CARING FOR CAREGIVERS: BALANCING FORMAL AND INFORMAL CARE
FOR FRAIL OLDER PERSONS

By

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A thesis submitted in conformity with the requirements for the degree of Master of Social Work Graduate Department of Factor-Inwentash Faculty of Social Work University of Toronto

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Abstract

The decrease in hospital recovery time created a transition to more care being performed in the home. There is a need to balance care needs from both demand and supply characteristics. This research sets out to address how the presence or absence of informal caregiver(s) impacts on resource allocation decisions made by home and community care case managers. This research used a mixed methodologies approach employing both semi-structured interviews with frontline workers and secondary data analysis of the Central and Toronto Central LIHN Resident Assessment Instrument for Home Care (RAI-HC). Overall total average hours of formal services did not differ between care recipients depending on the presence or absence of a caregiver. It is evident from the responses provided by the participants that street-level bureaucracy plays a large role in service allocation decisions. That is, decisions are being made based on diverse idiosyncratic observations, opinions and feelings.
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1. Introduction

1.1 Purpose
This thesis examines the nexus between formal and informal caregiving for older persons 'at risk' of losing independence from the perspective of frontline case managers. This thesis sets out to analyze how the presence or absence of an informal caregiver(s) impacts on resource allocation decisions made by home and community care case managers. This thesis also analyzes how the presence or absence of a caregiver(s), and/or the individual characteristics of an informal caregiver(s), impacts on formal service utilization.

1.2 Research Question
This thesis addressed two key questions:

1) What formal services do clients at different levels of need typically require, and how does the provision of formal service change if an informal caregiver is present?
2) How do ethno-racial variations, location of caregiver and personal characteristics impact on the allocation of formal resources?

1.3 The Balance Between Formal and Informal Care
For the purpose of this thesis, 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 including Community Care Access Centres (CCACs) and community support services (CSS) agencies. Such services may be delivered in different settings including the family residence, supportive housing, elderly persons’ centres, adult day programs or Alzheimer day
programs. In Ontario, a range of formal home and community care (H&CC) services is funded in whole or in part by 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, neighbours, friends and family members. Spouses and adult children constitute the main groups of informal caregivers in Ontario as in other jurisdictions. Informal caregivers may also assist in navigating formal services, linking individuals to services, and coordinating multiple services from multiple providers for older persons with complex needs. It has been estimated that over 70% of all care to older persons is provided by informal caregivers with an economic value of over $80 billion (Change-Ability Inc., 2009). For further definitions please see Appendix A: Operational Definitions.

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 alternative level of care (ALC) beds, and long-term care (LTC) beds. There are crucial, although not well documented, links between formal and informal care. For instance, a recent report commissioned by the Ontario Ministry of Health and Long-Term Care points to a continuing decline in informal caregiving resulting from generalized social trends including a decline in traditional nuclear families and volunteerism. It is suggested that such a decline will result in heightened spending on formal home and community care (H&CC) or in greater reliance on residential long-term care (LTC) (Change-Ability Inc., 2009).

From a different perspective, other researchers have emphasized that a decline in informal caregiving may be due in some part to a failure on the part of the formal system to provide informal caregivers with sufficient supports. Such a failure may result from fiscal constraint, a continuing preoccupation with acute care, and the view that formal care should be provided only when families “fail” (Hollander, M.J., Chappell, N.L., Prince, M.J., & Shapiro, E., 2007).

There are two factors that insure this thesis is of relevance for research and future policy planning. Both demand and supply factors impact on service provision.
The demand factor involves the aging population, the increase in persons living with multiple chronic health and social needs and the attenuation of social networks which have traditionally supported those needs. The increasing aging baby boomer population and life expectancy, combined with declining fertility rates add to the rate of an exceptional number of older persons in society relative to alternate age groups. With this growth it is reasonable to assume an increase in the demand for both formal and informal community supports (Canadian Home Care Association., 2003; Statistics Canada., 2003). The demographic trends are relatively fixed and can not be changed.

On the supply side, major policy shifts over the past two decades in Ontario, as in other provinces, have resulted in fewer hospital beds and shorter lengths of in-patient hospital stays, in turn shifting a greater burden of care to the home and community. Historically, the provincial health care system relied on long hospital stays for treatment and recovery. However, waves of hospital restructuring that began in the early 1990s, substantially reduced both bed numbers and lengths of in-patient hospital stays, a fact that is considered by seniors a positive change for both the system and the public (Stabile, Laport, Coyte., 2006; Canadian Home Care Association., 2003). With more patients being discharged ‘quicker’ and ‘sicker’ and requiring more care in community settings, publicly funded CCACs have been required to direct greater proportions of available resources to post-acute care, with proportionally
fewer resources available for continuing care of older persons with chronic illnesses or ongoing support needs. This meant, in turn, that older persons with such needs were forced either to purchase the care they required, if they could afford to, or to rely more heavily on informal caregivers including family members and friends. Although there continues to be little documentation of the extent of this shift or its consequences, important questions have been raised about the impact on informal caregivers, who likely took on a greater burden of care along with a range of physical, emotional and financial costs. While available evidence suggests that even before this shift, informal caregivers provided 80% or more of all home care to older persons (National Advisory Council on Aging (NACA), 1999), less is known about the interface between the informal and formal care system, although it seems that there are only limited formal supports available to address caregiver needs (Decima Research Inc., 2002).

Thus, a key policy question concerns re-balancing informal and formal care for older persons, particularly those at risk of losing independence and requiring hospital and/or institutional care.

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 home and community the unit of care includes family members, neighbours 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 the emphasis is more often on managing chronic conditions, maintaining the highest level of functional capacity and wellbeing possible, and assisting older persons to adapt to changes that are part of the normal aging process.

### 1.4 Hypotheses

Research has identified two plausible hypotheses relating to the interface between formal and informal caregiving. The first suggests that paying into more formal support to older persons and their caregivers may result in having informal caregivers retract the amount of support they provide. This suggests that where informal caregivers are present, formal services may be trimmed down or substituted in the interest of minimizing system costs and disseminating resources further. It may also suggest that when formal supports are too readily available, informal caregivers may withdraw or reduce their efforts, driving up formal care utilization and costs. Thus, at best, investment in care for caregivers may be seen to produce marginal benefits, or at worst, they may be counterproductive, resulting both in higher formal costs, and less informal care.

The second hypothesis suggests that additional formal services produce a multiplier effect, as informal caregivers are able to do more. Formal support
services to older persons and their caregivers (the ‘unit of care’) result in desirable outcomes as older persons make less use of costly hospital and institutional care, and as caregivers avoid burnout (Stabile, et al., 2006; Dunér & Nordström., 2007). This latter hypothesis emphasizes that the presence of an informal caregiver appreciably establishes the care environment of the senior care recipient (Barron, Ironside & McMahon., 1998), and that this role should be supported to insure continued caregiving.

Both of the hypotheses assume that the unit of care involves both the individual and caregiver; this is different from the acute care model that focuses strictly on the individual. There is yet a third alternative hypothesis that paying into formal care may or may not create a substitution or multiplier effect and this may vary depending on idiosyncratic factors involving one’s ethnicity, characteristics of an informal caregiver including age, ability and location.

1.5 Conceptual Framework
In conceptualizing and conducting the analysis this thesis uses a diagnostic and policy planning tool called Balance of Care (BoC). The BoC was originally developed and applied in the UK. More recently it has been applied in different regions of Ontario. The Balance of Care Research Group in the Department of Health Policy, Management and Evaluation (HPME) at the University of Toronto with support from the Local Health Integration Networks (LHINs) and CCACs from nine regions (Waterloo, Toronto Central, Central,
North West, Central West, North East, Champlain, South West and North Simcoe Muskoka) in Ontario have made this research possible. The aim of the BoC is to determine the most appropriate care setting and combination of services required for an aging population to remain independently in the community at costs less or equal to a residential LTC placement. More specifically, the BoC focuses on ‘at risk’ clients, those who are at risk for loss of independence through admission to LTC (Coverdale & Negrine., 1978). This approach assumes the likelihood of losing independence and being institutionalized is due to two factors: the demand side which is based on the needs of people; and the supply side which is the capacity of the system to meet those needs in a community setting. The BoC also highlights the role of informal caregivers. 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. 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. This thesis addresses the importance of insuring the caregiver and care receiver are both getting adequate care to sustain them living independently within the community.
1.6 Theoretical Perspectives

Two additional theoretical perspectives inform this research because the BoC does not specifically aim to address the needs of caregivers there are additional theories that will add further depth during the analysis processes. The first, disability prevention theory which refers to an ‘intervention that attempts to prevent development of participation restrictions which are problems an individual may experience in involvement of life situations’ (World Health Organization., 2002). The prevention model requires involvement that attempts to prevent development of a senior’s or caregiver’s limitation which may be experienced in common everyday life situations. Applying this framework to ‘at risk’ seniors (those who are either at risk of LTC placement or of caregiver burnout) would result in the incorporation of prevention models into the home. Strategies for promotion of wellness, functional independence, minimization of disability and dependency should be emphasized within the current system. Using prevention models with seniors living at home can decrease the risk of hospitalization and LTC placement (Challis & Hughes, 2002).

The second theoretical perspective is street level bureaucracy. This was a term coined by Lipsky to capture the power that state employees encompass. Lipisky (1980) argued that policy implementation is ultimately in the hands of public workers. Public service workers who interact directly with the general public in the course of their jobs, and who have considerable diplomacy in the execution of their work are termed street level bureaucrats. Health care
workers, case managers, who grant access or deny access to government programs and services, are considered street level bureaucrats. The lack of provincial standards regarding allocation decisions at the micro-level has led to much disparity among CCAC's with regard to eligibility criteria and service allocation decisions. There has been a significant downloading of decision making onto front-line case managers. The current model of street-level bureaucracy within the CCAC's is not completely without value as case managers do need flexibility to use individual judgment to insure an appropriate mix of service. However, as Lipsky (1980) states there is need for a more balanced approach to making micro-allocation resource decisions whereby a standardized approach to addressing the needs of the 'unit of care' is developed. This lack of continuity makes it extremely difficult to measure outcomes approximating emergency service use and reuse as well as satisfaction with service.

The discretion which case managers currently have to alter and make resource allocation decisions has the potential to be very idiosyncratic. With the lack of provincial standards to guide case managers in making resource allocation decisions, case managers, in effect, develop policy by default. As studies have shown the result can be that, individual decisions at the micro level drive policy, instead of policy providing a plan for decisions.
1.7 Data and Methodology
This thesis used multiple data sources and combined methodology for triangulation. The data sources used include:

- Findings from the BoC project conducted in Central LHIN.
- In-depth follow-up interviews with 10 of the case managers who participated in the Central BoC expert panel.
- Secondary analysis of home care utilization data from two regions of Ontario (Central and Toronto Central LHINs).

1.7.1 BoC Methods
The Central LHIN BoC Project was designed to include experienced front-line case managers from across the health and social care continuum (n=16). The expert panel met to review detailed vignettes based on the Resident Assessment Instrument for Home Care (RAI-HC) The RAI-HC is an assessment tool used by the CCAC case managers to assess individuals for home care and LTC placement. The assessment items include client demographics, cognition, communication patterns, vision, mood and behaviour, social functioning, informal support, physical functioning (activities of daily living, ADLs, and instrumental activities of daily living, IADLs), continence, disease diagnosis, health conditions and preventative measures, nutrition and hydration status, oral health, skin condition, environmental assessment and current levels of service utilization (Ministry of Health and Long-term Care., 2003). The Central LHIN CCAC Case Managers constructed home and community care ‘packages’ of services that would appropriately support the profiled individuals in a community setting. Among the key findings held during the Central LHIN BoC simulation was consensus among Central LHIN CCAC Case Managers around the key role of informal
caregivers in maintaining the health, wellbeing and independence of older persons; Central LHIN CCAC Case Managers concluded, in fact, that the individual and caregiver should be considered an integral ‘unit of care’.

1.7.2 In-Depth Interviews
During the Central LHIN BoC simulations there was a lesser degree of consensus 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. Case managers brought different views to the table, provoking vigorous discussion about what needed to be done for older persons and their caregivers. Therefore, follow-up interviews were conducted to better understand the reasons for the lack of consensus around either providing additional services or subtracting services. This thesis used follow-up qualitative interviews with front-line case managers from across the care continuum (n=10) (including CCACs, community support agencies, supportive house, and adult day centres). The qualitative data specifically set out to identify if ethno-racial variations, location of the caregiver and personal characteristics impact on the decisions of case managers to allocate formal resources.

1.7.3 Secondary Data Analysis
Quantitative data were gathered from the RAI-HC from both Toronto and Toronto Central LHINs. 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 Central LHIN was used to identify the characteristics of caregivers within this region. The secondary data analysis from Toronto LHIN 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 or is living outside the home (the rationale for using separate approaches for each LHIN will be discussed below in the methodology section).

