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The Contributions of Non-kin Informal Caregivers

By

Tracey Anne LaPierre



**A thesis submitted to the Faculty of Graduate Studies and Research in partial
fulfillment of the requirements for the degree of Master of Science**

in

Family Ecology and Practice

Department of Human Ecology

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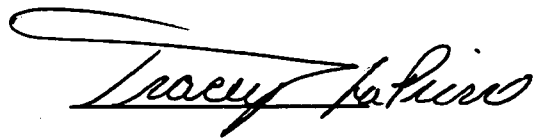
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The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled **The Contributions of Non-kin Informal Caregivers** here submitted by **Tracey Anne LaPierre** in partial fulfillment of the requirements for the degree of **Master of Science in Family Ecology and Practice**


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Dedicated to:

All Non-kin Informal Caregivers

ABSTRACT

The purpose of this research project was to examine the contributions of non-kin caregivers to determine whether non-kin make a substantial contribution to the long term informal care of the frail elderly. This examination included a comparison of non-kin caregivers and various family caregivers, and a comparison of the two largest sub-groups of non-kin caregivers, friends and neighbours. Competing hypotheses regarding the potential role of non-kin in long-term informal caregiving were drawn from exchange theory and symbolic interaction theory. Findings partially support the symbolic interaction perspective that the personal meaning attached to non-kin relationships allows for substantial caregiving relationships to develop. However, the contributions of non-kin are not homogeneous. Friend and neighbour informal caregivers differ in the types of tasks with which they assist and the total amount of time spent caregiving. This can also be attributed to differences in personal meaning attached to friend and neighbour relationships.

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CHAPTER ONE

INTRODUCTION

“Informal care is rooted not in commitment to tasks but in attachment to persons; it is a property of relationships, not of jobs; its dispositional base is involvement with other people, not the conscientious performance of a role” (Bulmer, 1986, p. 4).

Background of Inquiry

The Canadian population is aging due to increased longevity and decreased fertility rates (Statistics Canada, 1997). Although seniors are currently healthier on average than they have been in the past, most have at least one chronic condition (Statistics Canada, 1999a). Seniors 85 years of age and over report the most serious health problems and frequently experience physical and mental limitations which leave them in a dependent state that requires care (Forbes, 1998; Statistics Canada, 1999b). This age group is also the fastest growing segment of the senior population (Statistics Canada, 1999b). The result is a growing need for care among the senior population (Fast, Keating, Oakes & Williamson, 1997).

This increasing need for care is occurring during a time of decreasing health and continuing care resources (Anderson, Parent, Nishihama & Mueller, 1999; Fast, Forbes & Keating, 1999; Fast, Keating, Oakes & Williamson, 1997). Reduction in the length of hospital stays, limits placed on institutionalization and other formal services, and cut-backs to home care, are placing higher care demands on informal caregivers (Anderson, Parent, Nishihama & Mueller, 1999; Canadian Home Care

Association, 1998; Harlton, Keating & Fast, 1998; Health Canada, 1999). Estimates of the proportion of care provided to frail seniors by family, friends and neighbours range from 70% (Lesemann & Martin, 1993; National Advisory Council on Aging [NACA], 1999) to over 90% (Angus, Auer, Cloutier & Albert, 1995).

If current trends continue, there will be pressure on the informal sector to further increase the amount of care provided (Canadian Home Care Association, 1998; Harlton, Keating & Fast, 1998; Health Canada, 1999). However, the high personal costs experienced by informal caregivers, the increased labor force participation and attachment of Canadian women, changes in immigration and migration patterns, and declining family size are limiting factors in the informal sector's ability to increase levels of care to the elderly (Fast, Keating, Oakes & Williamson, 1997; Fast, Williamson & Keating, 1999; Fast & Skrypnek, 1994; NACA, 1999; Vanier Institute of the Family, 1994). As a result, the sustainability of the informal caregiving network is a growing concern (NACA, 1999), and elder care has become one of the most central policy issues in our aging society (Beland & Shapiro, 1995; Chappel, 1993; McDaniel & Gee, 1993).

There is a growing need to develop initiatives in order to sustain the informal caregiving network. The personal costs experienced by informal caregivers need to be reduced and a call for policies and programs which support informal caregivers has been issued (Greene & Coleman, 1995; NACA, 1999). A problem exists, however, in that before programs and policies can be developed to support and sustain members of the informal caregiving sector, there must be a more complete understanding of their contributions and consequences. This will insure that policies and programs will

be made available to all of those who need them, and that these programs can be designed to target the specific needs of various groups of informal caregivers.

Family, friends and neighbors are frequently cited as important sources of informal support for the elderly (Kemper, 1992; Novak, 1995; Wenger, 1997). However, those who conduct research on informal caregiving often exclude friend and neighbour caregivers, choosing to focus on specific kin relationships (Nocon & Pearson, 2000). Caregivers such as spouses and adult children are better understood than non-kin (Barnes, Given & Given, 1992), despite the fact that approximately 20% of all informal caregivers to the frail elderly in Canada are providing care to non-kin (Fast, Forbes & Keating, 1999; Keating et. al., 1999; LaPierre, Keating, Fast & Forbes, 1999).

The preoccupation with family caregivers and corresponding neglect of non-kin caregivers produces a climate in which the care provided by friends and neighbours is not acknowledged or supported. As a result, non-kin caregivers have become the invisible caregivers of the 21st century (Barker & Mitteness, 1990). When non-kin are included in survey samples, this category often is excluded from the analysis, not reported separately, treated as adjuncts to more central research interests, or placed in a residual category such as “other” which has no conceptual meaning (Campbell, Bruhm & Lilley, 1998; Chappel & Litkenhaus, 1995; Fast, Forbes & Keating, 1999; Peters, 1982). This tendency has left us with a large gap in the caregiving literature.

Another problem regarding non-kin caregivers is that a consistent categorization of non-kin is absent from caregiving research. Although it is generally

understood that non-kin are any individuals not related by blood or marriage, this definition can describe a number of different relationships. Some studies use a non-kin category to describe friends and neighbours (National Health and Welfare, 1993), while other studies have included other non-kin such as co-workers and same-sex partners in the non-kin category (Fast, Forbes & Keating, 1999).

Given the differences in the social norms and expectations surrounding various non-kin relationships (Bulmer, 1986; Fischer, 1977; Hess, 1972; 1979) differences in the caregiving contributions and consequences may also exist. The tendency to group all non-kin together may be resulting in a distorted picture of non-kin caregivers (Peters, 1982) by clouding the unique contributions and consequences of particular groups within the non-kin category. In order to acquire meaningful information it is necessary to “move beyond categorizing all non-kin as friends and begin distinguishing among neighbors, casual acquaintances, and more intimate relationships” (Crohan & Antonucci, 1989, p. 143).

Purpose of Study

The purpose of this research project was to examine the contributions of non-kin caregivers to determine whether non-kin make a substantial contribution to the long term informal care of the frail elderly. This examination included a comparison of non-kin caregivers and various family caregivers, and a comparison of the two largest sub-groups of non-kin caregivers; friends and neighbours.

Justification for Study

With increasing need for support from the informal sector anticipated in the future, the sustainability of caregiving from this sector is a growing concern. A few government and employment policies and programs have been implemented to support informal caregivers (Fast, Keating & Eales, 2000; Friedman, 1986). However, most programs are unavailable to the majority of caregivers, and certain categories of caregivers, such as non-kin, are at particular risk for being excluded from support (Fast, Keating & Eales, 2000; Greene & Coleman, 1995; Neal, Ingersoll-Dayton & Starrels, 1997). For example, the Caregiver Tax Credit is only available to co-resident caregivers, who are a child, grandchild, brother, sister, niece, nephew, parent, grandparent (including in-laws), aunt or uncle of the care recipient (Fast, Keating & Eales, 2000).

There are contradictory assumptions regarding the importance of the contributions of non-kin to the informal care of frail seniors. Some authors argue that the types of care non-kin caregivers provide are less important than the tasks family members provide, that their level of involvement is minimal, and that they cannot be relied upon to provide care for extended periods of time (Allan, 1986; 1988; Cantor, 1979; Penrod, Kane, Kane & Finch, 1995). Other researchers argue that non-kin make a substantial contribution to the informal care of frail seniors, and that the support they provide is drastically underestimated and unacknowledged (Adams, 1986; Armstrong & Goldsteen, 1990; Barker & Mittness, 1990; Young, Seale & Bury,

1998). The paucity of research about non-kin caregivers means that empirical data are severely lacking and that these contradictory assumptions remain unresolved.

Given that informal caregivers provide the majority of care to frail seniors, that non-kin comprise a substantial minority of the informal caregiving network (Fast, Forbes & Keating, 1999), and that contributions from non-kin are expected to play a more central role in the caregiving network in the future (Himes & Reidy, 2000; NACA, 1999), it is useful to know more about them. As well, considering the potential for differences in the contributions and consequences between various sub-groups of the non-kin category it is essential that these sub-groups be examined separately.

CHAPTER 2

THEORETICAL FRAMEWORKS AND LITERATURE REVIEW

In this chapter, the two theoretical frameworks used to understand the contributions on non-kin informal caregivers are outlined. Relevant literature, which either supports or refutes the assumptions of these two theories is reviewed. A rationale for determining what is substantial caregiving also is developed. Finally, the potential for differences between friend and neighbour caregivers is discussed and current research findings regarding friends and neighbours and their caregiving activities reviewed.

Understanding the Contributions of Non-kin Informal Caregivers

The contributions and importance of non-kin to the informal caregiving network are poorly understood and contradictory assumptions regarding the importance of the role they may play are prevalent. In the absence of much empirical evidence two theories were used in this study to explore possible levels of involvement of non-kin in informal caregiving. These theories are exchange theory and symbolic interaction theory.

Assumptions from an exchange perspective lead to the hypothesis that non-kin will not be substantial informal care providers to the frail elderly, because the voluntary and balanced nature of non-kin relationships would not tolerate unequal exchanges for extended periods of time. In contrast, from a symbolic interaction

perspective, the personal meaning attached to non-kin relationships might be very conducive to a substantial informal caregiving relationship. This theory would lead to the hypothesis that non-kin will be substantial informal care providers to the frail elderly.

The contrasting assumptions from exchange theory and symbolic interaction theory regarding the informal care of frail seniors by non-kin are important because they provide competing frameworks from which to view the role of non-kin in the informal caregiving network. A closer examination of exchange theory and symbolic interaction theory and a review of related literature highlight the assumptions about non-kin caregivers which have led to the hypotheses that were tested in this project.

Exchange Theory

Exchange relationships are influenced by orientations and rules that prescribe acceptable and appropriate behavior. Especially important are the effects of normative orientations on exchange patterns, which reflect societal views on acceptable and appropriate behavior in relationships (Ikkink & van Tilburg, 1998). Differences in how relationships are developed and maintained are reflected in norms surrounding role expectations, which are prescribed culturally and legally (Sabatelli & Shehan, 1993).

