UNDERSTANDING THE VALUE OF FAMILY CAREGIVERS.

by

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ABSTRACT

Home care has a model that depends on the unpaid support of family caregivers. This sample examines all active home care clients (N = 1698) receiving case management services between April 1, 2010 and March 31, 2011, 96% of clients report they have a family (informal) caregiver with 23% receiving help from spouses and 68% receiving help from child or other relative. Family caregivers who are stressed are providing an average of 34.27 hours per week of care, family caregivers who care for seniors with cognitive and physical impairment provide up to 45.85 hours per week and 50.4 hours per week respectively. Twenty-six percent of home care clients have stressed caregivers. Of the home care clients who were hospitalized 58% of them had stressed family caregivers and 34% of these home care clients became ALC. This study addresses the importance of supporting family caregivers to mitigate stress so they can continue to care.

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Glossary

ADL Long Form (ADL lg) – Activities of Daily Living are the daily personal tasks that a person must accomplished to function throughout the day (e.g. dressing, toileting, transfer from one surface to another, locomotion in their living space, eating, etc.). This scale is summative and ranges from 0 to 28, higher scores indicate higher levels of difficulties with these tasks. (Canadian Institute For Health Information [CIHI], 2009)

ADL Self Performance Hierarchy (ADL SP) – this scale considers four core elements (e.g. personal hygiene, toileting, locomotion in the living space, eating). The elements represent early, middle and late level losses therefore they are used to determine the level of disability of the individual. The score ranges 0 to 6, it is derived by an algorithm with higher numbers indicating higher level of disability (CIHI, 2009). (0-1, independent to supervision; 2, limited assistance; 3+ extensive assistance to total dependence).

ALC – Alternate Level of Care is a term to refer to patients who no longer need acute care services.

Case management – is a public funded service provided through the health authority. Case management services are provided by a case manager (health care professional) who assesses the individual (client) to determine the clinical needs of the individual and authorize services (e.g. home support services, respite, adult day centre, waitlist for assisted living or residential care) All clients who receive case management services have a TAI-Home Care assessment completed prior to receiving services.

CIHI – is the Canadian Institute for Health Information. "CIHI is an independent, not-for-profit corporation that provides essential information on Canada's health system and the health of Canadians." (CIHI, 2010)

Cognitive Performance Scale (CPS) evaluates the individual's level of cognitive functioning (CIHI, 2009). It ranges from 0 to 6, with higher numbers indicating increased cognitive difficulties (e.g. 0 -1, intact to mild intact; 2, mild impairment; 3+, moderate-severe impairment).

DAD Discharge Admission Database – a national standardized data base used to capture acute care encounters by patients, this information is submitted to CIHI on a quarterly base from all health authorities.

Depression Rating Scale (DRS) screens individuals for signs of depression. It ranges from 0 to 14 with scores 3+ suggestive of depression (CIHI, 2009).

MAPLe – Method Assessing Priority Leveling. This scale ranges from 1(low) to 5(very high). This scale is predictive of adverse health outcomes and institutionalization (Hirdes, Poss, Curtin-Telegdi, 2008). The splits used in this paper are MAPLe 1, 2 (low, mild), MAPLe 3 (moderate), MAPLe 4, 5 (high-very high).

PAIN is the pain scale indicating no pain (0) to mild pain (1), moderate daily pain (2) and severe daily pain (3) (CIHI, 2009).

RAI-Home Care (RAI-HC) is an evidence based assessment instrument developed by a not for profit health care research consortium. The RAI –Home Care “evaluates the needs, preferences and strengths of home care clients” (CIHI, 2010). The various scales and scores within the assessment tool describe the clinical characteristic of the client. Some of these scales are described above: ADL lg form, ADL SP, CPS, DRS, PAIN, MAPLe)

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Chapter One: Introduction

Home Care provided by health authorities in British Columbia supplements the existing care and support provided by the family. Frail seniors or adults with chronic disease are the most likely individuals to need home care to help them stay in their own homes. Frail seniors want to stay at home (Trice, 2006; Grunfeld, Glossop, McDowell, & Danbrook, 1997) and they depend on family to help them stay at home (AARP, 2007, 2011; Canadian Home Care Association, 2009; CIHI, 2010; Access Economics, 2010). This makes the informal (family) caregiver not only a resource to the frail senior but a resource to the health care system.

Home care is not standardized across Canada (Canadian Home Care Association, 2009). The Ministry of Health, British Columbia has identified the basic set of community health services that health authorities are to provide for seniors. These services include home care nursing, community rehabilitation services, assisted living, adult day centre, respite services, home support services, and collectively they are referred to as Home Care. Residential care is also considered a care option provided in the community.

Home support services are highly utilized. They are accessed through a case manager (clinician), who completes an assessment of the frail senior and determines the type of services needed to support the frail senior in the community. These services are designed to take some of the "burden" off the family. Home support services help the frail senior with personal care (e.g. bathing, dressing), medication reminders and assist them in performing tasks delegated by other health professionals (e.g. eye drops, passive exercises). These services are better able to meet the needs of the senior and relieve their family caregiver when the services can be scheduled. However there can be many unscheduled needs (e.g. toileting, changing of clothing if there is an accident, supervision) that the family remain responsible for. This emphasizes the importance of the family caregiver as a partner with home health in supporting the senior in the community.

A familiar debate around the sustainability of the health care system involves the increasing number of older people in our population and subsequently the costs to the health care system (Ruggeri, 2002; Foot, 2008; CHSRF, 2011a, CHSRF, 2011b). While a) older people use more health care as they age which does affect consumption of resources(CFSHR, 2002; CFSHR 2011b, Ruggeri, 2002), b) it is the more extensive treatments used to provide health care (e.g. cataract surgery, hip replacement) that drives the costs up (CHSRF, 2002). This paper is not going to tackle this ongoing argument; instead this paper will focus on the sustainability of the family (informal) caregiver. It is through the utilization of the family caregiver that some of the costs to the health care system, by an aging population, can be mitigated.

Informal caregivers are unpaid caregivers and are usually spouses or other family members although they can be friends or neighbours (CIHI, 2010). Throughout this paper, the term family and informal caregivers will be used interchangeably. There is no dispute that family caregivers are instrumental in providing care for seniors which translates to a cost savings to the health care system (AARP, 2007, 2011; Canadian Home Care Association, 2009; Access Economics, 2010; Hollander, Liu, & Chappell, 2009; Jakobsen, Poulsen, Reiche, Nissen, & Gundgaard, 2011).

Family (informal) caregivers provide care for a variety of reasons, however the reason that is understood the best is duty and emotional attachment (Wanless, 2005). The spouse tends to be the most common caregiver (Access Economics, 2010; Jakobsen et al., 2011) suggesting that old people are looking after old people, however this has been refuted by others indicating that children and children-in-law are more common caregivers (Wanless, 2006). In this current study sample, 96% of the active home care clients have an informal (family) caregiver; only 23% of these are spousal caregivers, 68% are children or other relatives and 9% rely on a friend or neighbour. While family caregivers are an invaluable asset, they can become stressed with the ongoing care and the behaviour of the senior (CIHI, 2010; Jakobsen et al., 2011). Seniors with no family caregiver or seniors with stressed family caregivers can have drastically different health outcomes (e.g. hospitalization, premature placement in residential care) (CIHI, 2010). These different health outcomes impact the costs of the health authority in different ways, emphasizing the important role of the family caregiver to the health care system as well as the essential importance of providing support for the family caregivers so that they are able to avoid becoming stressed. As the research will show, an unstressed family caregiver has a greater positive impact on the sustainability of fiscal resources as well as the outcome of the home care client.

Inarguably, the family caregiver contributes a valuable resource to the health system. Various methods have been described in literature to determine a value for family care giving (AARP, 2011; Access Economics, 2005, 2011; Hollander, Liu, Chappell, 2009; Jakobsen et al., 2011; Van Den Berg, Ferrer-I-Carbonell, 2007).

Hollander et al (2009) estimates the contribution of family caregivers around $25 to $26 billion to the health care system.

As the population ages, we will have a higher proportion of seniors needing services (Canadian Health Services Research Foundation [CHSRF], 2011) and more dependency on family caregivers who have the potential of becoming distressed. Therefore the demand for family (informal) caregivers will increase. Presently it is the baby boomers' parents that are the older segment of the population (Keefe, Legare & Carriere, 2007) however it is estimated that by 2021 the baby boomers will be in that older segment (Keefe, et a., 2007). The family structure (e.g. small families, no children) has been changing with the baby boomers so that the supply of informal (family) caregivers is decreasing (Keefe, et al, 2007).

