Relationship Between Home Care Services and Informal Caregivers

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Relationship between Home Care Services and Informal Caregivers

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Abstract

Background: Home care services include: home health aides, visiting nurses, homemaking services, meals, volunteer work, physical therapy, occupational therapy, speech therapy, day care/hospital, social work and respite care. The users of home care services often receive family/informal care. This study examined the relationship between the frequency/quantity of each home care service and the hours of informal caregiving. It classified the relationship into substituting, complementary or no-relationship.

Method: Secondary data analysis of a cross-sectional data set. Data collected in 2000/01 from various sites in Ontario for the RAI-HIP (Resident Assessment Instrument-Health Informatics Project) were analyzed using 2 different hierarchical logistic regression models. The dependent variable was hours of informal care. The independent variables were frequency (model 1) and hours (model 2) of the 11 types of formal services. Variables also entered into the models were client demographics (gender, age, marital status, education), client physical/functional characteristics (IADL involvement scale, ADL Hierarchy scale, Cognitive performance scale, ability to understand others, wandering, resists care, diagnosis of dementia), caregiver characteristic (expresses feelings of distress, anger, depression) and client/caregiver dyad characteristics (who the client lives with, number of caregivers that live with the client, relationship between the caregiver and the client).

Results: Clients with caregivers (n = 5308) received an average of 18.9 hours of informal care per week (s.d. = 32.4) with a median of 11 hours per week. Logistic regression demonstrated that greater hours of informal care were significantly associated with lower frequency and hours of home health aides, meals and respite care, but also significantly associated with higher frequency and hours of homemaking services, occupational therapy and day care/day hospital. There were no significant associations between hours of informal care and visiting nurses, volunteers, physical therapy, speech therapy and social work.

Conclusion: The type of relationship between the formal care service and the informal caregiving varied among the different types of formal care services. Home health aides, meals and respite care had a substituting relationship with informal care. Homemaking services, occupational therapy and daycare/day hospital services had a complementary relationship with informal care. Visiting nurses, volunteers, physical therapy, speech therapy and social work had no-relationship with informal care.

Statement of Purpose

The purpose of this study was to determine the type of relationship between the quantity of formal home care services and the quantity of informal caregiving for 11 types of formal home care services. This relationship could be categorized as substituting, complementary or no-relationship. A substituting relationship is one where as the quantity of formal care increases, the quantity of informal care decreases. A complementary relationship is the opposite, where as the quantity of formal care increases, the quantity of informal care also increases. No-relationship is where there is no significant association between the quantity of formal and informal care. The 11 types of formal home care services were: (a) home health aides, (b) nursing visits, (c) homemaking services, (d) meals, (e) volunteer services, (f) physical therapy, (g) occupational therapy, (h) speech therapy, (i) day care/day hospital, (j) social work, and (k) respite services.

Objectives

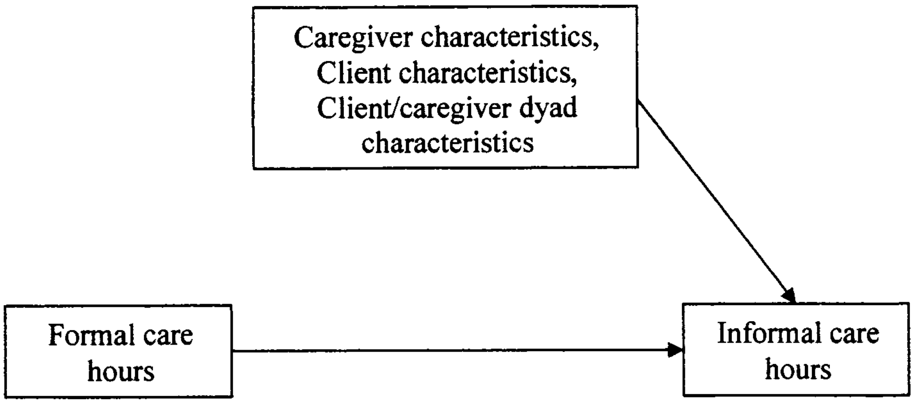
The objectives of this study were:

1. To determine the differences between clients of home care who have informal caregivers and clients who do not have informal caregivers.
2. To describe the demographic characteristics and the physical and functional characteristics of home care recipients who have caregivers.
3. To determine the amount of time spent on informal caregiving.
4. To determine the opportunity costs of informal caregivers.
5. To establish the determinants of informal caregiving time.
6. To determine the type of relationship between informal caregiving time and the quantity of formal home care service for 11 types of formal services.

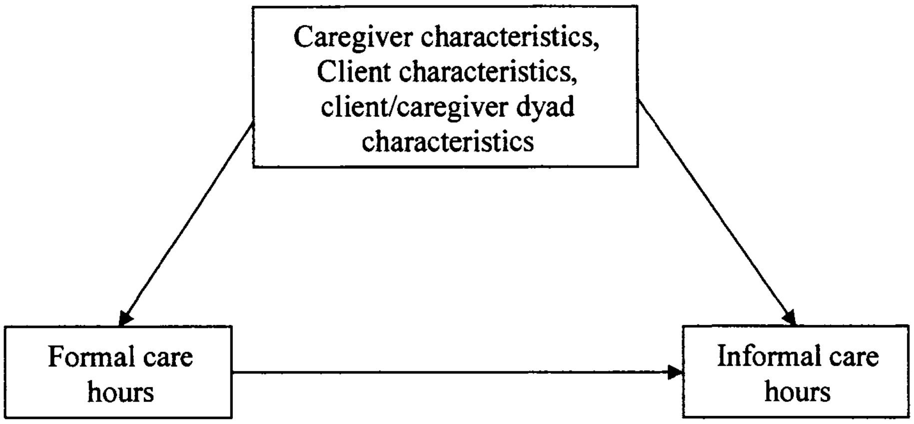
Conceptual Framework

Most studies examining the relationship between formal and informal care time are cross-sectional analyses and cannot determine the direction of the relationship. Research has been inconclusive on whether formal care determines informal care or informal care determines formal care or a combination of the two. For this study, we have chosen the concept that formal care time determines informal care time (see diagram below).

Previous research shows that caregiver characteristics, client characteristics and client/caregiver dyad characteristics may also determine informal care time. People with increased frailty and close to death receive higher hours of informal care per week. Informal care hours also increase with the client's age, ethnicity, severity of dementia, cognitive impairment, extent of behavioral disturbances, ADL disability and severity of health (Keating, Fast, Frederick, Cranswick, & Perrier, 1999; Kemper, 1992; Wimo, von Strauss, Nordberg, Sassi, & Johansson, 2002). Caregivers who are female, older and married provide more care while those who have children or are employed provide less care. Of female caregivers, those who live in rural areas and have lower levels of education, spend more time caregiving. Spousal caregivers, those who live in the same household and those who care for a patient of the opposite sex provide higher hours of care per week. Poor client-caregiver relationships and non-primary caregivers show lower hours of care per week (Keating et al., 1999).



As client, caregiver and client/dyad caregiver characteristics may also effect formal care hours, these variables (client, caregiver and dyad characteristics) need to be controlled for in the statistical analysis.



The type of relationship between formal home care services and informal caregiving could be categorized as substituting, complementary or no-relationship.

A complementary relationship between formal home care and informal care exists if an increase in one is associated with an increase in another (see Figure 1) (Hayward, Davies, Robb, Denton & Auton, 2004). Therefore increasing formal home care would increase informal caregiving after controlling for client characteristics, caregiver characteristics and client-caregiver dyad characteristics.

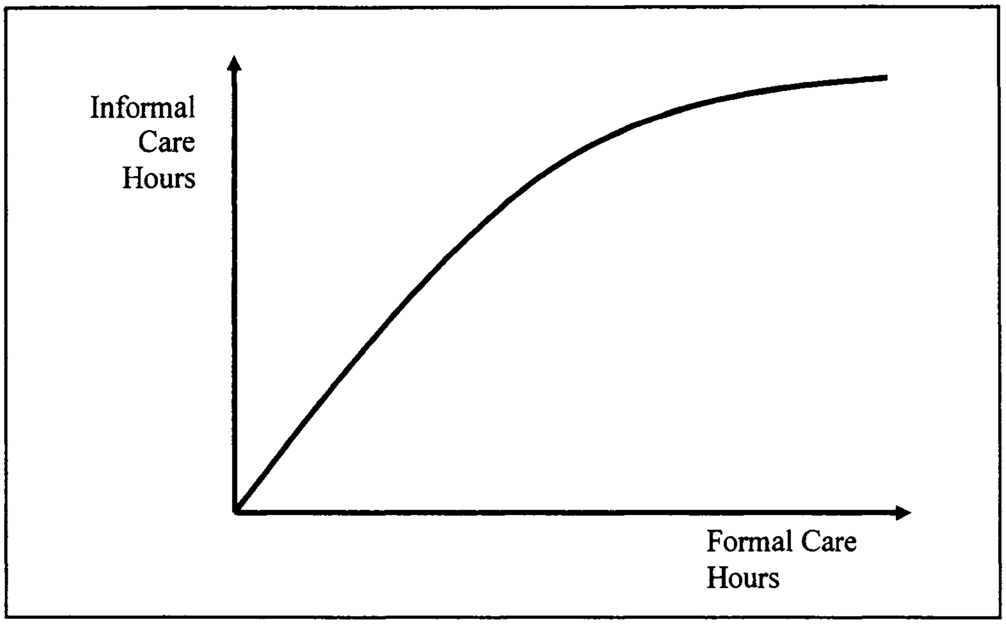


Figure 1. Complementary relationship between informal care time and formal home care time; As the hours of formal home care increases, the hours of informal care also increases (Hayward et al., 2004).

A substituting relationship between the formal home care and informal care exists if a decrease in one is associated with an increase in the other (see figure 2) (Greene, 1983). If a home care service is substituting, increasing its use would decrease the informal caregiving. Alternatively, decreasing the amount of formal care would increase the amount of informal caregiving.

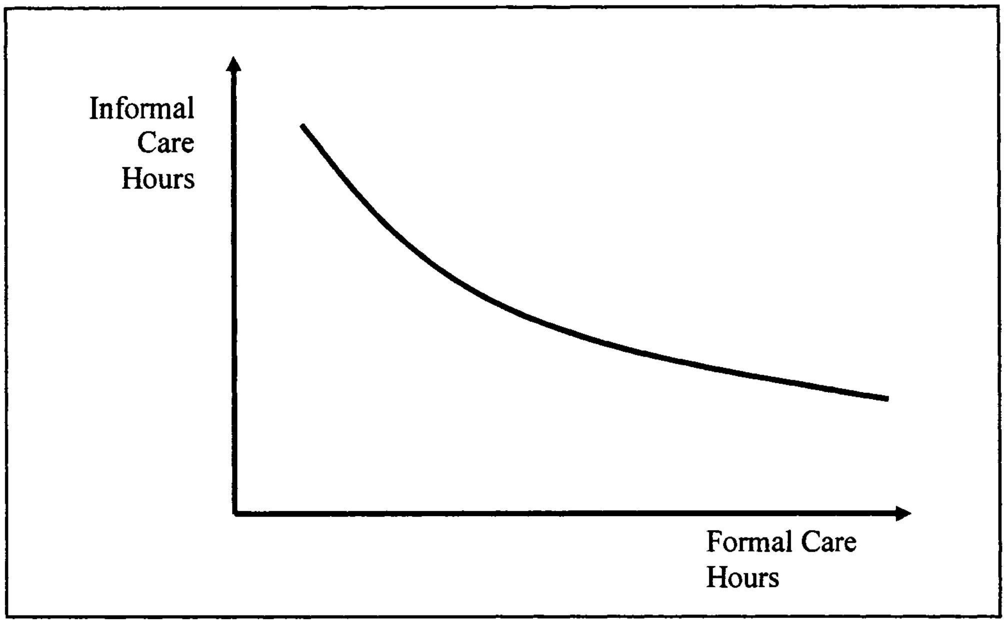


Figure 2. Substituting relationship between formal care and informal care; An increase in one is associated with a decrease in the other.

No-relationship is defined by a lack of an association between the hours of informal care and the hours of formal care. This lack of relationship has been explained with two concepts in the literature. A supplementation model exists where a care-recipient prefers care from an informal caregiver over that of formal care and therefore uses informal care until the needs of that individual exceed the resources of the caregiver and then the care-recipient supplements care with formal services (see figure 3) (Edelman & Hughes, 1990). In this model, the use of formal care will increase with the client's needs but the use of informal care does not change.

A second explanation for no-relationship between formal and informal care has been called the 'specialization of informal care'. In this situation, the formal care replaces informal care for a specific type of care, but the informal caregiver then switches the caregiving to another type of care (see figure 4) (Tennstedt, Crawford, & McKinlay, 1993).

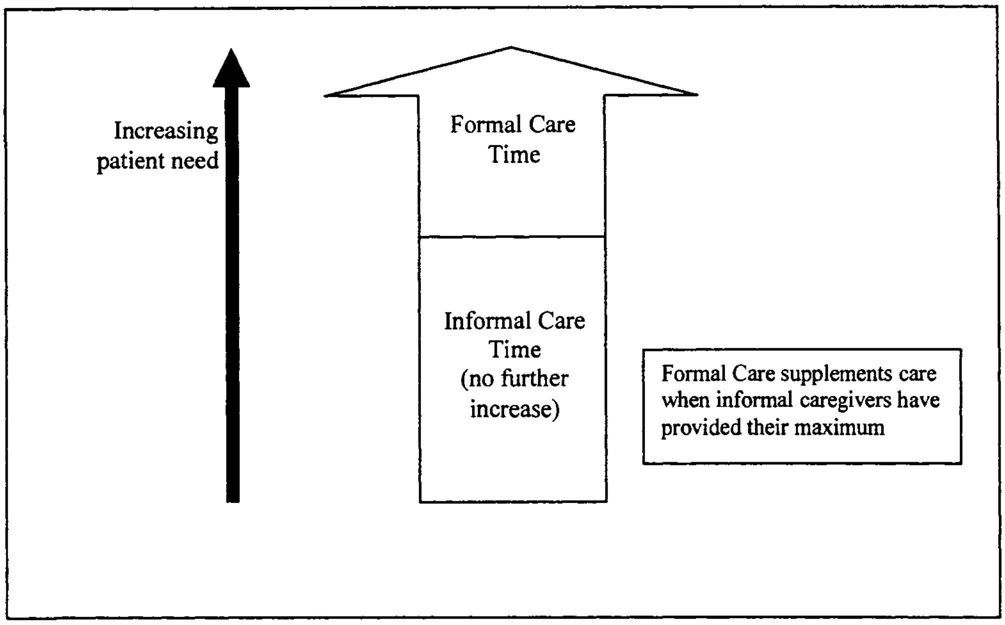


Figure 3. A supplementation model exists where informal care is used up to the caregiver's maximum capability and then formal care supplements any additional client need.

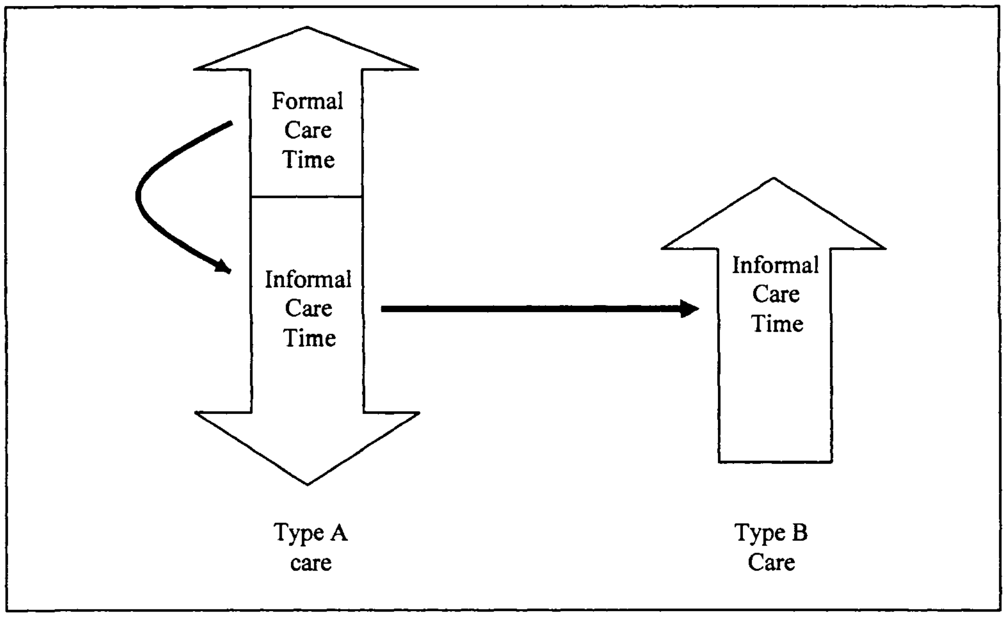


Figure 4. A specialization of care model: When formal care services are implemented for type A care, informal care time decreases for type A care but increases for type B care. Therefore, total informal care time does not change.