Family members are highly obligated to provide informal care to frail seniors (Brackman, 1995). Strong norms of filial obligation are believed to influence the commitment family members have to relationships, even when exchanges are unbalanced. In contrast, non-kin relationships are seen as ephemeral, voluntary and

lacking normative beliefs obligating them to provide instrumental support and personal care (Allan, 1986; 1988; Barker & Mitteness, 1990; Johnson, 1988; Koyano, Hashimoto, Fukawa, Shibata & Gunji, 1994; Penrod, Kane, Kane & Finch, 1995). From this perspective it seems unlikely that non-kin would be substantial informal care providers to frail seniors because of the lack of normative beliefs obligating them to provide this care.

An assumption of exchange theorists is that individuals will attempt to maintain distributive justice in their exchange relationships. Distributive justice occurs when rewards are proportional to costs and profits are proportional to investments (Homans, 1961). However, distributive justice is mediated by the norm of fairness, which Blau (1964) describes as the degree of proportionality expected in a relationship. Determining the degree of fairness experienced in a relationship is a subjective experience and can vary among individuals, across different types of relationships and over time (Roberto, 1989). Western cultures characterize non-kin relationships as egalitarian and equitable in nature (Armstrong & Goldsteen, 1990) and expectations of a balanced exchange of support exist (Allan, 1986). Thus, it is believed that non-kin relationships are not suited to the organization of instrumental exchanges among older people, who may not be able to give as much instrumental support as they need to receive.

Expectations are very important in evaluating whether a relationship conforms to the norm of fairness. Societal norms, socialization, and experiences within relationships all influence the degree to which deviations from egalitarian exchanges will be tolerated. When individuals involved in a relationship think that the

exchanges are not meeting their expectations and that the norm of fairness is being violated, they will either try to elicit increased rewards from the other party or they will reduce or cease their own investments in the relationship (Ikkink & van Tilburg, 1998; Sabatelli & Shehan, 1993). From this perspective it is assumed that unbalanced non-kin relationships will be terminated (Kendig, 1986). Therefore, it is unlikely that non-kin will maintain caregiving relationships when the costs of the relationship become high in comparison to the rewards.

Another important norm which influences exchange relationships is the norm of reciprocity. Reciprocity has to do with the mutuality of exchanges and carries with it expectations regarding when and how investments should be repaid (Ikkink & van Tilburg, 1998; Sabatelli & Shehan, 1993). Researchers have found that some individuals are aware of the reciprocal nature of their commitment, explaining their relationships as based on earlier kindness received or the provision of mutual support (Wenger, 1990). With regard to when investments should be repaid, non-kin may be expected to repay investments in a shorter time frame than family members (Ikkink & van Tilburg, 1998). It is assumed that long-term investments in non-kin relationships are risky because these relationships can be terminated easily.

Commitment refers to a person's willingness to participate in a relationship over a prolonged period of time (Leik & Leik, 1977; Rosenblatt, 1977; Rusbult, 1980; Scanzoni, 1979). Family relationships often are perceived as involving more commitment than non-kin relationships (Allan, 1986). When there is perceived commitment to a relationship, strict economic exchange principles that require

immediate and direct reciprocity can be relaxed and an exchange strategy that involves consideration of future rewards often is adopted (Leik & Leik, 1977).

Wenger (1990) found that in non-kin relationships where asymmetrical needs exist or where long-term support is required, reciprocity was difficult to maintain. When the reciprocal nature of non-kin relationships is impaired, does not exist, or where the returns no longer justify the demands, the relationships become strained and often break down, resulting in the loss of support. In old age, the most common reason for this breakdown is the development of heavy or escalating needs for instrumental help (Wenger, 1990).

Symbolic Interaction Theory

According to symbolic interaction theory, individuals act toward things on the basis of the personal meanings that these things have for them. These meanings are developed through the process of interaction and are not static, but can change over time (LaRossa & Reites, 1993). "All types of support are exchanged within specific relationships, and the nature of the relationship between the support provider and recipient may be significant in shaping its meaning and impact" (Cauce & Srebnik, 1990, pp. 609-10). Indeed, those who do caregiving research have noted some important differences in the types of tasks performed and the frequency of their performance by individuals of different relationships (Fast, Forbes & Keating, 1999; Neal, Ingersoll-Dayton & Starrels, 1997). Differences in the level of 'intimacy' and the 'relevance to daily life' of various caregiving relationships also have been noted (Cauce & Srebnik, 1990). It is likely that the types of tasks performed and the amount

of time spent caregiving will vary based on the personal meaning of the relationship between the caregiver and the care receiver.

Identities refer to self-meanings in a role (La Rossa & Reites, 1993). The more meaning that is attached to a particular role or aspect of a role, the more salient it becomes to the identity of that individual. The more salient it becomes the more motivated an individual will be to perform and excel in role related behaviours (McCall & Simmons, 1978). Hess (1972) argues that during times of relative 'rolelessness', where roles derived from occupational or familial status become depleted, the role of friend takes on increased importance and becomes central to the definition of self. Empirical research by Roberto and Kimboko (1989) supports this claim. They found that when the seniors in their study were asked if friends had become more important in their lives as they have grown older, the majority of respondents said yes. Those respondents who reported that friends had not become more important said that friends always had been important, or that they now had less opportunity to be with friends. Reasons stated for the increased importance of friends included the increased time available to spend with friends, that friends kept them from getting lonely and provided someone to talk to, and that friends took the place of the spouse or other family members who no longer lived near by or who had died (Roberto & Kimboko, 1989). It is possible then that, as people age, friendships become more important and increased personal meaning attached to these relationships may provide a suitable climate for a substantial caregiving relationship.

Although symbolic interactionists recognize the important influence of shared norms they also recognize that role behaviour may contain both stable and dynamic

aspects, which are negotiated within individual contexts and interactions (Antonucci & Akiyama, 1987; LaRossa & Reites, 1993). The stable and dynamic aspects of role behaviors are reflected in two related concepts: role taking and role making (Turner, 1962). Role-taking involves identifying social norms and expectations and conforming one's behaviours to them. Role-making, on the other hand, refers to the creation and modification of role behaviours based on the current context (LaRossa & Reites, 1993). One may take on the role of friend but, through interactions, that role is made into something that makes sense given the current context. Thus, social norms influence role behaviour only to the extent that an individual finds these social norms meaningful within a specific context or interaction. For example, social norms may discourage substantial informal caregiving by non-kin, but in the absence of family members to provide needed care, friends and neighbours may take on a substantial caregiving role.

A Rationale for Assessing Whether Caregiving Contributions Are Substantial

The theories and empirical findings reviewed here provide contradictory assumptions and evidence regarding the contributions of non-kin to the long term care of frail seniors. From an exchange theory perspective, it would be expected that the contributions of non-kin would be minimal. In contrast, the symbolic interaction perspective would predict that some non-kin contributions are likely to be substantial.

A challenge in testing these hypotheses is that there are no criteria in the eldercare literature for measuring whether or not the informal care provided by an

individual or group of individuals, is substantial. In this section of the thesis 1) primary caregiver status; 2) caregiving which directly contributes to the independence of seniors; 3) caregiving that has value because it results in a potential savings to the public sector or provides care that may otherwise not be provided; and 4) caregiving that is reliable and consistent over long periods of time despite consequences, are presented as indicators of substantial caregiving.

Primary Caregiver Status

Primary caregivers are recognized as providing the largest amounts of informal care to frail seniors and are the first line of defense when a new problem arises for the senior (Penrod, Kane, Kane & Finch, 1995; Tennstedt, McKinlay & Sullivan, 1989). Some policies and programs designed to assist informal caregivers are restricted to a single individual, the primary caregiver, and cannot be shared among two or more caregivers in the informal caregiving network (Fast, Keating & Eales, 2000). Primary caregiver status may therefore be viewed as an indicator of a caregiver making a substantial contribution to the informal care of frail seniors. Non-kin are more likely to be secondary caregivers than primary caregivers (Penrod, Kane, Kane & Finch, 1995; Tennstedt, McKinlay & Sullivan, 1989). Given that primary caregivers do more care than do secondary caregivers, a reasonable indication of substantial contributions on the part of non-kin caregivers would be that they are just as likely as various family caregivers to say that they are primary caregivers, or they represent a larger portion of primary caregivers than various subgroups of family caregivers.

Substantial Care Directly Contributes to the Independence of Seniors

The most important component of the quality of life for seniors is their independence (NACA, 1990). Remaining in their own homes is an important aspect of independence. It allows seniors to retain a greater level of self-sufficiency and control, and makes it easier for them to maintain valued social contacts. This reduces stress and provides peace of mind to seniors. "In addition, by continuing to live in the same neighbourhood and cultural milieu, seniors retain a sense of security and of belonging that helps them feel socially integrated, despite disabilities" (NACA, 1995, pp. 9-10). For frail seniors, living independently can be difficult or impossible without some form of support, and care that is provided at home is generally favoured over institutionalization or hospitalization (Anderson, Parent, Nishihama & Mueller, 1999; Ferrara, 1990). Thus, care that allows seniors to maintain their independence and age in place can be viewed as substantial because of the impact that it has on the quality of life of seniors.

Informal caregiving tasks include emotional support, social support, personal care, meal preparation, housekeeping, household maintenance and repair, household adaptations, shopping for goods, transportation, management of financial affairs and care management (Novak, 1995). However, these tasks are not equally important to the maintenance of seniors' independence. Although emotional support is the most universal caregiving task (Horowitz, 1985), and socialization is an important component of informal caregiving (Novak, 1995), these activities are not viewed as directly contributing to the independence of seniors (Anderson, Parent, Nishihama &

Mueller, 1999; Keating, Fast, Oakes & Harlton, 1996) and are therefore seen as less substantial care tasks.

Family members provide emotional support and socialization to their frail senior relatives (Baines, Evans & Neysmith, 1992; Horowitz, 1985), but it is their contributions to caregiving tasks such as personal care, meal preparation, housekeeping, household maintenance and repair, shopping, transportation, bills and banking and care management, that are viewed as important because they directly contribute to the independence of seniors and are the main focus of eldercare research and policy (Keating, Fast, Oakes & Harlton, 1996).

Empirical evidence suggests that non-kin also provide assistance across a wide range of substantial caregiving tasks, but the proportion of non-kin caregivers doing each task is smaller than the proportion of most family caregiver relationship categories (Fast, Forbes & Keating, 1999). However, the question of what proportion of caregivers assisting with each task are non-kin has not been asked. It is believed that the role of non-kin in the informal caregiving network is mainly one of providing emotional support and socialization (Matt & Dean, 1993; Rawlins, 1992). If this is the case, their contributions to the informal care of frail seniors could be viewed as less substantial than that of family caregivers. Providing similar or higher levels of assistance with personal care, bills and banking, household maintenance and repair, housekeeping, meals, shopping or transportation than spouses, adult children, adult children in-law, grandchildren or extended family will be indicators of substantial contributions to the independence of seniors for this study.

