PERSPECTIVES ON NEED
RESPITE CARE SERVICES FOR THE ELDERLY AND THEIR FAMILIES

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ABSTRACT

Respite Care programs for the elderly and their families are being recognized and developed within Long Term Care systems. Research on these programs is sparse and focused on outcome studies. Very little work has been published that addresses grounded theory building or exploratory needs assessments in the definition of need and objectives for respite care.

This exploratory study addresses the issue of need for respite from two perspectives. Within an urban Canadian center, focused interviews were conducted with a sample of family caregivers in high risk situations. Case scenario questionnaires were distributed and focused interviews conducted with Long Term Care Case Managers. Content analysis was used to identify themes and issues from all data sources.

The themes and categories that emerged from the data are discussed in relation to a system stimulation model and locus of control perspective as applied to understanding need and establishing program objectives and delivery patterns. Implications for needs assessments, program design, intervention, and future research are presented.
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CHAPTER 1
INTRODUCTION TO THE STUDY

It is estimated that by the year 2021, five million Canadians will be over the age of sixty five. The greatest growth proportionately, will be of the old old, those over 80. The 1978-79 health survey reported that 86% of elderly persons suffer from at least one health problem which is usually a chronic condition. (Government of Canada, 1983)

At the same time that the population is aging, the elderly continue to remain close to their families. The 1981 census reported that 2/3 of all elderly live with a relative (Government of Canada, 1983). It is assumed that the growth of the elderly population will create increased health and care needs in the future leaving both families and government wondering where and how these growing needs will be met.

In the area of health care there has been a shift in policy and emphasis towards the provision of community based services and supports in response to changing demographics (Chappell, Strain & Blandford, 1986; Government of Canada, 1982). Faced with increasing needs and financial constraints, policy makers are re-examining the role of residential care for the aged. Such care is expensive and serves only a small percentage of the population, making it a prime target for policy discussions (Allen, 1983). The growing realization that families continue to be involved in the care of the elderly and are effective in meeting many of the care needs of this aging population has led
to attempts to provide support and encouragement for family caregiving.

Respite care services refer to supports that are designed to meet the needs of family caregivers by providing some form of rest or relief for these caregivers. Such programs exist in most provinces but vary considerably in terms of their form and availability. Respite care programs have been established on the basis of assumptions that they will provide benefits to families and cost saving to governments. The service is often justified by referring to its potential for delaying institutionalization (Chappell et al., 1986). However, in Canada there has been little research on whether respite does in fact meet the needs of either informal or formal care systems.

Scharlach and Frenzel (1986) question how researchers should measure benefits of respite services. Is the focus to be cost effectiveness, a reduction in caregiver burden, or increased quality of care for the client? The force of cost restraints and limited state resources has increased the demand for accountability of services. This accountability has tended to focus on cost/benefits analyses (Auerbach & Gerber, 1976). Evaluations of community based services have shown mixed results to date (Chappell et al., 1986). Chappell and associates (1986) speculate that community and family support services may operate on the basis of erroneous assumptions about community needs and how these needs should be met.

The first step in the establishment of an effective and
adequate service is the thorough research of needs and careful establishment of program objectives (Allen, 1983). In the case of respite care, these steps have been overlooked. Before an evaluation of the effectiveness of respite care can be successfully completed, both needs and objectives must be clearly conceptualized.

Background of Respite Care in Vancouver

In Vancouver, the Long Term Care Program is administered through the Vancouver Health Department, Continuing Care Program. The services available through this program include various home supports, adult day care, and residential care.

Respite care services in Vancouver include eight institutional respite beds available in facilities at intermediate and extended care levels. The Long Term Care Policy Manual includes the use of companion or live-in homemakers as another type of available respite service. The stated purpose of this service is to provide respite care on a planned basis for vacation or temporary relief. While specific guidelines and definitions refer to institutional services as respite, it is acknowledged that adult day care and some homemaker services are also used for more regular and less formal respite.

The goals of respite as outlined in the policy manual include supporting the caregiver in maintaining the client at home, avoiding unnecessary or premature residential care and
preventing inappropriate acute care admissions.

The Continuing Care Program has expressed an interest in establishing more effective utilization of respite care resources. The Respite Service Project undertaken in 1985 described the structure and operation of existing respite services in the city, identified administrative difficulties in providing respite care, detailed cost and funding issues and suggested data collection techniques for tracking utilization of respite care beds. This work focused on the current approach to respite and did not examine the definition of need or program objectives nor did it address the possibility of a broader range of program alternatives.

Research Questions

In the report prepared by the Respite Service Project in 1985 concerns were expressed about what appeared to be the underutilization of the respite program. This observation was attributed to a lack of knowledge by families, insufficient or inappropriate respite resources and the refusal of services by clients and their families. Assumptions about need or the structure of the program were not questioned. The questions that should be raised here in response to this underutilization are, 1) why are families not accessing service and 2) why are they not finding the service appropriate.

The issue of need is the central starting point in any evaluation of a respite care program. Allen (1983), in her
comprehensive study and evaluation of respite services in Britain, found that the perception of need and criteria used to evaluate effectiveness varied according to one's position in the process. Dobelstein and Johnson (1985) also strongly believe that policy outcomes vary depending on whether policy decision makers, professional persons or consumers define the issues. The importance of addressing need and objectives from a variety of viewpoints as a beginning point in program evaluation has led to the formulation of the following research questions.

1. What is the definition of need for respite services from the perspective of Long Term Care Case Managers?
2. What is the definition of need for respite from the perspective of the caregiver?
3. Do these perceptions differ? If so, in what way?
4. Do either of these groups feel that the needs they have identified are being met through the respite care program that is currently available?

Research Objectives

Needs are often complex and difficult to define and conceptualize. In an attempt to answer the questions identified above, it is hoped that the following objectives will be achieved.

1. Develop a beginning conceptualization of what constitutes need from the viewpoints of program gatekeepers (case managers) and consumers (caregivers).
2. Identify the nature of services that each group believes will be effective in addressing the needs as defined in the first objective.

3. Provide the Continuing Care Program with observations and recommendations regarding the strengths and potential areas for change in the existing program.

Definition of Terms

Long Term Care Program (LTC): provincial health program providing community supports for chronically ill or disabled persons.

Respite Care (Service): any formal support that is seen to provide relief to the primary caregiver.

Family Caregiver (Carer): family member, usually residing with the client, who assumes primary responsibility for meeting the physical, social and/or emotional needs of the client.

Client or Care Receiver: elderly family member who is assessed and in receipt of services from the Long Term Care Program.

Formal Care Supports: services and resources available through government sponsored agencies.

Informal Care Supports: family, friends and neighbors involved in the provision of care and resources without financial compensation.

Need: lack of resources, abilities or opportunities to meet physical, social or emotional potential:
Summary

This chapter has provided an introduction to this research project by identifying popular concern with respite care services, the lack of research in the area and the importance of beginning program evaluations with a well grounded understanding of need and program objectives. The purpose of this study is to establish an understanding of needs from more than one perspective in the health care system and to generate hypotheses that contribute to the establishment of program objectives and service designs.
CHAPTER 2
CURRENT PERSPECTIVES IN THE LITERATURE

This chapter reviews the literature related to the role of family caregivers in aging families and the type of help or support that is available through formal care services. The chapter is organized into three sections. 1) The first area discussed is the type of involvement that families have in providing care for aged infirm persons, the strengths and limitations of family resources, and the effects this involvement has on the individual and family system. 2) The second issue addressed is the role of the formal care system in providing care for aged persons and support for caregivers. The ideologies and values behind the present system of services are examined as they relate to institutional and community based care. The potential for the development of a complementary relationship between formal and informal care networks is addressed along with barriers such development faces within the structure of present formal services. 3) This chapter ends with a discussion of research pertaining to respite care services in particular. Such services focus on providing support and linkage between formal and informal networks of support are the focus of this research project.

Western societies are aging and it is estimated that by the year 2001, 12% of the Canadian population with be over the age of 65 (Novak, 1985). This aging of the population brings with
it increasing levels of chronic illness and disability (Auerbach & Lewis, 1976). These trends have created fears of rising and unmanageable health care costs (Evans, 1985). Despite the impression that formal health services are being burdened with the care needs of elderly persons, studies have demonstrated that 80% of the care that elderly persons receive comes from informal sources (Chappell et al., 1986). In Canada 74% of elderly persons live with a relative (Chappell et al., 1986) and it is estimated that twice as many elderly in the community are as impaired as those already in institutions (Shanas, 1979b).