This study tested whether the relationship of home care service with informal caregiving varied for different types of home care service. For this study, home care services were made up of: (a) home health aides, (b) nursing visits, (c) homemaking services, (d) meals, (e) volunteer services, (f) physical therapy, (g) occupational therapy, (h) speech therapy, (i) day care/day hospital, (j) social work, and (k) respite services. Each of these services may have a different type of relationship (complementary, substituting or no relationship) with informal care.

Importance of This Study

This study will examine the relationship between formal care time and informal care time for a number of different care types.

Initial analysis of the data will provide an estimate of the hours of informal care provided for each client, thereby allowing calculations of opportunity costs of informal caregiving.

A complementary relationship suggests that increasing the formal home care service will increase the burden and costs on informal caregivers, thereby increasing total societal home care costs (Cannuscio et al., 2002; Covinsky et al., 2003; Pinquart &Sorenson, 2003). This will subsequently affect economic evaluations of home care services resulting in conclusions of a poor cost-effectiveness of the home care service. If a case manager is aware that a complementary relationship is likely for a particular service, implementation of that service should be accompanied by increasing assessment of the effect on informal caregivers and perhaps the implementation or enhancement of respite services. Informal caregivers should be informed of the effect that a complementary formal service will have on him or her in order to seek the aid of secondary caregivers or to request additional time off work or additional assistance from the formal care services.

A substituting relationship suggests that increasing the formal home care decreases the burden and time demands on caregivers (Cannuscio et al., 2002; Covinsky et al., 2003; Pinquart & Sorenson, 2003). Therefore as the cost of the formal service increases, the cost on the informal caregiver decreases. This type of relationship may produce more favourable economic evaluations of home care as the cost of care is shifted from the caregiver to the health system. Implementation of substituting services may be justified by its decrease on caregiver costs despite its effect on health system costs. Substituting services will be particularly helpful to caregivers who are approaching their limit of maximum caregiving capabilities.

No-relationship may suggest either a supplementary relationship or a specialization of informal care (Edelman & Hughes, 1990; Tennstedt et al., 1993). This suggests that home care services will do little to reduce the time burden on caregivers and increased use of such services may lean towards more unfavourable economic evaluations of home care. No-relationship also supports the hypothesis that caregivers do not generally change how much time they contribute to caring and supports the theory that caregivers want to or feel obligated to provide care or that formal home care is considered a second-line supplement to informal care.

Understanding the relationship between informal care and formal care will assist case managers in providing appropriate services and knowing when to provide additional support to a caregiver. Health policy analysts and decision makers would also benefit by recognizing the affect of additional service on societal costs.

Background

Home care is defined as "an array of services which enables clients, incapacitated in whole or in part, to live at home, often with the effect of preventing, delaying, or substituting for long-term care or acute care alternatives" (Dumont-Lemasson, Donovan, & Wylie, 1999)

Home care has three main functions: (a) substitution of hospital or long-term institutionalized care, (b) maintenance of an acceptable level of health and quality of life so that institutional care is not required, and (c) prevention of acute episodes where admission into a institution is necessary (Dumont-Lemasson et al., 1999). Home care services can be divided into four types of service: professional services, personal support services, homemaking services and ancillary services (Ontario Association of Community Care Access Centres, 2005). Professional care includes nursing and other allied health professional services such as physiotherapy, occupational therapy, dietetics, speech language therapy and social work. Personal support service is defined as assistance in personal hygiene and activities of living such as walking, eating, dressing, getting in and out of bed and climbing stairs. Homemaking service is composed of assistance in household activities including cleaning, laundry, shopping, cooking and planning meals, budgeting, mending, paying bills and caring for children. Ancillary services include provision of medical supplies and equipment, drug benefits, laboratory and diagnostic services and medical transport.

Home Care in Canada

According to the 1994/1995 National Population Health Survey of Canada, 2.4% of those over 18 years received public home care which is roughly equal to 523,000 Canadians. This statistic increased to an estimate of 1 million Canadians using home care in 2000 (Canadian Home Care Association, 2003). In 1994/1995, approximately two thirds of home care care-recipients were over 65 years and two thirds were female. The larger proportion of females corresponded to the percentage of females in the elderly population and there was no difference in the risk of using home care between males and females.

Home care, like other health services in Canada, is under the jurisdiction of the provinces and territories. As it is under provincial/territorial control, home care has developed separately in each region and differs with respect to 8 main factors: organization and governance, legislation, programs and services, eligibility, assessment and case management, coverage, funding and utilization and current initiatives. This diversity among the provinces and territories allows the system to cater for the needs of its population but carries some disadvantages: inconsistent research data, inability to compare across provinces and territories, difficulty in applying methods and techniques from one area to another, inequity and lack of standardized care. These disadvantages hamper the work of policy analysts and decision makers (Dumont-Lemasson et al., 1999).

The Canada Health Act classifies home care as an extended health care service. Therefore, monetary transfers from the federal government to the provinces and territories are also intended for home care along with other medical services. As an extended health care service, home care is not mandated to be universal, accessible, portable, publicly administered or comprehensive. Despite this, all provinces and territories have some form of public home care. Both the Kirby and Romanow reports on health care reform made recommendations of including home care services under the Canada Health Act (Kirby & LeBreton, 2002; Romanow, 2002).

The use of home care services has become more prevalent over the past decade in Canada. In 1997/98 public home care expenditure was $2,096 Million (Health Canada, 1998). Total home care expenditure increased by 350% from 1988/89 to 1998/99 with an average annual growth of 16.6%. Expenditure for the different services grew at different rates. Home support expenditure increased by 24.5% while professional services increased by 10.4% during this time period (Ballinger, Zhang, & Hicks, 2001). As a percentage of total health spending, home care spending accounted for 4% in 1997/98 which was a substantial increase from 1.2% in 1980/81 (Health System and Policy Division, Health Canada, 1998). This increase in home care spending was accompanied by a decrease in age standardized hospitalization rates by 19.6% and a decrease in total hospital days by 12.2% in Canada from 1995 to 2001 (Canadian Institute of Health Information, 2005).This increasing utilization of home care is secondary to an aging population, more severe client acuity, increasing staff expenses, improvements in technology, policies to control health expenditure, the perception that home care is cheaper and more cost-effective than institutionalized care, changes in hospital policy towards less beds, shorter inpatient stays or earlier discharge, increasing outpatient surgery and changing perceptions and demands for home care by the public (Canadian Home Care Association, 2004; Fast & Keating, 2000).

Variations in Home Care in Canada

The degree of utilization of home care services varies widely throughout Canada. Coyte et al. analyzed Canadian data from 1993 to 1995 and demonstrated that the rates of home care use after inpatient discharge can be 3.5 times the rate in a geographically neighboring region. The home care rates after same day surgery can show a seven fold difference between geographically neighboring regions. There are also provincial variations in per capita home care spending. This is secondary to differences in total home care spending, health policy differences on home care, variations in health system re-structuring and differences in costs of services and quantity of services used (Coyte, 2001). A major reason for the regional variability of home care is the variation in home care human resources. A shortage of paid home care providers is secondary to (a) the more attractive pay of institutionalized care, (b) lower benefits in home care jobs, (c) instability of working in different places, (d) hazards and safety issues from working in another person's home, (e) the prevalence of part time work in home care, (f) lack of job security, (g) the need for a vehicle and the high level of transit time required, and (h) the prevalence of shifts outside of regular working hours (Parent, Anderson, Gleberzon, & Cutler, 2001). Regional differences in home care utilization are reflected in the wide variability of home care expenditure among the provinces. This raises issues of equity and the need to include home care services as an essential service under the

Canadian Health Act. It also suggests a need to standardize home care and to develop a national home care program (Coyte, 2001). The development of a national home care program requires further research on a home care service that will optimize the efficiency and quality of care.

Home care in Ontario

The home care sector in Ontario is managed by 44 Community Care Access Centres (CCACs). The CCACs provide a single point of entry for all individuals who need home care. The functions of CCACs are explicitly described by the Ontario Association of CCACs: (a) to determine eligibility and purchase services, (b) to determine eligibility for and arrange long-term care, (c) to case manage the care of each individual and (d) to provide information and make referrals (Ontario Association of Community Care Access Centres, 2005). Each CCAC is governed by an independent, non-profit and accountable board of directors. One third of the board members must be either consumers or caregivers of long-term care services (Dumont-Lemasson et al., 1999).

When the CCACs were first established, they were mandated to contract out all services except for case management/coordination by the year 2000. Most CCACs have achieved this goal but due to human resource issues, especially in more rural and remote areas of Ontario, a few CCACs have been unable to completely contract out all services. In these regions, service providers are employed by the CCAC and the service is publicly provided (Dumont-Lemasson et al., 1999). Private home care service providers compete with each other in order to obtain contracts with the CCAC. Request for Proposals (RFP's) are used to determine the quality and cost-effectiveness of service providers and therefore to determine which service provider is chosen.

Separate from the CCACs, some individuals may be funded by the government to organize and pay for their own home care services under a self-managed program. This is performed with the aid of a voluntary organization called Centre for Independent Living in Toronto (Dumont-Lemasson et al., 1999).

Ontario restricts home care services to a maximum of 80 hours in the first month and 60 hours/month of homemaking/personal support services in subsequent months. There is also an upper limit of 43 hours service by a registered nurse or 53 hours service by a registered practical nurse. Professional services other than nursing such as physiotherapy, speech therapy, occupational therapy, dietetics services and social work, are provided as recommended. Additional homemaking/personal support services may be provided for a maximum of 30 days if "there exists extraordinary circumstances that justify the provision of additional service" (Dumont-Lemasson et al., 1999; Ontario Association of Community Care Access Centres, 2005). Most care-recipients are well below the maximum service limits. In 2001/02, the average number of nurse visits was 9.26 per month and the average number of personal support or homemaking services was 16.4 hours per month (Coleman et al., 2003).

Some provinces have a formal income assessment of their clients to determine the financial contribution to be made by the client. Ontario does not have such assessments. Services that have been deemed necessary and are under the limits outlined above are provided without a service fee. This policy applies to homemaking, nursing, physiotherapy, occupational therapy, speech-language therapy, social work, dietetics services, medical supplies and equipment, laboratory and diagnostic services and transportation. Drugs related to home care that are on the provincial formulary are also free of charge in Ontario (Dumont-Lemasson et al., 1999).

Five to six percent of total health expenditure of Ontario was spent on home care in 1997/98. Per capita home care expenditure for the same year varied from $90 to $124. When examining provincial data, Ontario had the highest home care expenditure per capita but statistics from Health Canada reported higher expenditure for the Northwest Territories (Dumont-Lemasson et al., 1999). In 2000/01, approximately 410,000 individuals received at public home care service in Ontario (The Ontario Home Health Care Providers Association & The Ontario Community Support Association, 2001). Home care utilization rates increased with age and were higher for women compared to men. The intensity of home care use also increased with age (Coyte & McKeever, 2001).

Cost-effectiveness of Home Care

This brief review of economic evaluations of home care suggests that the question on home care cost-effectiveness is yet to be determined.

A prospective cohort analysis performed in Australia compared 924 matched pairs of home care and hospital care episodes. It compared the total costs of three types of episodes: pure home care, mixed home care and in-hospital care. Costs were determined using clinical costing systems and activity based methodology. The study demonstrated that pure home care episodes had significantly lower total episode costs than both mixed home care episodes and in-hospital episodes. Costing methods only considered the cost to the health system and not towards the client, the family or society (MacIntyre, Ruth, & Ansari, 2002).

A randomized control trial of 116 patients who had persistent motor deficits after a stroke also came to similar conclusions (Teng et al., 2003). Teng et al. demonstrated that home care costs were significantly cheaper than usual (hospital) care costs. Their results also showed that home care clients had a better health status and lower caregiver burden but these differences where not statistically significant. These favorable results for home care are probably because the home care program was designed for each individual, empowered the client and family, allowed regular monitoring and therefore early detection and treatment of medical problems and facilitated quicker discharge after an emergency admission. Unfortunately, this study had a small sample size, high drop out rate and poor external validity as costs were specific to Quebec.

Both of these studies failed to include informal caregiver costs. A study that included values for indirect caregiver costs is a Canadian cross sectional study of subjects 65 years and older (Chappell, Dlitt, Hollander, Miller, & McWilliam, 2004). This study pooled subjects from both Winnipeg, Manitoba and Victoria, British Columbia. Two hundred and twenty-two community clients were compared to 358 facility clients. The survey had a good response rate and ensured a high level of data-quality by performing face-to-face interviews and using diaries to record data. Unfortunately it excluded chronic/extended care patients and patients who did not speak English. It demonstrated that costs increased substantially when caregiver costs were considered but that home care was still significantly cheaper than residential care when caregiver time was valued at minimum wage. There was no significant difference if caregiver time was valued at replacement costs (wage of a health care provider).

An English study concluded the opposite, that family/caregiver costs were lower for home-care clients than hospitalized patients (Bagust, Haycox, Sartain, Maxwell, & Todd, 2002). This was a randomized controlled trial that compared inpatient care with home care for pediatric patients with a variety of symptoms (breathing difficulties, diarrhea and vomiting, or fever). Direct costs included travel, food, child care and telephone and indirect costs was the time taken off work. There was no difference in the time taken off work between the 2 groups, but the home-care group had significantly lower direct costs than the hospital group. This study had a low drop out rate and is relatively strong evidence as it was a randomized control trial. Unfortunately, it used a recall method for data collection and the results only apply to pediatric patients in an acute medical episode.

An English study performed a cost minimization analysis comparing home care with hospital care (Shepperd, Harwood, Gray, Vessey, & Morgan, 1998). They used a randomized controlled trial of patients in five diagnostic groups: (a) recovering from a hip replacement, (b) recovering from a knee replacement, (c) recovering from a hysterectomy, (d) elderly medical patient, and (e) chronic obstructive airway disease. Costs that were included are staffing, running costs, capital, physiotherapy, occupational therapy, equipment, administration, telephone, travel, training and office space. The costs of general practitioner visits were also included. The authors utilized a discount rate of 6% for depreciation over a 10 year period. The health system costs did not differ significantly for hip replacements, knee replacements or elderly medical patients. Home care showed significantly greater health care costs for both hysterectomy and chronic obstructive pulmonary disease patients. The significance of this relationship remained for the chronic obstructive airway disease clients despite sensitivity analysis, but disappeared for hysterectomy patients. This study also looked at the cost undertaken by the caregiver. Direct costs (equipment and adaptations, consumables and travel) did not differ between the home care and hospital care for any of the five diagnostic groups. Indirect costs, which were measured as the loss of earnings and the days off work, also did not differ; these costs were very small as most caregivers were retired.