1.8 Outline
This introduction is followed by section 2 which provides a background on home and community care including, both the demand and supply side of the current issue in distribution of formal services to an aging population. This section also includes a literature review that identifies substitution and supplementation of home care services. The third section provides detailed information on the process of data collection and analysis. The fourth section identifies the results of the current research followed by a discussion of results. The sixth section discusses the limitations of the current research, followed by a summation of the current research and the implications for practice and policy. Please note that from this point forward the Central and Toronto Central LHINs will be referred to as Central and Toronto Central.
2. Background

2.1 Home Care
Home and community based care consists of both health and/or social care provided to those in need. H&CC aims to fulfill the following roles: maintenance and prevention including support provided to prevent long-term functional decline; and long-term and/or acute care substitution, that is, making home care available as a replacement for care in LTC or hospital settings (Hollander & Chappell., 2002).

2. Home care has become an increasingly relevant topic as more and more care is shifted into the community setting. As a result, home care has considerable presence in current policy making. In 2007, the Ontario Ministry of Health and Long Term Care (OMOHLTC) announced a new initiative, the Aging at Home Strategy, a 3-year, $700 million plan that promises to expand community living options “to enable people to continue leading healthy and independent lives in their own homes” (Ontario’s Local Health Integration Networks (LHINs)., 2006). The strategy is being implemented by LHINs, using population based funding allocations, and exercising the autonomy to take varying approaches as to how these funds are distributed. To date CCACs have placed a strong emphasis on home care services and a range of community support services. The Aging at Home Strategy has the potential to supply better integration of care, helping to remove the structured silos and divisions between services and providers, thereby resulting in a system capable of
offering more appropriate and cost effective care. To insure cost effective and adequate care it is necessary to consider how persons who would typically be placed on the LTC waitlist could be appropriately supported in the community at a lesser cost than that of providing care in a LTC setting. Toward this end, the question ‘How do we provide adequate integrated services in the community for less than, or equal to, present costs in such a way as to ‘divert’ informal caregivers from ‘burn out’ and care receivers from LTC waitlists?’ is raised.

Within Ontario the responsibility for assessing key elements of home and community care has been regionalized to a series of geographically based CCACs. The CCACs mandate includes assessment, authorization, and arranging for the provision of home-based health and professional services. CCACs also have responsibility for assessing clients for placement in residential LTC facilities in Ontario, and maintaining LTC waitlists. The services they arrange and pay for include: nursing, physiotherapy, occupational therapy, speech-language pathology, dietician services, social work, personal support and homemaking (Ministry of Health., 2003).

Taken together, the Aging at Home Strategy and the decrease in hospitalization recovery time, there is a decreased use per capita of institutional care. This shift away from institutional (i.e. long-hospital stays) care has resulted in a shift of caregiving duties to family members and
friends. Approximately 80% of homecare is provided informally by family members and friends, while the remaining 20% is provided by professionals and volunteers (Statistics Canada, 2003). In 2002 in Canada, 39% of women and 46% of men over the age of 65 received all of their care from an informal source (Statistics Canada, 2003). As people age, the likelihood of needing a mix of informal and formal services increases (Statistics Canada, 2003). Therefore, it is important to understand how best to balance formal and informal care.

2.2 Demand
The aging baby boomer generation and the increase in life expectancy have combined with declining fertility rates to contribute to the occurrence of an unprecedented number of older persons in society relative to other age groups. In 2001, 13% of Canadians were age 65 years and over. This number is projected to increase to 20% by 2026 (Statistics Canada, 2006). With this unparalleled growth, it is realistic to assume an increase in the demand for both formal and informal community support from the home care sector (Canadian Home Care Association, 2003; Statistics Canada, 2003). Although currently the mean age of persons living in LTC is over the age of 85, the majority of the over 85 population remains living in the community (Statistics Canada, 2003) and in need of care delivered in the home setting. To establish the optimum balance of formal and informal care delivery to
these aging individuals, it is necessary to first identify ‘the reality of existing care’ and its impact on the formal and informal systems.

Literature suggests that the relationship between formal and informal care may be different for individuals with varying levels of care needs. It is relevant to note that informal caregivers (in our current system) provide support to persons at all levels of care requirements including those with high intensity care needs. However, evidence has been established that indicates over time caregivers: are only able to provide limited care; experience ‘burn out’; or require care themselves (Barron, et al., 1998). Many people who provide care to an aging person must decide how to provide that care which includes identifying how to remain an able care provider as care needs increase. The General Social Surveys from both 1996 and 2002 show a willingness of caregivers to maintain caring for family and friends. The personal costs of caregiving are significant and there should be concern for caregivers’ ability to continue to provide care to the ‘oldest old’ in such ways as to maintain independent living in the community for both the caregiver and the care receiver (NACA., 1999).

2.3 Supply
There is often concern expressed among policy makers, academics and health care workers that the sustainability of the health care system is in question in relation to population aging. Predictions range from a crippling of the health care system to marginal effects on the system. It has been
suggested that an aging population will result in significant increases in health care costs (Ettner, 1994). Conversely, there has been research that suggests an aging population will only increase health care costs by 1% a year over the next 40 years (Barer, et al., 1987). Although health care utilization increases with age, seniors are not a homogenous group. The majority of seniors remain relatively healthy while only a small proportion of the group (typically those at the end stages of life) use health care resources at a disproportionate rate (Barer, et al., 1987). Having successful aging in place programs with focus, particularly for older persons experiencing multiple social and health needs, will be integral to future long term care policy. Successful aging in place relies on affordable and sustainable informal and formal home care services.

The public financing of formal supports remains under question as policy makers and service providers are concerned that these supports be used to substitute, rather than to supplement, family caregiving. It is generally thought that the reality of such a situation would increase public spending with no corresponding increase in care received by the senior population (Pezzin, Kemper & Reschovsky., 1996). What is clear is that many seniors prefer to ‘age in place’. This preference puts additional demand on both informal and formal care. Different home care models have been tested in Canada and abroad and have led to varying outcomes. Much research conducted prior to the 1990s indicated that homecare services for persons with severe ADL
restrictions may be more costly than LTC (Hollander., 2004). Currently, a growing body of international evidence suggests that when services are appropriately targeted to seniors in need, case managed appropriately, and used to provide both health and social care, favourable outcomes occur at both the individual and system level (Challis & Hughes., 2002; Ettner., 1994; van Raak, Paulus, & Mur-Veeman., 2005). When direct substitutions are made between resources (e.g. when dollars are earmarked to community care spaces instead of to additional long-term care beds when appropriate) cost effectiveness can be realized (Clarkson, Hughes & Challis., 2005). Managed in this way, homecare investments are less likely to be viewed as an “add on” cost to the health care system.

The question remains: how best to balance formal and informal care to sustain the system and achieve positive outcomes for the individual, their caregiver(s) and the system.

2.4 Literature Review: Substitution or Supplementation?

A substitution effect can occur in two dimensions. There is a formal to formal substitution and a formal to informal substitution. The formal substitution effect can occur when there is a downward substitution of formal care. That is, a shift in resources from more costly formal care to lighter care. For example, decreasing the rate of institutional care creates an increased demand for formal home care services. The formal to informal effect can
occur when that downward substitution (from hospitals to H&CC) spirals further to effect informal carers.

The BoC framework, while recognizing the role of caregivers, primarily focuses on the substitution of formal care. The BoC approach that has been implemented in the United Kingdom has made direct substitutions leading to cost efficiencies in the health care system in addition to improved outcomes for the complete ‘unit of care’. The BoC recognizes both the demand and supply side factors that impact on whether or not an individual requires residential LTC. Where the supply side refers to the availability of resources and service provision, the demand side takes into account the population characteristics (i.e. the needs of the ‘unit of care’). It is not possible to alter the needs from the demand side of the equation. However, changes can be made to the supply side. It is possible that the balance between formal and informal support can alter to meet the needs of the senior population and their caregivers in the community, which may prove to be of benefit not only on the individual level but also on the systemic cost effective level.

Similarly, the Comprehensive Home Option of Integrated Care for the Elderly (CHOICE), as practiced in Edmonton, has also made such direct substitutions, leading to cost efficiencies in the health care system in addition to better outcomes for seniors and their family caregivers (Beaulne., 1998; Hollander, et al., 2006).
There is a gap in research in terms of Canadian literature identifying common needs and experiences of the whole 'unit' of care. Many of the studies from the US focus on the effects of liberal Medicaid rules on LTC placement or lack of involvement of informal caregivers (Stabile, et al., 2006). Cutler and Sheiner (1993) found that with Medicaid funding encompassing LTC placement, seniors’ admittance to LTC increased and concluded that as Medicaid support increases, informal caregiving declines and admission to LTC increases. Ettner (1994) identified that increased Medicaid home care benefits reduced nursing home placement and increased use of formal care within the home. It was also noted that an increase in formal home care significantly reduced informal care and increased formal care for non-medical services. Again, Hoerger, et al (1996) identified that decreased financial requirements for LTC placement increased the use of LTC. However, subsidized home care increased the likelihood of an older adult remaining independent in the community. This suggests a substitution effect where formal care substitutes for informal care. However, the substitution effect may also occur in the opposite direction where informal care may substitute formal care.

A study conducted in Sweden identified that family caregivers provided not only social support but also care that can be provided by formal services (Larsson., 2006). This study also identified that often female spouses provide the bulk of the care with minimal support from public home care. In the United
States, it has been acknowledged that 78% of disabled elderly live within the community receiving most of their required support from family members; only 3% of those living in the home receive exclusively formal services (Ettner., 1994). It has been clearly documented that informal caregivers within the community provide a significant proportion of care to aging individuals (Ettner., 1994; Sundström, Malmberg & Johansson., 2006). Literature has identified that support from families has continued and that informal care provided to dependent seniors has increased (Sundström, et al., 2006). It is unclear under the current system if paying into more formal supports correlates to the number of informal hours provided. Supplementing formal and informal networks may allow for persons to maintain a sense of independence in old age. It remains to be established if those seniors who are physically or cognitively limited are unable to remain in the community due to a lack of informal infrastructure. Literature has suggested that the presence of an informal caregiver can reduce the likelihood of LTC placement. However, this effect has not as yet been conclusively established (Ettner., 1994).

A 7 year longitudinal study undertaken by Tennstedt, Crawford and McKinlay (1993) demonstrated a substitution effect when formal services were initially introduced. The substitution effect did not persist over time. The primary cause for substitution was loss of the primary caregiver to either bereavement or geographical move. It was established that substitution was closely linked
to the changing of needs (i.e. increase in disability). This study also identified that substitution was impacted differently depending on the type of care that was provided. The type of care that was more likely to be substituted by formal services was ‘help with arranging services’. Similarly, two other studies using a prospective design found the amount of formal care an individual received did not significantly reduce the amount of informal caregiving hours during the same period (Hanley, Wiener & Harris., 1991; Moscovice, Davidson & McCaffrey., 1988). A 7 year follow up study demonstrated that there was no evidence to assume a persistent substitution effect (Hollander & Chappell., 2002).

However, the current home care system in Ontario, is working from a curative and individual responsibility model. This focus, coupled with the increase in the aging population and the increase in aging informal caregivers, causes concern for both individual and system outcomes (Brooks and Miljan., 2003). Hong (2006) identified that older adults with unmet needs for activities of daily living (ADLs) and/or instrumental activities of daily living (IADLs) are more likely to experience weight loss, dehydration, falls, confusion, delirium and dissatisfaction with services. It is essential to have both health and social services available to seniors and their caregivers that provide for continued independence and successful aging at home. The frail senior as well as their informal care providers must be considered when working from a prevention model focus. The method of care needs to shift from an individual focus to a
‘unit’ focus which encompasses the ‘at risk’ older adult and the informal care provider(s). A preventative approach to home and community care would reduce the likelihood of informal caregivers developing chronic conditions and a crisis situation that would cause further strain on the health care system (Hong., 2006).