This paper draws on three areas, the analysis of informal caregivers (CIHI, 2010: Access Economics, 2010), methods of valuing family caregivers (Jakobsen et al, 2011, Access Economics, 2010) and a preliminary discussion of supply and demand of family caregivers (Keefe et al, 2007; Carriere, Keefe, Legare, Lin, Rowe, Martel, & Rajbhandary, 2008). The contribution of family caregivers is essential; we need to have a better understanding of how to support the caregiver so they can continue to care now and in the future.

This study can benefit Health Authorities by:

- Providing a cost factor that can be utilized by program planners for cost analysis when developing and implementing new services for seniors
- Providing comparison of family caregivers in the northern and rural locations with the existing national data

- Informing policy and clinical practice to support family caregivers now and into the future

This study can benefit health finance by:

- Adding to the health economics and finance literature on the value of family caregivers for seniors living in northern and rural areas within British Columbia.

Chapter 2: Literature Review

This literature review is an overview of grey literature such as provincial government reports (e.g. UBC Health Services and Policy Research), and national and international reports (e.g. CIHI, Canadian Home Association, Access Economics) as well as research publications (e.g. Hollander, et al., 2009; Jakobsen, et al, 2011). It will establish and identify the predominant themes from the literature surrounding/ concerning the informal (family) caregivers and the people they are caring for, methods for evaluating the value of informal caregivers and thoughts on the future demand and supply of family caregivers.

Sustaining Health Care

Concern over the sustainability of health care due to the aging population is a common and ongoing theme (Ruggeri, 2002; Foot, 2008; CHSRF, 2011a, CHSRF, 2011b). Although the population is aging, conflicting opinion exists as to whether the aging population is a threat to health care sustainability (CHSRF, 2011b). The sustainability of health care is a complex discussion with many facets. Some of the differences in opinion arise around the slow increase in costs over the last 10 years (Laupacis & Born, 2011). Although debates revolve around the use of acute care and physician services, it is the case that most seniors want to stay in their own homes, thus becoming primarily an issue of chronic and sustained cared rather than acute (Canadian Home Care Association, 2009; CIHI, 2010). Therefore an important area for sustainability discussions is around how to maintain frail seniors at home. Seniors do occupy hospital beds when there are no appropriate home-based and community-based services and this increases costs and places a burden on the system (CHSRF, 2011b). The use of alternative level of care (ALC) beds demonstrates home-based and community-based supports are not developed to support seniors (CHSRF, 2011b). In addition, seniors need a variety of services to remain at home (Canadian Home Care Association, 2009). Most of these services are not covered under universal health care and, as a result, provinces and health authorities are responsible for these services. If our current home care system depends on the family (informal) caregiver keeping frail seniors in the community, the future home care system will also have that dependency. However, the old (75+ years) baby boomers have not yet impacted the system in terms of home care services. Keefe et al (2007) and Carriere et al (2008) estimate that it will be another ten years before the pressures of the old baby boomers will be felt. Home care needs to develop and deliver cost effective home-based and community-based care in order to meet the predicted pressure which will be placed on it in the near future (CIHI, 2007).

Importance of Family (Informal) Caregivers

The family (informal) caregiver is key to making home-based and community-based care function to support the senior in remaining at home (Canadian Home Care Association, 2008; CIHI, 2010; McGrail, et al, 2008). The family caregiver provides assistance with such items as housekeeping, meal preparation, grocery shopping and transportation which are outside the role of the formal support services. The family caregiver also provides emotional support and companionship. However, some seniors living in rural and remote locations do not have informal help (Canadian Home Care Association, 2006) and nationally approximately 2% of seniors report no informal caregiver which impacts on how well they can manage by themselves (CIHI, 2010).

Human costs of being an informal caregiver

CIHI (2010) uses the RAI-Home Care data from four jurisdictions (Nova, Scotia, Ontario, Winnipeg Regional Health Authority, and Yukon) to identify the impacts that caring for an aging family member can have on informal caregiver. A synopsis of their findings reveal: 2% of older home care clients did not have an informal care giver which indicates that older home care clients need informal (family) caregivers to help them manage at home; 16% of the caregivers are distressed, and caregivers who provide more than 21 hours of care per week are two and half more times likely to be distressed compared to a caregiver who provides less hours per week. This report identifies higher numbers of "stressed" caregivers if the clients have significant clinical issues: e.g. depression symptoms 32%, moderate to severe cognitive difficulties 37%, and display aggressive behaviors 52%. The report confirms that spouses are at more risk of distress (1.6 times) compared to other caregivers.

This large sample of informal caregivers supports the hypothesis that family caregivers are more at risk to become "stressed" when the home care client has cognitive problems and needs help with daily activities. This report exposes the fact that the majority of seniors need the support of informal caregivers in order to stay in their homes or communities. The consequence of having no informal help or "stressed" informal help that can no longer manage is that the frail senior (home care client) can no longer be maintained at home. This identifies the importance of supporting family (informal) caregivers so they can continue to care for the frail senior, which in turn highlights the importance of addressing the immediate sustainability of the family caregiver.

Future of informal care

The supply of family (informal) caregivers is a concern for the future because our family structure is changing. Three articles (Keefe et al., 2007, Carriere et al.,2008 and Access Economics, 2010) discuss the future supply of informal (family) caregivers and point out that the current population of seniors are the parents of the baby boomers. Hence, the baby boomers are the informal caregivers for their parents. But the question becomes: who will be the informal (family) caregivers for the baby boomers? In approximately ten years the baby boomers will be entering the older age category (75+ years) which has the greater potential for needing family (informal) help to assist them with their daily activities (Keefe et al, 2007). There is agreement (Keefe et al., 2007, Carriere et al., 2008 and Access Economics, 2010) that there will be less availability of informal caregivers because baby boomers have had no children or fewer children than the generation preceding them, young people have greater mobility and leave for job opportunities, and women continue to enter the work force which decreases their availability for caring for others. In addition, it has been predicted that there will be less social commitment due to a greater number of relationship breakdowns, single people, and, most worrisome, the notion that the next generation (Gen X,Y) does not have the propensity to care (Keefe et al, 2007; Access Economics, 2010). The conclusions are that the demand or need for family (informal) caregivers will rise but the supply for family (informal) caregivers will decrease. This identifies the importance of having strategies to address the future sustainability of family caregivers.

Service utilization

Home care is a broad term covering home-based and community-based health services such as home care nursing, community rehabilitation services, case management services, assisted living services, adult day centre and home support services (McGrail, Broemeling, McGregor, Salomons, Ronald, McKendry, 2008; CIHI 2007). The core sample of clients for this study is identified by their service utilization of home care services, in particular case management services. Case management services involves a clinician (most commonly a registered nurse) who completes a clinical assessment (RAI-Home Care) to assess the client's needs and preferences to determine which supportive services (e.g. home support, respite, assisted living, etc) would best support the client to remain in the community. Therefore case managers authorize home support services, adult day centre services and respite services to give the family (informal) caregiver a "break" from caregiving. As well, case managers authorize assisted living based on the clinical need of the clients or waitlisted clients for residential care when clients' needs cannot be met with home-based or community-based services. The goal of home care, through case management, is to keep seniors in the community, avoiding or decreasing hospitalization and preventing or delaying the admission to residential care (McGrail et al, 2008). This is one strategy that strives to address the overall sustainability of the health care system by diverting seniors to home-based or community-based services (McGrail et at, 2008; Canadian Home Care, 2008).

McGrail and colleagues (2007) address home care utilization. Home care services are publicly funded through the health authority with a charge for some of the services such as home support services. The charge is based on the client's ability to pay, however; 70% of home support users in BC pay no user fee due their low income (McGrail et al. 2008). As seniors' age increases so does their use of home support services (McGrail et al, 2008). This report uses early data prior to the implementation of the RAI-Home Care assessment so no conclusions can be made about the service utilization of seniors due to distressed caregivers or home care service utilization based on the seniors clinical characteristics.

In terms of examining health service utilization of seniors outside of home health, an older report (Rotermann, 2003) confirms that seniors with 3 chronic diseases average 5.3 physician visits per year ($p < 0.05$) and the frequency of visits can increase with chronic diseases. As well, Rotermann (2003) identifies that although seniors are 13% of the population they account for 1/3 of acute hospitalization, have repeat admissions and stay longer per stay. In summary, seniors use more health services than any other age group (Rotermann, 2003; CIHI, 2007; CHSRF, 2011b). Not surprisingly, seniors who report their self-perceived health as poor, average seven medical consultations (visits) per year (Rotermann, 2003), receive more home support (McGrail et al. 2008) and have caregivers admitting that they are stressed (CIHI, 2010.)