Substantial Care has Value

Providing care to seniors in their own homes is valued because of the potential savings to the public sector (Medjuck, O'Brien & Tozer, 1992; Parker, 1990). Care provided by informal caregivers usually is unpaid. Given the current climate of fiscal restraint, caregiving that potentially reduces public sector costs could also be viewed as substantial. The amount of care provided is important because the more care provided informally, the greater the potential savings to the public. However, in order for a potential savings to the public to occur it would have to be assumed that the same number of hours provided informally would be replaced by public formal services. This is an idealistic assumption considering that home care and other formal services are currently experiencing cutbacks (Hollander, 1994; Wilkins & Park, 1998). This makes the value of the care provided informally even greater because without it many seniors may not receive the level of care that they need or desire. The amount of time spent caregiving, and the number of workers it would take to replace non-kin caregiving contributions will be used to measure the value and intensity of informal caregiving contributions. The amount of time spent caregiving by non-kin will be compared with the amount of time spent by various subgroups of family caregivers. Providing as much care, or more, than family caregivers will be evidence of substantial caregiving by non-kin. The number of workers it would take to replace non-kin caregivers will be used to put the contributions of non-kin at the population level into perspective.

Substantial Care to Frail Seniors is Reliable and Consistent Despite

Consequences

Exchange theorists would argue that if non-kin attempt to provide informal care for extended periods of time, the high costs of informal caregiving would result in an unbalanced and non-reciprocal relationship that will be terminated. As a result it is believed that non-kin will contribute to the care of frail seniors for short periods of time, such as during emergencies or temporarily difficult times (Allan, 1986; Litwak & Szelenyi, 1969), and that the nature of the relationship is not conducive to the provision of long term informal care. If care is provided only temporarily, when long term care is required the termination of the caregiving relationship may jeopardize the senior's independence and result in potentially high costs to the public, the senior, and other members of the support network. Providing assistance with one of the instrumental or personal care tasks mentioned previously for a lengthy period of time¹ could be seen as an indicator of reliable and consistent long-term caregiving.

From a symbolic interaction perspective, if the relationship is highly valued, meaningful support will continue for extended periods of time despite personal consequences. Informal family caregivers are recognized as maintaining their support over long periods of time, despite the high personal costs involved in providing care to frail seniors. Personal costs to informal caregivers are numerous and include social, physical, emotional and employment costs, as well as out-of pocket expenses and unpaid labour (Fast, Keating, Oakes & Williamson, 1997). Close non-kin

¹ It is reasonable to assume that after 6 months any temporary arrangement for care would have been replaced with a more permanent arrangement. Therefore, anyone provided care for 6 months or longer can be viewed as a long-term caregiver.

relationships that are highly valued and meaningful also may continue to provide reliable and consistent support despite high personal costs. Socio-economic consequences, emotional burden consequences and employment consequences are all indicators of high personal costs. Thus, providing long-term care to frail seniors despite consequences is an indicator of substantial caregiving.

In summary, there are a number of criteria that can be used to indicate substantial caregiving. Primary caregiver status, the types of tasks being done, the amount of care being provided, and caregiver reliability despite high personal costs, were used for this study. Evidence of substantial caregiving by non-kin comes from contributions in these areas. To put the contributions of non-kin informal caregivers into perspective their contributions will be compared to those of family caregivers, whose contributions are better understood and more widely recognized. However, not all family relationships are considered equal when considering informal caregiving. Spouses, adult children and adult children in-law are viewed as the main informal caregivers based on a hierarchy of obligation that is believed to exist within the family (Qureshi, 1990). While all other family members are usually grouped into one category (extended or other family) (Jani-Le Bris, 1993; Penrod, Kane, Kane & Finch, 1995; Qureshi, 1990; Qureshi & Walker, 1989), the position of grandchildren can be viewed as unique.

Most intergenerational relations occur vertically in the family structure, between grandparents, children and grandchildren (Bultena, 1968; Chappel, Strain & Blandford, 1986). These three vertical generations are often included in descriptions of one's close or immediate family (Finch, 1989). Grandparents have been shown to

provide babysitting, day care, co-parenting, and full-time parenting to their grandchildren (Fuller, Minkler & Driver, 1997; Pebley & Rudkin, 1999; Solomon, 1998). These interactions provide an opportunity to build strong, personally meaningful relationships that in many cases resemble parent-child relationships.

Grandchildren are also provided with many opportunities to help care for their grandparents when their parents are actively involved in providing informal care (Dellmann, Blankemeyer & Pinkard, 2000), or when they live in the same household as their grandparent (Tennstedt, Crawford & McKinlay, 1993). This assistance may arise out of a sense of obligation or desire to help their grandparent and/or a sense of obligation or desire to help out their parent by easing their (the parent's) caregiving burden (Piercy, 1998; Qureshi, 1996). Due to the interlocking nature of support structures across three generations there are stronger norms and expectations obligating grandchildren to provide informal care than there are for other extended family relationships (Finch, 1989; New York State Office for the Aging, 1993; Piercy, 1998; Pipher, 1999).

Discriminating Between Friend and Neighbour Informal Caregivers

Due to the differences in the development and maintenance of friend and neighbour relationships, and the social norms ascribed to them, the non-kin sector may be diverse in important ways. However, the majority of researchers have not distinguished between friends and neighbours as support providers (Crohan & Antonucci, 1989; Young, Seale & Bury, 1998). Friendship in Western cultures is

described as voluntary, informal, personal and private (Jerrome, 1991) and has been distinguished from other interpersonal relationships, such as neighbours and kin, by its basis in free choice and mutual attraction (Allan, 1986; Staler, MacEntee & Hill, 1993; Wenger, 1990). Neighbours often are described as people who live near one another. Researchers agree that an essential and key attribute of a neighbour is proximity (Bulmer, 1986).

Both exchange and symbolic interaction theories can provide clear conceptual rationale for why non-kin relationships should be examined separately. The roles, expectations, norms and personal meaning generally differ between friend and neighbour relationships (Bulmer, 1986; Fischer, 1977; Hess, 1972; 1979), and subsequently may influence caregiving patterns. For example, the maintenance of social distance and the respect for privacy are very important aspects of neighbour relationships (Bulmer, 1986), which limit the degree of intimacy and closeness that can be obtained. In contrast to neighbour relationships, friends are important later-life sources of moral and emotional support, companionship and affection (Armstrong & Goldsteen, 1990; Cantor, 1979; Roberto & Kimboko, 1989; Wenger, 1990).

The tendency of researchers to group many different types of relationships into the non-kin category may have resulted in a distorted picture of non-kin caregivers (Peters, 1982). Meaningful differences may exist in whether or not different subgroups of the non-kin category provide substantial care due to differences in roles, expectations, norms and personal meaning which differentiate friend and neighbour relationships. This leads to the hypothesis that differences will exist between friend and neighbour informal caregivers (the two largest non-kin subgroups) in the types of

tasks and amount of care provided, and the reliability of the caregiving relationship over time.

Differences in the Types of Tasks Performed by Friend and Neighbour

Caregivers

When limitations due to health problems occur, friends often provide instrumental support (Armstrong & Goldsteen, 1990; Cantor, 1979; Roberto & Kimboko, 1989; Wenger, 1990). Studies reporting on caregiving tasks exchanged between female friends indicate a variety of aid being given and received. Types of instrumental support noted include transportation, shopping, bill paying, donations of fresh produce and cooked food, sewing and mending, repair of home appliances, and yard work (Armstrong & Goldsteen, 1990). Especially for older and less mobile women, friends often are valued providers of mail and newspapers, garbage handling and general pick up and delivery needs (Armstrong & Goldsteen, 1990; Wenger, 1990). Support between male friends is less evident in the literature, although there are examples of cross-sex support especially among those who are widowed. Widowed men offer practical help and widowed women offer baked goods or do some shopping (Roberto & Kimboko, 1989; Wenger, 1990).

Due to proximity, and the awareness of other people's lives, which results from proximity, neighbours play an important role in the lives of the elderly. Wenger (1990) argues that neighbours tend to know a lot about each other due to close proximity. Because of this, the needs of the elderly are likely to be known or recognized first by neighbours. If the mail is not collected, sidewalks are not cleared

or someone calls out for help, it is a neighbour who is most likely the first to recognize that something is wrong and respond.

As people age, they tend to have increasingly positive attitudes towards their neighbours (Wenger, 1990). "Social relations between neighbours are a significant form of social exchange. In addition to sociable contact, neighbours may provide tangible assistance for each other in the form of tasks performed or services rendered" (Bulmer, 1986, p. 3). Younger, retired neighbours often take on the role of good neighbour and perform instrumental tasks. Common forms of neighbour help include monitoring, shopping, errands, and household maintenance (Wenger, 1990). Neighbour relationships can become increasingly important to the elderly when there is a decrease in mobility (Jayakody, 1993).

Help, friendliness and the maintenance of social distance are very important characteristics of neighbour relationships, but for many individuals the importance of privacy is a key element of their neighbour relationships (Bulmer, 1986; Wenger, 1990). As a result, it may be that certain types of caregiving assistance, such as personal care, would be deemed inappropriate from neighbours because receipt of such assistance would violate these norms, whereas the personal nature of friendships may allow for this type of assistance.

Differences in the Amount of Care Provided by Friend and Neighbour

Caregivers

Symbolic interactionists might look to the personal meaning attached to relationships to predict the amount of care provided by non-kin. Research on

informal support shows that emotional closeness is positively correlated with the amount of support exchanged (Antonucci & Akiyama, 1987; Wellman & Wortley, 1990) and the degree to which perceived equity influences relationship satisfaction (Roberto & Scott, 1986). Friends are important later-life sources of moral and emotional support, companionship and affection (Armstrong & Goldsteen, 1990; Cantor, 1979; Roberto & Kimboko, 1989; Wenger, 1990). Some friendships become so close that they become pseudo-kin or fictive kin relationships (Chatters, Taylor & Jackson, 1986; MacRae, 1992; Young, Seale & Bury, 1998). In particular, long-term friendships are characterized by delayed reciprocity and often approach kinship in terms of non-contingent assistance (Jerrome, 1990).

Due to the social norms of distance and privacy ascribed to neighbour relationships, it is possible that the personal meaning attached to neighbour relationships would be less than the personal meaning attached to friendships. This, in turn, could influence the caregiving relationship, resulting in friends providing more hours of care than neighbours. However, neighbours are ideal to help on a daily basis because of their geographic proximity (Litwak & Szelenyi, 1969; Litwak, Messeri & Silverstein, 1990; Litwak, Jessop & Moulton, 1994; Petchers & Milligan, 1987; Wenger, 1990), and it is the tasks that must be completed on a daily basis which are the most time consuming. Studies from various European countries have also found that neighbours are a more frequent source of help than friends (van Tilburg, 1995; Wenger, 1993). It is unclear then, whether friends or neighbours would provide more hours of support.