Currently, 70% of Canadian caregivers acknowledge that providing care for aging family members has been stressful (Decima., 2002). This fact is of concern in that stress has been recognized as one of the leading causes of chronic health conditions (Brooks & Miljan., 2003). Stress related to caregiving duties can be prevented, as the number one identifier to causing stress is the caregiver’s lack of choice in taking on the responsibility of caregiving and the number of caregiving tasks performed, using a preventative and social responsibility model (Decima., 2002; Brooks & Miljan., 2003). It is necessary to establish who provides care to our aging population and how these patterns are likely to change with the up coming generations in order to fully understand the consequences of caregiving and how to best implement services that are both cost and quality effective. It is important to understand informal caregiver characteristics, the support provided by informal caregivers, how ethno-racial variations may impact on the care provided, and how formal providers may best organize formal services based on the above factors. Informal care has been an integral part of providing care for frail seniors.
Literature continuously emphasizes the importance of informal caregivers. However, there have been considerable variations in assumptions about how the role of the informal caregiver currently is or should be taken into account. Therefore, how supports are offered and available to the whole unit of care (the specific client and their carers) is of consequence to policy makers, the general public and academics alike.
3. **Methodology: Data and Analysis**

This thesis used a mix of qualitative and quantitative methodologies from three sources:

- Central BoC simulations
- In-depth follow-up interviews with case managers
- Secondary data analysis from both Toronto Central and Central’s RAI-HC

The population of interest was informal caregivers and front-line service providers. The unit of analysis was individual as the research focused on the individual ‘unit of care’. The BoC projects are local level policy planning tools intended to identify how the current community care systems affect care receivers and their informal caregivers. This project consisted of a secondary data analysis provided by Central and Toronto Central CCACs Resident Assessment Instrument for Home Care (RAI-HC), and was supported by discussions from the Central BoC simulations and a qualitative data analysis of follow up interviews conducted with the pre-selected persons who participated in the Central BoC Simulations. A quantitative secondary analysis of the RAI-HC data set and a qualitative inductive analysis of semi-structured interviews were relied on to allow for triangulation of design. The use of triangulation improved credibility, reliability and validity. These methods provided an opportunity for the researcher to ‘cross-check’ data. Using the qualitative analysis provided greater insight and understanding into the data that was gathered from the RAI-HC and the Central BoC Simulations.
The researcher obtained ethics approval from the Ethics Review Office at the University of Toronto.

3.1 Central Case Managers
The qualitative analysis sample consisted of the pre-existing expert panel members that were involved for the purpose of the 'Setting the Balance of Care – Central Community Care Access Centre' that was held in June, 2008.

This research used a BoC approach to gather data. The BoC is a planning tool used to set evidence-based benchmarks for the most appropriate mix of community-based and institutional resources at the local level, that are needed to support an aging population. While conventional projections of care needs often assume that a growing population of older persons will demand a proportionality greater number of residential LTC beds, the BoC emphasizes that the need for such beds will also be determined by supply-side factors, including the availability of safe, cost-effective home and community care.

3.1.1 Data Source One: Central BoC Simulation
Key multi-measure indicators of need from the RAI-HC assessments were used to stratify 2,631 individuals on the Central CCAC LTC wait list into 36 relatively homogenous sub-groups. The RAI-HC is a tool used by CCAC case managers to assess the need for in-home services and/or admission to LTC. Six key measures in the RAI-HC are used to do the stratification. These measures included:
Cognitive performance including short term memory
Cognitive skills for decision-making
Expressive communication and eating self-performance
Level of difficulty with activities of daily living (ADLs) including eating, personal hygiene, locomotion, and toilet use
Level of difficulty with instrumental activities of daily living (IADLs) including meal preparation, housekeeping, phone use, and medication management
Presence of an informal/family caregiver in the home.

Each of the 36 sub-groups created was assigned a name, and the number of waitlisted individuals in each sub-group was calculated. Detailed profiles based on the RAI-HC data were developed for typical individuals in sub-groups that had sufficient population numbers to warrant analysis. In Central 14 of 36 groups had over 2.5% of their populations wait-listed; these 14 sub-groups accounted for 90% (2,374) of the 2,631 individuals on the LTC wait list.

An expert panel was selected using a deliberate reputational sampling technique that included front-line workers from across the care continuum. The expert panel met to review vignettes and constructed H&CC packages that would appropriately support the profile of individuals in each vignette in the community. The members of this panel were the potential Central CCAC Case Managers in this current thesis study and consisted of 16 experienced front-line workers from hospitals, LTC, supportive housing, attendant care, adult day programs and community support agencies. During the expert panel meetings there was great discussion around informal caregivers and how they fit into the community care equation.
3.1.2 Data Source Two: Central Case Manager Follow-up Interviews
Of the 16 case managers who participated on the Central Expert Panel, 10 agreed to take part in a follow-up interview. Rationale for case managers who did not participate: 2 individuals who could not be found; 1 individual stated they did not have the time; and 3 individuals, while originally demonstrating interest, did not respond back to arrange a date and time to conduct an interview.

The participants were experienced front-line workers from hospitals, LTC, supportive housing, attendant care, adult day programs and community support agencies. The interviews were to elaborate the logic that those professionals used when making resource allocation decisions during the Central BoC simulations. The follow-up interviews were instrumental in arriving at a better understanding of the logic behind certain decisions. Each Central CCAC Case Manager was fully informed of the purpose and aim of the follow-up interviews and was given an informed consent form to sign prior to the interview taking place (see Appendix B).

Follow up in-depth interviews were undertaken through follow-up telephone interviews or face to face interviews (See Appendix C) with the Central CCAC expert panel members who agreed to participate (N=10). The face to face interviews were conducted in a setting identified by the Central CCAC Case Manager as being convenient and private. During the telephone interviews,
the researcher was in a quiet secure room and the Central CCAC Case Managers were in a place of convenience for them. The researcher conducted the follow-up interviews subsequent to the Central CCAC BoC meetings held in June, 2008 and completed all interviews by January 2009. Using audio recorded and transcribed verbatim data, the researcher applied Nvivo software for analysis. This thesis followed a directed content analysis approach for analysis. This research was structured with specific theories and hypothesis and therefore used a deductive approach to content analysis. Ultimately, the data was analyzed to develop a collection of explanations to better understand the nexus between formal and informal care (Hsieh & Shannon., 2005). These interviews were coded into 5 main categories specifically relating to variations in services to determine if they were dependent on specific characteristics of clients and their informal caregivers. Five key factors were found to explain service use variations: redefining the ‘unit of care’; characteristics of caregivers; ethno-racial needs and variations; caregiver location and system barriers (see results section for examples of the coding).

3.2 RAI-HC Utilization Data
A 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).
- “Section P: Service Utilization” which records the mix and volume of home care services provided (See [https://chin.ccac-ont.ca/software/RAI-HC_MDS-HC%20form%20Case%20Manager%20Version(1.5c).pdf](https://chin.ccac-ont.ca/software/RAI-HC_MDS-HC%20form%20Case%20Manager%20Version(1.5c).pdf)).

As previously noted the RAI-HC assessment tool is used by CCAC case managers to assess individual needs for home care and LTC placement.

### 3.2.1 Data Source One: Central CCAC RAI-HC
The Central RAI-HC data did not have ‘Section P: Service Utilization’ and was therefore excluded from this analysis. For this particular analysis the researcher focused on ‘Section G: Informal Support Services’. This was used to identify the characteristics of the informal caregiver population in Central CCACs region. This provided a link between the qualitative interviews and secondary data analysis.

### 3.2.2 Data Source Two: Toronto Central CCAC RAI-HC
The quantitative data was relied on primarily to answer the first question, that is: ‘What formal services were clients receiving and did the services alter if
there was an informal caregiver present?’ The researcher focused on two specific sections of the RAI-HC, namely, Section G and section P of the Toronto Central RAI-HC. Section P: Service Utilization’ presents the services provided by formal support services over a 7 day period. ‘Section G: Informal Support Services’ provides the amount of informal caregiving hours over a 7 day period. Analyzing “Section G: Informal Support Services” identified the number of seniors who were receiving home care services, who had informal caregivers and who did not have informal caregivers. Analyzing “Section P: Service Utilization” identified the formal services seniors were receiving. This analysis was completed using SPSS version 11.5, a statistical computer software program. Specifically, these two sections were compared and analyzed using a two sample t-test with unequal variances to identify what formal services persons with a live-in informal caregiver(s) were receiving in comparison to those who either had a live-out informal caregiver(s) or those who did not have an informal caregiver.
4. Results

4.1 Key Themes
The semi-structured interviews identified 5 major themes that impact on:

one’s ability to remain living in their home; service utilization; and affordability.

4.1.1 Unit of Care
Many Central CCAC Case Managers mentioned the vital and supplemental role of informal caregivers. The role of caregivers was seen as the safety net keeping seniors in the community and out of emergency rooms and LTC homes (N=8). This conviction is exemplified through a Central CCAC Case Manager quote:

‘A vital role. If it were not for the caregiver, they would be unable to return home [from the hospital].’

All BoC expert panel members unanimously agreed that in the home and community sector, the unit of care is not strictly the individual, but rather the individual and caregiver.

In home and community, the unit of care includes family members and friends who provide the bulk of care for older persons. In addition to providing instrumental and emotional support, informal caregivers often serve as the link to the formal system, and they access and coordinate formal services, particularly for the growing number of individuals experiencing cognitive decline. Rather than considering the needs of informal caregivers and at risk older persons individually, there was unanimous agreement that older
persons and informal caregivers should be seen to constitute a single unit of care with needs to be addressed together. In home and community care, the role of informal caregivers is integral.

Care packages that were created during the Central BoC simulation revealed different approaches to supporting the whole ‘unit of care’. Some packages provide caregiver specific services (caregiver support group) while others provide shared benefit under generic service categories (congregate dining). While both services are mutually beneficial it is evident that the approach to supporting the unit of care can be variable.

In understanding the vital role informal caregivers play in caring for aging individuals in the community, it was thought to be important to identify typical informal caregiver characteristics and whether or not these characteristics impact on the type of services that are required for these persons to remain independently living in the community.

4.1.2 Personal Characteristics of Caregivers
The majority of Central CCAC Case Managers identified family members as the typical primary caregiver more so than neighbours, friends or volunteers (n=9). Central CCAC Case Managers noted that informal caregivers can be friends, neighbours or extended family but most frequently identified informal caregivers as immediate family members such as a child or a spouse. More specifically Central CCAC Case Managers stated that informal caregivers tended to be women: daughters, daughters-in-law or spouses, although they
were cognizant not to completely exclude sons (N=6). One case manager stated: ‘the majority of them are spouses or female.’

When Central CCAC Case Managers were asked about the type of support informal caregivers most often provide to their loved ones, emotional support was identified (N=8). It was noted that the type of support provided does differ depending on the relationship of the informal caregiver. When neighbours or friends are involved in care, often it is to provide support with instrumental activities of daily living (IADLs: transportation, shopping, cleaning, meal preparation etc) and only infrequently crosses the line to more personal care:

‘When neighbours do get involved they do not do the personal care or cleaning but more like IADLs. Picking up groceries, driving to the bank…’

Both spouses and daughters were seen as being more likely to provide the physical or personal types of support. Spouses were thought to be more likely to provide all types of support:

‘I think a spouse or a daughter tends to provide more physical care and be more supportive and involved on a general basis.’

The age range of informal caregivers was seen to be anywhere from 29-70 and there was discussion around the difficulty of caregiving for various reasons depending on the informal caregivers age. For example, some case managers pointed to the ‘sandwich generation,’ those informal caregivers
who attempt to maintain employment; care for a young family; and also provide care for an elderly family member. One Central CCAC Case Manager stated:

‘In my mind the challenge comes when you are in between ages. You have a full time job, family and there are expectations for you in many different arenas and it becomes exhausting.’

This concern extended into spousal caregivers who may have difficulty providing heavy physical care or may experience emotional challenges. This concern is evident from the comments of a Central CCAC Case Manager:

‘Older clients are sometimes not well enough to provide that care. Often you have two people that may have health issues.’

It was generally felt that ideally an informal caregiver would be a younger person with both the time and physical strength to care for an aging loved one:

‘I mean ideally I think a caregiver would probably be a child who is able to pitch in if their parent is unable.’

The idea of having children available to assist in the care process and having multiple informal caregivers (caregiving infrastructure) was described as a crucial factor to sustaining individuals at the community level. Although, this was also described as being highly unlikely. When asking Central CCAC Case Managers about who typically provides care, five of the Central CCAC Case Managers stated that such an informal infrastructure is possible and
effective when it occurs but that it is unlikely and uncommon. It was mentioned that typically there is one informal caregiver providing the bulk of caregiving. For example, one Central CCAC Case Manager mentioned:

‘There are infrastructures but this is not the majority of cases. Only sometimes do you see this. It would work better than those who have been abandoned by their children [who do] their shopping or take them to their doctor appointment. Having persons who have delegated roles would be ideal and most likely would ease the pain of having only one informal caregiver providing the bulk of the care.’

Knowing the characteristics and relationships of informal caregivers is important to the understanding of who is providing heavy care (ADLs) and who is more likely providing the lighter care (IADLs). This knowledge is necessary in order to provide appropriate and adequate support.

4.1.3 Ethno-Racial Variations and Considerations

Many Central CCAC Case Managers noted that ethno-racial differences not only alter the support an informal caregiver gives but the formal supports that the ‘unit of care’ is willing to accept (N=6). Case managers also mentioned that various cultures might place more emphasis on familial piety and the role of women as caregivers which would impact on service allocation. The roles informal caregiver(s) take on were thought to differ depending on ethnicity. For example:

‘White Canadians. I consider them as very isolated. They live alone and family has no contact so maybe it is the culture or community. This is what I have seen in my experience.’
This difference in caregiving roles was seen to be related to ethno-racial upbringing. Many Caribbean communities as well as South East Asian and Italian communities were seen to be more family oriented and this was in large part connected to their cultural expectations (N=7). One Central CCAC Case Manager expressed this anomaly as follows:

'There is this traditional ingrained cultural expectation from when they grew up, this filial piety. We have seniors from all over the world...to me there is generally this expectation that the parents, the older people, expect their children to take care of them.'