Economic evaluations of home care tend to be methodologically weak. Randomized controlled trials make it difficult to gain approval by ethics boards or recruit subjects thereby resulting in low response rates (Leff, 2001; Shepperd & Iliffe, 2001). Often there is a failure to include long-term costs and caregiver direct and indirect costs (van den Berg, Brouwer, & Koopmanschap, 2004). Costing caregiver time varies widely between studies. Some studies use opportunity costs (the wage the caregiver would be otherwise making). This can be considered inappropriate as many caregivers are retired (Soderstrom, Tousignant, & Kaufman, 1999). Using replacement costs may be more appropriate but produce the highest estimates (Chappell et al., 2004). Quantifying caregiving time and expenditure should involve the use of diaries to get an accurate value. But this is usually associated with a low response rate, so many studies gather data using the recall method (van den Berg et al., 2004). Measuring caregiver time is even more challenging as caregiver tasks are often mixed in with non-caregiver tasks making them difficult to differentiate (Andersson, Levin, & Emtinger, 2002). Many studies have compared care-recipients with a variety of diagnoses, but studies have shown that home care might only be cost effective for specific illnesses so that future research should focus on a specific diagnosis (Soderstrom et al., 1999).

This short review of the cost-effectiveness of home care demonstrates that there are a number of obstacles to determining whether home care is more or less cost-effective than hospital care. The studies by MacIntyre et al. (2002) and Teng et al. (2003) both concluded that home care was cheaper but did not include informal caregiving costs. Chappell et al. (2004) observed that informal caregiver costs were substantial but showed that home care was either cheaper or not significantly different from hospital care depending on the type of costing method. Bagust et al. (2002) showed that caregiver costs were cheaper for home care patients but these results may only apply to pediatric patients in an acute medical episode and may not be generalizable to a largely elderly home care population. Shepperd et al. (1998) showed that the cost-effectiveness varied with the diagnostic group and that health system costs were greater for some home care patients while caregiver out-of-pocket costs did not differ. The varied conclusions suggest that the cost-effectiveness of home care is yet to be determined.

Even if home care is proven to be cost effective, it still may not prevent the increasing total health expenditure costs. The implementation of a home care program frees hospital beds but then these will be quickly filled with other patients, so that home care may lead to an increase in total health spending. Home care may only be cost reducing if hospital beds are gradually decreased as home care facilities are increased (Chappell et al., 2004). Sheppard et al. suggested that closing wards with the implementation of home care would not be possible as the percentage of patients from each ward that can utilize home care is small preventing the closure of entire wards (Shepperd & Iliffe, 2001).

Informal Care

Informal care is care that is voluntarily provided with no formal financial payment. It is based on emotions such as love, responsibility and obligation that originate from family or community relationships (Fast, Williamson and Keating, 1999). Informal care tasks that have been reported include meal preparation, housekeeping, maintenance/repair, grocery shopping, transportation, bills and banking, personal care, checking up and emotional support (Keating et al., 1999).

Informal Caregiver characteristics

The 1996 General Social Survey showed that 2.8 million Canadians provided informal care for someone with long-term health problems or disability (Keating et al., 1999; Wilkins & Park, 1998). A telephone survey of households in British Columbia in 1994/95 demonstrated that 8.4% of households had a caregiver in it and 6.2% of the adult population provided informal care (Chappell, Penning, & Sorensen, 1995). In the United States, informal caregivers numbered 44.4 million making up 21% of the population (Hunt, Ginzler, & Barrett, 2004).

A substantially higher proportion of care for patients who live at home is provided by informal caregivers than formal (paid) caregivers. Data on 3,130 individuals, 65 years and older, collected in the 1987 General Social Survey, demonstrated that the ratio of percentage of informal care to percentage of formal care for each patient varied from 65%:19% for personal care to 95%:4% for assistance in managing money (Denton, 1997).

Keating et al. (1999) analyzed the Canadian data collected from the 1996 General Social Survey. Of a sample of 1,366 caregivers, 61% were female, more than half were a child of the care-recipient and less than 5% were a spouse. Fourteen percent lived in the same house and half lived in the same community. The average ages of female caregivers and male caregivers were 46 and 44 years respectively and there were no differences in education, employment and marital status between caregivers and non-caregivers. Forty percent of women and 33% of men cared for 3 or more patients (Keating et al., 1999). A 1994/95 survey of 1,789 caregivers in British Columbia also showed a similar proportion of women with slightly higher average age of 52 years. Approximately a half was employed and the average number of years of schooling was 13.1 years. When asked about the type of care provided, 97.8% provided emotional support, three quarters provided transportation and provided assistance to access information, two thirds provided leisure/social opportunities, 43% provided home maintenance, a quarter administered medication and 17% managed health care technology (Chappell et al., 1995).

In 2002, a national survey of 471 family caregivers randomly sampled across Canada was completed using computer-assisted-telephone-interviewing. This confirmed that caregivers were predominantly women. When the sample was asked why they had taken on this role, 63% stated that they chose to, 67% considered it a family responsibility while 35% stated that there was no one else available and 25% lacked home care services. Only 52% believed they had a choice in assuming the caregiver role (Decima Research Inc., 2002).

US statistics are similar. "The typical caregiver is a 46 year old female with at least some college experience and who spends more than 20 hours per week caring for her mother" (Hunt et al., 2004). The predominance of female, middle aged caregivers is supported in other studies (Cochrane, Goering, & Rogers, 1997; Covinsky et al., 2003; Scharlach, 1994).

Effects of Informal Caregiving

Research has shown that informal caregiving can have both positive and negative effects.

Benefits of Informal Care Giving

Often the negative effects of caregiving are emphasized but many benefits of caregiving have been documented. Caregivers have reported (a) increased satisfaction in the knowledge that they are helping those that once helped them; (b) increased confidence, self reliance and satisfaction from completing the challenging tasks of care; (c) a closer relationship with the client; and (d) improvements in patience and tolerance of others (Chappell et al., 1995; Houde, 1998; Scharlach, 1994). The observational study by Chappell et al. (1995) performed telephone interviews of 1,789 primary and secondary caregivers in three different languages (English, Mandarin and Punjab). As telephone interviews were used, the sample did not include people without telephones or who were not listed. More than half of the sample (51.7%) thought that caregiving had rewards such as seeing the care-recipient happy, observing improvement and increasing closeness with the care-recipient. Scharlack (1994) performed in-depth, personal interviews using open questions with 94 caregivers who were employed at least 20 hours per week and provided care for someone at least 60 years old. Over half of the sample gained satisfaction from helping someone they loved or returning the care that had originally been provided in the opposite direction. Over ten percent gained satisfaction from knowing that the patient was getting good care and from the closer relationship with the care-recipient. Some caregivers also noted enjoying the time spent with the care-recipient and increased personal growth. This study used a convenience sample which may have resulted in a bias towards caregivers who had a relatively lower level of caregiving burden. Beach, Schulz, Yee, & Jackson (2000) carried out a longitudinal study of caregivers at two points in time examining the change in caregiving and the effect on depressive and anxiety symptoms. Data was collected by interviewers at the home and at clinics. There was a 77% response rate, and of the sample of 680, 17% had incomplete data. The analysis controlled for age, race, education, gender, life events, caregiver physical function and quality of relationship. It demonstrated that an increase in informal caregiving was associated with a decrease in depression and anxiety; the authors acknowledged that their sample of care-recipients were relatively high functioning and did not require intensive care.

The 1996 General Social Survey in Canada demonstrated that more than three quarters of the subjects answered yes to positive gains of caregiving (Keating et al., 1999). Only a sixth of 1,789 caregivers interviewed in British Columbia in 1994/95 stated that there was no benefit from caregiving (Chappell et al., 1995) and two thirds of a sample of 94 caregivers in the US stated that the overall caregiving experience was positive (Scharlach, 1994). Over a third of the sample also reported a positive impact on their work because of enhanced job performance due to increased sensitivity towards the feelings and needs of coworkers, increased confidence in handling difficult situations and the perception that work became more meaningful and enjoyable.

Negative effects of informal care giving

The negative effects of informal caregiving can be divided into economic costs and non-economic costs.

Economic costs of informal care

Economic costs to the caregiver are composed of out-of-pocket costs, employment costs and unpaid labor (Fast, Williamson and Keating, 1999). Out-of-pocket costs accumulate when caregivers pay for transportation, medical equipment, medications or improvements to the patient's house, pay others to fulfill non-caregiving roles (e.g. housekeeping, child care) or spend money as a result of caregiving. A Canadian survey of 471 reported that 44% paid out-of-pocket costs due to caregiving responsibilities. Of these caregivers, about 40% spent $100 to $300 per month while a quarter spent over $300 per month (Decima Research Inc., 2002).

Employment losses include decreases in wages due to less working hours, more leaves of absence or switching from full time to part time work because of caregiving duties. Caregivers have also reported less time for job training, refusing employment opportunities, special projects or traveling abroad as additional sources of employment costs (Haley, Levine, Brown, Berry, & Hughes, 1987; Keating et al., 1999; NAC, 1999). There are also long term costs such as loss in benefits, reduced pension and reduced social security fund. The loss in job opportunity and training leads to reduced earning potential in the future (Fast et al., 1999).

Keating et al. (1999) used data collected in the 1996 General Social Survey in Canada and calculated that of 1,366 caregivers, 12% of women and 7% of men had to postpone or decline educational or employment opportunities because of caregiving duties. Sampling was completed by random digit dialing and interviews were performed over the telephone with an 85.3% response rate. The study by Chappell et al. (1995) described earlier on page 14, used telephone interviews of 1,789 households in British Columbia in 1994/95. It revealed that nearly a third of caregivers had to leave work to take the care recipient to the doctor, 28% felt that their performance had been affected and a quarter had to miss work because of caregiving duties. Cochrane et al. (1997) performed a Canadian survey of a very large sample of approximately 32,000 households using face-to-face interviews by trained interviewers. The response rate was 88% and statistical analysis demonstrated that caregivers were more likely to receive financial assistance.

In-depth interviews were performed on 50 volunteers who met the inclusion criteria of being at least 45 years, provided informal care at least 8 hours per week of care and for at least two caregiving activities and who had made some type of work adjustement because of caregiving duties (NAC, 1999). The study reported a total average out-of-pocket cost of $19,525 US per caregiver over the entire caregiving period, which ranged from 2 to 6 years. Two thirds of the caregivers stated that there was a decrease in earnings with an average total loss of $566,443 US per caregiver over the full caregiving period. Summation of wage and long term losses over the caregiving period resulted in an average total wealth loss of $659,139 US. Forty percent of this sample also reported a decreased ability to advance in the workplace. This study demonstrates substantial employment costs but unfortunately had a small sample size that consisted of volunteers. These results could not be applied to the general caregiving population because of the inclusion criteria.

The total cost of unpaid labor was calculated using data from the Statistics Canada 1996 General Social Survey on the time spent on various informal services, and by applying general wage rates and more specific wage rates. The total replacement cost of all unpaid labor from informal care in Canada was estimated to range from $5.1 to $5.7 billion dollars in 1996 (Fast & Frederick, 1999). Arno, Levin & Emtinger (1999) also performed a macro-cost-analysis of unpaid labor in the home care sector in the US and estimated that the national economic value of informal caregiving in 1997 was $196 billion US which was substantially larger than the total of formal home care spending ($32 billion) and nursing home care spending ($83 billion).

There are also economic costs to the caregiver's employer and to society. Caregiving responsibilities can lead to: (a) arriving to work late, (b) leaving work early, (c) taking long lunch breaks, (d) increased sick days and days off, and (e) decreased productivity. This may result in increased cost and decreased earning for the employer (NAC, 1999; Scharlach, 1994). The employer sustains additional costs from recruiting and training new staff when the caregiver resigns or switches to part time work (Coberly & Hunt, 1997). The 1996 General Social Survey in Canada reported that a third of caregivers stated that caregiving caused late arrivals or the need to leave early and 30% reported missing a day or more from work and 16% believed that caregiving effected job performance (Keating et al., 1999). A US cost analysis using data taken from three large scale studies, estimated that the total cost of caregiving to US companies is $11.4 billion US dollars annually. This statistic includes costs of replacing employees (recruitment, relocation, training and temporary inefficiency), costs of absenteeism, costs of partial absenteeism (arriving late/ leaving early/ long lunch breaks), costs of workday interruptions, costs of eldercare crises, and costs of providing emotional support, counseling and arranging coverage for caregivers (Coberly & Hunt, 1997).

Non-economic costs of informal care

Informal caregiving is associated with increased psychological, physical, social and emotional stress (Cochrane et al., 1997; Decima Research Inc., 2002; Haley et al., 1987; Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999). This is secondary to role reversal, sleep deprivation and the multiple roles and demands that the caregiver needs to satisfy. Informal caregivers may also experience feelings of guilt when they are unable to meet the caregiving demands (Keating et al., 1999). Caregivers complain of decreased personal time and less opportunity, time and energy for social activities (Alcock, Danbrook, Walker, & Hunt, 1998; Keating et al., 1999; White, Lauzon, Yafee, & Wood-Dauphinee, 2004). There is an increased likelihood of suffering from symptoms of depression and anxiety with caregiving. This risk increases with being female, with higher levels and time of care provided and if the patient suffers from depression or behavioral problems. Other determinants of caregiver psychosocial and emotional status include caregiver's health, income and whether the caregiver is the spouse or child of the patient (Beach et al., 2000; Cannuscio et al., 2002; Han & Haley, 1999; Lieberman & Fisher, 1995; Livingston, Manela, & Katona, 1996; Ory et al., 1999). There is evidence that the quality of life of the caregiver is lower with greater behavioral and emotional problems of the care-recipient (White et al., 2004) and that caregivers are also more likely to suffer from psychiatric problems if the patient has psychiatric diagnoses (Livingston et al., 1996). A review by White et al. (2004) noted that health related quality of life initially decreased at the start of caregiving but gradually improved with time.

A prospective cohort study in the US (Schulz & Beach, 1999) compared 392 caregivers and 427 non-caregivers with respect to mortality. After controlling for socio-demographic factors, clinical disease and sub-clinical disease, caregivers who reported emotional strain had a mortality risk that was 63% higher than non-caregivers. There was no significant difference in mortality between non caregivers and caregivers who did not report emotional strain. This study only included spousal caregivers and excluded patients who suffered from cancer or used a wheelchair.

A cross sectional analysis of data collected on 557 care-recipient/caregiver dyads examined the determinants of caregiver burden (Bédard, Kuzik, Chambers, Molloy, Dubois & Lever, 2005). The sample consisted of first time visitors to a memory clinic so that most care-recipients had only a moderate level of problem behaviors and dementia. All the care-recipients were diagnosed with Alzheimer's disease. The sample was voluntary but there was a good response rate. This study included care-recipient characteristics, caregiver characteristics and external supports in the hierarchical regression model. It demonstrated that instrumental activities of daily living and difficult, emotional and repetitive behaviors of the care-recipient were significant predictors of caregiver burden and that care-recipient characteristics accounted for 47% of the variability of caregiver burden. Female caregivers were shown to have a significantly higher level of caregiver burden.

Time of Informal Caring

Time spent on informal caregiving varied considerably among studies. A US survey of 1,247 caregivers in 2003 reported that 48% provided 8 hours or less of care a week while 17% provided 40 hours or more of care per week (Hunt et al., 2004). A meta-analysis of 228 studies by Pinquart et al. calculated an average of 35 hours per week of caregiving (Pinquart & Sorensen, 2003). A Canadian study of data collected in the 1992 General Social Survey examined the hours of unpaid care provided by people over 55 years and calculated an average of 2.58 hours per person per day (18 hours per week) for males and 2.16 hours per person per day (15 hours per week) for females; these statistics only included hours of care to other households and not within the caregivers household (Robb et al., 1999). A survey of 1,789 caregivers in British Columbia in 1994/95 showed that most caregivers (73%) provided care at least 7 days of the week; 31% provided 1 hour or less per day, 39% provided 2-4 hours per day and 11 % provided 5-7 hours per day while 19% provided 8 or more hours per day (Chappell et al., 1995). Some studies of individuals with dementia/Alzheimer's showed considerably higher hours of care with averages of over 80 hours per week (Covinsky et al., 2003; Yordi et al., 1997). Supervision and surveillance made up half of the care time of such individuals (Wimo et al., 2002).