Differences Between Friend and Neighbour Caregivers in the Reliability of Care Despite Consequences

According to exchange theorists, when a relationship becomes too costly (in terms of outcomes versus investment) and alternative relationships are available which may provide outcomes which exceed those in the current relationship, there is an increased likelihood that a person will leave a relationship (Thibaut & Kelley, 1959). Yet when maintaining a relationship is costly, and more profitable alternatives exist, internal and external 'barriers' can emerge which contribute to dependence and make the cost of dissolving the relationship even greater than maintaining it (Levinger, 1974; 1982).

An example of an internal barrier for caregivers is the feeling of obligation to the other party that fosters the feeling that the care receiver is dependent on the caregiver and increases the psychological costs if the relationship were terminated. External barriers can include primary group affiliations, community pressures, legal pressures, and material-economic considerations that contribute to dependence by increasing the social and/or economic cost of terminating the relationship. Therefore, "with greater levels of both private and public identification with a relationship come greater internal and external pressures to maintain the relationship" (Sabatelli & Shehan, 1993, p.401).

Neighbour relationships are less freely chosen than friendships and become more costly to terminate due to close proximity and shared locality (Allan, 1986; Kendig, 1986; Wellman & Wortley, 1990; Wenger, 1990). This close proximity and shared locality has led neighbours to be more closely associated with kin relationships than friend relationships (O'Connor, 1992). Empirical research from Japan has shown that

neighbours are more dependable than friends for certain tasks (Koyano, Hashimoto, Fukawa, Shibata & Gunji, 1994).

Therefore, from an exchange perspective one could argue that neighbours are more likely to provide care for longer periods of time and at greater personal cost than friends, making them more reliable care providers. From a symbolic interaction perspective one could counter that it is the personal meaning attached to these relationships which make them reliable, and with greater personal meaning comes greater commitment and more reliable care over extended periods of time. If friendships have more personal meaning than neighbour relationships then friendships will be a more reliable source of long-term informal care.

If the assumptions from exchange theory are correct then neighbours would be more likely than friends to provide assistance with tasks that directly contribute to the independence of seniors, provide greater amounts of care than friends, and be more reliable sources of care despite personal consequences. From a symbolic interaction perspective the reverse would be true. However, it is important to note that both theories assume meaningful differences between friends and neighbours.

CHAPTER 3

METHODS

In the previous chapter two competing theories that can be used to explain the contributions of non-kin caregivers were reviewed and a rationale was developed for determining whether or not their contributions are substantial. The potential for differences between friend and neighbour caregivers, also was discussed.

Assumptions from exchange theory, symbolic interaction theory, and a review of caregiving literature have led to two hypotheses that were tested in this project. The purpose of this chapter is to present these research hypotheses and outline how they were tested.

Hypotheses

The first research hypothesis is:

H₀: Non-kin will provide substantial amounts of informal care to the frail elderly.

H_a: Non-kin will not provide substantial amounts of informal care to the frail elderly.

As discussed in the previous chapter there was no criterion in the eldercare literature for measuring whether or not the informal care provided by an individual or group of individuals is substantial. For this research project, being a primary caregiver, assisting with tasks that directly contribute to seniors' independence, spending significant amounts of time doing these tasks, and providing reliable long

term care despite consequences were considered evidence of substantial caregiving. Since kin already are recognized as being substantial informal care providers, comparisons were made between non-kin and various kin groups to determine how non-kin compare.

The second research hypothesis is:

H₀: Differences exist between friend and neighbour informal caregivers in the type and amount of care provided and the reliability of that care.

H_a: Differences do not exist between friend and neighbour informal caregivers in the type and amount of care provided and the reliability of that care.

Friend and neighbour caregivers also were compared by looking at primary caregiver status, the types of tasks being done, the amount of care provided and the reliability of the care provided despite consequences, to determine if there were any meaningful differences between these two groups.

Source of Data

The Statistics Canada *1996 General Social Survey (GSS), Cycle 11: Social and Community Support* was the source of data used for this research study. The objectives of the GSS are: “to gather data on social trends in order to monitor temporal changes in the living conditions and well-being of Canadians; and to provide immediate information on specific social policy issues of current or emerging

interest” (Statistics Canada, 1998, p. 5). The GSS is conducted every two years with the core content changing to monitor current social trends. The core content for the 11th cycle of the GSS was social support. Questions were asked to determine the nature of the help received and provided; to understand the dynamic between an individual’s social network and help received and provided; and to identify unmet needs and the reasons for the needs (Statistics Canada, 1998).

Survey and Sample Design

Data for the 1996 General Social Survey were collected between February 1996 and December 1996. The majority of respondents were selected using the Elimination of Non-Working Banks technique of Random Digit Dialing (RDD). Seniors were over-sampled, thereby obtaining even more reliable estimates from this group. Due to over-sampling and other issues influencing estimation the data in this sample were weighted to obtain more accurate population estimates (Statistics Canada, 1998).

All respondents were contacted by telephone and data were collected by Computer Assisted Telephone Interviewing (CATI) using Computer-Assisted Survey Execution System software (CASES). Responses were obtained from 12,756 respondents, representing an 85.3% response rate. The target population for the GSS was all persons 15 years of age and over residing in Canada, however, residents of the Yukon and Northwest Territories, and full-time residents of institutions were excluded. Households without telephones were also excluded from the survey. These

households account for less than 2% of the total Canadian population (Statistics Canada, 1998), which may bias the sample slightly towards higher income groups who are more likely to have telephones in their homes (Statistics Canada, 1999c).

Sample

For this study, a sample of long-term informal caregivers to the frail elderly was selected. To be included in this sample the respondent had to be a family member, friend or neighbour providing assistance with personal care, bills and banking, household maintenance and repair, housekeeping, meal preparation and clean up, shopping or transportation to a senior over the age of 65 with a long term-health problem or disability for a minimum of six months. This resulted in a sample size of 1154. The second hypothesis further restricted this sample to friend and neighbour caregivers, resulting in a sub-sample size of 210.

Operational Definition of Variables

Dependent Variables:

The same dependent variables were used to test both hypothesis one and hypothesis two.

Primary Caregiver Status:

There was one dependent variable used to measure primary caregiver status:

Primary Caregiver – This variable indicates whether or not the caregiver was the primary caregiver for the care recipient in the 12 months preceding the survey (0=No, 1=Yes).

Types of Tasks:

There were seven dependent variables used in this study to measure the types of care tasks performed by informal caregivers:

Personal Care, Bills & Banking, Household Maintenance & Repair, Housekeeping, Meals, Shopping, Transportation - These variables indicate whether assistance with a particular task was provided by the caregiver to the care receiver in the 12 months preceding the survey (0=No, 1=Yes).

Amount of Care:

There were eight dependent variables in this study used to measure the amount of care provided:

Time Spent on Personal Care, Time Spent on Bills & Banking, Time Spent on Household Maintenance & Repair, Time Spent on Housework, Time Spent on Meals, Time Spent on Shopping, Time Spent on Transportation - These variables measure the number of hours per week spent on a particular tasks by the caregiver for the care receiver in the 12 months preceding the survey. Averages were calculated based on responses from caregivers who provided assistance with these tasks².

² These calculations provide evidence of the magnitude of the contributions of those actually doing each task. However, because of the elimination of individuals who did not provide assistance, calculations cannot be taken as evidence of the contributions of an entire caregiving group.

Total Time Spent Caregiving – This variable measures the number of hours per week spent on all tasks by the caregiver for the care receiver in the 12 months preceding the survey.

Reliability of Care Despite Consequences:

There were six dependent variables used to measure reliability of care despite consequences³:

Socioeconomic Consequences – This variable indicates whether the respondent experienced any socioeconomic consequences in the 12 months preceding the survey as a direct result of her/his caregiving activities. Socioeconomic consequences include incurring extra expenses, changing social activities, changing holiday plans, changing sleep patterns and having one's health affected. If the respondent did not experience any of these consequences the response was coded as 0. If she/he experienced one or more of these consequences the response was coded as 1. (0= No, socioeconomic consequences were not experienced, 1= Yes, socioeconomic consequences were experienced).

Burden Consequences – This variable indicates whether or not the respondent experienced any burden consequences in the 12 months preceding the survey as a direct result of her/his caregiving activities. Burden consequences include feeling burdened, having no time for one's self, feeling stressed, feeling angry, and wishing someone else would take over your caregiving responsibilities. If the respondent did

³ Factor analysis of questions related to caregiving consequences in the 1996 general social survey was conducted by Keating and colleagues (1999). The results of that factor analysis were used to create the three consequence groupings used in this study.

not experience any of these consequences the response was coded as 0. If she/he experienced one or more of these consequences the response was coded as 1. (0= No, burden consequences were not experienced, 1= Yes, burden consequences were experienced).

Job Adjustment Consequences⁴ – This variable indicates whether or not the respondent experienced any job adjustment consequences in the 12 months preceding the survey as a result of her/his caregiving activities. Job adjustment consequences include coming late or leaving work early, missing a day or more of work, changing hours of work, and having job performance affected. If the respondent did not experience any of these consequences the response was coded as 0. If she/he experienced one or more of these consequences the response was coded as 1. (0= No, job adjustment consequences were not experienced, 1= Yes, job adjustment consequences were experienced).

Socioeconomic Consequences Index⁵ – This variable indicates the number of socioeconomic consequences experienced. Socioeconomic consequences are: incurring extra expenses, changing social activities, changing holiday plans, changing sleep patterns and having one's health affected. This variable was coded from 1 to 5 depending on the number of socioeconomic consequences experienced.

Burden Consequences Index⁶ – This variable indicates the number of burden consequences experienced. Burden consequences are: feeling burdened, having no time for one's self, feeling stressed, feeling angry, and wishing someone else would

4 This variable was calculated only for employed caregivers.

5 This variable was calculated only for respondents who experienced one or more socioeconomic consequences.

6 This variable was calculated only for respondents who experienced one or more burden consequences.

take over your caregiving responsibilities. This variable was coded from 1 to 5 depending on the number of burden consequences experienced.

Job Adjustment Consequences Index⁷ – This variable indicates the number of job adjustment consequences experienced. Job adjustment consequences are: coming late or leaving work early, missing a day or more of work, changing hours of work, and having job performance affected. This variable was coded from 1 to 4 depending on the number of job adjustment consequences experienced.

Independent Variables

There was one independent variable of interest for each research hypothesis in this study. The independent variable for the first hypothesis is:

Relationship – The relationship of the caregiver to the care receiver was indicated as spouse (husband, wife), adult child (son or daughter), adult child-in law (spouse of son or daughter), grandchild, extended family⁸ (sibling/sibling-in-law, niece, nephew, uncle, aunt & cousin), and non-kin (friend or neighbour).

The independent variable for the second hypothesis is:

Non-kin Relationship – The non-kin relationship of the caregiver to the care receiver was indicated as friend or neighbour⁹.

⁷ This variable was calculated only for employed respondents who experienced one or more job adjustment consequences.

⁸ While there may be differences in the norms, expectations and personal meaning surrounding these various family relationships placed within the extended family category they are generally understood as being more distant relationships than spouses, children, children in-law and grandchildren. In addition, sample sizes are too small to compare their contributions to non-kin without combining them into a single category.