The Central CCAC Case Managers saw reason for concern that this expectation may cause children or family members to feel guilty if they are unable to provide complete care to their aging parents. Central CCAC Case Managers thought this view, in turn:

'may lead to caregivers' reluctance to accept services or they may not ask for assistance when they need it.'

Although there is an expectation for children to care for their aging parents, concern was raised in terms of families who have a lifestyle where they are unable to care for their parents (N=9). Central CCAC Case Managers identified that informal caregivers were more likely to accept services but the older adult themselves were less willing. As stated by a Central CCAC Case Manager:
'From what I have heard from family members is that they [the older adult] would not let anyone in [to the home]. Not to say that Anglo seniors will not do that. I mean, who would want a stranger into their home period. The other seniors get so angry because they wonder why they are getting this care from a stranger rather than my children.'

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), as compared to communities with less well-established infrastructures and human resources pools (such as the Somali community). Rather than expert panel members attempting to estimate exact costs, the approach taken was to add a ‘diversity overhead’ to H&CC packages. Central added a 2% diversity overhead for the purposes of interpretation, translation and cultural competence.

Understanding ethno-racial variations is critical in fully identifying the impact and use of formal services on such populations.
4.1.4 Service Mix Dependent on Caregiver Location

It was acknowledged by Central CCAC Case Managers that informal caregiver availability was a primary concern when configuring care packages for frail seniors wishing to remain in the community. The availability was identified not only in terms of the amount of time the informal caregiver was able to provide care (i.e., does the caregiver work), the geographical location of the informal caregiver but also the physical ability (frailty) of the informal caregiver (N=5). The statement of one Central CCAC Case Manager outlined this:

‘Depending on if the person has flexibility to take time off, it varies on amount of time they can actually take part in their family member[s care].’

The discussion concerning informal caregiver availability focused primarily around adult children’s involvement in the care process. When discussing spouses as caregivers, many Central CCAC Case Managers identified that not only the frailty of the care receiver but the informal caregiver frailty impacts on the need for formal services. If informal caregivers are completely available (live-in, non-working, able bodied) it seems that service providers would give less support as the informal caregivers would be able to be replaced and the more the informal caregiver could do. One Central CCAC Case Manager noted that:

‘Maybe meals on wheels would go out as the live-in caregiver would be able to provide meals.’
The same logic being applied to care allocation decisions was identified in terms of transportation and the service was not seen as beneficial if the informal caregiver was able to provide such care. The importance of providing care that allows informal caregivers to go ‘out and about’ to avoid isolation as well as provide emotional support to those who find the caregiving process difficult was seen as vital. The assessments conducted by Central CCAC Case Managers were seen to identify not only what the client needs but also the needs of the informal caregiver and availability of caregivers and family members as outlined by a Central CCAC Case Manager who stated:

‘Find out what the person needs, and what the family is available for and what they can do, then you find out what the system can put in...and then you augment and help the family out as much as possible.’

This assessment was also seen as important to ‘Identify if the caregiver is really overwhelmed or in need of other supports’. This is an important consideration during the assessment process as it would assist in recognizing signs of or potential for abuse.

Overall, Central CCAC Case Managers agreed that services would alter if there was an informal caregiver present. Some persons discussed an increase in services (N=7), others mentioned a different service mix in general and most talked about the importance of education, emotional and grievance support which all depended on the frailty of the care receiver, the informal caregiver and the overall availability of the informal caregiver. An
example of the type of education the Central CCAC Case Managers were outlining is apparent in the following statement:

‘Orient the caregivers and train them in procedures in actual nursing procedures if the caregiver is willing and has the capacity to undertake them… when you have someone who is willing and capable and that’s more acceptable to the client then you know you can use that type of support.’

Service providers develop services for older adults living in the community based on a variety of factors: caregiver location, availability and flexibility; care receiver mental and physical ability. All are significant factors that determine the assignment of home care assistance that in turn predicts the probability for a senior to remain living at home.

While stressing that caregiver needs are just as important as the needs of care recipients, there was no clear advice on how to go about supporting caregiver needs. Actual care decisions are impacted by and dependent on multiple variables that are individually chosen.

4.1.5 Recommendations for the System
The fourth topic identified through the qualitative analysis concerns the idea of system reform. The formal system is complex and many Central CCAC Case Managers felt that due to this complexity it is likely that informal caregiver(s) are unable to locate or are unaware of the services that would be of use to them (N=4). Informal caregiver education, and adequate access to services were the prominent systemic concerns discussed by CCAC case managers. The impact of the complexity of the system on the attainment of
required support was summarized by a Central CCAC Case Manager who stated:

'It is not clear to the caregivers what services are available in the community although there are a number of services. But they are not aware of that because it is a complex system.'

Many Central CCAC Case Managers discussed the importance of having an increase in information or education for informal caregivers to assist in system navigation. It was mentioned that this education may be easier to provide through a mode of technology such as, telephone or video conferencing and or web-based information centers. With the up-coming generation this seems a plausible idea as they are becoming more technology savvy (N=5). One Central CCAC Case Manager mentioned an E-health council that may be effective in accessing services:

'E-Health Council at the ministry and LIHN levels, they might come up with an easier system to access the health care for seniors and caregivers and everyone.'

Education was often thought to be provided through caregiver support groups or connections made during day programs. Caregiver support groups and day programs are seen as positive options for education and support. However, much discussion surrounded the challenge for informal caregivers of getting their loved ones to the programs and finding the time for themselves to attend the support groups (N=4). This difficulty was expressed in the following quote:

'It is difficult for families to actually get their family member to the day program. A PSW that arrives in the morning and motivates
them into getting dressed and getting on the bus, and the day program has the opportunity to provide a bath.’

Another quote that outlines the challenges informal caregivers may experience in attending support groups is:

‘A lot of caregiver programs available...but some people find these exhausting-- to go to them. How do we bring those services to those caregivers?’

Input from Central CCAC Case Managers clearly suggests that informal caregivers need to be better informed. How can the dissipation of information be undertaken to better inform informal caregivers of existing supports without requiring already often overextended persons to delegate more time? The case managers identified a need to better educate informal caregivers of the services available as well as to make these services easily accessible.

The Central CCAC Case Managers were asked the following question, ‘Finally, I am wondering who you think should bear the costs of services for informal caregivers?’ Central CCAC Case Managers had various ideas. Some people felt that out of pocket payment was not an option (40%). These Central CCAC Case Managers mentioned that full public payment would be ideal. This is exemplified through one CCAC Case Manager’s quote who said:

‘Out-of-pocket [payment] is out of the question, there is no way one can bare this cost.’
However, they recognized that this is not necessarily a viable option and concluded that a small fee might make the payment system more efficient and allow some members to feel more willing to accept services. Mixed payment was said to be the best option by four Central CCAC Case Managers (40%). For example, one CCAC Case Manager stated: ‘A combination of public funding and out-of-pocket or insurance.’

Two Central CCAC Case Managers felt that a two tiered system or private insurance would be most efficient (20%). Who stated:

‘We could go to a two tiered system. I think that for some services you may go to an ability to pay assessment which includes looking at assets….I find when you really have to pay for everybody getting everything when there are people who have the money to pay. [The question is] can society afford to keep doing that?’

It was concluded that service providers see the system as complex, a difficulty that creates barriers to access. The necessary services to enable informal caregivers to provide care for lengthier periods of time without burnout must be known and available if they are to allow informal caregivers to provide continuing care in the home and subsequently divert care receivers from LTC. Central CCAC Case Managers felt that a publicly funded system would be ideal but thought this was unachievable and suggested that a mixed payment system may be effective. Payment of a small fee by users was seen as important for the sustainability of information services. It was also felt that payment of a small fee had the potential to increase willingness to accept services.
4.2 RAI-HC Utilization Data

4.2.1 Personal Characteristics of Caregivers
When looking at the relationship of informal caregivers to care receivers from the Central CCAC RAI-HC it shows that the majority are children (56.1%) followed by spousal caregivers (29.8%). Figure 1 outlines the relationship status of caregiver to care receiver of the Central CCAC region.

**Figure 1:**
Central’s Caregiver Relationship

The RAI-HC data does not provide informal caregiver sex; it only provides the relationship of the informal caregiver. However, the researcher was able to compare the type of care adult children, spouses, relatives and friends provide for both Central and Toronto Central. Chi-Square tests were conducted to identify if a significant difference was present for IADL (meal preparation, housework, finances, medication management, transportation and shopping), ADL (dressing, toileting, bathing and feeding) and advice and emotional support care provided by each of the informal caregiving types (see
Significant differences were at the 0.001 level for IADL, ADL, and advice and emotional support. It should be noted that the difference among advice and emotional support, although statistically significant, does not appear to be practically significant. The percentage of informal caregivers that provide each type of care alters depending on the relationship between care receiver and caregiver. Both Central and Toronto Central data sets show similar trends with spouses providing all types of care at higher rates than other caregiver types (see table 1).

**Table 1:**
Type of Care Provided by Each Type of Informal Caregiver (Central)

<table>
<thead>
<tr>
<th>Type of Support Provided</th>
<th>Spouse (N=3829)</th>
<th>Adult Child (N=7212)</th>
<th>Other Relative (N=1234)</th>
<th>Friend /Neighbor (N=582)</th>
</tr>
</thead>
<tbody>
<tr>
<td>IADL*</td>
<td>93.6%</td>
<td>90.1%</td>
<td>78%</td>
<td>80.4%</td>
</tr>
<tr>
<td>ADL*</td>
<td>71.7%</td>
<td>46.3%</td>
<td>37.3%</td>
<td>22%</td>
</tr>
<tr>
<td>Advice &amp; Emotional Support*</td>
<td>97.5%</td>
<td>96.9%</td>
<td>94.7%</td>
<td>91.6%</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Type of Support Provided</th>
<th>Spouse N=1883</th>
<th>Child N=4419</th>
<th>Other Relative N=1294</th>
<th>Friend /Neighbour N=812</th>
</tr>
</thead>
<tbody>
<tr>
<td>IADL*</td>
<td>91.4%</td>
<td>85.7%</td>
<td>72.6%</td>
<td>72.4%</td>
</tr>
<tr>
<td>ADL*</td>
<td>70.2%</td>
<td>37.2%</td>
<td>27.7%</td>
<td>23.9%</td>
</tr>
<tr>
<td>Advice and Emotional Support*</td>
<td>98.2%</td>
<td>97.6%</td>
<td>94.3%</td>
<td>92.6%</td>
</tr>
</tbody>
</table>

*P< 0.05
The researcher was interested in identifying if the formal support hours differed based on differing informal caregiver characteristics (ie child vs spouse). On average, children spend fewer hours in caregiving roles than do spousal caregivers (see figure 2). Spousal caregivers spend more hours in the caregiving role than any other informal caregiver type (see table 2). When analyzing the behaviour of children caregivers, it was noted that they spend an average of 17.65 hours a week in comparison to spousal caregivers who spend 18.94 hours per week. The average of formal support hours did alter depending on whether an informal caregiver was a spouse (6.07 hours) or a child (6.32 hours). The total hours of formal support given increased by 0.25 hours when there was an adult child caregiver. The total number of hours (both formal and informal) that were given to care receivers with an adult child caregiver was 23.97 hours and the total number of hours provided to care receivers with a spouse as caregiver was 25.01 hours (see figure 2). After conducting an independent sample t-test, it can be concluded that there was no statistical significance between the number of informal caregiving hours (provided by either a spouse or a child) and formal caregiving hours provided (See Table 2).
Table 2: Comparison of Total Hours (per week) Spent by Formal and Informal Caregivers (Toronto Central)

<table>
<thead>
<tr>
<th>Utilization</th>
<th>Relationship of Informal Caregiver</th>
<th>N</th>
<th>Mean Hours Per Week (M)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Informal Caregiving</td>
<td>Spouse</td>
<td>1648 (23%)</td>
<td>18.9</td>
</tr>
<tr>
<td></td>
<td>Adult Child</td>
<td>3809 (52%)</td>
<td>17.7</td>
</tr>
<tr>
<td></td>
<td>Other Relative</td>
<td>1120 (15%)</td>
<td>17.5</td>
</tr>
<tr>
<td></td>
<td>Friend/Neighbour</td>
<td>715 (10%)</td>
<td>16.2</td>
</tr>
<tr>
<td>Total Formal Caregiving</td>
<td>Spouse</td>
<td>1871 (22%)</td>
<td>6.1</td>
</tr>
<tr>
<td></td>
<td>Adult Child</td>
<td>4379 (52%)</td>
<td>6.3</td>
</tr>
<tr>
<td></td>
<td>Other Relative</td>
<td>1282 (15%)</td>
<td>6.6</td>
</tr>
<tr>
<td></td>
<td>Friend/Neighbour</td>
<td>804 (10%)</td>
<td>6.4</td>
</tr>
</tbody>
</table>

Total Missing Informal Cases = 1116
Total Missing Formal Cases= 72

Figure 2: Total Amount of Support Provided by Formal Services and Informal Caregivers

4.2.2 Service Utilization

‘Section P: Service Utilization’ of the Toronto Central RAI-HC identified the types of home care services that persons are receiving most frequently in terms of hours given per week. Home health aids hours, home making and
meal services were the services that persons receive more commonly (see figure 3).