Methods for defining costs

Although family (informal) caregivers provide unpaid care which benefits the health care system, this has a detrimental effect on the economics of both the individuals and the community (Access Economics, 2005, 2010). Simply put, caregivers who are out of the workforce or have become part-time employees in order to be caregivers, eliminate or reduce their personal income, which in turn reduces tax dollars and the amount of money circulating in a community (Access Economics, 2005, 2010). An extension of this concept is the effect of distressed caregivers on the economy; if the stressed caregivers can no longer care for the senior, the senior is hospitalized, reducing the availability of acute care beds for others and may cause early residential care placement: a placement due to the caregivers' inability to continue caring rather than clinical need of the individual. As well there can be counteracting effect if the caregiving makes the caregiver sick; this can outweigh the monetary value that the family is providing to the health care system (Access Economics, 2010).

Placing a value on the contribution of family caregivers is a challenging concept. The literature describes three methods of deriving a value for the work of family (informal) caregivers. These methods are calculated by opportunity costs, replacement costs (or the proxy-good method), or by the well-being-value method. The opportunity costs examine the lost wage potential of the person who is caring (Access Economics, 2005; 2010; AARP, 2011) The replacement costs (proxy good method) method calculates a value by substituting what it would cost if a paid employee had to do the same caring (Access Economics, 2005, 2010; Jakobsen et al, 2011). The well being value method determines the cost not only to reimburse the care component but for the informal care giver's sense of well being (Van Den Berg & Ferrer-I-Carbonell, 2007).

Limitations of the various methods.

The replacement costs (good proxy) method values the work at the same rate as buying it from formal care sector i.e. the home care sector (Assess Economics 2010; Jakobsen et al. 201) This method is relatively simply as it takes the informal hours and multiplies by the current rate. The replacement cost (good proxy) method does not consider the efficiency of the care (e.g. economy of scale) being provided (Access

Economics, 2011) because a formal caregiver in residential care facility would look after a number of clients which should lower the cost of care. On the other hand, formal care cannot always mimic family (informal) care or provide it at the same cost because of other factors e.g. travel time to the home, regulations around continuous work, therefore there would be multiple workers to care for one person (Access Economics, 2010). In this last example, using replacement costs does not capture what it would cost a formal home care service to provide 24 hour care (Access Economic, 2010). By virtue of living with the senior, the spouse or other live-in primary caregiver provides 24/7 supervision that may not be accounted for in the claimed informal care hours. In a Canada Stats report, Cranswick & Dosman (2007) speculate that informal care is generally underestimated due to spouses feeling responsible for care duties.

The opportunity cost represents the potential wages that are lost. Therefore the calculation uses a standardized amount that the general population receives for employment considering gender and age (Access Economics, 2010, AARP, 2011) The obvious limitation here is that it does not consider the wide variation of wages from unskilled to professional and it does not calculate in "forgone leisure time" (Access Economics, 2010, p. 17).

The well-being evaluation attempts to calculate the cost to maintain the caregiver's sense of well being (Van Den Berg & Ferrer-I-Carbonell, 2007). This method is more involved as it tries to capture the subjective costs (well being) of caregiving so that a more comprehensive cost factor can be determined (Van Den Berg & Ferrer-I-Carbonell, 2007). The obvious limitation are the complexities of gathering this information (questionnaires) which is only reflective of the subject's own subjective view at that time rather than hard data.

This literature review provides a framework to explore the existing data. The strength of this study is the ability to link the clinical characteristics (RAI-Home Care information) with the actual service utilization (Home and Community Care administrative database and the Discharge and Admission database). The RAI-Home Care includes the extent of informal hours which will allow for the calculations for replacement costs. This paper addresses the following questions:

1. What are the demographic characteristics of clients needing informal care and who are their caregivers (relationship)?
2. What are the clinical characteristics of clients with stressed and not stressed caregivers?
3. What are the health outcomes for clients with stressed, not stressed, and no caregivers?
4. What are the replacement costs of family (informal) caregivers?

This paper will conclude with a discussion of the future supply of family (informal) caregivers.

Chapter Three: Method

Design and Sample

This was a retrospective examination of secondary data collected from April 1, 2010 to March 31, 2011 representing the active home care clients (N = 1693) receiving case management services in a northern and rural health area in British Columbia. Permission to use these databases for this project was granted by the Northern Health Research Committee. The information pertaining to this sample was gathered and linked from three data base resources:

- Clinical characteristics (RAI-Home Care) data base
- Home health service utilization and administrative data base
- Acute service (in-patient) utilization (DAD) data base

Procedure

The core sample was defined by the RAI- Home Care[1] assessment instrument because this assessment tool is used to admit all clients to case management service, the other two data bases were matched to this core sample. This data was linked by a unique identifier, the client's personal health care number (PHN). This step was completed by health authority employees to preserve privacy and confidentiality of the individual client. Once the data was matched the unique identifier (PHN) was deleted and replaced with a meaningless but unique number. Other potential identifiers were removed (e.g. birthdate replaced with age) and no names or addresses, postal codes or community names were collected. Once the unique identifier (PHN) was deleted, the clinical characteristic information, service utilization or acute care information was not sufficient

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[1] See Glossary

to identify a client. The raw data was not shared with the University of Northern British Columbia; only aggregated displayed data within the final report was shared.

The RAI-Home Care instrument is used at the point of entry by the clinician to determine appropriate services/care options for the client. At the aggregate level data, it is used to examine populations (e.g. frail elder, chronic disease population) in order to evaluate and plan services and inform policy. Therefore the RAI-Home Care supplied the clinical characteristics of the core sample (See Appendix 1), this was matched to home support and Assisted Living utilization and waitlist information from the home health service utilization and administrative data base. The sample by way of the discharge admission database (DAD) was matched to the acute care (in-patient) usage and indicated whether some of the sample had become alternate level of care (ALC), been waitlisted or discharged to residential care facility. The RAI-Home care provided the information to divide the sample into "have no informal helper" (n = 65, 4%) and "have informal helper" (n = 1628, 96%). The latter group was further divided into the sub groups, informal caregiver "stressed" (n = 423, 26%) or "not stressed" (n = 1205, 74%). The informal caregiver "stressed" was identified in the same manner as the CIHI (2010) report using the items "A caregiver is unable to continue in caring activities (G2a) and/or "primary caregiver expresses feelings of distress" (G2c). The RAI-Home Care (see Appendix 1) provided the basic functional/clinical characteristics, demographics, amount of informal care provided for instrumental and personal activities of daily living in the 7 days prior to assessment, and identified the category of family caregivers (e.g. spouse, child, etc) of the sample group.

Other information needed to give a comprehensive picture of the client and their informal help came from the other two data bases that have been identified. Some limitations surfaced. Only hospital (in-patient) admission data could be used since there was no consistent data base to capture emergency department visits, therefore it is impossible to determine if any clients of the sample set accessed the emergency department. Due to the configuration of the home health service administrative database, the home support visits with the hours and the Assisted Living utilization could be extracted in the needed format. However, determining the service utilization for respite use and adult day centre could not be extracted for this sample as the data base could not summarize past history by client. The subset for "no caregiver" was small at 65, limiting what testing could be done.

Data Analysis

The original data was collected at different points throughout the individual's contact with the health authority as per the Freedom of Information and Protection of Privacy Act (the Act). Once all sources of data were matched the data was aggregated to provide averages, total counts and ratios. The aggregate data was managed by excel spread sheet and a statistical software package (e.g. SPSS) to complete the descriptive and statistical analysis. Since the final groupings (subsets) were unequal in size and some had small numbers, non-parametric tests were briefly explored to determine if the information would add to the analysis. In the end, some Mann-Whitney tests were run to indicate the association between cognitive loss and the "stressed" caregiver (addressed in the results). However, this added layer of analysis would be more useful if the numbers were larger, therefore a descriptive analysis dominates the paper.

The final step was to calculate the average value of the contribution of the family (informal) caregiver per group (e.g. "not stressed" and "stressed"). As part of the assessment process, the clinician collected the "extent of informal help for instrumental and personal activities of daily living received over the last 7 days" (G3). Although the total subsample of individuals with a caregiver was 1623, some of these active clients had their assessment completed while they were in hospital and some were living in Assisted Living units. In an attempt to have a more accurate calculation of average informal hours, clients who had their assessments completed in the hospital were removed. Assessments completed in the hospital are done after the clients have been in the hospital for several days, which affect the amount of informal hours they would normally receive from their family caregivers. Clients who lived in Assisted Living units were also excluded from the calculation of average informal hours provided by a family caregiver. It was argued that Assisted Living units provide meals, light housekeeping and some personal care which takes some of the 'burden" off the family caregiver, therefore this group would look different in respect to informal hours as opposed to the clients managing on home support hours and their family caregivers within single family dwellings. This subset used for the calculations of informal hours had 729 individuals.