⁹ Respondents were asked to indicate their relationship to the caregiver from a list of kin and non-kin relationships. Role theory would suggest that when asked to identify the relationship and a choice must be made between friend and neighbour, that an individual will choose the relationship that is most salient.

Statistical Methods

The analysis for both research hypotheses involved cross tabulations, Pearson chi-square tests and one way analysis of variance (ANOVA). Statistics Canada (1998) recommends that only weighted results be released due to the over- and under-sampling of certain populations. For this project all analysis were weighted to be representative of the population.

Cross tabulations display variables in rows and columns and allows for the identification of relationships among the cross tabulated variables. Pearson chi-square tests were used to test for significant relationships among the cross tabulated variables. This measure is based on comparing the frequencies that would be expected if there was no relationship between the variables, to the observed frequencies in the sample.

There are two assumptions underlying the use of chi-square tests: 1) the sample is randomly selected; and 2) the expected frequencies are not small (StatSoft, 2000). It is recommended that the chi-square test not be used if 20% or more of the cells have expected frequencies of less than 5. Otherwise the observed significance level based on the chi-square distribution may not be correct (Norusis, 1991). Statistics Canada (1998) recommends that estimates calculated based on a cell size of less than 15 not be released. Confidentiality of respondent data and reliability of research findings are reasons for such guidelines. Therefore for this research project a minimum unweighted cell size of 15 was required.

One way analysis of variance (ANOVA) is based on a comparison of the variance due to the between-group variability with the within-group variability. If there are no differences between groups in the population the variance estimated based on within-group variability should be about the same as the variance due to between group variability. The F test tells provides an indication of whether these two estimates of variance are significantly different, indicating a significant difference in means (StatSoft, 2000). However, when doing multiple comparisons involving the same means the more comparisons that are made the more likely it is that results will indicate significant differences when there are none (SPSS, 1994). In order to be more confident that any significant differences found are valid differences, the Bonferroni post hoc test was used to adjust the observed significance level based on the number of comparisons being made.

For one way analysis of variance it is assumed that the groups being compared are independent of each other (SPSS, 1994). Homogeneity of variances between groups also is assumed, however Lindman (1974) shows that the F statistic is quite robust against violations of this assumption. The dependent variable is assumed to be measured on at least an interval scale level and normally distributed between groups (StatSoft, 2000). Overall, the F test is remarkably robust to deviations from normality (Lindman, 1974) and the skewness of the distribution usually has a minor effect on the F statistic (StatSoft, 2000).

Analyses

The analysis for hypothesis one and hypothesis two were very similar. The main difference was the independent variable being used. Both research hypotheses were focused on four different measures of substantial caregiving: primary caregiver status, types of tasks performed, amount of time spent caregiving, and reliability of care despite personal consequences.

Primary Caregiver Status

Primary caregivers are recognized as being substantial caregivers and are often the focus of research, policy and programs. If non-kin caregivers are more likely or as likely as other caregivers to be primary caregivers, or if they make up as large a proportion, or larger of primary caregivers than other relationships this can be viewed as evidence of substantial caregiving. For both research hypotheses, a cross tabulation of primary caregiver status by relationship was created and within group and between group proportions were analyzed. Pearson chi-square tests were used to determine if there were statistically significant differences between relationships.

Types of Care Tasks Performed

The importance placed on assistance with particular tasks varies depending on whether or not the task directly contributes to the independence of seniors. Tasks that are seen as contributing directly to the independence of seniors were included in this analysis. These tasks were personal care, bills & banking, household maintenance &

repair, housekeeping, meals, shopping and transportation. For both hypothesis one and hypothesis two, cross-tabulations of relationship by task were created and within group and between group proportions were analyzed. Pearson chi-square tests were used to determine if there were statistically significant differences between relationships. If non-kin caregivers were as likely or more likely to contribute to these tasks as spouses, adult children, adult children-in-law, grandchildren or extended family, or if they represented an equal or greater proportion of caregivers providing assistance with these tasks than these family groups, these contributions were viewed as substantial.

Amount of Time Spent Caregiving

The amount of time spent providing care informally is valued because without it other members of the informal caregiving network would have to contribute more (placing increased burden on a smaller group of people) and/or there would be an increased demand on more costly formal services (paid for publicly or privately through personal out of pocket expenses). For hypothesis one, the average number of hours per week spent on each task and in total were examined, to determine if non-kin make a substantial contribution. One way ANOVA and post hoc Bonferroni tests were used to determine if there were statistically significant differences in the average number of hours between relationships. If non-kin caregivers contribute similar or greater amounts of care as other family caregivers this can be seen as an indication that their contributions have value and were substantial. A second measure of 'amount of care' was the number of full-time employees it would take to replace the

care currently provided by non-kin at the population level. Full-time was calculated as 30 hrs per week (Statistics Canada, 2000), 50 weeks per year. This indicator gives a measure of the value of non-kin contributions at the population level.

For hypothesis two the average number of hours per week spent on each task and in total were examined. One way ANOVA determined if there were statistically significant differences between friends and neighbours in the average number of hours spent on each task per week and in total.

Reliability of Care Despite Consequences

An argument against non-kin caregivers being reliable contributors to the informal care of frail seniors is that they will only provide care for short periods of time, or in emergencies, and that they are not reliable sources of long-term care because they are not committed to continuing to provide this care. From an exchange perspective non-kin would not be expected to provide care if the costs (i.e. consequences) are too great, because there are no social customs or norms committing them to an un-balanced relationship.

Since the sample for this study was all caregivers who had been providing care for a minimum of six months, it can be assumed that these non-kin and kin caregivers have sustained caregiving involvement. For hypothesis one and two, the following analyses were done to measure the reliability of caregiving despite consequences. To analyse the provision of reliable support despite consequences two types of analysis were used. First, cross tabulations were produced to examine the proportions of caregivers of various relationships experiencing any socioeconomic, burden or job

adjustment consequences. Pearson's chi-square tests were used to determine if differences between relationships were statistically significant. This analysis provides an indication of whether or not there is a difference in the proportion of caregivers in each relationship who experience no consequences in a particular area.

Second, long-term caregivers who reported socioeconomic, burden or job-adjustment consequences were used to calculate the average number of consequences in each area by relationship. Analysis of Variance (ANOVA) and post hoc Bonferroni tests were used to determine if there was a significant difference in the average number of consequences for each index by relationship. This analysis provides an indication of whether among those who do experience consequences if some informal caregiving groups experience higher levels of consequences than others. It also provides a clearer picture of the magnitude of these consequences for those that experience them. Providing long-term care despite personal consequences was considered evidence of substantial caregiving.

CHAPTER 4

RESULTS

The purpose of this chapter is to present the results of the statistical analyses that were run to test the two hypotheses for this research project.

Hypothesis One

H₀: Non-kin will provide substantial amounts of informal care to the frail elderly.

H_a: Non-kin will not provide substantial amounts of informal care to the frail elderly.

The sub-sample used for hypothesis one consisted of long-term informal caregivers who were providing care to a senior due to a long-term health disability (N=1154). Of these 1154 informal caregivers 4.8% were spouses (n=55), 46.4% were adult children (n=536), 11.7% were adult children in-law (n=135), 11.1% were grandchildren (n=128), 7.8% were extended family members (n=90), and 18.2% were non-kin (n=210).

For hypothesis one there were four measures used to indicate substantial caregiving: primary caregiver status, types of tasks, amount of caregiving, and reliable long-term care despite consequences.

Primary Caregiver Status

Table 1 shows the cross tabulation of primary caregiver status by relationship. Chi-square tests were calculated comparing non-kin with various family sub-groups. The results of the chi-square tests comparing grandchildren and non-kin, and spouses and non-kin were suppressed due to small cell sizes. Approximately 20% of long term informal non-kin caregivers to the frail elderly were primary caregivers. Adult children ($\chi^2=35.39$, $p=.0001$) and extended family ($\chi^2=6.6$, $p=.01$) caregivers were significantly more likely than non-kin to be primary caregivers. Non-kin caregivers were just as likely as adult children in-law to be primary caregivers.

Non-kin comprise almost 11% of the primary caregivers in this sample, which was greater than the proportion of primary caregivers who were adult children in-law (5.9%) or extended family (7.7%). These results provide partial support for the hypothesis that non-kin make a substantial contribution to the informal care of frail seniors.

Table 1**Primary Caregiver Status by Relationship**

Were You The primary Caregiver?	Spouse	Adult Child	Adult Child In-law	Grandchild	Extended Family	Non-Kin	Total
Yes <u>n</u>	54	232	23	--	30	42	390
Row %	13.8	59.5	5.9	--	7.7	10.8	
Column %	96.4	43.5	17.4	--	34.1	20.1	34.2
Total <u>n</u>	56	533	132	121	88	209	1139
Total %	4.9	46.8	11.6	10.6	7.7	18.3	100

Note. -- Observed frequencies too small for release (n<15).

Types of Care Tasks Performed

Table 2 shows the cross tabulation of personal care by relationship. Chi-square tests were calculated comparing non-kin with various family sub-groups. The results of the chi-square tests comparing grandchildren and non-kin were suppressed due to small cell sizes. Non-kin were significantly less likely than spouses ($\chi^2=136.24$, $p=.0001$), adult children ($\chi^2=30.52$, $p=.0001$), adult children in-law ($\chi^2=5.43$, $p=.02$) and extended family ($\chi^2=22.194$, $p=.0001$) caregivers to provide personal care. Non-kin made up a smaller proportion of informal caregivers providing assistance with personal care than spouses, adult children, adult children in-law and extended family. These results do not support the hypothesis that non-kin make substantial contributions to informal care.

Table 2

Personal Care by Relationship

Did you provide personal care?	Spouse	Adult Child	Adult Child In-law	Grandchild	Extended Family	Non-Kin	Total
Yes <u>n</u>	50	163	27	--	30	23	321
Row %	15.6	50.8	8.4	9.3	7.2		
Column %	89.3	30.4	20.0	--	33.7	11.0	27.8
Total <u>n</u>	56	536	135	128	89	210	1154
Total %	4.9	46.4	11.7	11.1	7.7	18.2	100

Note. -- Observed frequencies too small for release ($n<15$).

Table 3 shows the cross tabulation of bills and banking by relationship. Chi-square tests were calculated comparing non-kin with various family sub-groups. Non-kin caregivers were significantly less likely than adult children ($\chi^2=47.216$, $p=.0001$), adult children in-law ($\chi^2=4.23$, $p=.03$) and extended family ($\chi^2=15.07$, $p=.0001$) caregivers to provide assistance with bills and banking and they just as likely as spouses and grandchildren to provide assistance with bills and banking.

Non-kin make up the second largest proportion of caregivers who are providing assistance with bills and banking (9.7%), which was larger than the proportion who are spouses (3.8%) adult children in-law (8.5%), grandchildren (6.3%), or extended family (9.4%). These findings partially support the hypothesis that non-kin make substantial contributions to informal care.