**Figure 3:**
Overall Mean Hours (per week) of Service Utilization (Toronto Central)

The formal services that clients receive most frequently are primarily home health care aids. The question remains: ‘Do these services alter if there is an informal caregiver present in any capacity?’ In order to address this question, the researcher performed a two sample t-test with unequal variances to test the hypothesis that the average total number of formal hours for persons with an informal caregiver is not different from the average total number of formal hours for persons without an informal caregiver. The P value was 0.054. Therefore, we do reject the hypothesis. Persons with an informal caregiver receive slightly more formal hours of support than persons who do not have an informal caregiver. There were two services that proved to be used more by persons with an informal caregiver and one service used more by persons
without an informal caregiver. Home health aide hours showed a significant increase in mean hours spent (P=0.001; mean difference=.740 hrs) when an informal caregiver was present. Visiting nurses (P=0.041; mean difference=.151hrs) are used more by persons without an informal caregiver (see table 3).

**Table 3:**
Comparing Home Care Services for Persons with a Caregiver in Any Capacity compared to no Caregiver (Toronto Central)

<table>
<thead>
<tr>
<th>Service</th>
<th>Caregiver In any capacity</th>
<th>No Caregiver</th>
<th>N</th>
<th>Mean Hours Per Week (M)</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home Health Aide</td>
<td></td>
<td></td>
<td>8315</td>
<td>2.75</td>
<td>p = 0.001</td>
</tr>
<tr>
<td></td>
<td>Caregiver</td>
<td></td>
<td>747</td>
<td>2.01</td>
<td></td>
</tr>
<tr>
<td></td>
<td>No Caregiver</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visiting Nurses</td>
<td></td>
<td></td>
<td>8314</td>
<td>.40</td>
<td>p = 0.041</td>
</tr>
<tr>
<td></td>
<td>Caregiver</td>
<td></td>
<td>749</td>
<td>.55</td>
<td></td>
</tr>
<tr>
<td></td>
<td>No Caregiver</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Speech Language Pathology</td>
<td></td>
<td></td>
<td>8316</td>
<td>.00</td>
<td>p = 0.237</td>
</tr>
<tr>
<td></td>
<td>Caregiver</td>
<td></td>
<td>749</td>
<td>.00</td>
<td></td>
</tr>
<tr>
<td></td>
<td>No Caregiver</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Homemaking</td>
<td></td>
<td></td>
<td>8315</td>
<td>1.73</td>
<td>p = 0.661</td>
</tr>
<tr>
<td></td>
<td>Caregiver</td>
<td></td>
<td>747</td>
<td>1.42</td>
<td></td>
</tr>
<tr>
<td></td>
<td>No Caregiver</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meals</td>
<td></td>
<td></td>
<td>8316</td>
<td>.85</td>
<td>p = 0.711</td>
</tr>
<tr>
<td></td>
<td>Caregiver</td>
<td></td>
<td>749</td>
<td>.79</td>
<td></td>
</tr>
<tr>
<td></td>
<td>No Caregiver</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Volunteer</td>
<td></td>
<td></td>
<td>8316</td>
<td>.02</td>
<td>p = 0.719</td>
</tr>
<tr>
<td></td>
<td>Caregiver</td>
<td></td>
<td>749</td>
<td>.02</td>
<td></td>
</tr>
<tr>
<td></td>
<td>No Caregiver</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational Therapy</td>
<td></td>
<td></td>
<td>8316</td>
<td>.06</td>
<td>p = 0.0001</td>
</tr>
<tr>
<td></td>
<td>Caregiver</td>
<td></td>
<td>749</td>
<td>.07</td>
<td></td>
</tr>
<tr>
<td></td>
<td>No Caregiver</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Day Center</td>
<td></td>
<td></td>
<td>8316</td>
<td>.37</td>
<td>p = 0.069</td>
</tr>
<tr>
<td></td>
<td>Caregiver</td>
<td></td>
<td>749</td>
<td>.19</td>
<td></td>
</tr>
<tr>
<td></td>
<td>No Caregiver</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Worker</td>
<td></td>
<td></td>
<td>8316</td>
<td>.03</td>
<td>p = 0.240</td>
</tr>
<tr>
<td></td>
<td>Caregiver</td>
<td></td>
<td>749</td>
<td>.25</td>
<td></td>
</tr>
<tr>
<td></td>
<td>No Caregiver</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Independent samples t-tests were also conducted to compare service provision for persons who have a live-in caregiver versus all others persons (see table 4).

**Table 4:** Comparing Home Care Services for Persons who Have a Live-in Caregiver and Persons Who have Either a Live-out or No Caregiver (Toronto Central)

<table>
<thead>
<tr>
<th>Service</th>
<th>Live-in Caregiver</th>
<th>Live-out /No Caregiver</th>
<th>N (%)</th>
<th>Mean Hours Per Week (M)</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Home Health Aide</strong></td>
<td></td>
<td></td>
<td>3659</td>
<td>2.92</td>
<td>p=0.041</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>5403</td>
<td>2.54</td>
<td></td>
</tr>
<tr>
<td><strong>Visiting Nurses</strong></td>
<td></td>
<td></td>
<td>3658</td>
<td>.47</td>
<td>p=0.036</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>5405</td>
<td>.38</td>
<td></td>
</tr>
<tr>
<td><strong>Speech Language Pathology</strong></td>
<td></td>
<td></td>
<td>3659</td>
<td>1.51</td>
<td>p=0.062</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>5403</td>
<td>1.84</td>
<td></td>
</tr>
<tr>
<td><strong>Homemaking</strong></td>
<td></td>
<td></td>
<td>3659</td>
<td>.49</td>
<td>p= 0.0001</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>5406</td>
<td>1.09</td>
<td></td>
</tr>
<tr>
<td><strong>Meals</strong></td>
<td></td>
<td></td>
<td>3659</td>
<td>.01</td>
<td>p=0.046</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>5406</td>
<td>.03</td>
<td></td>
</tr>
<tr>
<td><strong>Volunteer</strong></td>
<td></td>
<td></td>
<td>3659</td>
<td>.07</td>
<td>p=0.318</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>5406</td>
<td>.05</td>
<td></td>
</tr>
<tr>
<td><strong>Occupational Therapy</strong></td>
<td></td>
<td></td>
<td>3659</td>
<td>.01</td>
<td>p=0.80</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>5406</td>
<td>.00</td>
<td></td>
</tr>
<tr>
<td><strong>Day Center</strong></td>
<td></td>
<td></td>
<td>3659</td>
<td>.66</td>
<td>p = 0.0001</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>5406</td>
<td>.16</td>
<td></td>
</tr>
<tr>
<td><strong>Social Worker</strong></td>
<td></td>
<td></td>
<td>3659</td>
<td>.04</td>
<td>p = 0.699</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>5406</td>
<td>.05</td>
<td></td>
</tr>
</tbody>
</table>
For home health aide (P=0.041), visiting nurse (P=0.036) and day center (P=0.0001) support there was a significant difference between persons who have a live in caregiver and those who either have a live-out caregiver or no caregiver. This suggests persons with a live-in caregiver are more likely to receive home health aide, visiting nurse and or day center services than those who have a live-out caregiver or no caregiver at all. For meal (p=0.001) and volunteer (p=0.046) services there was a significant difference between persons who do not have a caregiver at all or who do not have a live-in caregiver and those who do have a live-in caregiver. This suggests that those who do not have a caregiver or do not have a live-in caregiver are more likely to have meal and volunteer services than persons who have a live-in caregiver. Case managers are more likely to remove meal services when there is a live-in caregiver because the thought is that the informal caregiver is able to provide the meals.

Analysis of caregiver distress identified that the amount of formal service utilization hours significantly differed between informal caregivers who are categorized as ‘distressed’ (unable to continue caregiving) and ‘not distressed’ (able to continue caregiving). The following chart outlines the differences between groups (see table 5).
### Table 5: Comparison of Total Hours Spent by Distressed and Not Distressed Caregivers (Toronto Central)

<table>
<thead>
<tr>
<th>Utilization</th>
<th>Distressed?</th>
<th>N</th>
<th>Mean Hours Per Week (M)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total Informal Caregiving Hours</strong></td>
<td>Yes: Cannot continue providing care</td>
<td>699 (9%)</td>
<td>19.7**</td>
</tr>
<tr>
<td></td>
<td>No: Can continue to provide care</td>
<td>7234 (91%)</td>
<td>17.4**</td>
</tr>
<tr>
<td><strong>Total Formal Caregiving Hours</strong></td>
<td>Yes: Cannot continue providing care</td>
<td>823 (9%)</td>
<td>4.9**</td>
</tr>
<tr>
<td></td>
<td>No: Can continue to provide care</td>
<td>8237 (91%)</td>
<td>6.3**</td>
</tr>
</tbody>
</table>

Total Missing Informal Cases = 1210  
Total Missing Formal Cases = 735  
**p<0.01

The analysis of persons with caregivers in comparison to those without did not identify any major service utilization patterns. However, analyzing caregivers in distress in comparison to those who are not distressed identified unusual results. This analysis identified that informal caregivers in distress provide on average 1.29 more hours of informal support and receive on average 1.46 hours less support than informal caregivers who are not in distress (p<0.01).

There was no significant difference in the total number of formal hours between people who have an informal caregiver in comparison to those who do not have an informal caregiver. There was, however, a difference in specific services provided depending on the presence of a caregiver. Home health aide hours were more likely to be increased with the presence of a caregiver and visiting nursing hours were more likely to increase if there was no caregiver present. It is also interesting to note, the difference in caregiving hours provided by spouses or adult children and the correlating increase or decrease of formal hours provided.
5. Discussion
It is evident from the responses given by the Central CCAC Case Managers that ethno-racial variations, location and availability of the caregiver and personal characteristics of both the care receiver and the caregiver impact on how service providers allocate resources.

The common themes (‘unit of care’, caregiver characteristics, challenges of the current system, ethno-racial considerations) pulled from the qualitative analysis are all essential factors that impact on the reasoning used by service providers to assign services. Most Central CCAC Case Managers mentioned the vital role of informal caregivers in keeping family members at home and avoiding hospitalization and long term care. This is an accurate assumption as literature supports the link between informal caregiving and avoidance of hospital and long-term care admission (Carstairs & Keon., 2009).

5.1 Challenges of The Current System
The current funding of CCAC services does not fall within the terms of the Canada Health Act. Although Ontario has chosen to fully insure these services and provide them without cost, there is no universal entitlement to services (although the Act establishing CCACs do guarantee the right to an assessment), individuals are able to purchase care from community service agencies beyond the levels paid by the CCAC. In June 2008, the province lifted service maximums for individuals on LTC wait lists (Government of Ontario, 2008). The formal system relies heavily on the care provided by informal caregivers yet, informal caregivers are not on the H&CC radar. The
issue here is that the system is tough to navigate and understand. Informal caregivers have no entitlement to CCAC services and accessibility becomes an issue when Community Service Agencies have user fees. Informal care is not considered part of formal health care. Older persons have no right to non-hospital and physician care and current policies in Canada provide very few benefits for caregivers' of older persons. How does this impact on the balance of formal and informal care?

Inherent in the failure to establish common entitlement is the danger that certain groups of seniors and their caregivers will be predisposed to inadequate support by nature of socioeconomic differences and their (in)ability to pay for care. This was a concern for 40% of Central CCAC Case Managers who believed out of pocket payment should not be an option. However, many Central CCAC Case Managers discussed concern around system sustainability and the inability for the system to provide the 'unit of care' with formal services at no cost. Some Central CCAC Case Managers mentioned that requiring the 'unit of care' to provide a small fee for services may be beneficial for system sustainability. For example, adult day programs require small fees for attending. Some of the Central CCAC Case Managers thought that a small fee would encourage seniors and their informal caregivers to use such services. Some persons are less likely to use a service they feel is a form of 'charity'. It was identified that a very minimal payment may reduce feelings of receiving charity thereby increasing
participation while simultaneously benefiting the system as a whole. System sustainability in this situation should be considered alongside the possible reduction in higher system costs (i.e. reduction in LTC or hospital usage). There will continue to be on-going debates surrounding the benefits versus drawbacks of requiring a user fee and how this relates to issues around equality.

5.2 Ethno-Racial Considerations
The Central CCAC Expert Panel members and follow-up interviews with CCAC Case Managers 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 also seen to impact on the “tipping point” (i.e. the point in time when one can no longer be sustained at the community level) for residential LTC.