The amount of informal hours was sorted and displayed in three ways. The first sort was to display the average amount of informal hours provided by "stressed" and "not stressed" caregivers. The next sort displayed the average amount of informal hours organized by the cognitive level of the patient as indicated by the cognitive performance scale (CPS), therefore CPS 0-1 (intact), CPS 2 (mild impairment) and CPS 3+ (moderate – very severe). These two sorts used the subset of 729 individuals described above. The final sort displayed the average amount of informal hours provided to cognitively intact clients who had functional losses as indicated by the activities of daily living self performance (hierarchy) scale, therefore ADL SP 0-1 (independent or supervision), ADL SP 2 (limited help) and ADL SP 3+ (extensive help to totally dependent). This last subset looked at the physical function ability of cognitively intact clients; this group was extracted from the 729 subset leaving a new subset of 290.

The replacement method (good proxy method) was used to calculate the value of family caregivers. The "cost of using an equivalent amount of care from the formal sector" (Access Economics, 2010, p. 15) was used to calculate the cost to the health authority if the health system had to replace the informal care hours. Therefore, once the average hours per week were determined this was multiplied by 52 weeks to arrive at a yearly amount which was multiplied by $40.00 per hour which is the standard third party rate used by the health authority. This provided the estimates for the value for family caregivers. This amount has been constant for the last two years. However at the completion of this paper, this amount had increased by 10%. Increases will be inevitable over time, increasing the value of the family caregiver.

Chapter Four: Results

The literature review addresses the desire of the senior to stay at home and the important role of the family caregiver to enable the frail senior to remain at home. The preliminary examination of the data shows the contribution of the family caregiver to the health care system.

The purpose of this chapter is twofold. One to gain a better understanding of the value of the family caregiver to the health system, by examining the clinical characteristics of the home care clients, the amount of informal hours provided by the family, and whether the caregiver describes his/herself as "stressed" or "not stressed". The second reason is to provide a dollar estimate to the value of the family caregiver. This section presents the picture of the current population of home care clients, thus the "what is" view.

Demographic Characteristics of Home Care Clients and Caregiver Type and Relationship

The first set of results (Table 1) presents the demographics of the community-based clients (N = 1693) who receive services through case management services. It also identifies the type (primary or secondary) and relationship of the caregiver. The majority of the clients (96%) have a caregiver. This is similar to the CIHI (2010) report which found that 98% of the home care population has a caregiver. However, this sample differs from the larger sample (CIHI, 2010) that found only 16% of caregivers reported being "stressed" whereas this current sample found 26% of caregivers identified as "stressed" and 74% "not stressed". This larger difference is considered noteworthy regardless of sample size variation from CIHI's Canadian sample (131,000) as this is the initial review of the RAI-Home Care data for this health area and variations need to be further investigated. The total sample has 61% females with the majority (73%) of all clients over 75 years of age.

Another notable difference (Table 1) is the majority of the clients who are cared for by a child or other relative (68%) which contradicts the results of other studies. Jakobsen et al, (2011) identifies the spouse (76%) as caregiver in the study of Danish dementia clients as did an Australian report identifying 41.5% spousal caregivers (Access Economics, 2010). This total sample (that has a caregiver) has only 23% of home care clients with a spouse as the primary caregiver. Approximately half of the total sample has a caregiver living with them, 42% of clients have a live-in primary caregiver and 11% of clients are living with their secondary caregiver. Twenty-four percent of the total clients with a caregiver did not have a secondary caregiver in the event that something should happen to their primary caregiver. This finding emphasizes the vulnerability of the primary caregiver if they have no back up to spell them off. The odds ratio (Table 2) of this home care client having a "stressed" caregiver is .30 if there is no secondary helper.

In the CIHI (2010) report, 1 in 6 caregivers are stressed; in this sample 1 in 4 home care clients have a "stressed" caregiver. The demographics of the clients with the "stressed" caregivers (Table 1) show more females (57%) with the greater number of the clients falling into the 75 -84 years age category. However 41% of this "stressed" group has a spouse as a primary caregiver and the odds ratio (Table 2) correspondingly describe that the likelihood (odds) of this client with a spouse caregiver falling into the "stressed" caregiver group is .47: double the risk of "child, other relative" (odds .21). The CIHI (2010) sample supports the finding that spouses are more at risk to become "stressed" caregivers. Slightly (Table 1) over half of the caregivers (55%) are "child, child-in-law, other relative".

The subset of clients with "no caregiver" (Table 1) is small (n = 65), preventing any meaningful comparability. The results show that 54% of the "no caregiver" group is male, versus the other subsets, "not stressed" group had 64% female and "stressed" group had 57% female. The "no caregiver" subset identifies that the most common (49%) age category in this group is the 19-64 years category which suggests that individuals with "no caregiver" access home care at a younger age. The other subsets "not stressed" and "stressed" have the majority of home care clients over 75 years. However, this "no caregiver" group needs more examination with a comparable group, perhaps the Yukon RAI data.

Sixty percent of home care clients in the "stressed" caregiver group have primary caregivers living with them (Table 1) another 40% have a primary caregiver but they do not live with the client. The odds ratio (Table 2) of "stressed" caregivers to "not stressed" provides more insight into the clients in the "stressed" caregiver group. This subsample of home care clients is more likely to be male (.30), in the 65 -75 age group (.32). However, the CIHI (2010) report did not find a strong association with caregiver "stressed" and age or sex (p. 13).

The results (Table 2) show that caregivers living with the client have higher odds of being stressed. The spouse (.47 odds) is twice as likely to be stressed compared to the child, other relative (.21 odds). The primary caregiver living with the client is two times more likely to fall in the "stressed" group (.37 odds) than a primary caregiver who did not cohabitate (.18 odds). As well, the secondary caregiver living with the client (.32 odds) versus secondary caregiver not living with the client (.25 odds) is approximately 1.3 times more likely to become stressed.

The majority (74%) of home care clients are in the "not stressed" caregiver group. In this group 64% are female, 44% are over 85 years and 73% of this group have a "child, child-in-law, other relative" as the family caregiver with only 16% having a spousal caregiver.

Table 1. *Demographics of Clients and Caregiver Information by Selected Groups*

	Has Caregiver				*No caregiver*		*Total*	
	Not-stressed		Stressed					
	n = 1205	% n	n = 423	% n	n = 65	% n	N = 1693	% N
Male	436	36%	183	43%	35	54%	654	39%
Female	769	64%	240	57%	30	46%	1039	61%
< 19 years			2	0.5%			2	0.1
19-64 years	163	14%	44	10%	32	49%	239	14%
65-74 years	132	11%	61	14%	16	25%	209	12%
75 – 84 years	382	32%	170	40%	11	17%	563	33%
85+ years	528	44%	147	35%	6	9%	681	40%
Spouse	197	16%	173	41%			370	23%
Child/other relative	878	73%	231	55%			1109	68%
Friend/neighbour	130	11%	19	5%			149	9%
Primary caregiver lives with client	428	36%	255	60%			683	42%
Primary caregiver does <u>not</u> lives with client	777	65%	168	40%			945	58%
Secondary caregiver lives with client	127	11%	59	14%			186	11%
Secondary caregiver does <u>not</u> live with client	793	66%	265	63%			1058	65%
Secondary -No such helper	228	24%	99	23%			384	24%

Table 2. *Demographics Odds Ratio of Stressed Caregivers to Not-Stressed Caregivers*

	Has Caregiver		*Odds Ratio*
	Not-stressed n = 1205	Stressed n = 423	
Male	436	183	.30
Female	769	240	.24
19-64 years	163	44	.21
65-74 years	132	61	.32
75 – 84 years	382	170	.31
85+ years	528	147	.22
Spouse	197	173	.47
Child/other relative	878	231	.21
Friend/neighbour	130	19	.13
Primary caregiver lives with client	428	255	.37
Primary caregiver does not lives with client	777	168	.18
Secondary caregiver lives with client	127	59	.32
Secondary caregiver does not live with client	793	265	.25
Secondary -No such helper	228	99	.30

The results in this first section set out to answer the question: What are the demographic characteristics of clients needing informal care and who are their care givers?

In the total sample, the majority of clients are female (61%), in the subset "no caregiver" the number of males is largest at 54%. The most common age category is 85+ (40%), then 75-84 years (33%). It is the older clients 75+ who are home care clients, most of whom have caregivers who are family, either spouse (23%) or child or other relative (68%). More than half of the clients have a caregiver living with them, either a primary caregiver (42%) or a secondary caregiver (11%).

Clinical Characteristics of Clients with Stressed and Not Stressed Caregivers

The clinical characteristics (Table 3) of clients with caregivers are divided into two main groups: "has caregiver" (n = 1628) versus clients with "no caregiver" (n = 65). The "has caregiver" group is further subdivided into "stressed" (n = 423) 26% and "not stressed" (n = 1205) 74%. This allows for a comparison between these two subgroups ("stressed", "not stressed") and the existing literature. The clinical characteristics provide an overview of cognitive and physical functioning, some diagnoses and whether the clients are resistive to care. The descriptive analysis is suggestive that clinical differences exist between the clients who have "stressed" caregivers versus "not stressed" caregivers.