Determinants of Caregiver Time

The variation in caregiving hours is secondary to client characteristics, caregiver characteristics, the relationship between the caregiver and client and environmental characteristics.

People with increased frailty and close to death receive higher hours of informal care per week. Informal care hours also increase with the client's age, ethnicity, severity of dementia, cognitive impairment, extent of behavioral disturbances, ADL disability and severity of health (Keating et al., 1999; Kemper, 1992; Wimo et al., 2002).

Kemper (1992) performed a study of over 5,000 care-recipients in the US who were either referred to the study by a health professional or volunteered for the study. Interviews were carried out via the telephone and a proxy was used in 30% of the cases. Informal caregivers were interviewed separately. Caregivers were expected to estimate the extra hours of care provided above that which would have been provided had the patient not been disabled. Such estimation may be difficult, thereby reducing the accuracy of the data. For this study, informal care was divided into resident informal care and visiting informal care. Classification was determined by whether the informal caregiver lived with the care-recipient (resident informal care) or lived in another household and therefore visited (visiting informal care). The study showed that compared to white

Americans, African Americans and Hispanic Americans had significantly higher hours of informal care. Hours of informal care also increased with increasing ADL disability, increasing cognitive impairment and increasing inappropriate behavior. Worsening health condition was also associated with an increase in hours of informal care.

A Swedish study by Wimo et al. (2002) conducted telephone interviews of 92 Alzheimer's patients or their caregivers who received informal care. A convenience sample was used with a response rate of 68%. Data from informal caregivers was collected using the recall method which decreases the internal validity of the values. Statistical analysis controlled for a variety of patient and caregiver factors. The significant determinants of informal care time were patient age, behavior disturbances, and whether they caregiver and client were living together. Informal care time increased with age and increasing severity of dementia and caregivers who lived with the care-recipient received more informal care.

The study by Keating et al. (1999) described on page 21, examined the caregiver characteristics that impact informal caregiving time. Caregivers who are female, older and married provide more care while those who have children or are employed provide less care. Of female caregivers, those who live in rural areas and have lower levels of education, spend more time caregiving. Spousal caregivers, those who live in the same household and those who care for a patient of the opposite sex provide higher hours of care per week. Poor client-caregiver relationships and non-primary caregivers show lower hours of care per week.

Areas where there are a lack of formal services results in an increase in informal caregiving time. Geography is a major determinant in the availability of formal services. Rural or remote areas where there are less formal home care services and which may require longer transportation times leads to higher time costs for the informal caregiver (Fast, Eales, & Keating, 2001). Regions with publicly funded home care have been shown to have less informal care hours than regions without public funding (Kemper, 1992).

Importance of Time Spent Caregiving

The time spent caregiving may correlate with many of the effects of caregiving. The more hours spent caregiving, the higher the risk of the caregiver suffering from depression and anxiety and the higher the perceived burden (Cannuscio et al., 2002; Covinsky et al., 2003; Lieberman & Fisher, 1995; Pinquart & Sorensen, 2003). Covinsky et al. collected self-reported data on 5,627 primary caregivers of dementia patients and demonstrated a significantly higher prevalence of caregiver depression in caregivers who provided larger hours of care. Alternatively research has shown that the hours of caregiving is not a determinant of caregiver burden. Bédard et al. (2005) used data from 557 caregivers in a hierarchical regression model for burden of caregiving. They demonstrated that hours of care was not a significant predictor for burden of caregiving after entering care-recipient characteristics and caregiver characteristics into the regression model. A longitudinal study of data taken from the Nurses Health study in the US concluded that the relationship between time of caregiving and depression and anxiety symptoms was not linear, but that risk increased substantially for caregivers who provided care for 35 hours or more per week (Cannuscio et al., 2002). There may also be a positive correlation between hours of care and caregiver physical and emotional strain and financial hardship (Ory et al., 1999). Logically, one can conclude that time spent caregiving directly correlates with economic costs as opportunity costs and time taken off work increases and time available for employment opportunities decreases. Analysis of the 1996 General Social Survey in Canada showed that time spent caregiving was a significant predictor of socioeconomic burden, guilt, perceived burden and loss of employment opportunities. For every hour spent caregiving the socioeconomic burden index increased by 0.75%. For males, as caregiving hours increased, guilt decreased. With increasing caregiving time, perceived burden increased and more employment opportunities were postponed or refused (Keating et al., 1999).

Literature Review

A literature review was performed of research previously published on the type of time relationship that exists between formal home care and informal care. The search terms used included: home care, formal care, informal care, family care, caregiving, relationship, complementary, substituting, time and hours. Search engines used were PubMed, PsychInfo and Google Scholar. Limitations applied to the searches included articles in English, articles about humans and the publication period 1995 to 2006. The searches usually produced large lists of articles that were narrowed by reviewing the abstracts. The reference lists of articles were then examined to find any additional useful articles. Eventually eighteen published articles were chosen for this literature review. The articles were published from 1990 to 2005. They were of varied quality of research and offered varying conclusions. Most of the studies were observational using cross-sectional data. A few collected longitudinal data and there was only one randomized control trial.

Types of Relationships between Formal and Informal Care

The relationship between the time of formal care services and the time of informal care may be complementary, substituting or have no relationship. A complementary relationship between formal home care and informal care exists if an increase in one is associated an increase in another (Hayward et al., 2004). An explanation for a true complementary relationship may be that formal home care services empower and encourage the involvement of informal caregivers. This type of relationship has also been described as a bridge between formal and informal service in that informal caregivers enable the care-recipient to access the formal services (Logan & Spitze, 1994). A substituting relationship between formal home care and informal care exists if a decrease in one is associated with an increase in the other (see figure 2) (Greene, 1983). This relationship may be because formal care decreases the responsibilities and therefore the caregiving time requirements of informal caregivers (Houde, 1998). A lack of association between informal care time and formal care time (no-relationship) may also be observed. This lack of relationship has been explained with two concepts in the literature. The first concept is a supplementation model, where a care-recipient prefers care from an informal caregiver over that of formal care. Therefore the care-recipient uses informal care until the needs of that individual exceed the resources of the caregiver and then the care-recipient supplements care with formal services (see figure 3) (Edelman & Hughes, 1990). In this model, the use of formal care will increase with the client's needs but the use of informal care does not change. A second explanation for no-relationship between formal and informal care has been called the 'specialization of informal care'. In this situation, the formal care replaces informal care for a specific type of care, but the informal caregiver then switches the caregiving to another type of care (see figure 4) (Tennstedt et al., 1993). If this exists, formal care service will have no effect on the *total* hours of informal care.

Evidence Supporting a Substituting Relationship

The majority of studies reviewed (8 studies) demonstrated a substituting relationship between formal and informal care.

A recent study by Li (2005) examined data on 3,161 elderly clients of Michigan's Home and Community based Medicaid Waiver Program. The study started in 1999 and collected data from the first program visit. Clients were followed for three years and data was collected approximately every 3 months using the MDS-HC. The original sample was 3,161 but after three years, only 888 subjects (28%) were left to be analyzed. Loss was secondary to death, institutionalization, moving or losing eligibility for the program. The author demonstrated that there was no statistical difference in the amount of informal care between clients present after 2 years and those in the final sample. This suggests that the high drop out rate should be of minimal concern with respect to the quality of the research. The amount of informal care declined after the patient started the home care program supporting the substituting relationship. The gradient of this decline decreased until the amount of informal care leveled off and there was little change in the quantity of informal care in the last year of follow up. The author questioned whether the decline being observed was just a natural decline after a crisis situation. As this was an observational study and there was no control group, this question could not be answered. It was noted that the gradient of the decline varied and that caregivers who lived with care-recipients showed less of a decline that caregivers who lived in a separate household. This study had a poor generalizability as the Michigan Home and Community based Medicaid Waiver Program was designed for low income individuals.

Another recent study examined US national data collected on single persons 70 years and older who had at least one living adult child or step-child. Data was collected on 4,752 subjects in 1995 and/or 1998 and subjects were interviewed at either the home or the institution. The study showed that the increased use of informal care significantly reduced the probability of using any home care or nursing home care, thereby supporting a substituting relationship. One should note that the research question of this study applies also to the relationship between informal care and formal care in both the nursing home and home care.

An earlier study used cross sectional analysis of data collected in the 1989 National Long Term Care Survey of the United States. Structured interviews were conducted personally or over the telephone, and people over 65 who lived in the community and had a caregiver were included in the sample. Logistic regression of formal service utilization demonstrated that the greater the informal hours, the lower the formal care hours. Although the association was significant, the author recognized that the relationship was minimal with an odds ratio of 0.98 (Houde, 1998).

The three studies that have been described originated from the US. A Canadian study by Denton (1997) used data from the General Social Survey of 1987. A sample of subjects at least 65 years of age was chosen. Those living on reserves or members of the armed forces were excluded. There was an 86.4% response rate and a resulting sample size of 3,130. Logistic regression models demonstrated that people who received informal care were less likely to receive formal care and those who received formal care were less likely to receive informal care. This negative relationship may support a substituting relationship but the author of the paper believed that "formal care is accessed when crucial elements of the informal network are lacking or when there is great need".

Three further studies in this literature review supported the hypothesis of a substituting relationship between formal care and informal care. Unfortunately, the design of these studies provided poor evidence for this relationship.

A study in the United Kingdom included 101 subjects with moderate to severe dementia and who had an informal caregiver (Schneider et al., 2002). Data collection was conducted by face to face interviews or over the telephone. The sample was classified into people with a co-resident carer and those without a co-resident carer. Analysis involved logistic regressions and the results showed that the group with co-resident carers had significantly larger quantities of informal care and also were less likely to use home help or meals on wheels.

A Swedish study examined the relationship between informal care and formal care by observing the change in levels of each over time. Johansson, Sundström & Hassing (2003) used population data collected in 1994 and 2000 in Sweden. During this time period, health policy had shifted towards tighter restrictions on home care eligibility. The author observed that from 1994 to 2000, home help utilization decreased in Sweden. Subsequently, the levels of family care increased suggesting a substituting relationship. A recent study by Nordberg, von Strauss, Kåreholt, Johansson, & Wimo (2005), used data collected on subjects 75 years and older living at home of rural community. Individuals were invited to participate. Non-participants were noted to be significantly older than participants and more women refused to participate than men. Personal interviews by nurses and examinations by physicians were performed in the home for 740 individuals. Tobit regression showed that people who received formal care had approximately one hour less of informal care than those who received no formal care, and that those who received informal care, had less formal care. Although these results were not significant, the trend was consistent at all levels of dementia and non-dementia and the author concluded that the relationship between formal and informal care was substituting.

A substituting relationship between formal and informal care has policy implications as it shifts the cost and the burden from the caregiver to the health system. If formal home care services are increasingly utilized, there will be a greater demand on the already limited governmental resources which may not be financially sustainable. Alternatively, a decrease in the provision of home care can result in an increasing burden on informal caregivers which is also not sustainable (Houde, 1998).

One may speculate that a substituting relationship may lead to an inappropriate shift of the caregiving responsibility from the traditional family/informal caregiver to the health system, but a longitudinal survey of 634 clients and 429 caregivers in Massachusetts starting from 1984/85 to 1991 concluded that only caregivers who truly needed assistance in care, utilized home care. The main predictors of substitution were loss of a primary caregiver, higher disability and greater amounts of informal care. The first two predictors suggest that informal care was only being replaced by formal care when there was a need for the formal service. The third predictor may suggest that the informal carers who provided greater amounts of care were overburdened and required respite (Tennstedt et al., 1993).

Evidence Supporting a Complementary Relationship

Only three of the studies included in this review supported a complementary relationship between informal and formal care.

One of these studies used population based data with a very large sample size and examined the effect of formal care on informal care and vice versa (Fassbender, 2001). This was a cross sectional study of data on 4,962 individuals collected from 1991 to 1995 with the Alberta Assessment and Placement Instrument. The author used a combination of causal modeling and survival analysis to analyze the relationship between formal and informal care. It demonstrated that a $1 increase in informal care costs resulted in an increase of $1.09 in formal care while a $1 increase in formal care produced a $0.30 increase in informal care costs. The study concluded that there was a complementary relationship between formal and informal care but that this decreased as the functional status of the patient declined.

Wimo et al. (2002) conducted telephone interviews of a convenience sample of 92 Alzheimer's patients living at home who have informal care. There was a 68% response rate and statistical analysis controlled for patient characteristics and caregiver characteristics. A complementary relationship was suggested by a positive correlation demonstrated between time of formal care and informal care (Wimo et al., 2002).

A survey of 471 caregivers randomly sampled across Canada also suggested that there is a complementary relationship between formal and informal care; the study noted that receiving formal home care services was associated with an increase in the intensity of family caregiving activities without reducing the amount of time required from family members (Decima Research Inc., 2002).

The strength of a complementary relationship may diminish with increasing needs of the patient because caregivers may have reached their natural limit so that changes in formal care no longer effect informal care hours (Clark, Xie, Adachi-Mejia, & Sengupta, 2001; Fassbender, 2001). If formal home care and informal care are complementary, an increase in home care utilization can lead to an increase in the caregiver costs and, therefore, societal costs of home care. Both formal and informal care add substantial costs to the home care sector so that future economic evaluations of home care which include caregiver costs may demonstrate that it is no longer cost effective if there is increased utilization of formal home care.

Evidence Supporting No-Relationship

Four studies in this review supported a lack of a relationship between informal care and formal care.

The most recent study was conducted in a region of British Columbia (Penning, 2002). The original sample of 1,012 subjects of a previous study was contacted for a follow up interview in 1997. There was a refusal rate of 10%, and 28% were lost to follow up because of death, illness, institutionalization and not locatable producing a final sample size of 661. The sample retained differed significantly from the original sample. The subjects lost were more likely to be male, had a lower income, poorer perceived health, lower cognition, and were more likely to receive publicly subsidized home care. Two-stage least squares regression controlled for client demographics, socioeconomic status, functional abilities, cognition and living situation. It demonstrated that formal care was not a significant determinant of informal care in either scope or intensity.

An earlier US study used a much larger population of 5,254 people who were diagnosed with an irreversible dementia and had either a cognitive or functional deficit or both (Yordi et al., 1997). The subjects were monitored for 36 months. The authors noted that the provision of home care did not have a significant effect on informal care.

Analysis of the 1994/95 National Population Health survey of Canada by Wilkins et al. showed that the frequency of informal care visits was not significantly different between those who received home care and those who did not (Wilkins & Park, 1998).

An early US study by Hanley, Wiener and Harris (1991) analyzed data taken from the 1982 National Long-Term Care Survey. The sample consisted of formal care users aged 65 or older, who reported at least one formal or informal care visit during the past week. Analysis showed that the amount of formal care did not significantly reduce the amount of informal care. In this study the quantities of care was measured in days instead of hours as opposed to our study which measures both.

Further Evidence

Five additional studies suggested that the relationship between informal and formal care could not be easily classified into the three groups and that the relationship may vary with time, client or caregiver characteristics or with the type of informal care provided.

The only randomized control trial in this review is a study by Pezzin, Kemper & Reschovsky (1996) of 3,619 people who were at least 65years of age, disabled and had unmet needs. The clients were randomized into two groups which differed by the amount of publicly funded home care allowed. The clients were evaluated at 6, 12 and 18 months after baseline. The death rate and non-response rate were both high at 28% and 15% respectively. Results demonstrated that the type of relationship between formal and informal care differed for married and unmarried clients. For unmarried individuals, the provision of formal care produced a small reduction in informal care (substituting relationship) while there was no significant relationship between formal and informal care hours for married individuals (no-relationship).

The study by Logan & Spitze (1994) concluded that the relationship between formal and informal care varied with whether the caregiver was a relative or a non-relative of the client. The sample consisted of 554 people, 60 years and older, living in New York. Personal interviews were conducted and the response rate was 67.3%. Logistic regression was used and controlled for a variety of client characteristics, availability of services and accessibility of services. Results showed that family/related caregivers usually decreased the likelihood of formal care use demonstrating a substituting relationship, but caregivers who were friends/neighbors increased the use of community based services supporting the complementary relationship where the caregiver enables the client to use the formal service.