Given the potential for health care needs to increase in the future and the already heavy involvement of families in the provision of care, it is important to look at the characteristics of families that provide care and the ways in which formal services become involved and support the extensive care provided by informal networks.

The Role and Effect of Family Caregiving

It has generally been seen as desirable that care for the elderly be provided by family and informal networks. The family is believed to provide individualized care that includes warmth and commitment (Chappell et al., 1986; Government of Canada, 1982) while being based on affection, duty and respect (Litwak, 1985). The Natural Supports Program of New York (1981) stated, "Natural support systems are held to be more desirable than formal support systems because the natural system is more
finely tuned to the variations in human need, is less costly to society, and builds the kind of family and neighborly strength that is thought to be conducive to a more humane society." (p.ii)

1. Dispelling the Myth of Abandonment:

For many years, a myth of abandonment has persisted that has led us to believe that in an industrialized and mobile society, families are no longer providing care for their older relatives (Brody, 1985). Extensive research has been done to dispel this myth. For many of the elderly, family support refers to their elderly spouse. For the old old, elderly children may be the source of family supports. For others, family is some combination of peer and intergenerational connections. The literature is not always clear on the definition of family. While much research has focused on intergenerational support patterns between children and aging parents, spouses and same generation supports are also a significant source of care.

Research that discredits this myth of abandonment by families includes a study by Arling and McAuley (in Quinn and Hughston, 1984) where it was found that families were the major source of care for elderly persons. Ward, Sherman and LaGory (1984) discovered most of the elderly in their study had strong informal ties and that family were the first avenue of support to be sought out when in need. The elderly continue to use their families as their primary support network and turn to
formal services only when family resources have been exhausted or are not available (Chappell, 1985; Shanas, 1979b). For those elderly who have family support, the chance of institutionalization is significantly lower than those who do not have access to this type of support network (Gibson in Nusberg, 1984; Masciocchi, Thomas & Moeller in Quinn and Hughston, 1984; Shanas, 1979a). It is the availability of informal support, more than the actual care needs, that determines the likelihood of institutionalization (Bader, 1985).

While some studies have focused on quantitative measures of contact between family members, there has also been discussion in the literature of the quality and content of these contacts. The elderly are a very heterogeneous group and there is great variation in their histories, strengths, and needs (Neugarten, 1982). Authors have suggested that families are better able to respond to the idiosyncratic needs of the elderly due to their intimate knowledge of the person and their ability to provide frequent and flexible support (Shanas & Sussman, 1977). Eugene Litwak (1985) has suggested that families are best suited to non-uniform tasks such as emotional and social support. Technical or instrumental assistance such as housework or medical supervision is better suited to the formal organization of bureaucratic services.

Among the strengths of family support is its ability to promote a sense of personal meaning, identity, security, love, and caring for the elderly person (Dobelstein, Andrew & Johnson,
Brody, Johnson and Fulcomer (1984) in their study of the normative aspects of aging parent and adult child relationships found a strong commitment to caregiving especially in respect to the role of providing emotional support. The family continues to be the first resource for emotional and social support, crisis intervention and bureaucratic linkages (Shanas, 1979a). It is a source of security.

The family is able to replace lost roles for the elderly person and provide a context where older people can continue to experience a sense of competency and influence over their environment (Kuypers & Bengston in Quinn & Hughston, 1984). At a period of life when roles and responsibilities are lessening, the family is an arena where the individual can continue to function as an integral member of society. Locus of control has been demonstrated to be important to the elderly person's sense of well-being (Brown & Granick, 1983; Guarnera & Williams, 1987). Elderly persons often have a degree of control over their relationship with their families that is impossible to duplicate with formal agencies (Kivnick in Quinn & Hughston, 1984).

New terms are entering the jargon associated with elderly and multigenerational families. Phrases such as 'modified extended family' and 'intimacy-at-a-distance' are now common in the literature describing family roles and structure (Government of Canada, 1982). Families are the major tie between the elderly and the community. Although they may be distant, the
elderly are not isolated from their families (Shanas, 1979b).

The assumption by the state of responsibility for economic and some instrumental support has made it possible for families to develop more functional relationships that focus on the provision of social and emotional support (Anderson in Shanas & Sussman, 1977). These services free families from immediate survival issues and provide an opportunity for them to develop roles as liaisons, linking older generations and the bureaucratic maze of formal services (Shanas & Sussman, 1977). In this way the family is able to complement state functions with affective and idiosyncratic contacts.

The continued involvement of families in the care of the elderly needs to be examined in the context of changing demographics and family trends. The absolute number and proportion of the elderly in the population is increasing especially amongst the old old, those over eighty (Fact Book on Aging, 1983). While the family is seen to be an effective place to meet many of the needs of this growing population, there are limitations to family resources. The rarity of multigenerational families, decreasing family size, geographic mobility of nuclear families and the growing involvement of women in the work force make the continued involvement of families amazing (Brody, 1985; Government of Canada, 1982; Natural Supports Program, 1981). Family support adjusts, rather than dissolves when faced with changes in demand and resources (Quinn & Hughston, 1984). Despite the growth of state services,
families continue to be involved in care. Chappell (1985) found that people who used formal supports were more likely to have contact and receive support from family and other informal sources. When institutionalization does occur, it is often the result of a chronic stressful situation combined with limited family resources (Brody, 1985).

2. Stresses of Caregiving:

This discussion has highlighted some of the research and writings that have attested to the benefits and continued involvement of families in providing care, but there are also negative outcomes of this situation. The abundance of literature aimed at dispelling the myth of abandonment may have created a 'myth of enrichment' (Mancini in Quinn & Hughston, 1984). Most studies have focused on objective measures of involvement and have not addressed the quality of this involvement. A direct relationship does not exist between the provision of care and the quality of the caregiving relationship (Mancini in Quinn & Hughston, 1984; Qureshi & Walker in Phillipson and Walker) 1986). Nydegger (1983) feels that researchers and practitioners have tended to see the family in a rosy light and have ignored the possible negative side of many family relationships.

As in families at any developmental stage, relationships may be conflictual, based on obligation and duty without affection, and in extreme cases, even abusive (Carrilio & Eisenberg, 1983). There may be conflict between generations and
family members related to expectations and competing demands (Johnson, 1983). Jarrett (1985) examined intimacy and affection factors within informal networks and found that the stress of caregiving can cause distancing between family members. Families are not invincible and more than affection is needed in order to maintain positive caregiving relationships.

The role of caregiver is very stressful. As Bader (1985) summarized,

"Such caregiving is typically full-time, physically and emotionally exhausting, expected and unappreciated by family, friends and fellow taxpayers". (p.39)

Caregivers must often deal with demanding, constant and stressful care responsibilities with few personal resources. Multiple emotions of guilt, resentment, duty, anxiety, love and insecurity are often faced by caregivers (Seelbach in Quinn and Hughston, 1984).

Many of the caregivers of the elderly are elderly themselves. It is these people who are vulnerable to becoming isolated. Limited opportunities for socialization, restricted friendship networks, physical, financial, and emotional strains of caring for a frail person are realities of life for many people (Brody, 1985; Crossman, 1981; Masciocchi, Thomas & Moeller in Quinn & Hughston, 1984; Silliman & Sternberg 1988).

In a study of caregiver support, Kay and Kirby (1987) found many of the caregivers depressed, agitated and socially isolated.

The caregiving relationship is usually a dyad, not a family
activity (Johnson, 1983). Shanas (1979a) has suggested a principle of substitution where the role is determined by serial availability according to descending order of intimacy. A wife is most often the caregiver, followed by a daughter if there is no spouse. The burden usually falls to one person and the responsibility is seldom shared. Many caregivers are old, female, and are the sole support for the disabled person (Gibson, in Nusberg, 1984). The stress of caregiving is more likely to outweigh the benefits when the burden falls to one person (Johnson, 1983). Isolation plays a major role in the stress that the caregiver experiences. Rogerson (1984) found that caregivers with outside contacts such as employment, experienced less stress than those caregivers who were more isolated in their role.

The uneven gender division of caregiving is another negative aspect of family networks (Qureshi & Walker in Phillipson & Walker, 1986). Studies have repeatedly shown that women assume the majority of caregiving duties (Brody, 1981; Brody, Johnsen & Fulcomer, 1984; Horowitz, 1985; Stoller & Earl, 1983). With the changing role of women in the work place and within families, women are increasing becoming caught between competing values and needs (Brody, 1981). As women become less available to provide daily and intensive care in the home, the question arises as to whether or not the elderly will receive less care. Johnson and Catalano (1980) refer to women as the hidden victims as they attempt to meet the needs of multiple
generations and deal with competing workplace demands. Middle aged women are often employed, taking care of one or two parent generations and trying to meet the needs of children and husbands. The conflict between resources and expectations is especially acute for these women and as a result they face greater risk of burnout (Horowitz, 1985). They are faced with the choice of taking on yet more responsibility or burdening the guilt of not doing what they or society feels should be done for the elderly family member.