The group "stressed" caregivers (Table 3) appear to be caring for clients with different clinical characteristics. For example, this "stressed" group has a larger number (69%) of clients with MAPLe 4-5 versus the "not stressed" group with 41%, likewise a larger number (53%) of "stressed" group have a CPS 3+ versus the "not stressed" group at 26%, DRS 3+ of 33% versus "not stressed" at 10%, daily severe pain at 16% versus "not stressed" at 12%, ADL SP 3+ at 27% versus "not stressed" at 16%, 25% have urinary incontinence versus "not stressed" at 20%, 23% have a psychiatric diagnosis whereas the not stressed have 18% and 6% - 10% resist care versus the "not stressed" at 3%. This corresponds with the results from CIHI (2010) that these characteristics are more likely to be associated with caregiver distress.

Table 3. *Clinical Characteristics of Clients in Selected Groups*

	Has Caregiver				No caregiver		Total	
	Not stressed		Stressed					
	n = 1205	% n	n =423	% n	n = 65	% n	N = 1693	% N
MAPLe 1-2	361	30%	39	9%	14	22%	414	25%
MAPLe 3	347	29%	93	22%	15	23%	455	27%
MAPLe 4-5	497	41%	291	69%	36	55%	824	49%
CPS 0-1	717	60%	146	35%	32	49%	895	53%
CPS 2	174	14%	51	12%	5	8%	230	14%
CPS 3+	314	26%	226	53%	28	43%	568	34%
DRS 0-2	1080	90%	284	67%	59	91%	1423	84%
DRS 3+	125	10%	139	33%	6	9%	270	16%
PAIN - no pain	626	52%	209	49%	37	57%	872	52%
PAIN - less than daily but not severe	436	36%	147	35%	22	34%	605	36%
PAIN – severe daily pain	143	12%	67	16%	6	9%	216	13%
ADL lg 0-9	1026	85%	329	78%	43	62%	1398	83%
ADL lg 10-19	115	10%	69	16%	6	9%	190	11%
ADL lg 20-28	64	5%	25	6%	16	25%	105	6%
ADL SP 0-1	888	74%	245	58%	37	57%	1170	69%
ADL SP 2	130	11%	64	15%	4	6%	198	12%
ADL SP 3+	187	16%	114	27%	24	37%	325	19%
Bladder control								
0-1 (continent)	690	57%	207	49%	32	49%	929	55%
2 (usually continent)	165	14%	65	15%	6	9%	236	14%
3-4 (frequently incontinent)	111	9%	46	11%	4	6%	161	10%
5 (incontinent)	239	20%	105	25%	23	35%	367	22%
3+ diagnoses	940	78%	340	80%	33	51%	1313	78%
Any psychiatric dx	221	18%	96	23%	19	29%	336	20%
Resists care								
Easily altered	32	3%	27	6%	5	8%	64	4%
Not easily altered	32	3%	41	10%	1	2%	74	4%

The odds ratios (Table 4) reinforce the expected; as the disabilities increase so do the odds of being in the “stressed” caregiver group. Hence, as the cognitive performance score (CPS) increases (indicating more cognitive loss) the odds (.17, .23, .42) of the caregiver being “stressed” increases. The caregiver who is caring for a client with CPS 3+ is 2.5 times more likely to become stressed. Likewise as the MAPLe scores increase the chance the caregiver caring for a client with MAPLe 4 – 5 is four times more likely to become stressed. Therefore as the clinical scores increase the caregiver has a higher chance of becoming stressed, likewise, this hold true for the Depression Rating Scores (DRS), the Pain scale, the ADL self performance scale, increased urinary incontinence, and for resisting care.

Table 4. *Clinical Characteristics Odds Ratios of Stressed Caregivers to Not-Stressed Caregivers*

	Has Caregiver		Odds Ratio
	Not -stressed n = 1205	Stressed n = 423	
MAPLe 1-2	361	39	.09
MAPLe 3	347	93	.21
MAPLe 4-5	497	291	.37
CPS 0-1	717	146	.17
CPS 2	174	51	.23
CPS 3+	314	226	.42
DRS 0-2	1080	284	.21
DRS 3+	125	139	.53
PAIN - no pain	626	209	.25
PAIN - less than daily but not severe	436	147	.25
PAIN – severe daily pain	143	67	.31
ADL lg 0-9	1026	329	.24
ADL lg 10-19	115	69	.38
ADL lg 20-28	64	25	.28

ADL SP 0-1	888	245	.22
ADL SP 2	130	64	.33
ADL SP 3+	187	114	.38
Bladder control			
0-1 (continent)	690	207	.23
2 (usually continent)	165	65	.28
3-4 (frequently incontinent)	111	46	.29
5 (incontinent)	239	105	.31
3+ diagnoses	940	340	.27
Any psychiatric dx	221	96	.30
Resists care			
Easily altered	32	27	.46
Not easily altered	32	41	.56

The clinical characteristics of the "no caregiver" group (Table 3) are outlined here. This is such a small group that no importance can be attached to these numbers. In this group 55% have a MAPLe 4-5, 37% fall into ADL SP 3+, 35% have urinary incontinence, 29% have a psychiatric diagnosis, and 8% resist care but this resistive behaviour can be easily altered. More investigation into this group needs to occur since their "no caregiver" status places them at risk of using other health care services.

For exploration purposes, the non-parametric test, Mann Whitney has been utilized to determine if there is an association between cognitive loss and caregivers indicating "stress"; the question is, are the various levels of CPS (coded CPS 0-1 as 1, CPS 2 as 2; CPS 3-6 as 3) associated with caregivers coded as stressed? The results show the mean rank CPS 2 ($M = 749$) is higher than the mean rank CPS 1 ($M = 646$) indicating an association between CPS 2 and stressed caregiver ($U = 177426$, $P = .000$), likewise the mean rank CPS 3 ($M = 700$) is higher than the mean rank CPS 1 ($M = 646$) indicated an association between CPS 3 and stressed caregiver ($U = 119328$, $P = .000$). This non-parametric test shows that the mean rank CPS 2 ($M = 392$) and mean rank CPS 3 ($M = 409$) is not significant ($U = 73934$, $P = .174$) indicating no difference between CPS 2 and CPS 3 for caregiver "stressed". This confirms what experienced clinicians know from practice that clients with higher CPS scores have caregivers indicating "stressed". This information did not add to interpreting the results so no further non-parametric testing was completed.

The results in this second section set out to answer: What are the clinical characteristics of clients with stressed and not stressed caregivers?

Although both "stressed" and "not stressed" groups are examined for the same clinical characteristics, this sample supports what has been found in the literature that the odds of caregiver stress increase with the increased level of disability. Therefore it is the clients with the higher scores on the clinical scales (e.g. MAPLe 4-5, CPS 3+, DRS 3+) that are more likely to have caregivers indicating they are "stressed".

Health Outcomes for Clients with Stressed, Not Stressed, and No Caregivers

Home care clients in the "stressed" caregivers or "no caregiver" groups are admitted to hospital or residential care (CIHI, 2010). Overall 50% of the total sample (N = 1693) are hospitalized (Table 5) at some time in the fiscal year April 1, 2010 to March 31, 2011. For the clients in the group "not stressed" 15% are ALC in the hospital whereas 34% of the clients in the "stressed" group are ALC, albeit almost the same amount is discharged home 32% and 33% respectively. Fifty-eight percent of clients with the "stressed" caregivers are hospitalized versus 48% of "not stressed", 34% are waitlisted for residential care versus 18% of not stressed and 36% are admitted to residential care versus 20% of not stressed. This suggests that clients in the “not stressed” group have different health outcomes compared to the home care clients in the “stressed” group.

Not surprisingly, (Table 6) when the odds of “stressed” caregivers are compared to “not stressed” caregivers, the clients being cared for by “stressed” caregivers have a higher chance of poor outcomes. The clients in the “stressed” caregiver group have 30% chance of being hospitalized compared to a 22% chance of not being hospitalized, demonstrating that the clients in the “stressed” group have a 1.4 times the chance of being hospitalized. Likewise the “stressed” group have twice the chance (2.2. times) of becoming ALC when compared against their chance of not becoming ALC. The clients in the “stressed” caregiver group have a greater chance (1.4 times) of not being discharged from the hospital and the same chance (1.4 times) of dying in the hospital, and almost twice the chance (1.8) of being waitlisted. In this sample the client in the “stressed” caregiver group are less likely (1.4 times) to be admitted from hospital to residential care. This may be due to the waitlist and admission policies that exist. From the total sample, whether in or out of hospital, the clients in the “stressed” caregiver group are waitlisted almost twice (1.8 times) as often. It holds true for admission to residential care, as well, that clients with “stressed” caregivers are admitted almost twice (1.7 times) as often.