Two studies demonstrated that the relationship between informal care and formal care vary with time. The more recent study was an analysis of 193 patients with schizophrenia, schizoaffective or bipolar disorder by Clark et al. (2001). The subjects were followed for 3 years with interviews every 6 months. There was a high level of missing values. These were imputed using the Monte Carlo Markov Chain method. The study showed that in the short term there was a complementary relationship between formal and informal care. Patients with bipolar disorder had a 1% increase in formal services with every 4% increase in informal services. Patients with schizophrenia had a similar relationship but not as strong. The relationship switched to a substituting one in the long term (3 years in this study) where for a decrease of 1% in formal care costs, there was a 4-6% increase in informal care.

The earlier study by Edelman & Hughes (1990) followed over 200 elderly home bound individuals in Chicago. The individuals were interviewed on acceptance to a home care program, and then at 9 and 48 months after acceptance. The most significant predictor of *follow-up* utilization of informal care (number of informal types of care and level of informal care) was *baseline* utilization of informal care accounting for 36 to 43% of variance. Formal care was also a significant predictor of follow up utilization of informal care; at 9 months, informal care decreased with increasing use of formal care (substituting relationship) but at 48 months, informal care increased with increasing use of formal care (complementary relationship).

These two studies showed very different variations of the relationship type with time which may be explained by the differences in their target populations.

A recent US study suggested that the relationship between formal and informal care may vary depending on the type of informal care provided. White-Means & Rubin (2004) used data collected from 3,649 individuals during the 1994 wave of the National Long Term Care Survey in the United States. With a unit decrease of formal care services, there was a four hour increase of weekly IADL informal care hours (substituting) and an 8 hour decrease in weekly ADL informal care hours (complementary). When considering total formal and informal care hours, there was no significant association which is expected as the IADL and ADL informal hour changes will tend to cancel out each other.

Summary

The majority of published work about the relationship between formal and informal care supported a substituting relationship. Unfortunately, half these studies, particularly the more recent work, were of a lower quality of research. There was also substantial amount of good evidence supporting a variety of relationships depending on caregiver or client characteristics or on time. The evidence supporting a complementary relationship and no-relationship also cannot be ignored. This suggests, that the true relationship between informal and formal care is yet to be completely understood.

Hypotheses

This study tested whether the relationship of home care service with informal caregiving varied for different types of home care service. For this study, home care services were made up of: (a) home health aides, (b) nursing visits, (c) homemaking services, (d) meals, (e) volunteer services, (f) physical therapy, (g) occupational therapy, (h) speech therapy, (i) day care/day hospital, (j) social work, and (k) respite services. Each of these services may have a different type of relationship (complementary, substituting or no relationship) with informal care.

No research has been found which investigates these relationships except for respite care. A longitudinal study of 228 caregivers who utilized respite care demonstrated that the use of respite care correlated with decreased hours of informal care and caregiver burden (Cox, 1997). There was no change in depression and anxiety symptoms. This demonstrates that there was a substituting relationship between respite care and informal care hours.

For the other types of formal home care services, it is logical that if the service can replace the duties performed by the informal caregiver, then use of the service will decrease informal caregiving hours, therefore making it a substituting service. Home health aides (personal hygiene, transferring etc.), homemaking and meal services are often performed by informal caregivers implying that these services are substitutes for informal care. Volunteers also generally perform similar tasks and may be a substitute for informal care.

Physical therapy mainly involves treatments with exercise, gait training, health education and environmental management (Collins, Beissner, & Krout, 1998). Other functions of a physical therapist include transfer training, using prostheses, balance training, endurance training and massage. These tasks are not generally performed by an informal caregiver and sessions with a physical therapist may improve the pain, function and disease activity of the patient (Lineker, Bell, Wilkins, & Badley, 2001) thereby decreasing the need of the patient and the time required of the caregiver. Occupation therapy has a similar role but mainly focuses on training the care-recipient on activities of daily living with the aim of increasing function and independence (McCormack, 1997).

This service has shown to produce a significant increase in the function of the client (Helewa et al., 1991), and therefore may diminish the dependence on the caregiver. This suggests that the relationship between physical therapy / occupational therapy services and informal caregiving is substituting.

Nursing visits can have a variety of functions including dressing wounds, giving medication, performing clinical tests and health education. These roles are not performed by informal caregivers suggesting that there is no relationship between nursing visits and informal hours. However, health education may involve empowering the client and family so that hours of informal caregiving may increase and the relationship may be complementary.

Speech therapy involves exercises to improve speech which cannot be performed by informal caregivers. Social work involves a variety of duties including case management and assessment, interagency collaboration, counseling, health education, care planning and advocacy for home care services (Egan & Kadushin, 1999). None of these functions are performed by informal caregivers suggesting that there is no relationship with informal hours.

To attend day care/day hospital, the care-recipient spends a substantial amount of time at the day care /day hospital facility possibly decreasing the time required by the caregiver leading to hypothesis of a substituting relationship.

This study examined the separate relationships of each formal care service with informal care and hypothesized that:

1. Home health aides, homemaking services, meal services, volunteer services, physical therapy, occupational therapy, day care/day hospital and respite care have a substituting relationship with informal care hours.
2. Nursing visits have a complementary relationship with informal care hours.
3. Speech therapy and Social work services will have no relationship with informal care hours.

Methodology

This study is a cross-sectional study and a secondary data analysis of data collected in 2000/01. Data was collected from care-recipients and caregivers via personal interviews by trained personnel. It was analyzed using basic descriptive analysis, chi-squared tests, t-tests, Mann-Whitney U tests and logistic regression models.

Participants

The data set analyzed in this study was collected for the Resident Assessment Instrument – Health Informatics Project (RAI-HIP) in 2000/01 at various sites in Ontario including Thunder Bay, Hamilton and Waterloo. The sampling of cities was not random as involvement of a CCAC depended on resources and interest. The CCACs used a sampling technique for choosing subjects that aimed to produce a sample that was representative of the population serviced by that CCAC. Baseline data were collected for all subjects and follow-up interviews were completed for some. Follow up data were not available for some clients because of death, entry to long term care or institutionalized care, or improvement in health removing the need for further home care. For this study, only the baseline data were used. Trained assessors completed a paper-based MDS-HC after interviewing the client and/or their caregiver. Each assessment form was computer entered by 2 independent individuals and the data compared to ensure data quality. The study was the largest at that time to collect and analyze MDS-HC data and included data on 5,571 individuals. Five thousand and eight of these individuals had an informal caregiver.

Minimum Data Set – Home Care (MDS-HC)

The MDS-HC is a 223-item tool that collects data on home care clients (interRAI, 2005). It is made up of 21 sections and includes questions on client demographics, functional characteristics of the client (cognition, communication ability, physical functioning, mood and behavior), medical diagnoses of the client, client medication and environmental factors that might affect the client's wellbeing. There are also questions on the home care service received by the client, the informal care received by the client and other caregiver questions. The MDS-HC has proven validity and reliability (Kwan, Chi, Lam & Chou, 2000; Landi et al., 2000; Morris et al., 1997). Landi et al. (2000) compared the MDS-HC scales to established measurements such as the Barthel Activities of Daily Living Index, the Instrumental Activities of Daily Living Index and the Mini Mental State Examination. They calculated high correlation coefficients that ranged from 0.74 to 0.81 demonstrating a good internal validity. Kwan et al. (2000) studied the data collected from 179 people using the MDS-HC, and found a high internal consistency with cronbach coefficients ranging from 0.6 to 0.8. Reliability of the MDS-HC was examined by Morris et al., (1997). Dual data was collected by trained interviewers using the MDS-HC from 5 different countries. The average weighted kappa values varied from .70 to .74 demonstrating that the MDS-HC is a reliable instrument.

Data Analysis

The data set consisted of 5,571 people. Only those who had a caregiver were included in the analysis as a relationship between formal and informal care is not possible if there are no informal caregivers. The lack of any informal caregiver for a client was concluded when the client/proxy responses were "no such helper" to a question referring to a primary informal helper and to a question referring to a secondary informal helper. Subjects with caregivers and subjects without caregivers were compared for significant differences in demographic, physical and functional characteristics. After removal of clients without an informal caregiver, the final data set with a sample size of 5,308 clients was used for further analysis.

The final data set was first analyzed to produce descriptive statistics of demographic variables of the individuals in our sample (age, gender, marital status, education, language and aboriginal status).

Two logistic regressions were then performed in the final data set. Both regressions had a dependent variable of 'hours of informal care per week'. The first regression had an independent variable of 'frequency of formal care' and the second regression had an independent variable of 'hours of formal care'. Of the sample of 5308, a subject was excluded from the regression if it was missing a value in any of the variables used in the regression.

A regression was used in order to determine the relationship between informal care and formal care while controlling for other variables. As the dependent variable (informal care) had a distribution that was significantly skewed to the right and did not meet the assumption of normality, logistic regression was deemed necessary for this analysis. Multinomial logistic regression was used because the dependent variable was an ordinal variable with 6 categories. The hours of informal care provided was initially recorded on the MDS-HC as 2 variables (hours of informal care provided during 5 weekdays in the last 7 days, hours of informal care provided during 2 weekend days in the last 7 days). The total hours of informal care provided per week were calculated and then the variable was recoded into 6 categories: '6' = no hours, '5' = .5 to 5 hours, '4' = 6 to 10 hours, '3' = 11 to 15 hours, '2' = 16 to 20 hours, '1' = more than 20 hours. These categories were chosen as they allowed a fairly even distribution of the sample among the categories. "No hours" was used as the reference condition to which comparisons were made.

There are 223 items on the MDS-HC available for use in logistic regression modeling. The following items were not present on the data set: name, case record no., health card no., postal code of residence and responsibility for payment. Items were not used as covariates in the regression if (a) there was no basis for a hypothesized association or lack of evidence in the literature that an association exists with the dependent variable, (b) the variable was a redundant measurement of an item chosen as a covariate, (c) there was very little variation within the variable, (d) the item had more than 5% missing values, (e) the correlation coefficient with the dependent variable was low ($r < .2$) or (f) there was multicollinearity ($r > .7$ between 2 covariates).

The following variables were automatically included in the regression model: (a) Client gender, (b) client age, (c) client education, (d) client wandering, (e) client resists care, (f) client diagnosis with dementia, and (g) type of relationship between caregiver and client.

Gender was included in the regression model as it is standard demographic variable that is considered in most research. A Swedish study of 92 people demonstrated that age was a significant predictor of informal care hours (Wimo et al., 2002) explaining its inclusion in the regression model. Although the literature review did not reveal a relationship between education and informal care hours, clients with less education are more likely to receive informal care (Denton, 1997) and therefore this variable was added to the regression. The literature review revealed that inappropriate behavior or behavioral disturbances such as wandering and resisting care led to significantly higher amounts of informal care time (Kemper, 1992; Wimo et al., 2002) and that subjects with dementia use significantly more hours of informal care (Covinsky et al., 2003; Yordi et al., 1997) justifying the inclusion of these variables in the regression model. The type of relationship between caregiver and client was included in the regression model as previous research has demonstrated that it is a significant predictor of informal care hours (Egan & Kadushin, 1999).

Units of Measurement

The independent variable, formal service, was recorded for 11 types of service: (a) Home health aides, (b) visiting nurses, (c) homemaking services, (d) meals, (e) volunteer work, (f) physical therapy, (g) occupational therapy, (h) speech therapy, (i) day care or day hospital, (j) social work in home, and (k) respite care. Amount of formal service for the first 10 types were measured as a frequency (number of days visited within the last 7 day period) and as time (total hours of care within the last 7 day period). Although the distributions of these variables were not normal, they were not categorized as logistic regression does not require normality. The 11th formal service, respite care, was measured as a dichotomous variable of 'receiving respite care' and 'not receiving respite care' in the last 7 days.

The covariates chosen can be classified into 4 groups: (a) client demographics, (b) client physical/functional characteristics, (c) caregiver characteristics and (d) client/caregiver dyad characteristics.

Client demographic variables were age, gender, marital status and education. Age was measured as a continuous variable. The MDS-HC records marital status into 6 categories but this was recoded into a dichotomous variable of 'married' and 'not-married' as previous literature demonstrated significant differences in hours of informal care between married clients and not-married clients (Kemper, 1992). Education was recorded into 9 categories but then recoded into a dichotomous variable 'schooling' and 'no schooling'. These two categories were chosen as a result of examining the mean hours of informal care for each of the original categories and observing that the 'no schooling' group received substantially higher hours of informal care.

Client physical/functional characteristics were IADL involvement scale, ADL hierarchy scale, cognitive performance scale, ability to understand others, client wandering, client resistance to care and diagnosis of dementia. The IADL involvement scale ranges from 0 to 21 and is a summation of the value for the items on self performance in meal preparation, ordinary housework, managing finances, managing medication, phone use, shopping and transportation. A higher score is interpreted as a more dependent client (interRAI, 2005). The ADL hierarchy scale ranges from 0 (independent) to 6 (total dependence) and is determined by the ADL self-performance score for personal hygiene, toileting, locomotion and eating (interRAI, 2005). The literature review revealed studies which demonstrated that hours of informal care and formal care increase with increasing ADL disability, emphasizing the importance of this variable in the regression model (Kemper, 1992). Cognitive performance scale (CPS) is based on whether the client is in a coma and 4 items from the MDS-HC: short-term memory, decision making, making self understood and eating. It ranges from 0 (intact) to 6 (very severe impairment) (Morris et al., 1994). Higher cognitive impairment has been shown to be associated with increasing hours of informal care (Kemper, 1992) confirming the suitability for including this variable in the model. 'Ability to understand others' was dichotomized into 'understands' and 'deficit in understanding others'. 'Wandering' and 'resists care' was dichotomized into being present or absent. Dementia (of any cause) was dichotomized into 'diagnosed' and 'not-diagnosed'.

There was only one variable under caregiver characteristics: whether the caregiver expresses feelings of distress, anger or depression. This was dichotomized into yes or no.

Client-caregiver dyad characteristics were (a) who client lived with, (b) number of caregivers living with client, and (c) relationship of primary caregiver with client. 'Who the client lived with' was a dichotomous variable of 'living alone or with a non-relative' and 'living with a relative'. The literature has shown that living alone decreases the probability of receiving informal care (Denton, 1997). Number of caregivers living with client could be 0, 1 or 2/more. For the regression it was treated as a continuous variable. The relationship of the primary caregiver with the client was recoded into 3 dummy variables. The three dummy variables compared a relationship of 'child or child-in-law', 'friend/neighbor' and 'other relative' to a reference group of 'spouse'.

Logistic Regression Models

Sequential (hierarchical) logistic regressions were used. In this type of logistic regression, the order in which the variables are entered into the model is controlled by the researcher. This method would demonstrate the variation accounted for by a variable *in addition to* what has already been explained by the previous variables in the model. The variables were entered in 5 sequential blocks. Table 1 show the sequence of the blocks in the regression model and also provides details of the coding of the covariates. The first block was client demographics and was entered first as we wished to remove the variance controlled by these variables. The second block was client physical/functional characteristics. This would demonstrate whether these characteristics had an additional effect on the variation of informal hours of care after controlling for client demographics (first block). The third block was caregiver characteristics and the fourth block was caregiver/client dyad characteristics. After the four blocks were entered in the regression, a fifth block representing the independent variable was entered. This fifth block consisted of 11 variables representing the 11 different formal services.

A significant model Chi-squared test and a non-significant Deviance chi-square test were indicators that the model was a good fit. The significance of the change in -2 log likelihood with the addition of each block was used to determine if the block made a significant contribution to the variation of the dependent variable. The increase in Nagelkerke R-squared and the percentage correctly classified were also indicators of the extent to which the block contributed to the variation in informal hours.