It is worth noting that while there is a vast amount of 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, the Central CCAC expert panel members made several key observations.

A first observation is that cultural diversity impacts on the design and delivery of formal H&CC at all levels while creating the central BoC care packages.

- “Culturally competent” or “culturally appropriate” services and programs were seen to be provided, whenever possible, in the language of the recipient and caregiver.
- CCAC Case Managers built in ongoing education and support for staff around issues focusing on 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.

Expert Panel members suggested that cultural diversity impacted on the balance between formal and informal care, and on the ability of older persons to age at home. Case managers observed that large, multi-generational households tended to be more prevalent in some communities than in others. In such households there were often many informal caregivers, so that potentially, at least, older persons with relatively high levels of need could be
supported at home, in a culturally appropriate environment. Many Central CCAC Case Managers identified the challenges of working with various cultures in terms of having the ‘unit of care’ develop trust and acceptance of services. It was seen that in certain cultures (Caribbean, South East Asian and Italian) adult children caregivers were more likely to be involved in caregiving tasks more so than Anglo-Saxon adult children. This was suggested to be related to the cultural background and upbringing of children in these communities.

The findings support the suggestion in previous literature that cultural tradition impacts on the reasoning for providing care and the acceptance or rejection of services (Dilworth-Anderson, Brummett, Goodwin, Williams, Williams, & Siegler., 2005; Lai., 2007). Central CCAC Case Managers did not mention that the services offered to these communities differ. They simply identified the difference in the type of care the adult child or children would be willing to provide and the amount or type of formal support that the ‘unit of care’ would be willing to accept. Central CCAC Case Managers clarified that when cultural upbringing stresses the importance of caring for aging relatives, it is difficult for family members and the care receiver to accept formal services. This reluctance to accept help can often cause informal caregivers extreme anguish as they are unable to provide the care that is expected of them (Dilworth-Anderson, et al., 2005).
Case managers also observed that emerging ethno-racial communities are 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. It is important to note here that Central is 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 this region tended to have higher levels of need than individuals elsewhere. Although the RAI-HC data are insufficient to demonstrate a direct link, Expert Panel Central CCAC Case Managers 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.

5.3 Idiosyncratic Approach
There were two general lines of thought, paralleling those in the literature. The first was that the provision of formal services to informal caregivers almost always paid dividends; by supporting informal caregivers, their capacity to provide informal care increased, and the risk of caregiver burnout 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 informal caregivers, including adult children, who 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 bare minimum. 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 informal caregivers and for older persons, and generate additional costs.

These different lines of thought were evident when constructing BoC H&CC packages. Case managers brought different views to the table, provoking vigorous discussion about what needed to be done for older persons and their caregivers. While differences were always resolved, it was observed that there were few best practices or guidelines to inform case managers as they made allocation decisions on a day-to-day basis. Case managers noted that while there are regulations, service limits and protocols pertaining to care recipients, there is little advice on how needs of informal caregivers should be addressed. While leaving considerable flexibility, this also left room for idiosyncratic and sometimes inequitable decisions. It became evident during
BoC simulations that providing care to informal caregivers varied between and within provider organizations.

The decrease in child birth, coupled with the fundamental changes in the provision of health care services has created an increased expectancy for mainly female (as 77% of caregivers are female) and increasingly female spouses to care for aging family members in the home (Decima, 2002). Therefore, the Central CCAC Case Managers were consistent with population trends when stating the majority of informal caregivers they work with are either a spouse or a female. Women are likely to provide care to their spouse and as the majority live on past their spouse they are more likely to have caregiving supplemented by care from formal sources (Decima, 2002; Statistics Canada, 2003). This was also projected through the RAI-HC data that identified children as the majority of informal caregivers followed by spouses, other relatives and friends/neighbours. A major concern for Central CCAC Case Managers was the situation of an elderly spouse attempting to care for their loved one in the home. The probability of spouses being in the primary caregiving role is only likely to increase based on demographic trends. This is identified as a concern for service providers and a reason to increase support services for both the informal caregiver and the care recipient, to insure continued independent and safe living in the community.
The Central CCAC Case Managers noted the type of care provided by informal caregivers differed depending on personal characteristics. If an informal caregiver is a female or a spouse, of either sex, they are more likely to provide personal care and heavy care needs. If an informal caregiver is a son or neighbour, they are more likely to provide assistance with instrumental activities. This is also supported by the Statistics Canada General Survey (2002) that identified a gender difference of providing caregiving tasks. The survey reported women providing more tasks inside the house and more personal care (34%) with males more likely to provide tasks outside of the house and personal care (11%). The survey also noted an age difference of performing the outdoor tasks. Younger caregivers were more likely to perform physically demanding tasks than older caregivers (in terms of outdoor heavy maintenance) (Statistics Canada, 2002).

Although the RAI-HC did not provide informal caregiver gender data, the RAI-HC did provide detailed information on the type of care a caregiver does provide. The RAI-HC data was in agreement with the Central CCAC Case Manager statements that spouses are more likely to provide ADL care, children are more likely to provide IADL care and all types of informal caregivers provide significant amounts of advice and emotional support. Literature also suggests that friends and neighbours are more likely to provide emotional and supportive care while family members and mainly spouses provide more personal care (Dunér & Nordström., 2007). Based on the
challenges seniors face with IADL care (mowing the lawn, meal preparation, housework, shovelling the snow etc) it is logical that younger caregivers are more likely to perform these more physically demanding tasks than older caregivers. The other BoC projects have identified IADL needs as the primary drivers for LTC placement (Williams, Challis, Deber, Watkins, Kuluski, Lum & Daub., 2009). Veteran's Affairs Canada (VAC) provides a comprehensive use of federally funded services to people who served overseas in WWI, WWII or the Korean Conflict (Pedlar & Walker., 2004). In the 1990s a shortage of priority access beds prompted a pilot study. This study focused on persons waiting for LTC and identified that the most frequent services used were lighter, non-professional forms of support. It was established that living at home costs $5000-$6000 per client per year, while the LTC option costs $45,000-$60,000 per client per year (Pedlar & Walker., 2004). This being recognized, there is an obvious financially influenced need to insure IADL supports are available for frail caregivers at risk of burnout.

The stress inherent in a caregiving role, justifies the concern expressed by Central CCAC Case Managers for spousal caregivers and for the mid age group of informal caregivers known as the ‘sandwich generation’. Currently, 70% of Canadian caregivers acknowledge that providing care is stressful (Decima., 2002). Stress has been identified as one of the leading causes of chronic conditions (Brooks & Miljan., 2003). When considering children caregivers who are also balancing employment and family responsibilities,
increased stress is inevitable (Lai, 2007) resulting in a corresponding increase in chronic conditions (e.g. hypertension). It should also be noted that increased caregiver stress does increase the chances for abuse. Caregiver stress is not an excuse for abuse it is however, important for care providers to be aware of and recognize the signs of or potential for abuse (Carstairs & Keon., 2009).

Central CCAC Case Managers mentioned that a caregiver living in a separate household from the care recipient, a caregiver with multiple responsibilities (a job and family), and a frail spousal caregiver may require more formal care than a child live-in caregiver, retired caregiver or an able bodied spousal caregiver. However, the majority of Central CCAC Case Managers also recognized the importance of providing adequate resources to insure any caregiving role did not lead to isolation. A study conducted by Dunér and Nordström (2006) documented that if informal caregivers are unavailable based on geographic boundaries or other familial responsibilities, that those in need of care receive less practical support and feel more isolated as their other informal networks (friends, siblings and neighbours) pass on due to old age or illness. Therefore, there is a greater necessity to provide both social and health related supports to care receivers, a fact which should be considered by persons implementing support services. Providing both social and health related supports would be mutually beneficial for the care receiver and the informal caregiver. Providing such services may limit feelings of guilt,
concern and inadequacy that informal caregivers may experience if they are unable to continue providing care.

This becomes more concerning when considering the Central CCAC Case Managers stated that the majority of informal caregivers do not have other caregiver supports to lean on but rather there is typically only one primary caregiver that provides the bulk of the care. Therefore the likelihood of having caregiving tasks lead to isolation is increased. The idea of having an informal infrastructure was considered to be positive so informal caregivers had others to balance tasks and to provide more free time for the informal caregiver to partake in other tasks that could reduce informal caregiver isolation. The use of an informal infrastructure was also acknowledged by Central CCAC Case Managers as a way to reduce system costs providing informal caregivers with more ‘availability’ and or ‘flexibility’ to provide care. Case managers stated that an informal infrastructure allows multiple people to provide various types of care limiting the need to increase formal support services.

While collectively emphasizing the needs of informal 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 informal caregivers who also had paid employment, others suggested that fewer supports might be warranted since such individuals were likely to be more capable and to have 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.

5.4 Substitution Effect
There was a small statistically significant difference in the total number of formal home care hours for persons with an informal caregiver in any capacity (both caregivers who are live-in and live out) as compared to those without an informal caregiver. There was no significant difference in total number of formal home care hours provided based on caregiver care-receiver relationship.

However, we did observe statistically significant differences in the mix of home care services provided. For example:

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

We can conclude that the average total number of formal hours does not alter depending on the presence or absence of an informal caregiver. However, persons with an informal caregiver are more likely to have an increase in home health aide hours and persons without an informal caregiver are more likely to have an increase in visiting nurse hours. There is no pattern that can be pulled from these results.
A pattern was observed when comparing informal caregivers who can continue to provide care and informal caregivers who cannot continue to provide care. The RAI-HC used to assess one’s need in the home and community setting provides minimal data on caregiver capacity restricting the ability to capture the essence of ‘what is really going on here’. The data available for analysis was a one-time assessment. This limited the researcher’s ability to identify if this outcome is a short-term or long-term trend. While there are limitations in the data that constrain the researcher’s ability to accurately link this result to broader conceptualizations, this pattern is noteworthy and may prove to have policy implications. This data demonstrates that at the point of assessment informal caregivers who were distressed provided more hours of informal caregiving duties than informal caregivers who were not distressed, yet received less formal support hours. This result inevitably leads to the question: ‘Does lack of formal support equate to an increased likelihood of informal caregiver distress?’ Although further research is required to identify the reasons for such discrepancies, several observations were made that could attribute to this outcome:

- Informal caregivers are distressed because they are receiving less formal care.
- Informal caregivers who are distressed may provide more hours of care as the care-recipient is at a higher level of need.

While the data cannot show a causal relationship, it indicated that “distressed” caregivers provided more hours of informal care but received fewer hours of formal care than those who were not distressed. This result suggests a threshold of just above 2 working days per week beyond which some caregivers may experience burn-out. It should be noted that many caregivers in Toronto Central were close to, or had already exceeded, this threshold. It does not 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 leads more probably to the consequences of too few formal supports.
6. Limitations

The RAI-HC data set is a relatively comprehensive assessment tool that allows providers to establish an understanding of the overall needs of clients. However, this assessment neglects what may be considered important caregiver and care receiver characteristics (i.e. ethnicity, sex). The assessment made certain aspects of analysis difficult or in some cases impossible as the data was not identified through the assessment tool used for analysis. Trained case managers all of whom are measuring for the same purpose, that is, to identify if a client is safe to remain living in the community and to identify formal supports to assist the client toward this end, administer the RAI-HC. Receiving data from a professional organization, gathered by trained professionals using a well documented and evaluated tool significantly increases the data’s trustworthiness. Secondary analysis on its own does not afford the more complete response provided by observational data or the development of theories. This limitation was reduced as the secondary data analysis was validated with themes derived from the interviews conducted individually with front-line workers.

The research conducted to support this thesis used qualitative data from Central CCAC’s front-line workers. However, the quantitative data used was predominantly from Toronto Central as the secondary data from Central did not have complete information from the RAI-HC sections used for analysis. This reduced internal validity to some extent. Where data were available, comparisons were made between both data sets and similar trends were
found. The analysis remains beneficial as it allows for greater generalizability as the research was pulled from multiple regions of Toronto.
7. Summary

7.1 Importance
The increase in the aging population and persons living with multiple health and social needs combined with the decrease in fertility rates add to the numbers of older persons in society relative to alternate age groups. There is an assumed increase in the demand for both formal and informal community supports from the home care sector. The major shift in the focus of care locations from hospital and institutional settings to home and community care raises concerns surrounding system sustainability. More patients are being discharged ‘quicker and sicker’ and requiring increased care in community settings. Publicly funded CCACs have been required to direct a greater magnitude of available resources to post-acute care, with proportionally fewer resources available for continuing care of older persons with chronic illnesses or ongoing support needs. Senior’s are forced to either receive services with co-payment methods, private pay services or rely more heavily on informal caregivers. If the informal network fails there will be fallback onto more costly formal services. For example, seniors will occupy hospital emergency rooms, inpatient hospital beds or residential LTC as default options. There is little documentation detailing the extent and consequences of this shift in care settings on informal caregivers, who likely assume a greater range of physical, emotional and economic burden.