Role expectations and values associated with filial responsibility are further sources of stress for caregivers. Filial responsibility refers to the attitude of personal responsibility towards one's parents for protection, care and financial support (Hanson, Sauer & Seelbach, 1983). As middle aged children face increasing likelihood of providing care for a parent over many years, they also experience a growth of filial anxiety (Quinn & Hughston, 1984). Providing care for the aged is a new phenomena in our society. Historically, we have tended to see caregiving as a serial, rather than reciprocal relationship (Seelbach in Quinn and Hughston, 1984). People have not been socialized to assume caregiving roles with parents and are in effect, acting as pioneers in this new area. They have no clear definition of the content and limits to their role as caregivers. (Masciocchi, Thomas & Moeller in Quinn and Hughston, 1984). While caregiving is becoming a normative stage for many families, we still know very little about it (Brody,

"Filial responsibility has not been explicitly taught or discussed, rather it has been passed on from one generation to the next in a set of implicit assumptions that foster misperceptions and dysfunctional communication." (Seelbach in Quinn & Hughston, 1984 p.100)

The ambiguity over filial responsibility creates conflict and value differences between generations as to the degree and content of contact between generations. The adult child is faced with conflict between values of independence and obligation (Johnson, 1983). Cantor (1983) found in a New York study that there were many value and expectation gaps between generations. Those families with very close relationships and high expectations experienced more strain related to their caregiving responsibilities than families who maintained some social and emotional distance from the parents. This supports a statement by Quinn (1984),

"Although there are positive outcomes in accepting a helping role with a parent, potentially negative consequences far outweigh positive ones when filial expectations are high". (p.27)

The limitations faced by families and individuals providing care coupled with unclear role prescriptions creates a situation that is conducive to the development of stress and conflict. This conflict can lead to frustration and disappointment as both generations face unmet needs. The reality is that many families
are facing a situation where they are not necessarily less willing, but perceive themselves as unable to meet the demands that they are faced with.

3. Control Issues as Related to Caregiver Coping:

Locus of control has been related to well-being amongst the elderly and their caregivers in a number of studies (Brown & Granick, 1983; Guarnera & Williams, 1984; Pagel, Becker & Coppel, 1985; Slivinske & Fitch, 1985). Many problems of aging are associated with a loss of control over the environment (Slivinske & Fitch, 1985). Kuypers and Bengston (in Quinn & Hughston, 1984) assert that it is important to have a sense of mastery over life circumstances and that the family provides a context for the elderly to develop and maintain a sense of control. But, for the caregiver, depression, low morale, and self image as well as the ability to cope with daily problems may be affected by the perception of external control (Brown & Granick, 1983; Pagel et al., 1985). Well-being for the caregiver as well as the care receiver includes having power over decision making and influence over welfare and the involvement of supports (Mancini in Quinn & Hughston, 1984).

This discussion has outlined evidence supporting the involvement of family in providing care for the elderly as well as the stresses and limitations that this support network faces. Understanding the needs of family caregivers and how policy and programs should support these situations, necessitates an understanding of family dynamics and locus of control in the
caregiving relationship both within families and between formal and informal networks.

"If the sense of control and hence the adaptive abilities of older people are to be enhanced, influences on adaptation such as locus of control and health must be better understood." (Brothen & Detzner, 1983)

If the goal of formal supports is to encourage and facilitate continued care by family members, many of whom are elderly themselves, dynamics such as health, self perception and locus of control will be important.

4. Need for Support:

Evidence points to a situation where dedicated informal networks are trying to cope with care demands that are stressful and at times beyond their abilities. Families make many sacrifices and therefore intervention should be focused on these spouses and children (Cantor, 1983). Families are an effective and cheap source of care. Formal supports should aim to support and not substitute for the efforts provided by family caregivers (Bader, 1985; Mindel, 1979; Stoller & Earl, 1983).

To begin with, many authors feel that it is necessary to adopt a holistic definition of health and well-being that incorporates physical, mental and environmental health. Psychological and social factors should be considered along with physical and medical status. (Chappell et al., 1986; Government of Canada, 1982; Wilkin & Hughes in Phillipson & Walker, 1986).

This kind of an approach to health involves the individual in
the definition of well-being as well as the content and delivery of services.

Once this kind of definition is adopted, a more complementary role between families and the state can develop. There is a need to increase the co-ordination and interface between formal and informal support networks (Brody, 1981; Chappell et al., 1986) in order to maximize the benefits to both care networks and care receivers. These two levels of support have the potential to complement each other (Litwak, 1985) and in fact need each other in order to meet the wide range of needs that older families can face (Qureshi & Walker in Phillipson and Walker, 1986). Shanas and Sussman (1977) have suggested that the basic goal of these two systems is the same—support and care of the aged person—and that they can aid each other in reaching this common goal.

Understanding the need for support is complicated. To begin with, a better understanding of the older family must be developed as the first step in creating supplemental roles (Brody, 1985; Shanas, 1979a). The coping ability of a family and the individuals within the system is related to the development of the family, the meaning that is assigned to an event and the flexibility and functioning style of that family (Kuypers & Bengston in Quinn and Hughston, 1984). The needs of the caregiver cannot be determined from objective accounts of the situation. The perceptions and personal reactions of each individual must be accounted for (Chappell et al., 1986;
Courtney, 1986; Koff, 1982) along with the family history, old
issues and values (Brody, 1985; Mindell, 1979; Quinn & Hughston,
1984). The needs of the caregiver must be balanced, but not
overshadowed by the needs of the client (Chappell et al., 1986;
Silliman & Sternberg, 1988; Qureshi & Walker in Phillipson &
Walker, 1986).

The caregiving family often faces a variety of needs and
requires variety and flexibility in the services that are
available (Brody, 1981; Cantor, 1983; Courtney, 1986; Litwak,
1985). Chappell (1986) found that knowledge of services and
community support was related to social and economic status and
not to need. Another study found that closed family networks
had little information and delayed involvement with formal
supports (Ward, Sherman & LaGory, 1984). These finding support
the suggestions made by many authors that formal support to
families must involve education and preventive services
(Auerbach & Gerber, 1976; Cantor, 1983; Government of Canada,
1982). Increased accessibility, public awareness, flexibility
and responsiveness are necessary components of services geared
to family support. Families must be able to seek out and access
services before a crisis develops.

In her 1986 thesis, Courtney identified the lack of
information regarding the link between family need and community
services. It is important for families to learn to deal with
bureaucracies if they are to provide the link between formal
services and the care needs of elderly persons in the community
(Shanas & Sussman, 1977). This requires training and skill development (Bader, 1985; Mindel, 1979).

Financial supports have been suggested as useful in increasing the resources and control of family caregivers (Quinn & Hughston, 1984), but other studies have shown that relief from emotional and personal strain is more important to caregivers (Arling & McAuley, 1983; Kirby & Kay, 1987). Along with emotional support, caregivers need counselling to increase their self-awareness of the emotional drains and conflict that they face (Bader, 1985).

The common theme throughout all of these suggestions for supporting the caregiver is the need for services to be flexible and oriented to a system assessment of need that accounts for both the carer and the care receiver. Qureshi and Walker (in Phillipson and Walker, 1986) discuss the need to provide care within the family rather than imposing external solutions or attempting to provide relief by taking roles or responsibilities away from the family.

This review of the literature has, up to this point, touched on the role of family caregivers, the stresses that they face and some of the suggestions that are made for providing support to the informal network. The next section provides an overview of the literature that addresses the present structure of health care supports. Perspectives on the ways in which this system has both succeeded and failed to meet the needs of family caregivers will be presented.
Social Policy and Family Support

Given the need to provide support to families of aged persons and to develop a complementary relationship between formal and informal support networks, social policies and program development have shown some progress in this area, but there are several factors that work to constrain the introduction of more responsive services.

1. Values and Assumptions of the Present Service System:

In Canada, the system of services and benefits for the elderly encompasses the areas of income, housing and health care services (Government of Canada, 1982). The development of these programs has grown out of a set of values and assumptions about the needs of the elderly population and the responsibility of the state in meeting these needs. Understanding the limitations and potential of the formal care system requires an examination of the ideological perspective from which it has been developed (Dobelstein & Johnson, 1985).