Individual variables were examined in the full model with all 5 blocks. A variable was considered to be a significantly associated with the dependent variable if the difference in the -2 log likelihood of a full model and a model missing the variable was significant in the likelihood ratio tests. These statistics were examined with the addition of each block to the model. If the significance of a variable disappeared with the addition of a new block, this suggests that the new block mediated the relationship between the variable and the hours of informal care (dependent variable). Significant odds ratios were also examined to determine the type of relationship between the independent variable (hours of formal care) and the dependent variable (hours of informal care). A significant odds ratio greater than one suggested a complementary relationship and an odds ratio smaller than one was taken as a substituting relationship. A P-value of less than or equal to .05 was considered significant.

Table 1

Covariates Used in the Logistic Regression Models

Variable	Coding
Client demographics	
Gender	Male = 1, female = 2
Age	NA (scale variable)
Marital status	Not married = 0, married = 1
Education	No schooling = 0, any schooling = 1
Client physical/functional characteristics	
IADL	Range: 0 to 21; higher score = greater dependence
ADL	Range: 0 to 6; higher score = greater dependence
CPS	Range: 0 to 6; higher score = greater impairment
Ability to understand others	Understands = 0, deficit in understanding = 1
Wandering	No = 0, yes = 1
Resists care	No = 0, yes = 1
Dementia (Alzheimer or other)	No = 0, yes = 1
Caregiver characteristic	
Caregiver expresses feelings of distress, anger or depression	No = 0, yes = 1
Client/caregiver dyad characteristics	
Who client lived with	Lives alone or with non-relatives = 0, lives with relatives = 1
No. of caregivers living with client	NA (scale variable)
Relationship of primary caregiver with client	3 dummy variables using a relationship of 'spouse' as a reference group.

Results

Demographics of Full Sample

The full sample consisted of 5,571 people. Almost 70% were female and there was a generally elderly population with an average age of 75.3 years with a standard deviation of 13.9 years. The sample was generally English speaking (86%) and only 1.5% was aboriginal. A predominance of female clients and elderly clients was also noted in a survey of clients in British Columbia in 1994/95 (Chappell et al., 1995). This survey also had a similar proportion of married clients to this study's sample but a smaller proportion of widowed clients.

Comparison of Clients With Informal Caregivers and Without Informal Caregivers

Our sample was made up of 263 clients without informal caregivers and 5308 clients with informal caregivers. These two groups were compared (see table 2). Clients with informal caregivers were significantly older in age, were more likely to be married and were more likely to live with relatives. There was no significant difference with respect to gender and education of the client. Clients without informal caregivers showed significantly better cognitive performance and had a higher ability to understand others. Clients without informal caregivers also had better (less dependent) IADL and ADL scores and were significantly less likely to have been diagnosed with stroke, congestive heart disease, Alzheimer's disease, dementia and Parkinsonism. Clients with informal caregivers stated lower levels of pain and were more likely to limit going outdoors due to fear of falling. There was no significant difference between clients with informal caregivers and those without with respect to vision, hearing adequately, making self understood depression rating scale, behavioral symptoms, prognosis and number of medications.

Table 2

Comparison of Clients with Caregivers and Clients without Caregivers.

Client Characteristics	Clients without caregivers	Clients with caregivers	P value (type of test)
Gender			
Male (%)	32.6	30.4	.468 (chi-squared)
Age (mean (sd))	71.10 (15.71)	75.48 (13.78)	.000*** (t-test)
Marital status			
Married	8.6	37.9	.000 ***(chi-square)
Not married	91.4	62.1	
Education			
None	1.7	2.7	.184 (Chi-square)
Primary/high	69.8	73.6	
Tertiary Education	28.4	23.7	
Lived with whom			
Alone or non-relatives	86.9	44.2	.000 ***(chi-squared)
Lived with relatives	13.1	55.8	
Cognitive performance scale (mean (s.d.))	.38 (.78)	.86 (1.31)	.000***(Mann-Whitney)
Communication/hearing			(Mann-Whitney U)
Hears adequately (%)	76	70.5	.098
Makes self understood (%)	89.7	85.6	.055
Understands others (%)	88.0	83.0	.032*
Vision			
Adequate vision (%)	75.1	72.0	.145 (Mann-Whitney U)
Depression rating scale	1.13 (2.20)	.95 (1.85)	..215 (t-test)
Behavioral symptoms (%yes)			(Mann-Whitney U)
Wandering	1.3	2.1	.374
Verbally abusive	4.7	3.2	.185
Physically abusive	0.0	0.6	.220

Socially abusive	1.3	1.1	.804
Resists care	2.6	4.3	.192
IADL (mean (sd))	5.24 (4.76)	10.86 (5.95)	.000*** (t-test)
ADL (mean (sd))	.26 (.88)	.66 (1.27)	.000*** (t-test)
Diagnosed disease (% no disease)			(chi-square)
Stroke	91.8	84.4	.007**
Congestive heart disease	95.3	88.2	.004**
Coronary artery disease	83.7	81.0	.363
Hypertension	63.9	62.0	.124
Alzheimer's	98.7	94.4	.013
Dementia (other than Alzheimer's)	99.1	93.1	.001**
Psychiatric diagnosis	87.1	90.3	.125
Cancer	89.3	87.9	.106
Diabetes	81.5	79.6	.578
Parkinsonism	99.6	96.3	.030*
Arthritis	56.2	56.0	.714
Hip fracture[a]	95.7	95.9	.982
Emphysema/copd/asthma	85.4	85.1	.647
Pain score (%) [b]			
0	27.2	35.9	.001**
1	13.4	13.8	(Mann-Whitney U)
2	34.9	33.9	
3	24.6	16.4	
Falls (%yes)			(chi-square)
Unsteady gait	44.2	49.3	.129
Limits outdoors due to fear of falls	28.3	39.4	.001**
Prognosis of < 6 months to live (%yes)	1.3	2.2	.351 (chi-square)
Number of medications (mean (sd))	5.38 (2.94)	5.70 (2.77)	.090 (t-test)

Note: Descriptive statistics are given as percentages unless indicated that it is given as a mean and standard deviation.

[a] The chi squared analysis for hip fracture had 1 cell with an expected count of less than 5.

[b] Pain score: A higher number means a more severe pain.

*p < .05. **p < .01. ***p < .001.

Clients with Caregivers: Descriptive Statistics

Of the total sample, 5,308 clients had caregivers. Of these clients, nearly three quarters had one caregiver living with them while 15% did not have any caregiver living with them (see table 3). Of the 5,299 primary caregivers, 46% were a child or child-in-law of the client and 32% were a spouse. There were 3,554 secondary caregivers. Of these, the majority (64%) was a child or child-in-law.

Table 3

Descriptive Statistics of Clients with Informal Caregivers.

Variable	Number	Percent
No. of caregivers living with client (N=5308):		
- 0	817	15.4
- 1	3881	73.1
- 2 or more	610	11.5
Relationship between primary caregiver and client (N=5299):		
- child or child-in-law	2427	45.8
- spouse	1717	32.4
- other relative	689	13
- friend/neighbour	466	8.8
Relationship between secondary caregiver and client (N= 3554):		
- child or child-in-law	2286	64.3
- spouse	98	2.8
- other relative	709	19.9
- friend/neighbour	461	13.0
Caregiver status (number and % yes):		

- caregiver is unable to continue in caring activities	433	8.2
- primary caregiver is not satisfied with support received from family and friends	160	3.0
- primary caregiver expresses feelings of distress, anger or depression	571	10.8

Of the clients with caregivers, 8% of the caregivers felt that they were unable to continue caring for the client, 3% were not satisfied with the support that they were receiving from family and friends and 11% expressed feelings of distress, anger and depression.

Total number of hours of informal caregiving ranged from 0 hours to 800 hours per week (this total may have included informal care from more than one caregiver explaining why the maximum value exceeds the number of hours in a week) with a mean of 18.9 hours per week, a median of 11 hours per week, and a standard deviation of 32.4 hours per week. The values were significantly skewed to the right (skewness = 10.504, standard error = .034) and was significantly leptokurtic (kurtosis = 197.27, standard error = .067) (see figure 5).

Using the more conservative value of 11 hours of informal caregiving per week, a client therefore utilizes 48 hours per month or 572 hours per year. Valued at the Ontario minimum wage of $7.75 (Canada Online, 2006), this equates to $372 per month or $4433 per year per client. The opportunity cost of informal caregiving can also be valued using replacement cost, which is the wage of a person paid to perform the task. In Canada, the average wage of a homemaker or housekeeper is $9.60 per hour (Service Canada, 2005). If informal caregiving time is valued using replacement cost, the cost of unpaid labor would increase to $461 per month or $5491 per year per client.

The total cost in Canada can be calculated using the average number of hours of informal care of 18.9 hours per week and the estimate of 1 million care-recipients in Canada in 2000

(Canadian Home Care Association, 2003). Assuming that this study provides a valid percentage of clients who have caregivers, the total unpaid labor costs of informal caregivers in Canada in 2000 would be calculated to be $7.3 billion CAN (using minimum wage) or $8.9 billion CAN (using replacement costs).

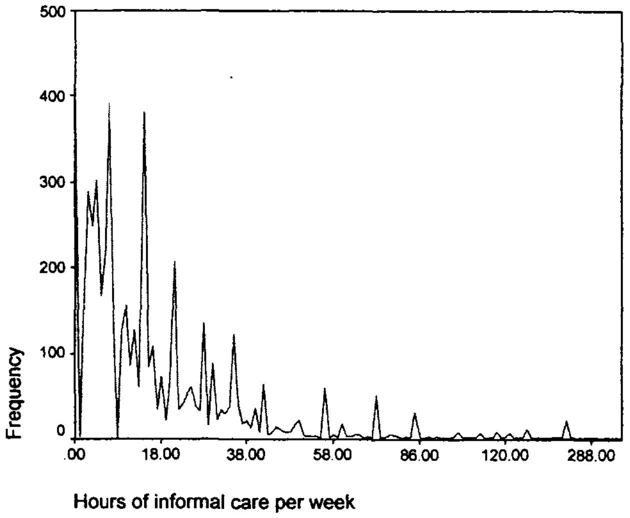


Figure 5. Frequency graph of hours of informal care received by the client per week.

Covariates in the Regression Model

Fifteen variables were chosen to be included in the regression model as covariates because of evidence in the literature and/or because of a high correlation ($r > .2$) with the dependent variable (hours of informal care received) and/or if they did not meet the exclusion criteria (redundant with another chosen variable, significantly skewed distribution, > 5% missing values). The univariate correlation coefficients between the 15 chosen variables were examined and demonstrated the absence of multicollinearity (see table 4).

Table 4
Spearman's Correlation Coefficients Between the Variables Included in the Regression Model.

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
1. Gender	—	.09	-.30*	-.02	-.17*	-.13*	-.10*	-.10*	-.06*	-.05*	-.05*	-.13*	-.20*	-.05*	.25*	.01	.04*
2. Age		—	-.21*	-.05*	.14*	.01	.14*	.13*	.03	.05*	.13*	.00	-.21*	-.08*	.30*	-.08*	-.01
3. Marital Status			—	.02	.23*	.13*	.06*	.04*	.06*	.05*	.09*	.15*	.62*	.20*	-.49*	-.26*	-.21*
4. Education				—	-.11*	-.06*	-.06*	-.03*	-.02	-.07*	-.01	-.01	-.08*	-.04*	-.05*	.01	.02
5. IADL					—	.57*	.47*	.35*	.17*	.21*	.32*	.25*	.36*	.17*	-.06*	-.10*	-.14*
6. ADL						—	.34*	.28*	.16*	.21*	.20*	.20*	.24*	.11*	-.09*	.00	-.07*
7. CPS							—	.52*	.24*	.27*	.51*	.23*	.17*	.09*	-.01	-.01	-.05*
8. Ability to understand others								—	.23*	.25*	.38*	.19*	.11*	.06*	-.02	-.01	-.03
9. Wandering									—	.24*	.31*	.16*	.07*	.03*	-.03*	-.03	-.01
10. Resists care										—	.26*	.23*	.09*	.06*	-.01	-.03*	-.01
11. Dementia											—	.21*	.12*	.04*	-.01	-.04*	-.05*
12. Caregiver expresses feelings of anger, distress or depression												—	.18*	.09*	-.08*	-.03*	-.08*
13. Who client lives with													—	.37*	-.32*	-.15*	-.21*
14. No. of caregivers living with client														—	-.03*	-.08*	-.17*
15. Caregiver is a child or child-in-law															—	-.36*	-.29*
16. Caregiver is an 'other relative'																—	-.12*
17. Caregiver is a friend or neighbour																	—

* $p < .05$.

Logistic Regression Results

Table 5

Results of the Logistic Regression Describing Each Block in the Regression Model

Block	N	model [a]	Block [b] (df)	Deviance [c]	R-square [d]	Classification [e]
1	5248	709.16	709.16 (20)	15935.50	.131	36.6
2	5232	2393.80	1362.69 (25)	14935.76	.381	44.7
3	5231	2438.28	48.42 (5)	14887.34	.387	44.6
4	5117	2834.23	749.47 (25)	14142.03	.441	46.0
5A[f]	5039	3065.61	508.92 (55)	13633.11	.473	47.1
5B[f]	5113	3041.92	221.18 (55)	13920.85	.46	47.1

[a] This is the chi-square statistic for the model which includes all the blocks up to this step. P values were all .000

[b] This is the difference in -2 log likelihood with the addition of this block. All values were significant at $p < .001$. df = degrees of freedom.

[c] All deviance chi-square values had a p-value of 1.000 demonstrating a good fit.

[d] Nagelkerke R-squared was used

[e] This is the percentage correctly classified.

[f] Block 5A is the independent variable: frequency of formal visits. Block 5B is the independent variable, hours of formal visits per week. The fifth block was either 5A or 5B in 2 separate regressions. They were not used in the same regression.

Table 5 details the statistics for each block of the regression model. The final models included 5039 and 5113 subjects making up 95% and 96% of the full sample respectively. Subjects were excluded if they had a missing value for any of the variables used in the regression. The full regression model had a good fit with a significant model chi-squared. With the addition of each block there was a significant change in the -2 log likelihood and the deviance was non-significant demonstrating that the addition of each block to the regression significantly improved the model. At each step, the Nagelkerke R-squared increased and the final models accounted for 47 and 46% of the variance of hours of informal care. The percentage correctly classified also increased with the addition of each block so that the final models correctly classified 47.1% of the sample.

Significance of Individual Variables

If the change in -2 log likelihood between the model and the model reduced by a variable is significant, the variable is a significant predictor of the dependent variable. These statistics of the likelihood ratio tests are shown in the table 6.

Table 6

Chi Square Statistic for the Likelihood Ratio Tests of Each Variable with the Addition of Each Block and for the Final Regression Models

Variable	Block 1	Block 2	Block 3	Block 4	Model 5A	Model 5B
Intercept	35.81*	11.39*	12.33	30.51	33.19	36.01
Gender	46.59*	11.60*	10.90	8.90	5.77	8.71
Age	20.19*	58.65*	56.90*	18.79*	18.10*	19.59*
Marital Status	494.66*	282.96*	268.02*	7.88	6.02	6.75
Education	30.78*	5.37	5.50	4.64	4.28	4.78
IADL[a]		775.01*	746.58*	557.69*	637.73*	584.86*
ADL[b]		98.90*	97.44*	86.31*	91.27*	101.55*
CPS[c]		9.28	7.90	6.42	6.18	7.76
Understanding[d]		6.82	7.00	6.99	6.50	5.93
Wandering		8.41	7.81	7.93	7.28	7.82
Resists care		7.05	7.80	7.38	7.98	7.67
Dementia		9.88	11.32*	9.17	9.03	8.60

Caregiver feelings[e]	45.37*	29.71*	19.41*	23.20*
Who lived with[f]		191.16*	135.68*	163.29*
No. lived with[g]		108.96*	84.34*	103.67*
Relationship: child[h]		32.96*	23.48*	26.28*
Relationship: other[i]		33.64*	24.66*	30.57*
Relationship: friend[j]		28.21*	21.85*	26.96*
Home Health Aides			35.51*	10.90
Visiting Nurses			10.02	2.83
Homemaking services			5.15	14.60*
Meals			116.04*	98.01*
Volunteer services			7.37	6.23
Physical Therapy			2.20	2.52
Occupational Therapy			34.58*	33.33*
Speech Therapy			4.68	6.85
Day care/hospital			21.38*	11.20*
Social worker			5.63	3.76
Respite Care			13.10*	11.88*

Note. The results refer to the regression model that includes the block and preceding blocks. The final regression models are Model 5A and Model 5B. Model 5A uses the frequency of the last 11 variables and Model 5B uses the hours of care of the last 11 variables. The chi-squared statistic is the difference between the -2 log likelihood of the final model and a model reduced by a variable.