There are three main hypotheses within the literature that addresses the balance between formal and informal care. The first suggests a substitution
effect where paying into more formal support to assist the ‘unit of care’ may result in informal caregivers to retract the amount of care they provide. The second suggests a multiplicative outcome where providing additional services to the ‘unit of care’ would allow for informal caregivers to do more while avoiding burnout. The third hypothesis states that providing additional formal care may or may not create a substitution or multiplier effect and this will vary depending on the decisions made by the street-level bureaucrats.

7.2 Results
The BoC Central CCAC Simulations identified the need to address the ‘unit of care’ when making resource allocation decisions. The ‘unit of care’ was taken into consideration in all cases when developing home and community care service packages. For example, the Central BoC expert panel members had ‘caregiver support’ added into all home and community care packages. Caregiver support consisted of either in home support, support groups, education and social work support. However, there was less consensuses on how to best fit informal caregivers into the community care equation. The difference was present when some panel members wanted to increase services to support the unit of care and others wanted to reduce the services. In home and community, 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 home and community care, 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.

Central CCAC Case Managers identified that informal caregiver characteristics (age, sex, relationship to client) impacted on the type of formal services that would be offered. Formal services would vary based on informal caregiver characteristics as Central CCAC Case Managers stated that these characteristics impacted on the type of care an informal caregiver would provide. Informal caregiver availability and/or flexibility was also considered by Central CCAC Case Managers and do alter to what degree formal services are offered to the unit of care. This was discussed in terms of adult children caregivers who frequently have only limited amounts of time for caregiving after meeting the varied demands of working life and immediate family members. Spousal caregivers who may also be a frail senior attempting to provide difficult and heavy care were also considered in the interviews. Central CCAC Case Managers considered frail and/or unavailable informal caregivers to be in need of increased formal support over informal caregivers who were easily available (e.g. live-in) and physically able. The Central CCAC Case Managers were most likely to reduce meals on wheels and transportation services if there was an informal caregiver present and
available. Central CCAC Case Managers stated that ethno-racial differences would not impact on the type and amount of formal support offered to the 'unit of care'. However, many Central CCAC Case Managers felt the Caribbean, South East Asian and Italian communities were more likely to be family oriented and less likely to accept formal services due to upbringing, filial piety and caregiver guilt.

Many Central CCAC Case Managers mentioned challenges within the system to insure adequacy of care provision. Several mentioned the complex system makes it difficult for informal caregivers to identify and access available services. Central CCAC Case Managers also identified that the lack of formal caregiver assessment was a concern. It is difficult for service providers to identify informal caregivers in need of extra support within a short assessment period that is traditionally directed to one client rather than the total 'unit of care'. Although, the majority of Central CCAC Case Managers mentioned that it is a priority to identify the ability and availability of the informal caregiver during assessment. The concern here is that ones assessment of the informal caregiver is based on individual prejudices and biases thereby making these resource allocation decisions very countervailing.

The secondary data analysis identified no significant difference in overall formal service hours provided to persons with an informal caregiver and persons without. In fact, this analysis provided further support for the
qualitative analysis. The secondary data analysis provided no clear pattern for service allocation decisions. There are two factors contributing to this finding; first, the decisions made by the street level bureaucrats counteract; and second, decisions made by the bureaucrats are bound by systemic constraints (e.g. caps on resources). For example, case managers who consider it important to increase services with the presence of an informal caregiver and case managers who see it most efficient to decrease services with the presence of an informal caregiver counteract creating a balance of overall formal service hours. There is no evident straightforward pattern from either the qualitative or quantitative analysis to suggest a substitution or a multiplier effect. In fact, the evidence suggests a countervailing street level bureaucrat approach to resource allocation decisions.

7.3 Implications for Practice and Future Research
Overall, there were few systematic differences in actual patterns of home care utilization related to informal caregiving. Although the quantity of data analyzed was not sufficient to determine why this is, case managers on BoC Expert Panels did observe that:

- Home care resource allocation decisions are subject to a variety of external constraints including provincially set service ceilings which reduce variation particularly among individuals at higher levels of assessed need who have already reached their ceilings (at the time of writing CCAC service ceilings had now been lifted for individuals on LTC wait lists).
- While explicitly considering the needs of caregivers, individual case managers may respond in different, and sometimes countervailing ways, in effect, washing
out any 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.

There have been a number of hypotheses developed to explain the interface between formal and informal care and how case managers allocate resources. Future research is needed to adequately reject or accept the multiple hypotheses that are currently reflected in academic literature. It is important to conduct future research which aims to identify the requirements and concerns of informal caregivers and how these impact on the system as a whole. There has been a considerable focus on case management, a term used to refer to on-going assessment, planning, navigating and coordinating care for an individual. Successful case management has been recognized as: identifying the needs of both clients and informal caregivers and providing them with appropriate care which can be delivered by a team of case managers or an individual case manager (Hutt, et al., 2004). The concern exists that case managers do not have the appropriate tools necessary to adequately assess informal caregivers’ needs, and do not have the flexibility (due to systemic resource constraints) necessary to incorporate appropriate health and social services to satisfactorily meet the needs of clients and informal caregivers when considering them together as a ‘unit of care’.
7.3.1 Substitution, Multiplier or Idiosyncratic approach to care?
It is important to acknowledge that informal caregiver availability and flexibility was a large driver for defining a need to increase or decrease formal supports. Central CCAC Case Managers mentioned that informal caregiver availability involved the amount of time the informal caregiver was able to spend providing assistance, the geographical location of the informal caregiver and the frailty of the informal caregiver. Currently, only a minimal amount of research has been conducted to identify how services recommended alter depending on the presence or absence of informal caregivers. Even less research has looked at the way services alter depending on the location and availability of the informal caregiver. Basing service provision on the above noted informal caregiver characteristics, is a subjective way to assign services. ‘Need’ could be interpreted by service providers very differently.

The occurrence of subjectivity can be demonstrated within the Central CCAC Case Managers of this research. Four Central CCAC Case Managers identified the need for informal caregivers to attain education. However, education for informal caregivers was interpreted as different things between Central CCAC Case Managers. Some Central CCAC Case Managers saw informal caregiver education as a way for them to better understand the available services and others saw education for an informal caregiver as learning how to properly undertake certain nursing procedures. Offering an informal caregiver the opportunity to appropriately learn how to provide
nursing care also needs to be considered in terms of a cultural context. An individual, who is having difficulty providing care and is hiding it well, may accept the nursing education needed to provide care as they feel it is their obligation. This may lead to increased strain on not only the informal caregiver/care receiver relationship but also on the health of the caregiver. It would be of benefit to look further into this area of focus to develop a better understanding of how caregiver availability impacts on service provision. It would also be beneficial to address the supports provided to the ‘unit of care’ as well as how to systemically develop an assessment tool that better determines the current needs and concerns for the whole ‘unit of care’.

Future research on the outcomes for client and caregiver providing ‘nursing care’ that is provided by an informal caregiver rather than a trained health care worker is needed to determine the outcome for both the individual and the system (costs not only for home care but hospitalization and LTC rates would also need to be monitored) level.

Currently there is not a systematic approach in place to provide support for the ‘unit of care’. The absence of structured practices to maintain adequate and uninterrupted caregiving for the senior population is unacceptable. Filial piety and family obligation are not reliable sources for provision of care and it is not responsible of the system to depend on a sense of obligation (Lai., 2007). It is essential to proceed cautiously before assuming that because
someone is from a certain cultural community that they will have children who are able and willing to provide care. There is a shift occurring where living arrangements, employment and family structures are changing and altering the perceived expectation of filial piety and family obligation (Dilworth-Anderson, et al., 2005; Lai., 2007). The current system seems to cause a substitution effect of reduced formal services with the presence of an informal caregiver. The concern is that this will lead to an increased likelihood for informal caregiver burden and/or burnout causing increased need for LTC placement or hospitalization. If older persons and their caregivers are going to thrive, not just survive at home, there is a need for services which are seen as part of a preventative model, rather than the curative model that now dominates.

7.3.2 Preventative Model
Suitable assessments will allow for better identification of the ‘unit of care’ in greatest need of services. Targeting is an important piece for integrated community care as it can identify the small proportion of seniors and informal caregivers that use a disproportionate amount of health and social care resources. Once identified, these ‘units of care’ will subsequently benefit from active case management (Hutt, et al., 2004). There is a need to have both the frail senior as well as their informal caregiver assessed. Prevention strategies for home care would insure inclusion of assessments for not only the individual but the informal caregiver. This would reduce the likelihood of caregivers developing chronic conditions and/or producing crisis situations
that would cause further strain on the health care system (Hong., 2006). The idea is: provide care now in order to avoid crisis later. Not only is targeting of the client-caregiver dyad crucial for appropriate care delivery but active case management is integral to a prevention model. Using active case management for the ‘unit of care’ is contingent on proper targeting, open budgets to provide both health and social care and continuity of case management (Hughes & Challis., 2004). Research to date has focused primarily on providing these approaches to care to individuals at risk. Future research is necessary to identify if these care strategies are successful for the ‘unit of care’ as well as for the system as a whole.

There is a need for culturally appropriate approaches to assessments and support services that is linked to cultural values and beliefs and how those may impact on one’s willingness to accept services. One method recommended by a Central CCAC Case Manager was to use a family approach to assist the informal caregiver(s) and senior to understand why the service is being recommended and even explain the service as ‘extending family’. Literature has identified that informal caregivers go through caregiving stages and this process is complex. During the beginning stages of caregiving they are more focused on the inter-relational aspect of caregiving and are less likely to recognize the taxing effect of caregiving. This is the phase during which service providers may see informal caregivers as resistant and denying the need for extra help. At this point informal caregivers do not see the need
for, nor do they seek, assistance. It is the role of service providers and social workers to provide adjustment counselling in order to use a prevention model of care (Caron & Bowers, 2003). Attempting to assist informal caregivers in the early phase of caregiving or those who have a cultural background of expectation to provide the care can make prevention models difficult. Using educational models, rapport building and culturally competent techniques may improve the use of formal services to these subgroups of informal caregivers.

7.3.3 Preventative Model: Supplement
There is a need to enhance health and social services to support both the care recipient and the informal caregiver. Canadians have a right to health care regardless of their family circumstances. An evaluation of (Système de services intégrés pour personnes âgées en perte d’autonomie) SIPA, a program of integrated services for frail older persons, implemented in Quebec, demonstrated that informal caregivers found transportation and homemaking services to be the most useful and satisfactory elements of support. These two forms of social care prevented LTC placement and reduced stress experienced by informal caregivers (Béland et al., 2006).

Therefore, implementing social services is economically and socially ideal for both at risk seniors and their care providers. The Central CCAC Case Managers of this thesis discussed that meals as well as transportation were the two forms of support that they would be likely not to provide if there was an informal caregiver present (depending on the informal caregivers availability). This practice is contradictory to the findings discussed above.
Interestingly, a study by Tennstedt, et al, (1993) identified that the two lowest types of care to have a substitution effect were ‘housekeeping’ and ‘transportation’. If research shows that providing meals and transportation services is supportive and beneficial, there is need to discuss the street level bureaucracy occurring when decisions are being made to either provide or not provide health and social services to the ‘unit of care’. Health and social programs need to provide equal and adequate support. The service could include transportation services, affordable and accessible housing, grocery shopping, meal prep, financial management and increased homemaking services that involve homemaking for both the client and their live-in informal caregivers. Currently our system focuses on curative care which emphasizes the need for health services and places minimal emphasis on social services. The system is reliant on an individual’s informal network to sustain people in the community. As outlined in Chapter 3 of the Ministry of Ontario’s ‘A Guide for Seniors and their Families about Home, Community and Residential Care Options in Ontario ’: ‘If your family or friends cannot help with essential tasks then a residential setting may provide the help you need’ (Ministry of Health, 2003). This clearly portrays the reliance the current system has on the services provided by informal networks. It has been identified that the primary predictor of informal caregiver stress is the lack of choice in responsibility (Decima, 2002). Furthermore, studies have shown that community options are both more cost effective for the system and more satisfactory for the
informal caregiver if the caregiver feels valued, supported and as though they chose to provide care (Hollander, et al, 2006).

High quality community alternatives need to be in place so informal caregivers do not feel burdened with guilt if they are unable to provide unlimited amounts of care. Culturally competent social workers that are able to communicate the availability and the usefulness of care support are a necessary part of the system that will encourage informal caregivers to relieve feelings of guilt and to be willing to accept support.