Table 3

Bills & Banking by Relationship

Did you assist with Bills & Banking?	Spouse	Adult Child	Adult Child In-law	Grandchild	Extended Family	Non-Kin	Total
Yes <u>n</u>	12	198	27	20	30	31	318
Row %	3.8	62.3	8.5	6.3	9.4	9.7	
Column %	80.0	57.6	36.0	27.8	50.8	22.8	45.4
Total <u>n</u>	15	344	75	72	59	136	701
Total %	2.1	49.1	10.7	10.3	8.4	19.4	100

Table 4 shows the cross tabulation of household maintenance and repair by relationship. Chi-square tests were calculated comparing non-kin with various family sub-groups. Non-kin caregivers are significantly more likely than spouse ($\chi^2=5.045$, $p=.02$) or extended family ($\chi^2=3.91$, $p=.04$) caregivers to provide assistance with household maintenance and repair and they are just as likely as adult children, adult children in-law and grandchildren to provide this assistance. Over 60% of non-kin caregivers assist with household maintenance and repair. Non-kin represent the second largest group providing assistance with this task (17.7%). These results support the hypothesis that non-kin make substantial contributions to the informal care of frail seniors.

Table 4

Household Maintenance & Repair by Relationship

Did you assist with Household Maintenance & Repair?	Spouse	Adult Child	Adult Child In-law	Grandchild	Extended Family	Non-Kin	Total
Yes <u>n</u>	8	167	54	37	13	60	339
Row %	2.4	49.3	15.9	10.9	3.8	17.7	
Column %	34.8	53.9	63.5	71.2	40.6	60.6	56.4
Total <u>n</u>	23	310	85	52	32	99	601
Total %	3.8	51.6	14.1	8.7	5.3	16.5	100

Table 5 shows the cross tabulation of housekeeping by relationship. Chi-square tests were calculated comparing non-kin with various family sub-groups. The results of the chi-square tests comparing spouses and non-kin were suppressed due to small cell sizes. Non-kin caregivers are just as likely as adult children in-law, grandchildren and extended family caregivers to provide assistance with housekeeping. Only adult children ($\chi^2=11.039$, $p=.001$) caregivers are significantly more likely than non-kin caregivers to provide assistance with housekeeping. Non-kin make up the second largest group contributing to housekeeping (12.8%), representing more caregivers than spouses (5.2%), adult children in-law (9.8%), grandchildren (9.5%) or extended family (4.6%). These results provide partial support for the hypothesis that non-kin make substantial contributions to informal care.

Table 5

Housekeeping by Relationship

Did you assist with Housekeeping	Spouse	Adult Child	Adult Child In-law	Grandchild	Extended Family	Non-Kin	Total
Yes <u>n</u>	17	191	32	31	15	42	328
Row %	5.2	58.2	9.8	9.5	4.6	12.8	
Column %	73.9	61.4	37.6	55.4	46.9	42.4	54.1
Total <u>n</u>	23	311	85	56	32	99	606
Total %	3.8	51.3	14.0	9.2	5.3	16.3	100

Table 6 shows the cross tabulation of meals by relationship. Chi-square tests were calculated comparing non-kin with various family sub-groups. Adult children ($\chi^2=7.614$, $p=.004$), and adult children in-law ($\chi^2=8.263$ $p=.003$) caregivers are significantly more likely than non-kin caregivers to provide assistance with meals, whereas non-kin caregivers are significantly more likely than extended family ($\chi^2=3.18$, $p=.05$) caregivers to assist with meals. Non-kin are just as likely as spouses and grandchildren to provide assistance with meals. In addition non-kin comprise 16.3% of caregivers providing assistance with meals, while spouses make up 4.1%, adult children in-law 14%, grandchildren 9%, and extended family 5.3%. These results provide partial support for the hypothesis that non-kin make a substantial contribution to informal care.

Table 6

Meals by Relationship

Did you assist with Meals?	Spouse	Adult Child	Adult Child In-law	Grandchild	Extended Family	Non-Kin	Total
Yes <u>n</u>	25	312	85	55	32	99	608
Row %	4.1	51.3	14.0	9.0	5.3	16.3	
Column %	45.5	58.3	63.0	43.0	36.0	47.1	52.8
Total <u>n</u>	55	535	135	128	89	210	1152
Total %	4.8	46.4	11.7	11.1	7.7	18.2	100

Table 7 shows the cross tabulation of shopping by relationship. Chi-square tests were calculated comparing non-kin with various family sub-groups. There were no significant differences in the proportion of non-kin caregivers who provided assistance with shopping compared to any family caregiving group. Non-kin caregivers represent 18.6% of caregivers who provide assistance with shopping, which was more than spouses (2.6%), adult children in-law (9%), grandchildren (11.4%), and extended family (7.4%). These results support the hypothesis that non-kin make substantial contributions to informal care.

Table 7

Shopping by Relationship

Did you assist with Shopping?	Spouse	Adult Child	Adult Child In-law	Grandchild	Extended Family	Non-Kin	Total
Yes <u>n</u>	14	277	49	62	40	101	543
Row %	2.6	51.0	9.0	11.4	7.4	18.6	
Column %	93.3	80.1	64.5	87.3	69.0	74.3	77.4
Total <u>n</u>	15	346	76	71	58	136	702
Total %	2.1	49.3	10.8	10.1	8.3	19.4	100

Table 8 shows the cross tabulation of transportation by relationship. Chi-square tests were calculated comparing non-kin with various family sub-groups. Approximately 73% of non-kin caregivers provide assistance with transportation. Non-kin caregivers are just as likely as spouse, adult children in-law, grandchildren and extended family caregivers to provide assistance with transportation. Only adult children ($\chi^2=11.43$ $p=.001$) caregivers are significantly more likely than non-kin caregivers to provide assistance with transportation. Non-kin represent 17.2% of caregivers who provide assistance with transportation, which was more than spouses (1.6%), adult children in-law (12%), grandchildren (9.9%) and extended family (7.5%). These findings provide partial support for the hypothesis that non-kin make substantial contributions to informal care.

Table 8

Transportation by Relationship

Did you assist with Transportation?	Spouse	Adult Child	Adult Child In-law	Grandchild	Extended Family	Non-Kin	Total
Yes <u>n</u>	9	298	69	57	43	99	575
Row %	1.6	51.8	12.0	9.9	7.5	17.2	
Column %	60.0	85.9	92.0	80.3	72.9	72.8	81.8
Total <u>n</u>	15	347	75	71	59	136	703
Total %	2.1	49.4	10.7	10.1	8.4	19.3	100

Amount of Caregiving

Table 9 shows the mean number of hours spent per week on personal care, bills and banking, household maintenance and repair, housekeeping, meals, shopping, transportation and in total, by relationship. Analysis of Variance (ANOVA) and post hoc Bonferroni multiple comparisons found a significant difference between the average number of hours per week spent by non-kin and other relationships only for housekeeping, meals and overall time spent on all tasks. For housekeeping spouses spent significantly more time on average per week than non-kin, with a mean difference of 2.2 hours per week. For meals, spouses spent on average 12.53 hours per week more than non-kin. Spouses also spent on average 14.17 more hours per week providing care overall than non-kin, and adult children spent 2.17 hours more per week.

Table 9**Mean Hours Spent Caregiving by Relationship**

Tasks	Spouse	Adult Child	Adult Child In-law	Grandchild	Extended Family	Non-Kin
Personal Care	9.41	3.24	2.01	--	1.28	6.48
Bills & Banking	.48	.27	.38	.31	.34	.23
Household Maintenance & Repair	--	1.46	.77	.78	1.18	1.06
Housekeeping	3.56*	1.71	1.52	1.79	1.23	1.36
Meals	14.66*	3.67	4.86	1.38	6.13	2.13
Shopping	1.18	.93	.99	.65	.95	.66
Transportation	--	1.06	1.09	.58	1.01	.74
Total	16.38*	4.38*	3.79	1.88	3.11	2.21

Note. -- Observed frequencies too small for release (n<15).

* Indicates that the mean difference between this group of caregivers and non-kin caregivers is significant at the .01 level

Overall, these findings provide partial support for the hypothesis that non-kin make a substantial contribution to the informal care of frail seniors. Another indicator of the amount of care was to determine how many full-time employees it would take to replace the informal care provided by non-kin at the population level. It would take 26, 926 full time employees working 30 hours per week, 50 weeks of the year, to replace the informal care provided by non-kin in 1996. This finding gives us an idea of the magnitude of non-kin contributions at the population level.

Reliability of Care Despite Consequences

All of the caregivers in this study had been providing informal care for a minimum of six months. In fact the majority (52% to 74%) of caregivers in this study had been providing care for two years or more. Table 10 shows the cross tabulation of socioeconomic consequences by relationship. Chi-square tests were calculated comparing non-kin to various family sub-groups. Almost half of non-kin caregivers (47.4%) reported socioeconomic consequences as a result of their caregiving activities. This was significantly less than the proportion of spouse ($\chi^2=42.99$, $p=.0001$), adult children ($\chi^2=42.994$, $p=.0001$), adult children in-law ($\chi^2=38.807$, $p=.0001$), or extended family ($\chi^2=4.098$, $p=.03$) caregivers reporting socioeconomic consequences. Non-kin were just as likely as grandchildren to report socioeconomic consequences.

Table 10

Socioeconomic Consequences by Relationship

Experienced At least one Socioeconomic Consequence?	Spouse	Adult Child	Adult Child In-law	Grandchild	Extended Family	Non-Kin	Total
Yes <u>n</u>	40	379	103	64	53	99	738
Row %	5.4	51.4	14.0	8.7	7.2	13.4	
Column %	74.1	72.9	81.7	50.4	60.2	47.4	65.7
Total <u>n</u>	54	520	126	127	88	209	1124
Total %	4.8	46.3	11.2	11.3	7.8	18.6	100

Table 11 shows the cross tabulation of burden consequences by relationship. Chi-square tests were calculated to compare non-kin to various family sub-groups. Burden consequences affected a significantly smaller proportion of non-kin caregivers than adult children ($\chi^2=12.479$, $p=.0001$) or adult children in-law ($\chi^2=13.413$, $p=.0001$) caregivers, even though a majority of non-kin caregivers (61.4%) reported experiencing burden consequences. Non-kin caregivers were just as likely as spouses, grandchildren and extended family caregivers to report experiencing burden consequences.

Table 11

Burden Consequences by Relationship

Experienced At least one Burden Consequence?	Spouse	Adult Child	Adult Child In-law	Grandchild	Extended Family	Non-Kin	Total
Yes <u>n</u>	26	365	101	68	49	121	730
Row %	3.6	50.0	13.8	9.3	6.7	16.6	
Column %	59.1	74.9	80.8	59.6	58.3	61.4	69.5
Total <u>n</u>	44	487	125	114	84	197	1051
Total %	4.2	46.3	11.9	10.8	8.0	18.7	100

Table 12 shows the cross tabulation of job adjustment consequences by relationship. Chi-square tests were calculated to compare non-kin to various family sub-groups. The results of chi-square tests comparing non-kin to spouses were

suppressed due to small cell sizes. Non-kin caregivers were significantly less likely than adult child caregivers to report having job adjustment consequences ($\chi^2=11.454$, $p=.001$), and just as likely as adult children in-law, grandchildren and extended family caregivers. Almost 40% of non-kin caregivers reported job adjustment consequences.