Neysmith (1986) believes that there is a mix of objectives in many social policies. Collective responsibility of the state and society for meeting needs is combined with values of merit and individual responsibility. While some programs such as income security are presented as a societal obligation these programs continue to act as social safety nets. Public provisions are minimal and the bulk of responsibility for ensuring that needs are met continues to fall to families and
individuals. A pension system that rewards those whose income allows them to save for their own retirement is an example of this kind of attitude put into practice.

Society only reluctantly recognizes its obligation to meet the collective needs of the population and in doing so provides a minimum level of support. In the case of aging families, many services reinforce the belief in family responsibility. Supports are designed to provide care in the absence of family, rather than in conjunction with family (Weihl in Shanas & Sussman, 1977). Many home supports such as meals on wheels, or housecleaning, are withheld if it is felt that family members are available to fulfill the tasks. In order to develop services that adequately complement the existing involvement of informal networks, there needs to be a move away from this ethic of personal responsibility (Lyndon B. Johnson School of Public Affairs, 1977).

Beliefs and attitudes about the family have influenced the role that the state has taken in providing services. The family continues to be seen as a fragile institution. A delicate balance is believed to exist between government action and the independence of families (Natural Supports Program, 1981; Nusberg, 1984). The state is able to justify limited involvement and even a retreat from providing support as an attempt to restore the autonomy of families (Binney & Estes, 1988). The belief that state supports foster dependency combines with the belief that families are responsible to plan
for and meet their own needs as they age. The result is a minimal involvement of the state in family affairs. Intervention is geared only at pathological and deviant situations (Nusberg, 1984).

In Canada, there has been a belief in the 'holiness' and independence of the nuclear family. Conservative ideologies have lead to a practice of minimal involvement in areas that are believed to be private responsibilities of the family. The reluctance of our legal and judicial system to recognize child and spouse abuse and now elder abuse is a prime example of our reluctance to allow the state into the homes of its citizens.

Views of aging and the role of the aged in society also contribute to the development of social policies. The tendency towards non-interference in the lives of the elderly and families is reinforced by theories of aging such as Cummings and Henry's (1961) theory of disengagement. This theory supports policies that isolate elderly and remove them from mainstream society (Townsend in Phillipson & Walker, 1986). Ageism and stereotypes of the elderly are reinforced by the belief that aging is synonymous with dependency and disability (Chappell et al., 1986). Health care and support services for the elderly do not contribute to productivity. One Canadian report (Government of Canada, 1982) felt it necessary to justify services for the aged on the basis that they "should be seen as the mark of a civilized society" (p.47).

While attitudes about personal responsibility and the role
of government in meeting collective needs have influenced social policies in general, health care services in particular have been shaped by a traditional medical model of service delivery. This model focuses on pathology and healing, rather than physical, social and environmental health (Chappell et al., 1986; Wilkin & Hughes in Phillipson & Walker, 1986). Funding for services is directed at acute and institutional care. Services such as respite and other family supports that are not directly medical and disease based must continually justify themselves in order to receive government funding (Carrilio & Eisenberg, 1983).

Some authors have hailed the growth of geriatric specialties within medicine as a move to better understanding the needs of the elderly, but this trend serves to further compartmentalize the needs of the elderly (Wilkin & Hughes in Phillipson & Walker, 1986). Needs continue to be defined by outsiders on the basis of objective disease related criteria (Kaufman, 1980) rather than being based on social situations and individual perceptions.

The medical model that underlies the development of health services has influenced the type of services that are available and the way in which the formal system has developed to at times replace and at times complement the efforts of family. The next section provides a review of these policies.

2. Policy Development:

The literature contains two arguments; one supporting a
complementary role between formal and informal and another viewing the present state services as replacing family involvement. Formal health care services are seen by some to detract from family involvement (Kaufman, 1980; Natural Supports Program, 1981). These services are argued to be both the cause and effect of the decline of family involvement in caregiving. While there exists a potential for the development of a complementary role between these two sources of support, the formal system has failed to complement the existing reciprocal and informal supports (Townsend in Phillipson & Walker, 1986).

Brody (1985) believes that the focus on providing incentives to encourage families to continue caregiving ignores the already high involvement that many families have in the care of the elderly. Policies that limit options and resources available to families serve to perpetuate myths of family abandonment (Brody, 1985; Kaufman, 1980). The inadequacy of home supports that forces some families to seek institutionalization as a solution is an example of how the lack of supports results in the substitution of state for family care.

Townsend (in Phillipson & Walker, 1986) adopts a more Marxist argument when he states that much of the dependency of the elderly and their families has been structured by existing policies.

"Dependency of elderly has been structured by long term economic and social policies: elderly people are perceived
and treated as more dependent than are or need to be by the
state." (p. 15)

The system gives people few choices and treats the elderly as
passive recipients of service. Policies rule the schedule and
availability of home supports as well as the routine and content
of institutional life. The elderly person has little input in
what services he or she will receive and how that support will
be delivered.

A lack of family policies has been identified as a
significant factor in the inability of the present system to
adequately assess or provide support to families (Natural
or services that incorporate family involvement are rare (Novak,
1985; Townsend in Phillipson & Walker, 1986). The needs of the
elderly are isolated from their family and social contexts
(Natural Supports Program, 1981). There is little consideration
of interdependent relationships between generations and networks
of support. Townsend states (1986),

"In general a picture emerges of a very rough relationship
between need and service and little relationship of service
to the initiation or restoration of reciprocal services
among neighbors or members of family" (p. 41).

In recent years there has been increasing concern and
discussion about providing family support in the community.
This recognition has led to the development of Long Term Care
programs across the country. Despite this apparent shift in
priority to community care, the formal system has experienced limited success in being able to conceptualize and operationalize effective community support (Government of Canada, 1982; Townsend in Phillipson & Walker, 1986). Essentially, the problems facing aging families are new to individuals and society alike. There is still a lack of knowledge about how to define or assess intervention (Koff, 1982).

Earlier, the medical model was described as the underlying model in the development of health care supports. Politically, the health care system has been the easiest area in which to expand services for the elderly. Given the medical bias of this system towards a healing model and the use of high cost institutional services, Long Term Care seems to be tied to a system that has little interest in it (Kaufman, 1980). Community based services are essentially add ons in this system and do little to change the basic structure of health care services (Chappell et al., 1986). Wilkin and Hughes (in Phillipson & Walker, 1986) believe discussion of community services is only a lip service being paid to the need for family support. The state has no coherent strategy for changing the basic underlying assumptions of a medically based support system.

The shift in focus to community care can also be seen to coincide with a time of economic restraint (Chappell et al., 1986) and is really an attempt to find low cost care options.
This connection has been made by other authors. Carrilio and Eisenberg (1983) feel that the rhetoric of strengthening families is really a conservative attempt to shift burden of care to families without giving them any support to carry out the role. Brody (1985) states her position even stronger when she says that the "call for filial responsibility masks social irresponsibility" (p. 27). This shifting of burden to families has many hidden costs for both individual families and society (Bader, 1985; Carrilio & Eisenberg, 1983) as elderly face unmet needs and families abandon caregiving due to burn-out.

What the literature seems to say here is that despite its potential, the formal system has not yet developed a complementary role to the support of informal networks. The mix of ideologies and objectives undermines attempts to provide community based support to families. Still, there is still a strong potential for such a supplemental relationship to develop between families and formal care networks. (Chappell et al., 1986; Litwak, 1985). Litwak (1985) has described the two levels of organization and support networks as having different structures and resources that make them capable and best suited to meeting different kinds of needs. A Canadian report (Government of Canada, 1982) stresses that the role of government should be to maximize the abilities and resources of individuals and families in order to facilitate their ability to meet their own needs and potential.

In order to achieve this kind of relationship between the
state and families, the separation between health and social services must be dissolved. Supports must address health, economic and social needs in a coherent, comprehensive system of resources (Evans, 1985; Government of Canada, 1982). Economic and social policy must not be separated (Neysmith, 1984). Economic factors, productivity, resource and opportunity costs all have a significant influence on the attitudes that policy makers adopt towards the needs of elderly and the resources that will be made available to them and their families.

Community based service programs geared at the needs of elderly persons and their caregivers have made some progress towards supporting the role of families in the caregiving relationship. As one text stated, the,

"maintenance of continuity and preservation of independence is not simply an ideal wished for by society to relieve its guilt about the plight and neglect of the elderly or to recover from the burden of supporting them" (Quinn, Hughston & Hubler in Quinn & Hughston, 1984, p.216).