[a]IADL involvement scale. [b]ADL Hierarchy scale. [c]Cognitive performance scale. [d]Ability to understand others. [e]Caregiver expresses feelings of distress, anger or depression. [f]Who client lived with. [g]No. of caregivers living with client. [h]Caregiver is a child or child-in-law of the client (dummy variable). [i]Caregiver is an 'other relative' of the client (dummy variable). [j]Caregiver is a friend or neighbour of the client (dummy variable).

* $p < .05$.

Client Demographics

Client gender was a significant predictor in models including the 1st and 2nd blocks. The Chi-square statistic of the likelihood ratio test decreased from 46.6 when the model included only the first block to 11.6 with the addition of the 2nd block suggesting that a large part of the association between gender and informal hours of care was mediated by client physical/functional characteristics. The significance of this variable disappears with the addition of the 3rd block of variables as the chi-square statistic of the likelihood ratio tests decreased from 11.6 to 10.9.

Client age was a significant predictor of informal hours with the full model including all 5 blocks. Some of the odds ratios were significant in model 5A (see table 7). The significant odds ratios ranged from 1.011 to 1.014. Although these odds ratios were significant, the importance of age as a predictor of informal care time was small as the odds ratios were very close to '1'.

Table 7

Odds Ratios of Client Age on the Hours of Informal Care.

Hours of informal care category	Odds Ratio when compared to 'no hours of informal care'	95% confidence interval
>20	1.00	0.99 to 1.01
16 to 20	1.00	0.99 to 1.01
11 to 15	1.01*	1.00 to 1.02
6 to 10	1.01*	1.01 to 1.02
0.5 to 5	1.01*	1.00 to 1.02

Note: Model 5A was used as this was the model with the lowest chi-square statistic in the likelihood ratio tests. Each odds ratio is a ratio of the odds of receiving a specific category of hours of informal care to the odds of receiving no hours of informal care for every increase of 1 in the age of the client in years.

* $p < .05$.

Marital status of the client was a significant predictor if the model only included up to block 3. The significance of this association disappeared with the inclusion of client/caregiver dyad characteristics; the chi-square statistic of likelihood ratio tests decreased from 268 to 7.9 with the addition of block 4. This suggests that block 4 acted as a mediator for the relationship between marital status and informal hours of care. This can be explained because people who are married are more likely to live with their spouse and more likely to have a spousal caregiver. As demonstrated later, spousal caregivers more likely to provide larger amounts of informal care time.

Education of the client was a significant predictor only if the first block was included in the regression. The significance of this variable disappeared with the addition of client physical/functional characteristics suggesting that these characteristics acted as a mediator for the relationship between education and informal care time.

Client Physical/Functional Characteristics

IADL score of the client was a significant predictor in the full regression model. For model 4 (the model with the lowest chi-square statistic in the likelihood ratio tests), the odds ratios were all significant. They ranged from 1.06 to 1.34 (see table 8). As the odds ratios were greater than one, the hours of informal care are greater with higher IADL disability.

The ADL score of the client was a significant predictor in the full regression model including all 5 blocks. In model 4 (the model with the lowest chi-square statistic in the likelihood ratio tests), the odds ratios ranged from 0.61 to 0.84 (see table 9). This suggests that with increasing ADL dependency, the hours of informal care decreases.

Table 8

Odds Ratios of the IADL Score of the Client on the Hours of Informal Care.

Hours of informal care category	Odds Ratio when compared to 'no hours of informal care'	95% confidence interval
>20	1.34*	1.30 to 1.39
16 to 20	1.22*	1.17 to 1.27
11 to 15	1.19*	1.15 to 1.22
6 to 10	1.13*	1.09 to 1.16
0.5 to 5	1.06*	1.03 to 1.09

Note: Model 4 was used as this was the model with the lowest chi-square statistic in the likelihood ratio tests. Each odds ratio is a ratio of the odds of receiving a specific category of hours of informal care to the odds of receiving no hours of informal care for every increase of 1 in the IADL involvement scale.

* $p < .05$.

Table 9

Odds Ratios of ADL Hierarchy score of the Client on Hours of Informal Care.

Hours of informal care category	Odds Ratio when compared to 'no hours of informal care'	95% confidence interval
>20	0.84*	0.74 to 0.96
16 to 20	0.70*	0.59 to 0.83
11 to 15	0.65*	0.56 to 0.75
6 to 10	0.61*	0.53 to 0.71
0.5 to 5	0.71*	0.61 to 0.81

Note: Model 4 was used as this was the model with the lowest chi-square statistic in the likelihood ratio tests. Each odds ratio is a ratio of the odds of receiving a specific category of hours of informal care to the odds of receiving no hours of informal care for every increase of 1 in the ADL Hierarchy scale.

* $p < .05$.

The cognitive performance scale, the client's ability to understand others, wandering, resisting care and dementia were not significant predictors of informal hours of care.

Caregiver Characteristics

Whether the caregiver expressed feelings of distress, anger or depression was a significant predictor of informal hours of care for the full models. Only the odds ratio comparing the probabilities of >20 hours of informal care to no hours of informal care was significant (see table 10) demonstrating that caregivers who feel distressed, angry or depressed are more likely to provide large hours of informal care (>20 hours).

Table 10

Odds Ratios of Whether the Caregiver Feels Distress, Anger or Depression on the Hours of Informal Care.

Hours of informal care category	Odds Ratio when compared to 'no hours of informal care'	95% confidence interval
>20	1.89*	1.06 to 3.35
16 to 20	1.75	0.91 to 3.36
11 to 15	1.51	0.83 to 2.74
6 to 10	1.10	0.61 to 2.01
0.5 to 5	0.88	0.47 to 1.64

Note: Model 5A was used as this was the model with the lowest chi-square statistic in the likelihood ratio tests. Each odds ratio is a ratio of the odds of receiving a specific category of hours of informal care to the odds of receiving no hours of informal care for when a caregiver feels distress, anger or depression compared to when the caregiver does not.

* $p < .05$.

Client/Caregiver Dyad Characteristics

Who the client lived with was a significant predictor of informal hours of care in the full model with all 5 blocks. The significant odds ratios were generally greater than 1 (see table 11) demonstrating that clients who live with relatives receive higher hours of informal care (11 or more hours). The odds ratio comparing ‘0.5 to 5 hours’ to ‘no hours’ of informal care was also significant but less than 1 suggesting that if a client lives with a relative they are less likely to get a small quantity of informal care (5 hours or less).

Table 11

Odds ratios for Who the Client Lives With on the Hours of Informal Care.

Hours of informal care category	Odds Ratio when compared to ‘no hours of informal care’	95% confidence interval
>20	2.99*	2.06 to 4.34
16 to 20	1.77*	1.12 to 2.80
11 to 15	2.46*	1.69 to 3.58
6 to 10	1.120	0.79 to 1.60
0.5 to 5	0.68*	0.48 to 0.97

Note: Model 5A was used as this was the model with the lowest chi-square statistic in the likelihood ratio tests. Each odds ratio is a ratio of the odds of receiving a specific category of hours of informal care to the odds of receiving no hours of informal care when comparing a client who lives with relatives to a client who lives alone or with non-relatives.

* $p < .05$.

The number of caregivers living with the client was also a significant predictor in the full model including all 5 blocks. The significant odds ratios were greater than 1 (see table 12) demonstrating that with increasing number of caregivers living with the client, the hours of informal care are higher.

Table 12

Odds Ratios of the Number of Caregivers who Lived with the Client on the Hours of Informal Care.

Hours of informal care category	Odds Ratio when compared to 'no hours of informal care'	95% confidence interval
>20	2.53*	1.92 to 3.33
16 to 20	1.92*	1.36 to 2.70
11 to 15	2.15*	1.63 to 2.83
6 to 10	2.12*	1.65 to 2.73
0.5 to 5	1.17	0.93 to 1.49

Note: Model 5A was used as this was the model with the lowest chi-square statistic in the likelihood ratio tests. Each odds ratio is a ratio of the odds of receiving a specific category of hours of informal care to the odds of receiving no hours of informal care for every increase of 1 caregiver living with the client.

* $p < .05$.

The type of the relationship between the caregiver and client was represented by three dummy variables. All 3 dummy variables were significant predictors of hours of informal care.

The first dummy variable, *'is the caregiver a child or child-in-law of the client?'* showed only one significant odds ratio of 0.57 (see table 13) and demonstrates that caregivers who are a child or child-in-law are less likely to provide large hours of informal care (>20 hours).

The second dummy variable '*Is the caregiver an 'other relative' to the client?*' (i.e. not a child, child-in-law or spouse) produced significant odds ratios that ranged from 0.28 to 0.53 demonstrating that 'other relatives' are less likely to provide large hours of informal care (11 hours or more).

The third dummy variable *'is the caregiver a friend or neighbor of the client?'* produced significant odds ratios that ranged from 0.36 to 0.47. This demonstrates that caregivers who are friends or neighbors are less likely to provide large hours of informal care (11 hours or greater)

As these three groups (child/child-in-law, other relative and friend/neighbour) were all less likely to provide large hours of informal care, we can determine that the reference group (spousal caregivers) was more likely to provide large hours of informal care.

Table 13

Odds Ratios for Dummy Variable for the Relationship between Caregivers and Clients on the Hours of Informal Care.

Hours of informal care category	Dummy Variables for relationship between caregiver and client (reference group = spousal relationship)		
	Child/child-in-law	Other relative	Friend/neighbor
>20	0.57*	0.48*	0.36*
16 to 20	0.54	0.28*	0.41*
11 to 15	0.71	0.53*	0.47*
6 to 10	0.99	0.71	0.73
0.5 to 5	1.38	1.15	1.08

Note: Model 5A was used as this was the model with the lowest chi-square statistic in the likelihood ratio tests. Each odds ratio is a ratio of the odds of receiving a specific category of hours of informal care to the odds of receiving no hours of informal care when comparing a client receives care from a child or child-in-law/other relative/friend or neighbor to a client who receives care from other types of relationships.

* $p < .05$.

Independent Variable: Frequency and Hours of Formal Services

The *frequency* of home health aide visits was a significant predictor of informal hours of care while the *hours* of home health aide visits was not. The odds ratios are shown in table 14 and demonstrate that as the frequency of home health aides visits increased, the hours of informal care decreased.

Table 14

Odds Ratios for the Days (Model 5A) and Hours (Model 5B) of Home Health Aides on the Hours of Informal Care. .

Hours of informal care	Odds Ratio when compared to 'no hours of informal care' (95% confidence interval)	
	Model 5A	Model 5B
>20	0.84* (0.78 to 0.91)	1.01 (0.98 to 1.04)
16 to 20	0.91* (0.84 to 1.00)	1.03 (0.99 to 1.06)
11 to 15	0.92* (0.85 to 0.99)	1.01 (0.98 to 1.04)
6 to 10	0.93 (0.87 to 1.00)	1.03 (1.00 to 1.06)
0.5 to 5	0.98 (0.92 to 1.05)	1.03 (1.00 to 1.06)

Note: Each odds ratio is a ratio of the odds of receiving a specific category of hours of informal care to the odds of receiving no hours of informal care for every increase of 1 (day or hour) in the quantity of home health aid service.

* $p < .05$.

The hours of homemaking services received was a significant predictor of hours of informal care but the frequency of homemaking services was not significant. The odds ratios shown in table 15 demonstrate that with higher hours of homemaking services, there was increasing hours of informal care. The odds ratios are only marginally greater than 1 suggesting that 'hours of homemaking services' is not a strong predictor.

Table 15

Odds Ratios for the Days (Model 5A) and Hours (Model 5B) of Homemaking Services on the Hours of Informal Care.

Hours of informal care	Odds Ratio when compared to 'no hours of informal care' (95% confidence interval)	
	Model 5A	Model 5B
>20	1.03 (0.96 to 1.12)	1.07* (1.02 to 1.13)
16 to 20	1.01 (0.92 to 1.11)	1.06* (1.01to 1.13)
11 to 15	1.07 (0.99 to 1.15)	1.09* (1.04 to 1.15)
6 to 10	1.05 (0.98 to 1.13)	1.08* (1.02 to 1.13)
0.5 to 5	1.01 (0.94 to 1.09)	1.06* (1.00 to 1.11)

Note: Each odds ratio is a ratio of the odds of receiving a specific category of hours of informal care to the odds of receiving no hours of informal care for every increase of 1 (day or hour) in the quantity of homemaking services.

* $p < .05$.

Both the frequency and hours of meals services were significant predictors of the hours of informal care. The odds ratios for the frequency of meals service were all significant and ranged from 0.71 to 0.94 (see table 16) suggesting that the more days that the client is visited by the meals service, the lower the hours of care provided by the informal caregiver. Only 3 of the 5 odds ratios for hours of meals service were significant. They were less than 1 suggesting that as hours of meals service increased, the hours of informal care decreased.

Table16

Odds Ratios for the Frequency (Model 5A) and Hours (Model 5B) of Meals service on the Hours of Informal Care.

Hours of informal care	Odds Ratio when compared to 'no hours of informal care' (95% confidence interval)	
	Model 5A	Model 5B
>20	0.71* (0.66 to 0.76)	0.86* (0.83 to 0.90)
16 to 20	0.81* (0.74 to 0.89)	0.94* (0.89 to 0.98)
11 to 15	0.78* (0.72 to 0.84)	0.91* (0.87 to 0.96)
6 to 10	0.85* (0.79 to 0.90)	0.97 (0.93 to 1.00)
.5 to 5	0.94* (0.88 to 1.00)	1.01 (0.97 to 1.04)

Note: Each odds ratio is a ratio of the odds of receiving a specific category of hours of informal care to the odds of receiving no hours of informal care for every increase of 1 (day or hour) in the quantity of meals service.

* $p < .05$.

Both the frequency and hours of occupational therapy were significant predictors of the dependent variable. The significant odds ratios were greater than 1 (see table 17) suggesting that as the number of days visited by the occupational therapist increased or as the hours of occupational therapy increased, the hours of informal care also increased.

Table 17

Odds Ratios for the Frequency (Model 5A) and Hours (Model 5B) of Occupational Therapy on the Hours of Informal Care.

Hours of informal care	Odds Ratio when compared to 'no hours of informal care' (95% confidence interval)	
	Model 5A	Model 5B
>20	1.74* (1.14 to 2.66)	1.62* (1.09 to 2.40)
16 to 20	1.38 (0.83 to 2.27)	1.39 (0.88 to 2.21)
11 to 15	1.47 (0.95 to 2.28)	1.47 (0.98 to 2.20)
6 to 10	1.65* (1.10 to 2.49)	1.58* (1.08 to 2.31)
0.5 to 5	0.74 (0.47 to 1.15)	0.76 (0.50 to 1.15)

Note: Each odds ratio is a ratio of the odds of receiving a specific category of hours of informal care to the odds of receiving no hours of informal care for every increase of 1 (day or hour) in the quantity of occupational therapy.

* $p < .05$.

Both the frequency of visits and the hours of day care/ day hospital were significant predictors of the hours of informal care. All the odds ratios for frequency of daycare/day hospital visits were significant and very large (see table 18). They ranged from 6.45 to 7.38 suggesting that the greater the number days the client attended a day care or day hospital, the larger the hours of informal care. Only two of the odds ratios for hours spent at a day care/ day hospital were significant and they were 1.28 and 1.31 suggesting that as the hours spent in day care or day hospital increased, the hours of informal care increased. These odds ratios are much smaller than those for the frequency of day care/day hospital visits demonstrating that the frequency of visits, rather than the hours of in day care or day hospital, has a greater impact on the hours of informal care.

