstrong P, Amaratunga C, Bernier J, Grant K, Pederson A, Willson K.(2002). *Exposing privatization: Women and health reform in Canada*. Aurora, ON: Garamond Press.
- Baranek, P. M., Deber, R., & Williams, A. P. (2004). *Almost home: Reforming home and community care in Ontario*. Toronto, ON: University of Toronto Press
- Buhr, G., Kuchibhatla, M., & Clipp, E. (2006). Caregivers' reasons for nursing home placement: Clues for improving discussions with families prior to the transition. *The Gerontologist*, 46(1), 52-61.
- Canadian Caregiver Coalition (2009). *Facts on Family Caregivers*. Retrieved on July, 21, 2009 from: <http://www.ccc-can.ca/content.php?doc=43>
- Carstairs S, Keon WJ. (2009). *Canada's aging population: Seizing the opportunity*. Special Senate Committee on Aging, Final Report, April. www.parl.gc.ca/40/2/parlbus/.../senatel.../AgingFinalReport-e.pdf.
- Challis, D., & Hughes, J. (2002). Frail old people at the margins of care: Some recent research findings. *British Journal of Psychiatry*, 180, pp.126-130.
- Change-Ability Inc. (2009). *Caring about caregivers: Policy implications of long-range scenario planning*. Report to Ontario Ministry of Health and Long-Term Care. www.p sno.ca/pdf/CaringAboutCaregiversPolicyImplications.pdf.
- Change Foundation. *Who is the puzzle maker? Patient/caregiver perspectives on navigating health services in Ontario* (2008). The Change Foundation Health Integration Report, Toronto, ON: The Change Foundation. Downloaded from <http://www.changefoundation.ca/docs/ChgFdnPuzzleWeb.pdf>.
- Clarkson, P., Hughes, J., & Challis, D. (2005). The potential impact of changes in public funding for residential and nursing-home care in the United Kingdom: The residential allowance. *Ageing & Society*, 25, pp. 159-180
- Fast J, Eales J, Keating N. (2001). *Economic impact of health, income security and labour policies on informal caregivers of frail seniors*. Ottawa, ON: Status of Women Canada, March. Downloaded from <http://www.swc-cfc.gc.ca/pubs/pubspr/0662654765/2001030662654765e.pdf>.
- Hollander, M.J., Chappell, N.L., Prince, M.J., & Shapiro, E. (2007). Providing care and support for an aging population: Briefing notes on key policy issues. *Healthcare Quarterly*, 10, pp 34-45.
- Hollander, J., Liu, Guiping, Chappell, N. (2009). Who cares and how much? The imputed economic contribution to the Canadian healthcare system of middle-aged and older unpaid caregivers providing care to the elderly. *Healthcare Quarterly*, 12(2).
- Keefe J, Légaré J, Carrière Y. (2007). Developing new strategies to support future caregivers of older Canadians with disabilities: Projections of need and their policy implications. *Can Public Policy*, 33(Supplement):S65–S80.
- Muramatsu, N., Yin, H., Campbell, R., Hoyem, R., Jacob, M. & Ross, C. (2007) Risk of nursing home admission among older Americans: Does states' spending on home-and-community-based services matter? *The Journals of Gerontology*, 62b(3).
- Peckham, A., (2009). *Caring for caregivers: Balancing formal and informal care for frail older persons* [Thesis]. University of Toronto: <http://hdl.handle.net/1807/18975>.

Stabile M, Laporte A, Coyte P. (2006). Household responses to public home care programs. *J Health Econ* 25(4).

Williams, P., Challis, D., Deber, R., Watkins, J., Kuluski, K., Lum, L., Daub, S. (2009). Balancing institutional and community based care: Why some older persons can age successfully at home while others require residential long-term care. *Healthcare Quarterly*, 12(3).

Williams AP, Spalding K, Deber RB, McKeever P. (2005). *Prescriptions for pediatric home care: Analyzing the impact of the shift from hospital to home and community on children and families*. Toronto, ON: University of Toronto, SickKids Foundation, March.