The future of attempts to further these aims is the subject of the next section.

3. Future Development and the Growing Care Gap:

Qureshi and Walker (in Phillipson & Walker) believe that the future will bring a widening of the 'care gap' as the needs of elderly families increase and state resources are reduced. Others feel that the growth of needs and an increasing belief in the right to services will bring about a change in social policy
Demographics suggest that the future will bring a conflict between the aged population and the working generations as each battle for limited resources (Government of Canada, 1982; Kernaghan & Kuper, 1983). The aged will be increasingly regarded as burdensome and unproductive (Binney & Estes, 1988). Other authors have suggested a different interpretation of these shifting dependency ratios that looks to the younger generation with their lower birth rates as the cause of these statistics, rather than the aging population (Evans, 1985; Novak, 1985). Focusing on the elderly as the group responsible for rising health costs and public deficit is a kind of blaming the victim (Binney & Estes, 1988). Evans (1985) argues that increased service costs are due to conscious and deliberate choices that are made within the health care system and are not the function of uncontrollable factors. In a system that medicalizes problems and makes them a source of corporate profit (Novak, 1985) a bias exists towards expensive care and institutional services.

Carrilio and Eisenberg (1983) assert that this artificial conflict between generations and competition for apparent scarce resources deflects attention away from state responsibility for service provision. The growth of private services and the move to privatize many government services will have a negative impact on the elderly. Profit based services will further the focus of resources on the acute needs of a younger productive
The absence of any strong lobby group in Canada makes it difficult for older generations to assert their right to service (Government of Canada, 1982). Despite the great diversity of this population, they have begun to show increasing political influence when threatened with action such as the de-indexing of public pensions.

The needs of the elderly are often chronic and require long term planning. It is important that statistics that support continued family involvement not be used to justify non-action on the part of government (Koff, 1982). Policies that call for increasing family care often result in increasing the responsibility of women and exploiting the guilt and duty already faced by many caregivers (Binney & Estes, 1988; Brody, 1981; Quershi & Walker in Phillipson & Walker, 1986). It is important that policy makers and service providers realize that the strength of families cannot be increased by increasing the burden that they must shoulder (Carrilio & Eisenberg, 1983). The future potential for the development of appropriate and supplemental services that serve to support family caregiving requires a better appreciation and understanding of the role, benefits and limitations of this support network.

Respite Care Services as a Family Support

Respite care services constitute one of the few direct attempts to provide family support for caregiving and bridge the
gap between formal and informal care services. To date, there has been limited research on the needs and outcomes associated with such programs. Allen (1983) conducted a comprehensive study of respite services in Britain. She addressed needs, utilization and outcomes of a number of institutional and residential respite programs from a variety of viewpoints including professionals, clients, and caregivers. The Foundation for Long Term Care in New York (1983) has also produced a report that examines respite at a number of sites in the state.

These two reports discuss respite as it applies to institutional based services only. As well, the British and American health care systems differ from the Canadian model and this limits any generalizations that can be made from their findings to the Canadian experience.

Much of the other published research in the area of respite has focused on quantitative outcome measures of small scale or isolated programs. While some studies have looked at respite programs that include institutional, day care and in-home services (Caserta, Lund, Wright & Redburn, 1987; Kirby & Kay, 1987; Spence & Miller, 85-86) most have focused on institutional based respite only (Allen, 1983; Berman, Delaney, Gallagher, Atkins & Graeber, 1987; Courtney, 1986; Foundation for Long Term Care, 1983; Scharlach & Frenzel, 1986; Seltzer, Rheume, Volicer, Fabiszewski, Lyon, Brown & Volicer, 1988).
1. Objectives of Respite:

The research that does exist identifies several purposes and objectives for such programs. Delucy, Galle & McCue (1986) define respite as,

"temporary care of frail elderly and disabled to permit family caregivers to relinquish their duties, stress and responsibilities for time-limited periods to maintain their physical and emotional strength". (p.467)

By providing relief for the caregivers, respite maximizes formal resources. Many programs are developed in the hope that they will delay or prevent institutionalization (Allen, 1983; Berman et al., 1987; Brader, 1985; Foundation for Long Term Care, 1983) and improve the quality of care that the family caregiver is able to provide in the home (Scharlach & Frenzel, 1986).

Spence and Miller (1985-86) have identified the difficulty policy and program designers face in conceptualizing what respite is or should be. Respite is a service that is directed at the family, not individual health needs. Unlike most welfare or health care services, respite is directed at the able-bodied person. Other authors have also identified this dilemma and how respite care services have often become defined as an indirect intervention on behalf of the identified client.

"Respite care explicitly recognizes that the needs of disabled individuals can often be met most effectively by providing support for their caregivers." (Scharlach & Frenzel, 1986, p.81).
Scarlach and Frenzel (1986) go on to identify the role that respite plays in developing an integrated and complementary relationship between formal and informal supports.

"In this way, respite care services reinforce and build upon the existing strengths of the natural support system and thereby promote a much needed interface between formal and informal providers of care while implicitly recognizing the impossibility of separating social and health-related needs of long term care." (p. 81)

2. Identified Need for Respite:

   In her study, Allen (1983) identified the tendency of many respite programs to be established on the basis of a set of assumptions that such support programs would necessarily be a 'good thing'. The pressure to provide cost effective service and to maximize community use of limited state resources, has resulted in a situation where respite programs have been established without extensive needs assessments or research on objectives. In an earlier section of this chapter, the burden and stress faced by caregivers was documented. In response to this realization of the involvement that families have in caregiving, respite programs have been established. However, it is not always clear whose needs are being addressed (ie. budget needs, caregiver or client needs) and what the hoped for outcomes are.

   Most of the studies on respite care have identified the importance of assessing the caregivers' needs and providing
services that will relieve the stress and burden faced by these caregivers (Allen, 1983; Crossman et al., 1981; Scharlach & Frenzel, 1986; Zarit, Reever & Bach Peterson, 1980). The caregivers' perceptions of their situation as well as objective indicators of responsibility were seen as important in assessing need. (Crossman et al., 1981; Foundation for Long Term Care, 1983) The fact that many caregivers are women and face certain stresses and role expectations related to their gender (Bader, 1985; Scharlach & Frenzel, 1986; Zarit et al., 1980) are other important factors in understanding the need for respite care services.

The need for some kind of relief from the constant burden faced by caregivers was found to be prominent in most of the study samples (Berman et al., 1987; Crossman et al., 1981). Berman et al. (1987) found that the caregiver's lack of relief from constant burden was the most common cause of institutional placement. Zarit and associates (1980) found that the burden of the caregiver was related more to social supports than the client's behavior and the duration of care. It was felt that respite was needed to expand the support network of the caregiver. In a study of users of respite in Vancouver, B.C., Courtney (1986) found that mental strain, physical strain and the influence of support networks were the most important factors that led to the need to use respite. Along with time away from caregiving responsibilities, some authors felt that respite should incorporate emotional support and counselling
While the discussion of respite needs has focused primarily on the caregiver, the care receiver's needs have also been identified as important. Care receivers may have multiple medical and care needs that can include dementia. These factors complicate the caregiving situation (Bader, 1985). Spence and Miller (85-86) concluded that it was important to assess the needs of the client in determining if respite would be beneficial to the family caregiving situation. Allen (1983) found that possible negative outcomes of respite placement needed to be weighed against the benefits to the caregiver in assessing need and appropriateness of respite care. It may be possible for both the client and caregiver to benefit from respite therefore both the individuals as well as their relationship must be part of service planning (Kirby & Kay, 1987).

3. Outcomes of Respite Programs:

The program evaluation and outcome studies revealed both expected and surprising results. Scharlach and Frenzel, (1986) in their study of a veterans respite program in California found improved physical and mental health, better relationships with the care receiver and increased confidence to continue as caregiver after the use of institutional respite. They found that the impact on morale was greater than physical needs. Kirwin (1985-86) concluded that adult day care benefited families by providing both relief and a link with formal
services. Generally, most studies reported short term benefits for the caregiver (Allen, 1983; Spence & Miller, 1985-86) although there were sometimes neutral or negative outcomes reported for the care receiver such as increased confusion (Allen, 1983; Foundation for Long Term Care, 1983; Seltzer et al., 1988).

Courtney (1986) in her study of how respite care met the needs of caregivers, found that needs were met only during the care episode and that there was limited carry over once the caregiving responsibilities resumed. The relief and support was not seen to have a lasting effect.