Table 18

Odds Ratios for the Frequency of Visits to (Model 5A) and Hours Spent at (Model 5B) the Day Care or Day Hospital on the Hours of Informal Care.

Hours of informal care	Odds Ratio when compared to 'no hours of informal care' (95% confidence interval)	
	Model 5A	Model 5B
>20	7.38* (1.19 to 45.58)	1.28* (1.01 to 1.61)
16 to 20	8.90* (1.43 to 55.23)	1.31* (1.03 to 1.66)
11 to 15	6.45* (1.04 to 40.02)	1.25 (0.98 to 1.58)
6 to 10	6..07 (0.98 to 37.57)	1.21 (0.95 to 1.53)
0.5 to 5	6.50 (1.05 to 40.12)	1.25 (0.99 to 1.59)

Note: Each odds ratio is a ratio of the odds of receiving a specific category of hours of informal care to the odds of receiving no hours of informal care for every increase of 1 (day or hour) in the quantity of day care or day hospital.

* $p < .05$.

The variable for respite care was dichotomized into whether a client received respite care or not. The utilization of respite care was a significant predictor of hours of informal care. Although this variable was a significant predictor in both full models, the odds ratios were non-significant except for when comparing the odds of a client receiving '11 – 15 hours per week' of informal care to 'no hours' of care in the second regression model; odds ratio = 0.16 (see table 19). This suggests that the presence of respite care decreases the hours of informal care.

Table 19

Odds Ratios for the Whether the Client and Caregiver Receive Respite Care on the Hours of Informal Care.

Hours of informal care	Odds Ratio when compared to 'no hours of informal care' (95% confidence interval)	
	Model 5A	Model 5B
>20	1.57 (0.42 to 5.92)	0.71 (0.24 to 2.08)
16 to 20	1.49 (0.34 to 6.63)	0.66 (0.18 to 2.42)
11 to 15	0.33 (0.06 to 1.77)	0.16* (0.04 to 0.71)
6 to 10	0.83 (0.21 to 3.39)	0.42 (0.13 to 1.40)
0.5 to 5	0.39 (0.07 to 2.03)	0.30 (0.08 to 1.17)

Note: Each odds ratio is a ratio of the odds of receiving a specific category of hours of informal care to the odds of receiving no hours of informal care when comparing clients who received respite care to those who did not.

* $p < .05$.

Visiting nurses services, volunteer services, physical therapy, speech therapy and social worker at home were not significant predictors of hours of informal care.

The above results can be used to classify each of the 11 formal services into one of three types of service: substituting, complementary or no-relationship (see table 20).

Table 20

Classification of the Relationship Between Informal Care and Formal Home Care Service for 11 Types of Formal Care.

Formal service	**Type of service**
Home Health Aides	Substituting/no-relationship[a]
Visiting nurses	No-relationship
Homemaking services	No-relationship/Complementary[b]
Meals	Substituting
Volunteer services	No-relationship
Physical therapy	No-relationship
Occupational therapy	Complementary
Speech therapy	No-relationship
Day care or Day hospital	Complementary
Social worker in home	No-relationship
Respite Care	Substituting

[a] The frequency of home health aides visits had a substituting relationship with informal care while the hours of home health aides services had no-relationship with informal care.

[b] The frequency of homemaking services had no-relationship with informal care while the hours of homemaking services had a complementary relationship with informal care.

Discussion

The purpose of this study was to further the research on the relationship between formal and informal care in the home care system. A large data set collected during the Resident Assessment Instrument – Health Informatics Project (RAI-HIP) was used for this research. This data set included individuals with and without caregivers who received home care. Preliminary analyses showed that home care clients with informal caregivers showed some significant differences to those without informal caregivers. Clients with informal caregivers were older, more likely to be married, more likely to live with relatives, showed poorer cognitive, IADL and ADL function, suffered from less pain and were more likely to be diagnosed with stroke, coronary heart disease, Dementia and Parkinsonism. Only subjects with caregivers were included for further analyses.

The average number of hours of informal caregiving time received by a client with a caregiver was 18.9 hours per week with a median of 11 hours per week. Using the more conservative value of 11 hours per week, a client therefore utilized 48 hours per month or 572 hours per year. The opportunity costs of informal caregiving was $4433 per client per year (using minimum wage) and $5491 per client per year (using replacement costs). The statistics demonstrate that there are substantial unpaid labor costs on the individual caregivers and that these costs should be included in economic evaluations of home care. The full economic cost would be even greater as we have not considered out-of-pocket costs and employment costs.

The total cost of informal caregiving in Canada in 2000 was calculated to be approximately $7.3 billion (using minimum wage) and $8.9 billion (using replacement costs). These costs are larger that that calculated by Fast and Frederick (1999). This increase may be secondary to a higher wages, an aging population or increase in informal caregiving from 1995 to 2000. Such large numbers demonstrate the impact of these costs on society. Such high costs also demonstrate the importance of considering informal caregiver opportunity costs in economic evaluations of home care.

Individuals with caregivers were included in the regression analyses. The regressions were performed with a dependent variable of 'Hours of informal care' and independent variables of 'frequency of formal care' and 'hours of formal care' while attempting to control client demographics, client physical/functional characteristics, caregiver characteristics and caregiver/client dyad characteristics. The results of these regressions were used to classify the relationship between each formal service and informal care as substituting, complementary or no-relationship.

Among the covariates added to the regression model, seven variables were noted to be significant determinants of informal care hours.

Age was a significant determinant of informal caregiving hours with an odds ratio of 1.01. Although this is not substantially different from '1', this relationship is supported by work by Wimo et al. (2002).

With increasing IADL dependency, there was greater use of informal care but with increasing ADL dependency, there was less use of informal care. These relationships are only partially consistent with previous research. Li (2005) also concluded that IADL disability and informal care hours had a positive relationship but, contrary to what we found, concluded that informal care hours also increased with increasing ADL disability. Kemper (1992) demonstrated that increasing informal care was associated with increasing ADL dependency, which is also different from our results. Li (2005) concluded that informal care increased with cognitive dysfunction and Wimo et al. (2002) noted increases of informal care time with increasing behavioral disturbances. Our study found no significant relationship with cognition, wandering, resisting care, the ability to understand others or a diagnosis of dementia.

Caregivers who felt distress, anger or depression were more likely to provide very large amounts of informal care (> 20 hours). Clients with co-resident caregivers or caregivers who are spouses, and clients with a larger number of persons living with them receive significantly more hours of informal care. These significant factors were also demonstrated in research by Fast, Eales, & Keating (2001).

Substituting Home Care Services

Home health aides, meals service and respite care demonstrated a substituting relationship with informal caregiving. This is consistent with the original hypotheses. Home health aides and meals service provide services that may have been performed by informal caregivers reducing the time required to complete these tasks. Respite care is designed to provide caregivers time away from their caregiving duties which explains the substituting relationship. The home health aides also demonstrated a mixed relationship with informal hours of care: the greater the number of days the home health aide visited per week then the lower the hours of informal care, but no significant relationship existed between the hours of home health aides services and hours of informal care. Home health aides perform personal tasks such as hygiene and transferring that are only required for a relatively short period of time everyday but is usually performed daily. Therefore short daily visits rather than the large number of hours on one day per week has a greater impact on reducing informal caregiving hours.

Complementary Home Care Services

Homemaking services, occupational therapy and day care/day hospital showed complementary relationships with informal care as the hours of informal care increased with increasing utilization of these services. This is not consistent with our original hypothesis.

Homemaking services was originally hypothesized to reduce the time of informal caregiving by reducing the time spent on these tasks by informal caregivers. Instead hours of informal care increase with increasing utilization of homemaking services. It should be noted that the odds ratios were only marginally greater than 1 suggesting that the complementary effect may not be important in practice. As homemaking services perform the tasks such as cleaning and shopping that fall on informal caregivers, it is unexpected that this relationship should be complementary. Perhaps informal caregivers feel they need to supervise homemaking health professionals or perhaps the informal caregiver feels obligated to help the home care employee due to feelings of guilt and obligation to their loved one. More research is required to explain this unexpected relationship and to perhaps determine if homemaking services actually benefit the caregiver and/or the care-recipient.

Occupational therapy may involve teaching techniques and exercises that need to be practiced regularly when the therapist is not present. A caregiver may aid the client in performing these exercises thereby increasing the informal caregiving time.

Day care and day hospital is a service supplied by a multidisciplinary team for more complex patients which require collaboration from different types of health professionals. Patients referred to a day hospital may also require management of psychosocial issues. Some day hospitals require informal caregivers to attend some sessions with the care-recipient and sessions may only run for half a day. The complexity and the social issues of the client as well as the demands on the informal caregiver's time by the day hospital may explain the complementary relationship demonstrated between day care/day hospital and informal caregiving time. The frequency of visits has a greater affect on the hours of informal caregiving than the actual amount of time spent at the day care/day hospital. Perhaps transporting the client to and from the day care/day hospital location is a substantial demand on the caregiver's time. Further research is required to explain this relationship.

Home Care Services with No Relationship

Speech therapy and physical therapy had no association with the hours of informal care. Speech and physical therapists perform tasks that cannot be carried out by an informal caregiver explaining the lack of relationship. Occupational therapy is similar in that it also performs specialized tasks but instead it demonstrates a complementary relationship with informal caregiving time. This suggests that speech therapy and physical therapy are services that apply more to the client as an individual rather than occupational therapy which applies to the client's functioning in the home and therefore requires informal caregiver involvement.

Social work tasks may or may not replace tasks originally performed by the caregiver but the lack of an association suggests that either the caregivers do not perform such tasks or there may be specialization of informal care where the caregiver switches his/her efforts to other caregiving areas (Tennstedt et al., 1993).

Volunteer services perform similar tasks as an informal caregiver and this formal service was expected to reduce the time spent by the informal caregiver. The lack of relationship demonstrated in this study suggests either a supplementation model or a specialization of informal care. In a supplementary relationship, the volunteer services supplemented the informal care when the needs of the client exceeded the resources of the informal caregiver (Edelman & Hughes, 1990). The volunteer service then met that additional need but the hours spent on informal caregiving did not change. Specialization of informal care existed if the volunteer replaced duties performed by the informal caregiver but the informal caregiver then switched efforts to another type of caregiving task (Tennstedt et al. 1993).

Visiting nurses had no-relationship with informal care. Nurses generally perform tasks that are specialized and not performed by the caregiver. It was hypothesized that nurses enabled caregiver to perform some of these tasks thereby increasing the hours of informal care, but the lack of a relationship suggests that perhaps this does not occur.

Recommendations

The findings of this study may be relevant and important at many levels. The information may be useful to the work of case managers, home care service providers, CCACs, home care planners and policy developers and to provincial and federal levels of government.

Recommendations for Case Managers

Case management involves the organization of home care services for an individual based on their functional, physical and social needs. Case management would also evaluate the demands on the informal caregiver and the extent to which they can provide care. Recognizing that services such as respite care, home health aids and meals services reduce the informal caregiving time allows the case manager to arrange these services for informal caregivers that are approaching their maximum caregiving threshold. If complementary services such as occupational therapy or day hospital are considered beneficial to the individual, then substituting services should be arranged in order to counter-balance the increase demands on the informal caregiver's time. Home Health Aides should be arranged as shorter and more frequent visits rather than long less-frequent visits as it has a greater impact on reducing the demands on the caregiver.

Recommendations for Home Care Service Providers

Home Care Service Providers can use this information in order to ensure that there as many, or even more, substituting services available as there are complementary services. As the substituting services reduces the time burden that complementary service produces on the informal caregiver, these two types of services can be 'linked' together. Therefore arrangement of a complementary service should automatically lead to a substituting service being offered. Day hospitals have a substantial impact on informal caregiving time and the planned implementation of a day hospital should consider linking the day hospital program with home health aides, respite care and meals services within the same physical location. Day hospital services should also be offered for full day sessions instead of half day sessions as it reduces the time burden on the informal caregiver.

Recommendations for Home Care Planners

Home care planners are present at the local, provincial and federal level and one of their objectives would be to ensure that the demand for home care meets the supply. Recognition of the different types of home care services and that some are substituting and some are complementary towards informal caregivers allows planners to ensure that there is a balance between these two types of services. Planning ahead should ensure that there is adequate respite care, home health aides and meals services to counteract the complementary effect of occupational services and day hospital.

Recommendations for Health Policy Developers

The results of this study can be used to develop health policy which recognizes the demands on the informal caregiving time. The large opportunity costs calculated from this study justify the need for a national home care program that is covered by the Canada Health Act and therefore reduces the individual burden on the informal caregiver.

Policy can also be developed at the local level to ensure that complementary services are automatically linked with substituting services and therefore preventing an excessive burden on the informal caregiver.

Recommendations for Health Resource Allocation and Health Care Funding

Health care expenditure is of growing concern in Canada and many other countries. Home Care can add to the cost of health care and may require judicious health resource allocation. The results from this study can be used as evidence to justify a distribution of resources and funding which ensures that more funding is available for home health aides, respite care and meals services as they may be required to counteract the complementary effect of occupational therapy and day hospital. Health care funding planners also need to be aware that by linking complementary services with substituting services, there would be additional demands on total home care costs.

Further Research

Further research is required to gain a better understanding of why the relationships between the services are complementary, substituting or have no relationship. Research is particularly required to determine why homemaking services is associated with higher informal caregiving times, why occupational therapy is complementary and why the frequency of day hospital visits have such a substantial impact on informal caregiving time.

This research question would be better evaluated with a longitudinal study to demonstrate the effect that home care services have informal caregiving time rather than the association between these 2 variables.

Limitations

This was a cross-sectional study and therefore only capable of demonstrating associations and not causations. Although every effort was made to ensure a representative sample of the CCAC clientele, there is not assurance that the sample used was representative. This study only included clients with caregivers and therefore the results and conclusions are not applicable to the entire home care population. Data collection was performed by personnel trained in the data collection tool but was dependent on the information provided by clients, caregivers and health professionals. The recall method was used to determine caregiving time which reduces the accuracy of the information. The validity of the informal hours was also weakened as it would have been difficult to accurately determine informal care hours because it is often mixed in with the time spent on normal household duties. The logistic regression model did not include caregiver demographics (age, ethnicity, education, marital status and employment status), caregiver support (other caregivers, financial) or distance between the client and caregiver which may be determinants of hours of informal care. Researches on the determinants of caregiving time have shown that gender, age, ethnicity and marital status have significant correlations with caregiving time. A study of 898 American caregivers in 1990 used regression analysis to show that whites provided less caregiving time compared to blacks and females provided more caregiving time compared to males (Martin, 2000). A similar study of 5924 people residing in Chicago also supported this relationship between race and caregiving time but found no statistical difference in caregiving time between men and women (McCann, Hebert, Beckett, Morris, Scherr & Evans, 2000). McCann et al. also demonstrated that caregiving time increased with age for married caregivers. The conceptual framework was a source of weakness of this study as the analyses was based on the assumption that formal service effects informal care, but in reality this relationship may exist in the other direction or may exist in both directions.

This study used quantitative measures of hours and days. It did not consider the effect of services on quality of life of the caregiver, satisfaction of the caregiver or burden felt by the caregiver. A service may show no effect on the informal hours of care, but this does not necessarily mean that the service did not benefit the caregiver by improving quality of life or reducing burden. The change or lack of change of the hours of informal caregiving should not be equated with caregiver quality of life, caregiver level of satisfaction or caregiver burden.

This study solely examined the effect of each type of service on the informal caregiver. This should not reduce the importance and value of the service to the client.

Conclusion

The relationship between quantity of formal home care services and the quantity of informal caregiving varies with the type of formal care. Home health aides, meals and respite care have a substituting relationship with informal caregiving time; as the quantity of these services increase, the informal caregiving time decreases. Homemaking services, occupational therapy, day care or day hospitals have a complementary relationship with informal caregiving time; as the quantity of these services increase, the informal caregiving time also increases. Visiting nurses, volunteer services, physical therapy, speech therapy and social work have no association with the hours of informal caregiving.

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