Table 5. *Health Outcomes for Clients by Selected Groups*

	Has Caregiver				*No Caregiver*		*Total*	
.	Not stressed		Stressed					
The DAD identified 850	n =	%	n =	%	n =	%	N =	%
Clients in the hospital	1205	n	423	n	65	n	1693	N
# Hospitalized	578	48%	244	58%	28	43%	850	50%
Average # days hospital	12.4	--	14.7	--	9.3	--	12.1	--
# became ALC	181	15%	144	34%	8	12%		
Average # days ALC	13.3	--	17.8	--	8.1	--	13	--
Status								
# who died in hospital	70	6%	44	10%	1	2%	115	7%
# discharged home	391	32%	140	33%	19	29%	550	32%
# admitted to residential care from hospital	92	8%	45	11%	8	12%	145	9%
# waitlisted (total) this fiscal year	215	18%	145	34%	9	14%	369	22%
# admitted to residential care (total population)*	237	20%	152	36%	13	20%	402	24%

This third section set out to answer: What are the health outcomes for clients with stressed, not stressed and no caregivers?

To summarize, 50% of the total sample has been hospitalized, with 24% of the total sample admitted to residential care. The clients in the "stressed" caregiver group are more likely to become ALC (2.2 times), more likely to be waitlisted (1.8 times), less likely to be discharged from hospital (1.4 times). This supports the notion that clients with stressed caregivers have less favorable outcomes.

Table 6. *Health Outcomes Odds ratio of Stressed Caregivers to Not Stressed Caregivers*

	Has Caregiver		*Odds Ratio*
	Not stressed	Stressed	
	n = 1205	n = 423	
# Hospitalized	578	244	.30
# Not Hospitalized	627	179	.22
# became ALC	181	144	.44
# did not become ALC	397	100	.20
# who died in hospital	70	44	.39
# did not die in hospital	508	200	.28
# discharged home	391	140	.26
# not discharged home	187	104	.36
# admitted to residential from hospital	92	45	.33
# not admitted to residential from hospital	486	378	.44
# waitlisted (total) this fiscal year	215	145	.40
# not waitlisted	990	278	.22
# admitted to residential care (total population)*	237	152	.39
# not admitted to residential care	968	271	.22

Replacement Costs of Family (Informal) Caregivers

The second purpose of this study is to estimate the value of the family (informal) caregiver. The replacement cost method is used as the literature indicates that the majority of caregivers are spouses (Access Economics, 2010; CIHI, 2011; Jakobsen et al., 2011), however in this study, the surprising result observed is 68% of caregivers are in the category "child, child-in-law, other relative". Hence it can be argued that the opportunity cost method should be considered. The age group of these caregivers is unknown therefore the argument can be extended that regardless of whether the caregivers would be employable or not, if they are not available they would have to be replaced. Following this logic the replacement method is used to give one estimate of what the family caregiver contribution to the health system might be. The replacement costs for the informal care hours is calculated three different ways, the difference between "stressed" and "not stressed" to the general sample of 729 (Table 7), then recalculation of the same sample but by grouping the various cognitive levels and the third calculation is a subset of physically disabled but cognitively intact (290) clients. The split of informal hours into two groups "greater than" 21 hours per week and "less than" 21 hours per weeks is used. CIHI (2010) results show that 21+ hours of informal care per week is associated with caregiver stress.

Some interesting results are observed. Nevertheless, due to the small numbers of the sample size, all assumptions need to be used cautiously. "Stressed" caregivers (Table 7) provide on average more hours per week of informal help (34.27 hours) than the "not stressed" counterparts (16.98 hours). As expected, caregivers who care for individuals with declining cognitive abilities (Table 8) provide on average increasing amounts of informal care hours, clients with a CPS 2 on average receive 21.56 hours of informal care and client with a CPS 3+ on average receive 45.85 hours of informal care. This holds true for caregivers who cared for individuals with declining physical abilities (Table 9), clients who need limited assistance (ADL SP 2) on average receive 33.41 hours per week and extensive assistance upwards (ADL SP 3+) on average receive 50.4 hours.

Lastly, this fourth section addressed: What is the replacement cost of the family (informal) caregivers?

As the average informal care hours per week increased depending on the group (Table 7, 9, 10) there is a corresponding increase in the replacement costs. Therefore, the groups "stressed" and "not stressed" have cost estimates ranging from $71,281 to $35,318 respectively, the cost estimates for informal care corresponding to the increasing cognitive scores range from $32,739 (CPS 0,1) to $95,368 (CPS 3+) and the cost estimates for informal care corresponding to the increasing physical difficulties range from $46,571 to $104,832. This information reveals that the family caregiver provides a significant contribution to the community and to the health organization by maintaining the senior in the community. The odds ratio of "stressed" caregiver group is almost three (2.7) times higher (.38 odds) if the caregivers are providing 21+ hours per week versus the caregivers (.14 odds) who are providing less than 21 hours per week (Table 9). This supports the CIHI (2010) finding that the caregiver providing 21+ hours had two and half times the odds of being distressed (p.13).

Summary

In summary, the overall results reveal some differences in the northern data compared to the literature. The noteworthy differences are the higher number of caregivers reporting being "stressed": this sample has 26% of caregiver "stressed", or 1 in 4 caregivers reporting stress which varies from the 1 in 6 ratio identified by CIHI (2010). Another difference is the caregiver relationship; the most common family caregiver for the total sample is the child/other relative (68%). This has a number of implications for health care, specifically the sustainability of the family caregiver into the future. Lack (24%) of a secondary helper (for total group) is another important finding because of what it means to the primary caregiver: they have no back up support for caregiving. The range of replacement costs, whether grouped by "stressed", "not stressed" caregiver groups, by cognitive performance score, or by ADL self performance score, demonstrates the average hours of informal care increases as the care needs increase. This sample supports the CIHI (2010) finding that shows caregivers providing over 21 hours per week are more likely to become "stressed".

Table 7. *Replacement cost of informal (family) caregiver grouped by Not-stressed and Stressed.*

	Has Caregiver					
Degree of Distress	Non-stressed		Stressed		Total	
# Primary carers	n = 563	77%	166	23%	729*	100%
Providing 21+ hours/wk	165	29%	102	61%	267	37%
Providing < 21 hours/wk	398	71%	64	39%	462	63%
Average hours/week	16.98	--	34.27	--	20.92	--
Total hours per annum	882.96	--	1782.04	--	1087.84	--
Total Replacement costs, $40/hr	$35318.40	--	$71281.60	--	$43513.60	--

*Does not include clients who had assessments completed in hospital or people living in Assisted Living as described in methods

Table 8. *Providing informal hours per week Odds Ratio of by Stressed and Not-Stressed caregiver*

	Has Caregiver		*Odds Ratio*
	Not-stressed	Stressed	
Providing 21+hours/week	165	102	.38
Providing < 21 hours/week	398	64	.14

Table 9. *Replacement Cost of Informal Caregiver grouped by Level of Cognitive Loss*

	Cognitive level							
	CPS 0-1		CPS 2		CPS 3+		Total	
	n = 439	60 %	n =204	28 %	n= 86	12%	N =729	100%
Primary carers (stressed)	71	16%	61	30%	34	40%	166	23%
Primary carers (not stressed)	368	84%	143	70%	52	60%	563	77%
Who is the caregiver?								
Spouse	4	0.9%	4	2%	0		8	1%
Child/other relative	268	61%	133	65%	61	71%	462	63%
Friend/neighbour	55	13%	16	8%	5	6%	76	10%
Secondary caregiver lives with client	50	11%	32	16%	21	24%	103	14%
Secondary caregiver does <u>not</u> live with client	277	63%	121	59%	45	52%	443	61%
Secondary – No such helper	112	26%	51	25%	20	23%	183	25%
Providing 21+ hours/wk	111	25%	86	42%	70	81%	267	37%
Providing < 21 hours/wk	328	75%	118	58%	16	19%	462	63%
Range of hours	Caregivers reported no hours to 168/week							
Average hours/week	15.74		21.56		45.85		20.92	
Total hours per annum	818.48		1121.12		2384.2		1087.84	
Replacement cost, $40/hr	$32,739.20		$44,844.80		$95,368.00		$43,513.60	

Table 10. *Replacement Cost of Informal (Family) Caregiver grouped by Level of ADL Self Performance of Intact Cognitive Clients*