Contrary to the objective of delaying institutionalization, several studies found that users of respite became more receptive to institutionalization. Respite seemed to have the effect of acting as a transition to more permanent institutionalization (Allen, 1983; Courtney, 1986; Foundation for Long Term Care, 1983; Scharlach & Frenzel, 1986) as families were able to become more familiar with institutional life and were given time and opportunity to re-evaluate their role and future as caregivers.

Although not preventing institutionalization, there is some speculation that the relief that respite offers may relieve stress and prevent the development of abusive or dysfunctional caregiving relationships (Allen, 1983; Foundation for Long Term Care, 1983).

These limited studies of respite point to the need to have
a flexible and wide range of services available to provide physical, emotional and social relief for caregiving families (Bader, 1985; Kirby & Kay, 1987; Zarit et al., 1980). Respite must integrate the needs of the caregiver into the system of long term care supports (Scharlach & Frenzel, 1986). The service needs to be flexible and able to respond to emergency and changing circumstances of the elderly (Murden & Faro, 1987). Accessibility and awareness of service options must be increased for caregivers (Caserta, Lund, Wright & Redburn, 1987; Courtney, 1986).

Allen (1983) identified the benefits of having free standing respite facilities that are specifically geared to the needs of short stay respite clients. Within larger long stay facilities the needs of short stay clients may be given low priority by staff who have limited time to assess and respond to the unique situation of a respite client surrounded by more permanently institutionalized elderly. Staff should be sensitive to the needs of short stay clients (Foundation for Long Term Care, 1983).

Respite needs to incorporate more than just short stay institutional placements. A comprehensive system of facility, day care, and in home respite would provide the opportunity for families to access a variety of services to suit their needs.
Summary

This literature review has focused on three areas: the role of the caregiver and caregiving relationship; the role of the state and social policies in developing supportive and complementary services; and research findings related to respite care services. Respite care services are a relatively new phenomena and research on such programs is still at an early stage. In order to understand the role and potential for respite care, it was necessary to examine the social and political contexts within which such services are developing.

It was found that families continue to remain highly involved in the care of elderly persons despite high stress levels, competing demands and limited personal resources. Without some form of support and assistance, many caregiving families are at risk of breakdown and face a loss of control over their family and personal lives. Services that are available have developed within the health care system. Despite attempts to recognize family involvement and shift to community based services, values of personal responsibility, family autonomy and a medical model of service provision have continued to shape the content and delivery of many of these services. This review has identified the failure of the formal system to develop a supplemental role to family caregiving.

Respite care services, the focus of this study, were found to be often based on inadequate research or understanding of caregiver and family needs. While respite care offers an
attempt to support family caregiving efforts and build a more complementary relationship between formal and informal care, its potential is limited by these gaps in knowledge. It is not acceptable that such an important area of service be developed on the basis of assumptions about need and what constitutes appropriate services objectives and delivery.

This study, as will be outlined in the next chapter, takes an exploratory, grounded theory approach to developing a conceptualization of need for caregiver support and respite. The potential for future conflict and competition over scarce resources and the growth of a care gap as our population ages, demand that researchers and policy makers take a new and fresh look at the way we understand care needs and the way in which services are delivered.
CHAPTER 3

METHODOLOGY

This chapter provides a description of the methodology followed in this study. A qualitative, grounded theory approach was used in an attempt to build substantive theory relating to the need for respite care services for the elderly and objectives for such services.

Rationale for Qualitative Approach

The area of respite care services for the elderly and their families is a relatively new undertaking within health care programs. Research to date has been relatively sparse as earlier chapters have noted. Canadian research has focused on small scale, quantitative outcome studies. Very little published work addresses the issue of 'need' in the community through substantiating research or provides data for establishing objectives for such services. Understanding or evaluating respite services in a quantitative manner is very difficult and impractical when you consider that the salient variables are not known. The beginning point for research in this area as in other new service areas must be with the establishment a grounded understanding of what constitutes 'need' for such a service. From this basis, the researcher can formulate hypotheses concerning appropriate service objectives and interventions best suited to meeting these needs.
A qualitative grounded theory approach attempts to generate, not verify, theory (Glaser & Strauss, 1967). Qualitative data is rich in depth and detail. It attempts to understand people in their own terms through recording their actions and words. The method is both holistic and inductive (Patton, 1980). Following this approach, the researcher collects, codes, and analyzes data simultaneously. He or she conceptualizes and formulates theory as it emerges from the data (Glaser & Strauss, 1967).

The benefits of this approach are varied. It allows the researcher to study a phenomena from the point of view of the participants. Through the simultaneous collection, coding and analysis of data, one is alert to new information and new ways of perceiving the phenomena under study. Respondents are given open-ended opportunities to express their opinions and relate their perceptions of the situation. Data are not forced into predetermined categories or shaped by existing points of view. Miles and Huberman (1984) state:

"Qualitative data are more likely to lead to serendipitous findings and to new theoretical integrations; they help researchers go beyond initial preconceptions and frameworks (p.15).

This study was not aimed at establishing accountability or verifying effectiveness of a respite service. It was aimed at establishing a beginning conceptualization of what constitutes need for respite care and developing hypotheses about how that
need may best be addressed.

Sample Selection

This section addresses the criteria and procedures involved in the sample selections for this study.

Two groups were studied in this research project. The perception of need and criteria used to evaluate effectiveness can vary according to one's position in the process (Allen, 1983). Whether one's viewpoint is that of an administrator, gatekeeper, client, or caregiver, how need is seen and what kind of services are felt to be appropriate or necessary may vary. It is therefore important to consider multiple viewpoints in developing a holistic understanding of the concept. Time restraints limited the number of perspectives to be studied in this project to two.

When looking at the issue of need for respite services, the family caregiver's viewpoint is essential. Unlike many other health care services, respite care is targeted at the 'well' family member. Existing objectives and stated purposes of respite services identify the caregiver as the major recipient of benefits. As the consumer of the service, their perspective is key to understanding community need for respite. It is the caregivers' needs that the program has been designed to meet.

LTC case managers as referral agents also have an important role in the interpretation of need for services. It is these people who control much of the information dispersal and access
to programs. Families access services through these 'gatekeepers'. Regardless of what policy manuals may say, it is these gatekeepers that determine how the service is carried out and who it reaches (Allen, 1983). They constitute the interface between need and service and therefore become an important place to enter the LTC system in research.

It was decided to focus the research on these two groups, family caregivers and Long Term Care Case Managers. Given the design and purpose of this study, it was necessary to keep the sample sizes relatively small to enable the collection of detailed qualitative data. In a qualitative, grounded research project, the purpose is not to establish generalizable findings, but to explore in depth the variation and scope of perceptions of these two groups.

1. Case Managers:

Criteria:

A sample size of ten was decided upon. Although the original intention was to randomly sample these ten from across the city, time and administrative considerations resulted in the sample being confined to case managers in two health units. Of the ten approached, nine agreed to participate in the study.

Selection Procedure:

Approval was sought from Continuing Care administrators, the health unit administrator and the Long Term Care Coordinators in each office. The researcher then attended staff meetings at each unit to present the research proposal and
answer questions that the groups had regarding the procedures or their involvement. Short questionnaires including a letter of explanation were then left with the case managers. The completion of the questionnaire constituted their consent to participate in the project. Nine case managers completed the questionnaire.

2. Family Caregivers:

This sample was chosen from one health unit in the city by applying a predetermined set of criteria to a random sample of LTC program clients. The sample was not purposive in that the original sample was obtained by random selection. Again, the initial aim was to contact and interview ten family caregivers. Primary concern was to ensure variety, not necessarily representativeness of the sample. While consideration was again given to drawing the sample from a broader geographic area, negotiating entry to files in numerous health units and arranging with numerous assessors and supervisors to access the clients and their caregivers would have proven too time consuming given the time and task parameters of this project.

Criteria:

A set of criteria was identified and used in obtaining a sample of high risk caregivers. The following are those criteria and the rationale behind their use.

1. Client be over the age of 65.

As this study was focusing on the needs of families caring for elderly infirm relatives, the arbitrary and customary age of
65 was adopted to identify those considered to be elderly.

2. The client be assessed at an IC2, IC3 (intermediate care level 2 or 3) or EC (extended care) levels by the Long Term Care program.

Although caregiver relief may be necessary in any caregiving situation, those where the client's physical needs are great or there is an element of confusion or dementia present the greatest risk of breakdown and need for support. Clients assessed at intermediate care levels often face multiple medical problems and experience functional dependency in several areas of daily functioning and personal care. The extended care client is usually immobile and requires assistance with transfers as well as other personal care tasks. At these levels of care, some level of dementia and/or memory impairment is common.