Table 12

Job Adjustment Consequences by Relationship

Experienced At least one Job Adjustment Consequence?	Spouse	Adult Child	Adult Child In-law	Grandchild	Extended Family	Non-Kin	Total
Yes <u>n</u>	--	232	54	41	22	41	394
Row %	--	58.9	13.7	10.4	5.6	10.4	
Column %	--	58.4	49.5	39.0	47.8	39.8	51.4
Total <u>n</u>	--	397	109	105	46	103	767
Total %	--	51.8	14.2	13.7	6.0	13.4	100

Note. -- Observed frequencies too small for release ($n < 15$).

Non-kin make up 13.1% of caregivers reporting socioeconomic consequences, 16.2% of caregivers reporting burden consequences and 10.1% of caregivers reporting job adjustment consequences. These findings suggest that non-kin provide long-term care despite experiencing personal consequences. However, the proportion of non-kin experiencing these consequences was sometimes less than for other family relationships.

In addition to whether long-term caregivers experience consequences in general, the number of consequences experienced also may be important. Looking only at caregivers who experience each consequence and comparing the number of consequences provides an indication of whether the intensity of consequences experienced differs by relationship. Table 13 shows the mean number of consequences experienced in each category by relationship. There was no significant difference in the number of job adjustment consequences between non-kin and other relationships. Analysis of variance comparing non-kin with spouses on the job adjustment consequence index were suppressed due to small cell sizes.

Adult children and adult children in-law experienced on average less than one more burden consequence than non-kin. There were no significant differences between non-kin and extended family, grandchildren or spouses in the average number of burden consequences experienced. Spouses experienced on average less than one more socioeconomic consequence than non-kin. There were no significant differences between non-kin and extended family, grandchildren, adult children in-law or adult children in the average number of socioeconomic consequences experienced. Overall, when caregiving consequences are experienced non-kin did not differ from various family caregivers in the intensity of those consequences. These findings provide partial support for the hypothesis that non-kin make a substantial contribution to the informal care of frail seniors.

Table 13**Consequence Indexes by Relationship**

Index Mean	Spouse	Adult Child	Adult Child In-law	Grandchild	Extended Non-Kin Family	
Socioeconomic Index	2.97*	2.54	2.49	2.29	1.91	2.17
Burden Index	1.88	2.49*	2.56*	2.14	2.17	1.74
Job Adjustment Index	--	2.05	2.05	2.05	2.01	1.98

Note. -- Observed frequencies too small for release (n<15).

* Mean difference is significant at the .05 level

Hypothesis Two

H₀: Differences exist between friend and neighbour informal caregivers in the type and amount of care provided.

H_a: Differences do not exist between friend and neighbour informal caregivers in the type and amount of care provided.

The sub-sample for hypothesis two consisted of non-kin long-term informal caregivers who were providing care to a senior who had a long-term health disability (N=210). Of these non-kin caregivers 59.1% were friends (n=124), and 40.9% were neighbours (n=86).

For hypothesis two, friends and neighbours were compared along four dimensions to determine if there were any meaningful differences between the two

groups: primary caregiver status, types of tasks, amount of caregiving, and reliable long-term care despite consequences.

Primary Caregiver Status

Table 14 shows the cross tabulation of primary caregiver status by non-kin relationship and the results of the chi-square test. Previous research has shown that primary caregivers provide greater amounts of care than secondary caregivers (Penrod, Kane, Kane & Finch, 1995; Tennstedt, McKinlay & Sullivan, 1989). Friend caregivers were significantly more likely than neighbour caregivers to be primary caregivers. Friends also made up a significantly larger proportion of non-kin primary caregivers (76.2%) than neighbours. This supports the hypothesis that differences exist between friend and neighbour caregivers in the amount of care provided.

Table 14

Primary Caregiver Status by Non-kin Relationship

Were You The Primary Caregiver?	Friend	Neighbour	Total
Yes <u>n</u>	32	10	42
Row %	76.2	23.8	
Column %	26.0	11.6	20.1
Total <u>n</u>	123	86	209
Total %	58.9	41.1	100
<u>Note.</u> Chi Square= 6.525 Significance=.008			

Types of Care Tasks Performed

Tables 15 to 19 show the cross tabulations of household maintenance and repair, housekeeping, meals, shopping and transportation by non-kin relationship, as well as the results of chi-square tests. Unweighted cell sizes were too small to report cross-tabulations or chi square tests for personal care or bills and banking. There were significant differences in the proportion of friends versus neighbours who assisted with household maintenance and repair, housekeeping, meals and transportation. Friend caregivers were more likely than neighbour caregivers to assist with housekeeping and transportation. Neighbour caregivers were more likely than friend caregivers to assist with household maintenance and repair and meals. Friends made up a larger proportion of non-kin assisting with housekeeping, shopping, and transportation than neighbours. Neighbours made up a larger proportion of non-kin assisting with household maintenance and repair, and meals, than friends. These findings support the hypothesis that differences exist between friend and neighbour informal caregivers in the type of care provided.

Table 15**Household Maintenance & Repair by Non-kin Relationship**

Did You Assist With Household Maintenance & Repair?	Friend	Neighbour	Total
Yes <u>n</u>	21	39	60
Row %	35.0	65.0	
Column %	44.7	75.0	60.6
Total <u>n</u>	47	52	99
Total %	47.5	52.5	100

Note. Chi square = 9.505 Significance = .002

Table 16**Housekeeping by Non-kin Relationship**

Did You Assist With Housekeeping?	Friend	Neighbour	Total
Yes <u>n</u>	27	15	42
Row %	64.3	35.7	
Column %	57.4	28.8	42.4
Total <u>n</u>	47	52	99
Total %	47.5	52.5	100

Note. Chi Square= 8.267 Significance= .004

Table 17**Meals by Non-kin Relationship**

Did You Assist With Meals?	Friend	Neighbour	Total
Yes <u>n</u>	47	52	99
Row %	47.5	52.5	
Column %	37.6	60.5	46.9
Total <u>n</u>	125	86	211
Total %	59.2	40.8	100

Note. Chi Square= 10.695 Significance= .001

Table 18**Shopping by Non-kin Relationship**

Did You Assist With Shopping?	Friend	Neighbour	Total
Yes <u>n</u>	62	40	102
Row %	60.8	39.2	
Column %	73.8	75.5	74.5
Total <u>n</u>	84	53	137
Total %	61.3	38.7	100

Note. Chi Square=.047 Significance= .497

Table 19**Transportation by Non-kin Relationship**

Did You Assist With Transportation?	Friend	Neighbour	Total
Yes <u>n</u>	66	33	99
Row %	66.7	33.3	
Column %	79.5	62.3	72.8
Total <u>n</u>	83	53	136
Total %	61.0	39.0	100
<u>Note.</u> Chi Square= 4.862 Significance= .02			

Amount of Caregiving

Table 20 shows the mean number of hours spent per week on household maintenance and repair, shopping, transportation and in total, by non-kin relationship. Unweighted cell sizes were too small to report mean number of hours spent per week on personal care, bills and banking, housekeeping and meals. Analysis of Variance (ANOVA) found a significant difference between friend and neighbour caregivers in the mean number of hours spent overall on caregiving. Friends provide significantly more hours per week on average than neighbours. These findings provide mixed support for the second hypothesis. While there were no significant differences in the amount of time spent per task by friend and neighbour caregivers, friend caregivers provide significantly greater amounts of care overall.

Table 20**Mean Hours Spent Caregiving by Non-kin Relationship**

Task	Friend	Neighbour
Maintenance & Repair	1.35	.90
Shopping	.70	.59
Transportation	.75	.73
Total	2.76 *	1.40

Note. * Mean difference is significant at the .05 level

Reliability of Care Despite Consequences

All of the non-kin caregivers in this sample had been providing informal care for a minimum of six months. In fact 45% to 68% had been providing care for two years or more. Tables 21 to 23 show cross tabulations of socioeconomic consequences, burden consequences and job adjustment consequences by non-kin relationship, as well as the results of chi-square tests. Friend caregivers were significantly more likely than neighbour caregivers to report socioeconomic consequences. There was no significant difference in the proportion of friend and neighbour caregivers reporting burden consequences. A majority of both friend and neighbour caregivers reported burden consequences as a result of their caregiving activities, and a majority of friend caregivers and large minority of neighbour caregivers reported socioeconomic consequences. A large minority of friend and neighbour caregivers reported job adjustment consequences. These findings provide

partial support for the hypothesis that differences exist between friend and neighbour caregivers.

Table 21

Socioeconomic Consequences by Non-kin Relationship

Experienced At Least One Socioeconomic Consequence?	Friend	Neighbour	Total
Yes <u>n</u>	66	33	99
Row %	66.7	33.3	
Column %	53.7	37.9	47.1
Total <u>n</u>	123	87	210
Total %	58.6	41.4	100

Note. Chi Square= 4.802 Significance= .02

Table 22

Burden Consequences by Non-kin Relationship

Experienced At Least One Burden Consequence?	Friend	Neighbour	Total
Yes <u>n</u>	75	46	121
Row %	62.0	38.0	
Column %	64.1	57.5	61.4
Total <u>n</u>	117	80	197
Total %	59.4	40.6	100

Note. Chi Square=.874 Significance= .216

Table 23**Job Adjustment Consequences by Non-kin Relationship**

Experienced At Least One Job Adjustment Consequence?	Friend	Neighbour	Total
Yes <u>n</u>	21	20	41
Row %	51.2	48.8	
Column %	35.0	46.5	39.8
Total <u>n</u>	60	43	103
Total %	58.	41.7	100
<u>Note.</u> Chi Square= 1.385 Significance=.165			

In addition to whether friend and neighbour caregivers experience consequences in general, the number of consequences experienced may also be important. Looking only at caregivers who experience each consequence and comparing the number of consequences they have provides an indication of whether the intensity of consequences experienced differs by relationship. Table 24 shows the mean number of consequences experienced in each category by non-kin relationship. There were no significant differences between friend and neighbour caregivers who experienced consequences, on the number of socioeconomic or burden consequences experienced. For non-kin who did experience job adjustment consequences, there was a significant difference in the mean number of consequences experienced by friends and neighbours, with friends experiencing approximately one more employment consequence on average. These findings provide partial support for the hypothesis that differences exist between friend and neighbour informal caregivers.

Table 24**Consequence Indexes by Non-kin Relationship**

Index Mean	Friend	Neighbour
Socioeconomic Index	2.19	2.14
Burden Index	1.66	1.87
Job Adjustment Index	2.38*	1.56

Note. * Mean difference is significant at the .01 level

Study Limitations

A key limitation to any research study that utilizes secondary data analysis is that the study was restricted to the variables that were included in the original study. In addition, despite the fact that the sample sizes used in this study were relatively large N=1154 and N=210, many of the cell sizes were too small to be released and the results were suppressed. This limited the number of comparisons that could be made and the types of analyses that could be done.