	ADL Self Performance							
	ADL SP 0-1		ADL SP 2		ADL SP 3+		Total	
	n = 211	%	n =22	%	n= 57	%	N =290	100%
Primary carers (stressed)	63	30%	9	41%	23	40%	95	33%
Primary carers (not stressed)	148	70%	13	59%	34	60%	195	67%
Secondary caregiver lives with client	28	13%	7	32%	18	32%	53	18%
Secondary caregiver does <u>not</u> live with client	130	62%	10	46%	26	46%	166	57%
Secondary – No such helper	53	25%	5	23%	13	23%	71	24%
Providing 21+ hours/wk	117	55%	7	32%	10	18%	134	46%
Providing < 21 hours/wk	94	45%	15	68%	47	82%	156	54%
Range of hours	Caregivers reported no hours to 168/week							
Average hours/week	22.39		33.41		50.4		28.76	
Total hours per annum	164.28		1737.32		2620.8		1495.52	
Replacement cost	$46,571.20		$69,492.80		$104,832.00		$59,820.80	

Chapter Five. Conclusions

Whether dealing with a temporary illness or simply in need of ongoing medical/health support, Canadian seniors want to stay at home and to facilitate this; their health care must be provided within the home. The home care sector relies on family (informal) caregivers to assist frail seniors with personal daily tasks (activities) so that they may stay in the community. Like any business, health care has to consider where it is now and where it must be in the future to remain responsive to its home care clients (customers). In this paper, some postulations have been made: a) that family caregivers can become stressed and the home care client can have poor health outcomes because of this (e.g. waitlisted for residential care, be hospitalized, become ALC), and b) family caregivers are an economic resource to home health care therefore are subject to supply and demand.

A core sample of active home care clients on service between April 1, 2010 to March 31, 2011 in a rural and northern health area has been reviewed to gain a better understanding of the needs of our home health population and their family caregivers and consideration for how we might plan for the future. Within the home care sector in British Columbia, frail seniors needing home-based or community-based care access this service through health authority case managers. Therefore it is the frail senior who is the client and the care services are provided to the frail senior; however in providing this service to the senior, another benefit is that the service provides a break for the family caregiver. Appropriate service or care options to the senior supports and enables the family caregiver to continue their caring activities. The current caregiver literature (Canadian Home Care Society, 2009) identifies that family caregivers provide 80% of the chronic ongoing care; this northern sample indicates that 91% have family caregivers (23% spouse, 68% child or other relative) providing some support to frail seniors. These numbers suggest that currently there is a higher degree of family involvement in this northern sample than what was previously identified from the literature.

The Value Contribution of Family Caregivers

One of the goals of this paper is to determine the value contribution of the family (informal) caregiver. This offers some important insights into the number of hours provided and the types of clients receiving these hours. The results clearly demonstrate that informal caregivers increase the amount of caring (hours) as the senior becomes increasingly frail. This is well supported in the literature (CIHI 2010, Access Economics, 2010). The "stressed" caregivers provide, on average, more hours than their "not stressed" counterparts: 34.27 hours per week compared to 16.98 hours per week. According to other studies (CIHI, 2010) as well as the finding of this study, the greater number of hours provided by the caregiver speaks to one reason why caregivers become stressed. This obviously translates into a larger value contribution $71,281 per year (on average) for the "stressed" caregiver, whereas the "not stressed" value contribution is $35,318 per year (on average). Likewise, the family caregivers caring for seniors with increasing cognition problems provide more hours of care. The results show that family caregivers caring for seniors with moderate to severe memory problems (CPS 3+) provide more care (45.85 hours/week). Family caregivers caring for seniors with a mild impairment (CPS 2) differ somewhat, the number of caregivers providing over 21 hours is less than the number of caregivers providing less hours which moderates the average hours of care. Even so, the results still indicate that as cognitive impairment increases, the family caregivers increasingly provide more care. The value contribution of the family caregiver in caring for the senior with cognitive impairment ranges from $32,739 per year (15.74 hours per week) for the home care client who is cognitively most able, to $44,844 per year (21.56 hours per week) for the home care client with a mild cognitive impairment. However, there is a noticeable increase in the value contribution that occurs when family caregivers provide care for the senior with moderate to severe cognitive impairment (45.85 hours per week). The value contribution of the family caregiver for seniors at a higher level of cognitive impairment is $95,368 per year. Jakobsen et al (2011) attributes 4.97 to 6.91 hours per day for family caregivers in the Danish dementia study, extrapolating that this would result in 34.79 to 48.37 hours per week, although the upper end of the informal caregiving hours is close to the northern BC sample, the range of hours (Danish study) is much tighter than in the northern BC sample.

Another split of the home care clients examines cognitively intact clients by their level of physical disability and the amount of care provided by their family caregiver. This subsample of 290 people also supports that as frail seniors become more physically impaired the family caregiver provides more care. The lowest split (ADL SP 0-1) describes a home care client that remains quite functional in the four core areas of personal hygiene, toileting, locomotion in their own living space and eating, however this does not mean they do not need assistance with other daily activities (e.g. meal prep, medication reminding, normal housekeeping, dressing, safety aspects of getting in and out of the bath tub, help with walking outside). This home care client at the lowest level of physical impairment on average receives 22.39 hours of assistance per week. This average amount of hours is the highest number of hours when considering the other groups (i.e. not stressed at 16.98 hours per week, cognitively intact at 15.74 hours per week). Not surprisingly, the highest level of physical disablement on these four core area indicate that the family caregiver is providing 50.4 hours per week, overall the highest number of hours per week of any group (i.e. stressed 34.27 hour per week, CPS 3+ 45.85 hours per week), therefore the value contribution of these family caregivers ranges from $46,571 per year to $104,832 per year. By examining the average hours of care provided by the family caregiver, it becomes apparent that even with home care and family caregivers together, smaller numbers of clients with significant clinical (cognitive and physical) needs are able to be kept in the community. This northern BC sample indicates that with our currently services/care options we are only able to keep 12% of home care clients with CPS 3+ (subsample n = 790) in the community, and 20 % of home care client with ADL SP 3+ (subsample n = 290) in the community. This study reinforces the experiential knowledge of clinicians: a) the more hours provided by the family (informal) caregiver, the increased likelihood of the family caregiver of becoming stressed; b) family caregivers supporting seniors with increasing problems with cognition and physically impairment provide more hours of care to their family member which can lead to the family caregiver to become stressed. This supports the concept that stress is dynamic; caregivers who are "not stressed" can become "stressed" because of their caring activities (amount of hours provided) and the needs (clinical characteristics) of the person they care for increase.

Stress and the Family Caregiver

Home health care needs to have a better understanding of the stress of the caregiver. In this sample, one in four caregivers report being "stressed" compared to the

CIHI sample that has one in six caregivers admitting to being "stressed". This recognizes the uniqueness of the regional data and the importance of examining the data separately so that results are not masked by the larger, more densely populated regions. CIHI (2010) reports that informal caregivers who provide 21+ hours per week are two and half times more likely to have stressed caregivers. The northern BC sample is comparable with the informal caregiver who provides 21+ hours (odds ratio .38), almost 3 times higher than the informal caregivers providing less than 21 hours (odds ratio .14). The northern sample outlines the clinical characteristics of seniors who have caregivers who are more at risk to become "stressed". Seniors who have higher MAPLe scores (MAPLe 4-5), increased cognition problems (CPS 3+), have symptoms of depression (DRS 3+), daily pain, increased disablement (ADL SP 3+), any urinary incontinence, co-morbidities (>3), and are resistive to care all contribute to the potential for their caregiver to be stressed. This list supports the Canadian findings by CIHI (2010). It is necessary to identify appropriate strategies that relieve some of these stress factors, making the family caregiver feel supported and able to continue to care. While the northern sample has a higher percentage of stressed caregivers, the risk factors that contribute to stress are common and this leads to the notion that the services or resources may not be in place to make the family caregiver feel supported.

This also demonstrates the dynamic nature of becoming stressed. This current sample reveals that the majority of 74% are "not stressed", but nevertheless this can change to "stressed" as the senior they care for becomes increasingly frail (either cognitively or physically). This increased ratio of stressed caregiver may be due to rural communities having fewer services. In a survey of nine regions, including rural British

Columbia, the Canadian Home Care Association (2006) reports gaps in service that include limited or lack of resources, such as adult day centers, home support service and lack of family supports. Certainly these are factors that influence the family caregiver's ability to continue caring (Canadian Home Care Association, 2006). A stressed caregiver is less likely to continue caring (CIHI, 2010, Canadian Home Care, 2006).