3. The caregiver reside in the same home as the client.

This study was focusing on the needs of caregivers faced with daily and continual caregiving responsibilities. Caregivers residing outside the home may have different needs and face different issues than those residing with the client.

4. The caregiver must be identified as the primary source of support.

Concern in this study was with the burden faced by persons carrying the bulk of responsibility for caregiving.

5. The Long Term Care file contain some notation referring to caregiver stress, burden, or need for respite.
This criteria further focuses the sample on a high risk population.

6. The caregiver be fluent in English.

Detailed and direct information about perceptions and needs is hampered by the use of interpreters.

Procedure:

The caseload printouts for March, 1989 were obtained from each case manager in the target health unit. These books include client names, addresses, care levels, and assessment dates. These books were reviewed to compile a list of all clients assessed at IC2, IC3 or EC levels and with non-institutional addresses. From the original population of approximately 1500 Long Term Care clients in this health unit, a sampling frame of 198 was compiled from the review of case books. A random sample of seventy-five names were chosen from this list.

The next step was to review the charts of these seventy-five Long Term Care clients. This was done using a one page data sheet that gathered information relating to the criteria outlined above (see Appendix D). Of the original sample of seventy-five, twenty-two met all of the original criteria. Further investigation revealed that two clients had died, two were hospitalized, two cases were not appropriate as caregiving situations and another did not have an English speaking caregiver. Another six refused to participate for a variety of reasons including fear of client reprisal and personal
discomfort with research involvement.

Initial contact with the primary caregivers of the remaining nine clients was made by the case manager involved in each situation. The case managers briefly explained the purpose of the research project and determined if the caregivers were interested in participating. Once verbal consent was obtained through this telephone contact, the researcher mailed explanatory letters to each family caregiver (see Appendix A). These letters were followed up by a telephone call from the researcher to establish the caregiver's continued willingness to participate and to arrange an interview time at the convenience of the family.

The resulting sample of nine consisted of two daughter-in-laws, four daughters, and three wives. All caregivers in the sample were female. Two interviews were conducted with other family members present to help interpret and relieve caregiver anxiety about the interview.

Data Collection Procedure

Data were collected from two groups of respondents. Each group will be dealt with separately in this section.

1. Family Caregivers:

Interviews were conducted with family caregivers in their homes between March 1988 and May 1988. Each interview lasted 60 to 75 minutes. All interviews were audio recorded by the researcher and later transcribed.
The interviews were conducted using a flexible focused format. There was no fixed order or wording of the questions. The interview followed a discussion format that adjusted to the topics and issues raised by the caregiver while also addressing basic issues outlined by the researcher. (See Appendix C for a copy of the outline and suggested prompts used by the researcher during these interviews.) The general issues addressed in the interview were:

1. The caregiver experience, sources of stress and difficulty.
2. Available informal and family supports and caregiver attitudes towards using these supports.
3. Use of formal supports and the benefits derived.
4. Caregiver perceptions of the balance between use of formal and informal supports.
5. Perception of future needs and ability to cope.
6. Knowledge and attitudes concerning respite services.
7. Suggestions for change and improvement in formal supports.

As the interviews progressed and concepts began to emerge from the data, questions focused more on the caregiver's perception of their role and attitudes towards accepting support from either informal or formal sources.

2. Case Managers:

Data were gathered from this group of respondents using two methods. Initially a case scenario questionnaire was
distributed to each case manager. This questionnaire consisted of four brief case descriptions of situations where the caregiver was experiencing some form of stress or difficulty coping. The scenarios were compiled by the researcher and were designed to reflect a range of caregiver ages, gender differences, generational variations, resource availability, and relationships with clients and extended families. The client descriptions incorporated a variety of diagnoses, functional abilities, duration of disability and prognoses. Personal experience of the researcher and feedback from pretests and the research itself confirmed the aim of representing a variety of 'typical' high risk community situations.

In response to the scenarios, the case managers were asked to: 1) Identify the major issues in the situation; 2) Identify the supports and stresses to the caregiver; and 3) Provide recommendations for services (see Appendix E).

Each questionnaire was completed individually and took between 45 and 60 minutes. The researcher reviewed each questionnaire and used the information as a basis for conducting follow-up interviews with the case managers.

Focused interviews were again used with this second sample. Each interview was conducted at the case manager's health unit during April, 1988. Approximately 60 minutes was needed to complete the interview. These interviews were audio recorded and later transcribed. As with the caregiver interviews, the question wording and order was not fixed and was adjusted
according to issues raised by the questionnaire and topics of importance as seen by the case manager (see Appendix F for an outline of sample questions and prompts).

Open-ended questions and a discussion format was used to elicit information on the following issues:

1. Relevance of the questionnaire and issues raised as compared to perception of community need.
2. Perception of need in the community for respite or caregiver support services.
3. Benefits and limitations of formal respite services.
4. Criteria for assessing need for respite services.
5. Perception of family involvement, support and responsibility for caregiving.
6. Recommendations for changes or improvements to better meet identified need.

Data Analysis

Data was analyzed using guidelines for constant comparative analysis developed by Strauss (1987) and qualitative analysis techniques developed by Miles and Huberman (1984). The following is a descriptions of the methods used to organize and understand the data produced by this study. While some procedures preceded others, many occurred simultaneously.

1. Open Coding:

Once the interviews were transcribed, a system of open coding was used to identify the topics, issues and possible
themes emerging from the data. Each interview was listened to and then read to obtain general impressions of the content. The transcriptions were then reviewed line by line, coding the substance of the content in the margins.

Open coding reflected what the data were pertinent to, what categories were being indicated and what was happening to the data (Strauss 1987). Many of the codes reflected the respondents own words and thus arose directly from the data. Other codes were related to constructs found in the literature related to this topic. This process of open coding provided the spring board for development of later core categories and construction of themes. As the researcher moved through the data the codes changed and the analysis process required continual review of previously coded data to create a cohesive impression of the data.

The transcriptions and all initial coding was reviewed repeatedly to identify categories by clustering open codes according to more general themes. These categories reflected relationships between statements made by respondents to various questions. For each set of interviews seven to eight categories of issues were eventually identified.

2. Axial Coding:

Axial coding involved intense analysis around one category at a time. Each category was dimensionalized and its properties identified. Concepts were developed through analysis of conditions, consequences and interactions of various
subcategories and codes. The researcher began to identify and hypothesize about relationships between various categories and subcategories.

Once the interviews were all coded and categories identified, copies of the interviews were made. Each transcription was color coded to facilitate identification of the originating interview. Individual comments of the respondents were separated (cut and paste method) and clustered according to the conceptual categories identified. Comments within each category were then further examined and analyzed to identify underlying conditions, themes and issues. The comments were organized with a narrative on sheets of paper to create a core text of the data.

3. Development of Core Categories:

Once the interviews had been coded, broken down and reorganized according to conceptual categories emerging from the data, the process of identifying core categories became the focus of the analysis. Core categories are central themes that appear repeatedly throughout the data, relate easily to other categories and have clear implications for more general theory (Strauss, 1987). It is the core categories that generate theory from the data. The researcher looked for relationships between subcategories and their properties and worked to render the core category dense and saturated. Core categories were proven repeatedly by their relationship to other categories and their ability to account for maximum variation in the data and
analysis with a few concepts (Strauss 1987).

Core categories did not suddenly appear at the end of open and axial coding. While the researcher worked through the beginning stages of the analysis, ideas and impressions began to emerge. These were further developed after the initial groundwork was completed.

4. Memo Writing:

Memo writing occurs at all stages of the analytic process and forms the backbone on which categories and core themes are developed. This process involved stopping at any stage to write down insights, questions, hypotheses. Memos were kept separate from the data. They were the major integrative mechanism for understanding the data and formed a running record of the theory development.

5. Integrative Diagrams and Charts:

This process further aided the researcher in developing and fully integrating concepts. While Strauss (1987) gives this technique some attention under a discussion of memo writing, it is Miles and Huberman (1984) that explored this method of analysis in detail.

Displaying data in a visual and summary way through the use of a matrix, chart, checklist or figure can aid the researcher in further conceptualizing and integrating core categories and is useful to the reader of the research in understanding the interrelationships between categories and core themes.

This method was used by the researcher in the latter stages
of analysis in order to summarize relationships between subcategories and the main theme and to illustrate similarities and differences in the two respondent groups.