CHAPTER 5

DISCUSSION

The purpose of this research project was to examine the contributions of non-kin caregivers to determine whether non-kin make a substantial contribution to the long term informal care of the frail elderly, and whether or not the contributions of friend and neighbour caregivers can be viewed as distinct. In the first part of this chapter major findings regarding the contributions of non-kin are discussed in the context of the conceptual framework and research literature addressed earlier. In the second part of this chapter, major findings comparing the contributions of friend and neighbour caregivers also are discussed in relation to the conceptual framework and research literature review. Implications of this study for future research, theory, policy and practice also are presented.

The Contributions of Non-kin Long-Term Informal Caregivers:

Are They Substantial?

Social exchange theory and symbolic interaction theory were used to derive two competing hypothesis about whether or not non-kin are substantial informal long-term caregivers to the frail elderly. This study tested those competing hypotheses using four measures to indicate substantial caregiving: primary caregiver status, types of tasks, amount of caregiving, and reliable long-term care despite consequences. The contributions of family members, especially spouses, adult children and adult children in-law, are already recognized as being substantial, so non-kin caregivers were

compared to family caregivers along the four dimensions previously mentioned to determine if non-kin also can be considered substantial long-term informal care providers.

In terms of the types of tasks with which non-kin provide assistance non-kin do not make a substantial contribution to personal care. They are also not as likely as family caregivers to be the primary caregiver of the care recipient. However, for assistance with bills and banking, household maintenance and repair, housekeeping, meal preparation and clean up, shopping and transportation, non-kin comprise the second largest group of informal caregivers providing assistance with these tasks. For these tasks the contributions of non-kin can be considered substantial because they directly contribute to the independence of seniors. Many seniors argue that it is assistance with instrumental tasks, rather than personal care, that keeps them independent the longest (Keating, Fast, Oakes, & Harlton, 1996), and it is precisely in these areas that home care services are cutting back (Hollander, 1994; Wilkins & Park, 1998). If non-kin were to cease providing informal care a relatively large chunk of the informal caregiving network would be lost and not easily replaced.

Comparing the average number of hours per week that assistance was provided for each task, and in total, by relationship, there were remarkably few significant differences. The results of this analysis show that in general when non-kin were providing assistance with certain tasks they were not spending significantly less time on these tasks than family members who provide assistance. The exception to this is spouse caregivers who spend more time assisting with housekeeping and meals than non-kin. Since there were no differences between adult children and non-kin in

the average amount of time spent per task, the greater number of hours per week spent by adult children caregivers must be a result of providing assistance with more tasks¹⁰.

These findings provide partial support for the hypothesis that non-kin make a substantial contribution to the informal care of frail seniors with regards to the amount of time they contribute. The amount of care provided by non-kin did not differ significantly from adult children in-law, grandchildren or extended family caregivers, so their contributions can be viewed as being as substantial as these groups. However, the amount of time contributed to informal caregiving by non-kin is not as substantial as the amount of time contributed by spouses or adult children.

While the role of non-kin in the informal caregiving network may not be as central as the role of spouses and adult children, overall the findings of this study provide partial support for the hypothesis that non-kin make a substantial contribution to the informal care of frail seniors. Certainly the 26, 926 full time workers it would take to replace the care provided informally by non-kin in 1996 is substantial. When you consider the financial cost involved in replacing informal care by non-kin with formal services (either public or private), the personal costs to family caregivers who may feel obligated to take on even more caregiving responsibilities if non-kin dropped out of the informal sector, and the amount of needs that would be unmet by deficiencies in the formal and informal sector, it is easy to see the value of non-kin contributions to the long-term informal care of frail seniors.

10 The task load of non-kin caregivers compared to family caregivers was not measured in this study but may prove insightful in future studies.

Social exchange theorists argue that non-kin are not reliable sources of long-term care because they are not obligated to continue providing care when the costs become too great. The results of these analyses show that non-kin were the second largest group of long-term informal caregivers, with adult children being the only relationship more highly represented. While the proportion of non-kin experiencing negative consequences often was less than the proportion of various family caregivers, the provision of this long-term care was not without personal consequences for non-kin. For example, 47.4% report socioeconomic consequences, 61.4% report burden consequences, and 39.8% of employed non-kin caregivers report job adjustment consequences.

This evidence of long-term reliable support by non-kin despite consequences was counter to a strict social exchange interpretation. However, inherent in this social exchange hypothesis was the assumption that exchanges between frail seniors and their caregivers will be unbalanced because seniors cannot reciprocate in kind. Armstrong (1991), however, observed “soft” non-instrumental support, such as emotional support, being exchanged for instrumental support from younger, more able-bodied companions, and there may be other types of exchanges taking place within relationships that maintain the balance of costs versus rewards. Alternatively, it is argued that as people age there is less concern with maintaining the equity of exchange that is typically associated with friendship (Armstrong, 1991), especially with regards to instrumental support (Armstrong & Goldsteen, 1990). Thus, while the findings of this study were more conducive to a symbolic interaction explanation of non-kin caregiving, social exchange theory cannot be dismissed.

The personal meaning of others is taken into consideration by symbolic interactionists (LaRossa & Reites, 1993) and should be incorporated into future caregiving research. Within a caregiving context the 'other' would be the care recipient. From the perspective of the care recipient support from family often may be expected and sometimes taken for granted, whereas instrumental support from friends, precisely because it is voluntary and non-obligated support, seems more significant and acceptable (Antonucci, 1985; Crohan & Antonucci, 1989). Jerrome (1991) argues that families are obligated to associate with each other, while friends do so through choice. Support from non-kin may therefore be interpreted as more meaningful and less likely to be taken for granted or abused. In addition, the essential equity of friendship relationships allows older people to maintain their self-respect and self-esteem even when requesting help (LaRossa & Reites, 1993; Roberto & Scott, 1986). The impact of the nature of the caregiving relationship on the care recipient should be explored in future studies.

Family theorists point to filial obligation to explain the development and maintenance of kin caregiving to the frail elderly (Brackman, 1995; Lee, Kim & Kwang-Su, 1997), and have offered the lack of social and moral expectations as a reason for non-kin to not provide care, but no attempt has been made to explain why non-kin do provide care and how they come to find themselves in these caregiving arrangements. This study gives an initial glimpse of the contributions and consequences of non-kin informal caregivers compared to family caregivers and how friend and neighbour informal caregivers differ. A symbolic interaction perspective was useful in understanding these findings, however future research needs to examine

more closely the personal meaning involved in the development and maintenance of non-kin caregiving arrangements.

The Contributions of Friend and Neighbour Long-Term Informal Caregivers: Are They Distinct?

The second hypothesis was whether there were differences in the caregiving contributions of friends and neighbours. Both exchange theory and symbolic interaction theory provided conceptual rationale for why differences may exist in the caregiving contributions of these two groups. However, empirical research in the area of elder care has failed to distinguish between different types of non-kin caregivers and as a result some important distinctions between the caregiving contributions of these two groups have been overlooked.

Friends were more likely than neighbours to take on a more central caregiving role as primary caregiver, which could be a result of the greater personal meaning generally attributed to friendships than neighbour relationships. It could also be due to the maintenance of social distance and respect for privacy that are key elements of neighbour relationships (Bulmer, 1986; Wenger, 1990). However, neighbours made greater contributions than friends in other areas. Neighbours made up a larger proportion of non-kin assisting with household maintenance and repair, and meals, which may be a reflection of their closer proximity in general to the care receiver than friend caregivers.

Although friend caregivers were significantly more likely than neighbour caregivers to assist with housekeeping, shopping and transportation, there were no significant differences in the average amount of time per week spent on these activities. In fact, there were no significant differences between friend caregivers and neighbour caregivers in the mean number of hours spent per week on any task. There was, however, a significant difference in the average amount of time spent per week overall on caregiving activities, with friends spending nearly twice as much time caregiving per week on average. These results are better explained by a symbolic interaction perspective which would argue that friends provide more hours of care per week, and assist with more personal types of care, because of the greater personal meaning attached to these relationships.

Overall, differences exist between friend and neighbour informal caregivers in the types of tasks with which they provide assistance, the total amount of time they spend caregiving, and the degree to which they experience socioeconomic consequences and the intensity of job adjustment consequences. While the difference in the proportion of friend and neighbour caregivers experiencing socioeconomic consequences, and the difference in the intensity of job adjustment consequences were significant they are not necessarily meaningful. Friend caregivers are less than 16% more likely than neighbour caregivers to experience at least one socioeconomic consequence, and on average, friends experience less than one more job adjustment consequence than neighbours.

Significant differences between friend and neighbour informal caregivers in the types of tasks performed and the amount of time spent caregiving overall are very

meaningful. Understanding the types of tasks that friend or neighbour caregivers are more likely to assist with gives us a better idea of where they fit into the caregiving network. In addition, differences in the average amount of time spent caregiving per week have provided some insight into the caring capacity of these two groups. The amount of time that individuals are willing to contribute to the informal care of friends is obviously greater than the amount of time they are willing to contribute to the informal care of neighbours. Variation exists in the caring capacity of these two groups because of general differences in the personal meaning attached to friend and neighbour relationships.

The results of this study have implications for future policy and practice in the context of long-term informal elder care in Canada. Existing policies and programs are more commonly designed to be of use to family informal caregivers than non-kin informal caregivers. This is done by restricting policies and programs to particular family relationships. It is certainly easier to define who belongs in the category relative than defining who belongs in the category friend (Adams & Blieszner, 1995), and restricting services and support to family caregivers is certainly more economical in the short run. However, if non-kin caregivers are excluded from informal caregiving services, and there is no support for them in their caregiving contributions we run the risk of jeopardizing their contributions. Losing the support currently provided informally by non-kin caregivers would result in a greater burden being placed on the formal sector, a greater burden being placed on informal family caregivers, and the needs of many seniors not being met (Noon & Pearson, 2000).

There is a dearth of policies and programs that are designed to support and sustain informal caregivers in general and more should be developed. However, those who are designing these policies and programs need to be aware of the substantial contributions of non-kin and insure that unnecessary and unjustified restrictions are not placed in the eligibility requirements. While some programs and policies may need to be developed that target specific groups of high risk caregivers there should be support available for all informal caregivers.

It is also important that the informal care provided by friends and neighbours not become exploited, or used as excuse for service providers to withhold, discontinue or fail to implement services for frail seniors (Nocon & Pearson, 2000). Bulmer (1986) cautions that the incorporation of friendship or neighbourliness into formal social care packages carries the dangers of bureaucratization and the loss of a more spontaneous approach to helping. Great care needs to be taken when implementing any findings from this type of research into practice. “(R)ather than seek to control friendships or harness them to therapeutic goals, we may have to be content to simply help them to happen, and to recognize and value them if they do” (Reed & MacMillan, 1995, p. 236).

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