All family caregivers have the potential for becoming "stressed," and when this point is reached, a plethora of unfavorable health outcomes can occur. This northern sample indentifies that the caregiver's spouse is also at risk (.47) to become "stressed" and likewise so is any primary caregiver (.37) living with the client. Even if the client receives public home care, it does not mean that the informal caregiver receives any benefit (i.e. relief or respite) (Pezzin, Kemper and Reschovsky, 1995). Similarly, public home care has little effect in relieving the stress of the caregiver who does not live with the home care client (Pezzin, et al., 1995). One of the strengths of this current study is the ability to match home care clients with their actual utilization of hospitals and their final status (e.g. ALC, died, discharged home, waitlisted, admitted to residential care). Although experienced clinicians have observed these outcomes, there was no capacity for quantifying it until now.

Home care clients who have stressed caregivers are at risk for negative outcomes. The home care client with a "stressed" caregiver has 30% risk of being hospitalized, 44% risk of becoming ALC, 39% risk of death, 40% chance of being waitlisted for residential care and 33% chance of being admitted to residential care from the hospital. None of these are desirable outcomes for seniors who want to stay at home. Another result that signals a potential issue is the lack of a secondary helper. Only 24% of this sample has a "back up" helper to support the primary caregiver. This lack of back up puts the primary caregiver at a risk (odds ratio .30) of becoming "stressed," which in turn can lead to poor outcomes for the frail senior.

The Future of Family Caregiving

It is speculated by Stats Canada that spousal caregiving by the elderly (10%) is under reported, perhaps because spouses feel that helping their partner is part of their duty or role (Cranswick & Dosman, 2007). This northern sample shows that 23% of spouses report being the primary caregiver. This finding is similar to the Canadian results from the CIHI (2010) report which indicates that 30% of the Canadian home care clients are married, with 75% of them being the spousal caregiver. A Danish dementia study indicates a higher amount of spouses (76%) who provide informal care to their spouse, whereas an Australian report indicates 41.5 % of informal caregivers are spouses.

The most common (68%) caregiver is the "child, child-in-law, other relative" and not the spouse (23%) as discussed. This highlights a future issue. The current group of home care clients is the parents of the baby boomers; therefore their adult children are the carers (Keefe, Legare, & Carriere, 2007). This leads to the question of the future availability of family (informal) caregivers, or in business terms, the "supply" of family caregivers. Who will become the family caregivers who will look after the baby boomers? Although some research shows that spouses are the more frequent caregivers (Jakobsen et al, 2011; Access Economics, 2010; Keefe et al, 2007) this northern sample did not support this. In fact, the most frequent caregiver was "child, child-in-law, other relative" (68%), and if we consider that these family caregivers are baby boomers looking after their parents, we have to consider in turn who these baby boomers will have to care for them. On a positive note for married baby boomers, the increased life expectancy for men closes the gap leading to an increased survival of couples, which in turns reduces the number of people living alone at least for a while (Keefe, et al, 2007). Nevertheless, women continue to live longer and it is projected that as early as 2021 the proportion of women 85+ years who do not have children will increase significantly (Keefe et al, 2007). This is in part due to the fact that as the baby boomers' parents die, the cohort coming up will be the baby boomers themselves who have had zero or fewer children than their parents before them (Carriere, et al. 2008).

The supply of family caregivers will be smaller in the future. Various social factors that play a role have been discussed in the literature. Firstly, baby boomers have had fewer children: some chose to not have children while others have only one or two children (Keefe, et al. 2007), and therefore families have fewer family members to draw from. The second set of factors have more to do with informal caregivers not being available to provide adequate care: women, who are typically the caregivers, are remaining in the workforce longer and young people are moving away to secure jobs causing geographical dispersion (Assess Economics, 2010, Keefe, et al., 2007). The third set of factors relate to social commitment: with a higher divorce rate, it is not known if the children or step children of blended families will have the commitment for caring and it is suggested that the future generation will not be willing to provide the care (Assess Economics, 2010, Keefe, et al., 2007). Our population is aging because of the large number of baby boomers coupled with the fact that they are living longer (Carriere et al, 2008). When these phenomena are combined with a decreasing number of offspring and subsequently a decreasing availability of potential informal caregivers, we have a supply and demand problem.

Limitations

The following limitations are identified for the reader. This is the preliminary examination of the RAI-Home Care data for this health jurisdiction, therefore yearly examinations need to be completed to identify any trends in the "stressed" and "not stressed' groups and to identify any changes in amount of informal hours that are provided. The replacement cost is used because the "extent of informal hours" are provided on the RAI-Home Care instrument and therefore is part of the assessment process of the case managers. The replacement cost method provides a higher estimate than the opportunity costs method, therefore health organizations may prefer to use the method that provides the lower estimate. The rationale to use the replacement cost method stemmed from the belief that if the informal caregiver could no longer care for the senior, the estimate should reflect what it would cost the health organization to replace that same level of care.

Summary

Regardless of the method used to calculate the value of family caregivers, the resulting message highlights the critical fact that family caregivers provide more hours of care to family members as that family member becomes more impaired either physically or cognitively. It also supports the hypothesis that providing over 21 hours per week places the caregiver at higher risk to become stressed which leads to less favorable results for the senior and for the health care system. There will be a smaller cohort of children of baby boomers who will bear the responsibility not only for their parents but other relatives that have no children as well. More worrisome is the inference that this next generation may not have the propensity or desire for taking on this responsibility.

Public policy will need to address how family caregivers can be supported. Informal caregivers identify that they need more respite to "spell" them off, accessible information on how to care for their family member and where to find useful information along with emotional and financial support for themselves (Canadian Home Care Association, 2008). Clinical practice policy needs to address ways that stress can be identified more quickly in family caregivers (for prevention or delaying) and examine ways that clinicians can focus time on emotional care and education for family caregivers. As pointed out earlier, ALC bed utilization is an indicator that communities do not have capacity (resources) to support frail seniors or their families (CHSRG, 2011b). Finally, health jurisdictions will have to be courageous about rechanneling funding from other health care sectors (e.g. acute) to develop the community capacity to support frail seniors and their family caregivers (CHSRF, 2011a).

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Appendix 1

PROFILE OF DATA BY VARIABLES

N=1693, n (no care giver) = 65, n (has caregiver) = 1628
Sections G*. Informal Support
1a has informal helper (primary)
1e lives with client coded in assessment
1f relationship coded in assessment as 1-spouse, 0 child or child in law, 2 other relative, 3 friend

Stress/Distress Care Giver Status
G2a caregiver is unable to continue in caring activities
G2c primary caregiver expresses feelings of distress, anger, depressions

G3 extent of informal help (ADL & IADL) a) sum across 5 weekdays, b) sum across 2 weekend days

Section I* Bladder Continence
Usually continent in assessment coded 2
Any frequency of incontinence coded in assessment as 3 occasional, 4 frequently incontinent, 5 total incontinence (no control)

Conventions: No = 0, Yes = 1; Gender: Male = 0, Female = 1

Groupings (What do these people look like?)	Groupings (what do these people look like?)
1. Has informal care giver (96%) Sub group 1a caregiver expresses distress Sub group 1b caregiver not distressed	2. No informal care giver (4%)

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*MDS-HC Canadian Version August 2010, v1.1

Identifier	FILTER BY INFORMAL HELPER G1a RAI-HC data base*		FILTER BY STRESS Expressed distress G2a or G2c RAI-HC data base		FILTER BY LIVES WITH Lives with client G1e RAI-HC data base		FILTER BY "WHO" Relationship G1f RAI-HC data base		
	Yes (1)	NO (0)	Yes (1)	NO (0)	Yes (1)	No (0)	Spouse -1	Relative 0,2,	Other -3 Friend/neighbour
1									
2									
3									

Identifier	DEMOGRAPHIC RAI-HC data base		CLINICAL CHARACTISTICS RAI-HC data base								
	Gender	Age	CPS	ADL Long	ADL hierarchy	DRS	PAIN	MAPLe	Bladder Continence (incontinence) I1		
									Usually - 2	Any freq 3,4,	Total- 5
1											
2											
3											

Identifier	CLINICAL CHARACTISTICS RAI-HC data base - Section J			
	3+ diagnoses (any)		Psychiatric diagnoses	
	Yes	No	Yes	No
1				
2				

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*MDS-HC Canadian Version August 2010, v1.1

Identifier	COMMUNITY SUPPORT OPTIONS (PROCURA)			
	H/S		W/L residential care	
	# visits	# hours	Yes	No
1				
2				

Identifier	Informal Help G3a,b Any IADL or ADL help in last 7 days RAI-HC data base	
	Weekdays # hours	Weekends # hours
1		
2		
3		
4		

Identifier	HEALTH OUTCOMES								
	Residential Care – admitted RAI-MDS 2.0 data base		Acute care – admitted Discharge admission database (DAD)				ALC Discharge admission database (DAD)		
	Yes	No	Yes	NO	freq	Ave. LOS	Yes	No	# of days

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*MDS-HC Canadian Version August 2010, v1.1