Regulations have changed over time. In general, the province has set capped budgets for each CCAC, and specified maximums (on a per client basis) for homemaking and personal support services. The regulations under the Canada Health Act do allow CCACs to provide services beyond the specified maximum under “extraordinary circumstances”, defined in terms of those needing palliative care, and those on LTC wait lists (CCAC, 2008). However, there has been a tendency for CCACs to prioritize post-acute care. Such budget priorities have a disproportionate impact on care for seniors, and may encourage premature placement in LTC institutions. Individuals and their carers who are unable to navigate the complex system of home and community care may move to LTC earlier than necessary, even though the total system cost may be higher and the impact on individuals and their families worse. At present, CCAC case management is the main mechanism
for coordinating and managing care across organizations and monitoring outcomes. It is important to recognize what shapes funding priorities as setting out funding mechanisms to support the ‘unit of care’.

It has been repeatedly emphasized that the hospitalization of the elderly often results from informal caregiver breakdown rather than increasing pathology of the older person (Hong, 2006; Stabile, et al., 2006). This suggests that increasing supports to informal caregivers in the community is most likely to provide them with enough resilience to allow them to prolong care, thereby diverting LTC placement and ultimately reducing hospitalization (Chenier, 1993). Our current system neglects the need to identify the challenges faced by informal caregivers, yet our system sustainability relies on their continued involvement and support. There is need to support longitudinal research to insure all practices implemented are effective at both the individual level and system level. Health policy must determine the most effective way to integrate concern for the health of the elderly with concern for the health of the nation. There are varying views on whether the costs of health care for the elderly are higher than the costs for other parts of the population. There is need for systematic information to identify how to meet demands for efficiency and equity (Chenier, 1993).

Attempts to evaluate success are complicated. One problem in evaluating success is that the effects vary depending on the starting point (i.e., if a system
is currently supporting informal caregivers well, then it is difficult to develop a program that demonstrates significant positive results). It is easier for a poorly running system to show improvement. Time frames matter – positive outcomes may only become apparent after a few years, particularly since vulnerable populations may be able to 'muddle through’ for a short (but unsustainable) time period (Hollander & Chappell., 2002). There needs to be involvement of informal caregivers in research projects and policy development and methods used to determine effectiveness on a yearly basis and allow programs to develop for 2-3 years prior to deeming them either ineffective or effective.

7.4 Conclusions

From this research two major conclusions can be drawn:

1. As identified in the Central BoC Simulations the ‘unit of care’ for community settings needs to steer away from the traditional acute care approach and address both the individual client and their caregiver(s).

2. From the qualitative and secondary data analysis it is evident that case managers are considering informal caregivers when making resource allocation decisions. However, the approach used to address the caregivers is based on individualized observations, biases and feelings.

There was no evidence to suggest either a complete substitution or multiplier effect. There was, however, significant evidence to suggest that street-level
bureaucracy plays a large role in service allocation decisions. That is, decisions are being made based on diverse idiosyncratic observations, opinions and feelings. While street level bureaucrats require some flexibility in making decisions there is great need to produce accountability guidelines. The current approach to resource allocation decisions has case managers, in effect, developing policy by default.

Flexibility in decision-making is useful for front-line case managers since one size does not fit all. However, this flexibility is in need of increased guidelines and accountability measures. There is evidence from other professional street level bureaucrats that flexibility with decision making can be maintained alongside accountability procedures and policy guidelines. Police officers are an example of street level bureaucrats that have decision making power yet are constrained to guidelines. For example, police officers use their own discretion prior to the use of firearms and tasers. However, the use of such weapons is only acceptable under minimal circumstances and if the use of a taser is considered unacceptable the officer would be held accountable.

Looking at other professions involving street level bureaucrats it seems likely that the home and community care sector needs to incorporate regulations, consensus conferences and accountability guidelines. Developing such measures has potential to reduce counteracting resource allocation decisions.
One Central CCAC Case Manager stated clearly: ‘To truly have aging at home we have a long way to go.’ The general consensus was that significant improvements have been realized in the area of providing homecare to the aging population but many concerns remain that need to be dealt with before seniors can safely and securely age in place.

A first step suggestion based on the results of the research conducted for this thesis can be made. It would be helpful for services providers to be accountable for the decisions made and have use of an assessment tool that is more than an individualized tool. A ‘unit of care’ assessment tool that would better aid in service provision guidelines for the ‘unit of care’ must be developed and made available to front line workers responsible for making care decisions. Education for case managers, guidelines for care and accountability measures must also be developed to insure case managers are held responsible for resource allocation decisions.

Further exploration of the feasibility of providing integrated, community based care for both the informal caregiver and care receiver is warranted in order to reduce or postpone caregiver burden thereby resulting in fewer aging persons seeking LTC placement and/or hospitalization.
Reference:


Appendix A: Operational Definitions

**RAI**: in 2001 the MOHLTC and CCACs under the Community Care Connects (C3) project, developed an expert panel. This panel reviewed and evaluated assessment tools resulting in a recommendation that the MDS-HS (RAI) be used as the primary assessment tool for all CCACs to employ when assessing the need for in-home services and admission to LTC (Fact Sheet, n.d).

‘At risk’ seniors are persons who are ‘at the margins’ of losing independence or those who are currently occupying or deemed eligible for a LTC bed.

**Caregiver or informal caregiver**: As defined by the Ministry of Health and Long-Term Care, a family/informal caregiver is an individual who provides care to a loved one (family or friend) who is either physically or mentally disabled or is chronically ill or frail.

For the purpose of this thesis, **formal supports** refer to home care services where formal support is provided through formal care giving agencies. Ie. Home health aids, visiting nursing, homemaking services, meals, volunteer services, day programs or day hospital care, social work support, physical therapy (PT) and occupational therapy (OT).

**Front-line workers** were asked to be members of expert panels for the BoC meetings and asked to participate in follow-up interviews. Front-line workers wear many hats that include playing a large role in private and public living facilities. Front-line workers are in hospitals, communities, acute care facilities, and LTC homes. These workers are from varied professional backgrounds and include nurses, social workers, personal support workers (PSWs) and case managers.

**Caregiver ‘burn out’** usually refers to people who provide extensive care (either formal or informal) that are in a state of physical, emotional and/or mental exhaustion which may be accompanied by a shift in attitude. This research focused more specifically on informal caregiver burn out and examined the potential of informal caregiver burn out for caregivers supporting frail seniors in the community.

**Substitution effect**: refers to the effect that providing formal services to a frail senior living in the community has on the amount of time spent by an individual’s primary informal caregiver.
Appendix B: Informed Consent

CONSENT AGREEMENT
Caring for Caregivers: Balancing formal and informal care for frail older persons

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You are invited to participate in a research project examining how the presence or absence of an informal caregiver shapes, or should shape, home and community care (H&CC) packages for frail older persons.

This project follows-up your participation in the Central Balance of Care (BoC) project conducted in June 2008 in which you, and other senior managers from across the health and social care continuum, assessed the characteristics and needs of individuals currently on the long-term care (LTC) wait list and constructed H&CC packages to meet their needs. In doing this, considerable emphasis was placed on the need to consider both the individual and informal caregiver.

However, because of time constraints, it was not possible to explore in any depth, different assumptions about how informal care and formal care should best be balanced in H&CC packages. For example, one assumption appeared to be that when informal caregivers are present, additional formal services are required. Another assumption appeared to be that the presence of an informal caregiver could reduce the need for, or change the mix of formal services. Further, questions were raised about the extent to which this balance would differ in ethno-racial communities.

This project uses in-depth qualitative interviews to clarify how the presence of informal caregivers impacts on decisions around the volume and mix of formal H&CC services provided to frail older persons, including those in different ethno-racial communities.

It is being conducted by Allie Peckham, Masters Student, Faculty of Social Work, University of Toronto, as part of her degree requirements. It is supported by the multi-year Canadian Institutes for Health Research (CIHR) Team in Community Care and Health Human Resources, Co-directed by Professors A. Paul Williams and Raisa Deber at the University of Toronto with co-investigators at Ryerson University.

Purpose of the Study:
To document assumptions about the role and needs of informal caregivers, and how these impact on H&CC care packages for frail older persons. The results of this study will inform Aging at Home strategies now being implemented across Ontario.

Description of the Study:
You are asked to participate in a 30 minute face-to-face or telephone interview scheduled at a time convenient to you in which you will be asked your views on the balance of informal and formal care for frail older persons. Some questions will ask about the assumptions underlying the care packages constructed by you and other managers during the Central Balance of Care research project conducted in June 2008. With your permission, the interview will be audio tape recorded for the purposes of analysis.

Risk or Discomforts:
There are no significant risks to participating in this study. You can, at any point, decide to withdraw from the study without any consequences. In this event, you will be asked if the data collected to the point of withdrawal can be used in the study. If you request the data to be destroyed upon your withdrawal any data collected to that point will be destroyed.

Benefits of the Study:

155 College Street, 4th floor
Toronto, Ontario M5T 3M6
Phone (416) 978-8326  Fax (416) 978-7350  www.hpmc.utoronto.ca

GREAT MINDS FOR A GREAT FUTURE
Your responses will assist in clarifying the balance between informal and formal care for frail older persons. The findings of this research will be communicated to policy-makers, providers and consumers to inform ongoing Aging at Home strategies in Ontario.

Confidentiality:
All comments will remain confidential. No identifying characteristics or names will be attached to any comments. The results of the study will be safely stored on a dedicated computer with a password protected drive in a locked office in the Department of Health Policy, Management and Evaluation (HPME) at the University of Toronto for 7 years after completion of the project; subsequently, they will be deleted. Only the researcher and members of her thesis committee will have access to the data.

Incentives to Participate:
You will not be paid to participate in this study. However, you will be sent a summary report of the results of the study when available.

Costs and/or Compensation for Participation:
There are no costs associated with participation in this study.

Voluntary Nature of Participation:
Participants may withdraw from the study at anytime and for any reason. There will be no penalty or negative repercussions for an individual who withdraws from the study. If the you do decide to withdraw, data that has already been collected will be shredded and discarded unless specific permission is given to use it in the final results of the study.

Questions about the Study:
If you have questions or require more information about the study itself, please contact Allie Peckham at 647.637.7645 or Professor A. Paul Williams at 416.978.8327.

If you have questions regarding your rights as a participant in this study, you may contact the University of Toronto Ethics Review Office at:
ethics.review@utoronto.ca
Telephone: 416.946.3273
Fax: 416.946.5763
Address: 12 Queen’s Park Crescent West, 3rd Floor, Toronto, ON M5S 1S8 (McMurrich Building)
Hours: 8:45 am- 5:00 pm EST (September-June); 8:45 am-4:30 pm EST (July & August)

Agreement:
You will be asked to sign two copies of this consent form. Your signature below indicates you have read the information in this agreement and have had a chance to ask any questions you have about the study. Your signature also indicates that you agree to be in the study which includes being audio-taped for the purpose of assisting in note taking and transcription. You are free to change your mind and withdraw your consent to participate at any time. By signing this consent agreement you are not giving up any of your legal rights.

__________________________  ______________________
Name of Participant (please print)  Date

__________________________  ______________________
Signature of Participant (Agree to participate)  Date

__________________________  ______________________
Signature of Participant (Agree to be Audio Recorded)  Date

__________________________  ______________________
Signature of Researcher  Date

Thank you for your participation in our study.
Appendix C: Interview Schedule

Follow-up Interview Schedule

I would like to begin by asking you a few general questions about how informal caregivers should be taken into account when designing home and community care (H&CC) packages for frail older adults.

While informal caregivers are often close family members (e.g., a spouse or child), they can also be neighbors, friends, and volunteers. By contrast, formal caregivers typically include professionals and other paid workers.

In particular, I am interested in understanding how you think the presence or absence of informal caregivers should impact on the volume and mix of formal services provided to frail older adults, and to informal caregivers themselves, including those in different ethno-racial communities.

1. In your experience, what role do informal caregivers typically play in caring for frail older adults in the community? What role should they be expected to play?
   Probes: instrumental support, emotional support, financial support

2. Typically, what are the characteristics of informal caregivers? Do their roles differ depending on characteristics?
   Probes: Family members, neighbors, friends, volunteers
   Males/females
   Younger/older?
   Live-in?

3. In making decisions about formal care for frail older adults, how should the needs of informal caregivers be taken into account?
   Probes: Add services to support caregiver capacity?
   Reduce services since caregiver is present?
   Change the service mix?

4. Currently, in your region what services are available specifically for caregivers? What changes, if any, would you like to see?

5. 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?

6. Considering the informal caregiver as a multiplicity of persons providing an informal infrastructure to a particular person, what might this look like? Does it differ between ethno-racial communities, how might this impact on the supports provided?
7. Now I’d like to ask you more specifically about two of the care packages constructed by case managers during the Central Balance of Care meetings in June, 2008. (Provide respondent with copy of vignette and care package for high needs and low needs sub-groups). Both of these care packages assume the presence of a live-in informal caregiver.

In your view, do these packages appropriately take into account the role of the informal caregiver? What would you change, if anything?

- Would the services provided to informal caregivers 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

  How would ethno-racial differences be taken into account?

8. Finally, I am wondering who you think should pay the costs of services for informal caregivers?
   Probes: Public funding
   - Private insurance
   - Out-of-pocket payment