6. Report and Thesis Writing:

The last stage of any analysis and research process is the writing of a report. The report contains a summary of the findings organized according to the conceptual categories that emerged from the research. Anecdotal support is used to illustrate the categories. A separate discussion section relates the core categories or themes to the findings and literature. Conclusions in the form of hypotheses and substantive theory relate the issues of community need and formal system supports to the dilemma of creating a balance of state and family caregiving.

Summary

This chapter has outlined the need to address this research topic using a qualitative grounded theory design. Data collected from family members and case managers was used to develop concepts and substantive theory relating to understanding community need for respite services and development of proposed program objectives.
CHAPTER 4
PRESENTATION OF RESEARCH FINDINGS

This chapter outlines the findings of the research in narrative form. The quotes have been edited from verbatim transcripts in order to present concise representations of the responses. During the data analysis, data from each set of interviews were arranged into broad categories or themes. It is these categories that create the outline for this presentation. The interviews with the case managers will be discussed separately from those with caregivers. Each theme will be identified and followed by quotes and summary statements that reflect the range of expression of this area. A short summary of each theme will include some initial interpretive comments. The following chapter provides further detailed interpretation and a theoretical discussion of the implications of these findings.

Case Manager Questionnaires

In this section of the research, nine case managers completed questionnaires. The respondents were from two geographically adjacent health units. There were four nurses, three social workers, one occupational therapist and one physiotherapist included in the study. Their experience in the Long Term Care Program ranged from nine months to six years, with most having at least three years experience.
The responses to the case scenarios in the questionnaires were brief and in note form. For all the respondents, a broad variety of family issues and stresses were identified and numerous services suggested as supports. The questionnaires provided a base for discussion in the interviews and thus data from these questionnaires is integrated into the interview responses.

Case Manager Interviews

This section provides a summary of the comments and themes that emerged from the interviews with case managers. The data have been grouped into broad themes including the respondents' recognition of need, perceived benefits of respite, barriers to meeting need from within formal and informal networks and finally their thoughts and recommendations for change.

Before proceeding with the presentation of these themes, responses to two specific questions in the interview will be presented as they provide a context for the other responses. Firstly, all of the case managers commented specifically on the questionnaire. They found the scenarios representative of issues and dilemmas they see in the community. The questionnaire was described as "quite familiar" and "very typical and appropriate". These comments support the assumption that responses and discussion of these cases reflects case managers' reactions and thoughts about community needs.

As in their work situations, there were gaps in the
information. This meant that care plans were made on the basis of certain assumptions. Questions were raised indicating the need for further clarification of some situations.

Interviews were initially based on a discussion of the questionnaire which can be taken as indicative of community issues. The interviews progressed beyond this focus and encompassed broader discussion of case loads and attitudes towards the community and LTC program.

Respondents in this study were not provided with a definition of respite but rather were asked to define respite as they interpreted the concept. This project was intended to focus on individual perceptions of what respite is or should be rather than reflect an official definition. When asked to describe their view of respite, case managers provided a broad definition that incorporated a variety of services considering physical, emotional, and mental health. It was seen to provide "a reprieve or break", "rest and stimulation", and to "relieve emotional and physical strain". This could be accomplished through respite beds, adult day care, homemakers or caregiver support groups.

Respite was defined by the benefits it provides, not by the structure of the service. Primary focus of respite was seen as meeting the needs of the caregiver. It puts energy and support into the caregiving system and therefore has a simultaneous impact on the client and other members of the family system. It is a "chance for them to have some stimulation and enjoyment and
rejuvenate each other".

With this understanding of the basis for the interview and the respondents' views of respite, this presentation will now proceed with the discussion of themes.

1. Recognition of Need:

Much of the discussion in the interviews focused on how the case managers perceived need for respite services. Their responses are divided into a discussion of issues related to the family and informal supports and issues addressing the role of formal supports.

Issues of the Family and Informal Supports

This section includes discussion of the limitations of informal resources, role issues, the extensive responsibility of caregiving and the need to validate individual needs.

A. Limitations of Informal Resources

All of the case managers recognized that there are very real limitations on the resources of families and their ability to cope with the demands of caregiving. Many of these limitations related to individual skill level, family functioning style, patterns of handling conflict and the history of the relationship.

One case manager described the need to identify personal limitations of the caregiver when assessing their need for services.

"She phones up and says that she is having problems coping with the care of her mother and she can't go on. She wants
to put her on a wait list. I will visit. That daughter may be for whatever reason not able to cope with care once it gets into a lot of personal care, so my feeling would be in that situation that this family is not able to care for this person versus ten others where the family is able to cope with personal care."

In addition to skill level and ability to deal with stress and conflict, the history of the family relationships was also identified as an important influencing factor. As one case manager stated,

"I think that one of the most difficult things that families find is caring for an elderly relative who has been an unpleasant person in the past and is now in need of a fair amount of personal care. They find it difficult to give the care and do things for that person because they are probably still difficult and unpleasant."

Along with interpersonal issues impacting on the caregiving potential many external limitations and competing demands were also commented on. Many caregivers, especially those in the middle generation, face competing work and family demands. Resources were described as limited due to shrinking family networks, geographic distances, and care demands from other generations.

Some of the case managers identified the need for family members to limit their involvement in the caring of an elderly relative in order to balance competing demands in their lives.
"The daughter that has her own young family is willing to put the amount, whether it is a weekly visit or whatever, but they have limitations in terms of juggling their own roles and lives--and it is probably wise. If they start taking on all the parental problems...it really would become overwhelming."

There was general agreement amongst the respondents that families are very involved and supportive in the care of elderly relatives but that this support has limitations. This case manager discussed the inability of families to increase support in the face of increased demands.

"in a normal family the support from the family is the same but when the situation becomes horrendous, it (family support) still stays the same....It doesn't kick in more"

B. Role Issues:
Roles issues were another area of consideration. Here gender role was associated with caregiving.

"Let's face it, women are always taking care of, and I am aware of that. Let's help the women as much as possible."

This case manager summarized some of the difficulties that families have adjusting to what they see as role reversal.

"Somebody that they have looked to as a parent and looked to for guidance and advice is suddenly their child. Some people are very uncomfortable with that....It is a difficult situation to know how far to go in reversing roles and how much they should allow their elderly relative
Caregivers were seen to lack role models for their newly acquired responsibilities.

C. Extensive Responsibility:

Most case managers saw the task of providing care as an all-consuming responsibility. They described a great number of demands, physical tasks and responsibilities. It was felt that this high degree of responsibility leads to mental and emotional strain on the part of the caregiver and the need to have some relief or respite from the situation.

"In a lot of these cases they have been trying to cope for several years....They (the client) can't be left alone so the caregiver is housebound, trapped in a situation."

As one case manager stated,

"We would be keeping the caregivers in a better state of health and psychological well-being if we had some respite for them."

When describing the effect caregiving has on every aspect of the caregiver's life, case managers presented the need for services to address physical, emotional and psychological needs.

D. Validation of Individual Need

Several of the case managers discussed the need to give caregivers the time and opportunity to pursue interests and activities separate from their caregiving role. Services such as respite were seen as important in order to provide support and validation to caregiver's right to improve the quality of...
their lives.

"A lot of the caregivers are retired and they have always thought of retirement as doing certain things....If they are being a caregiver, they need time out to pursue their own personal goals."

The following quote by a case manager reflects how many caregivers have difficulty identifying their own needs or giving themselves permission to seek help or support.

"For some caregivers, they need a lot of encouragement and counselling to pursue some of the fun things while being a caregiver. I know one lady whose husband had very bad alzheimer's and she said to me ‘I can't have fun and laugh. This isn't a laughing situation.'"

Case managers saw a strong need to establish services that take into consideration the unique circumstances and needs of caregivers. The need for support was presented as extensive and varied given the resource limitations and extensive burden faced by many families. One case manager stated that "relying on family isn't a good long term solution".

Issues Related to the Role of Formal Supports

Case managers also discussed their perception of the role of Long Term Care and other aspects of formal care services. Given the family and community need for respite and family support services, this section examines what case managers saw as the role of formal supports under the headings of economic justification, the need to assume supplemental roles, the need
to balance client and caregiver needs and the benefits of supporting family care.

A. Economic Justification:

Providing support to the caregiver was seen as a cost effective intervention that benefits the caregiver, client and the Long Term Care Program by facilitating ongoing family and community care.

"Unless we are going to put all of these people in facilities, we are relying on families to take responsibility for the care of these clients. If we don't give them some kind of support and learn what their needs are, how can we expect them to do an adequate job of caring for clients."

In addition to this concern for the best interests of the client, support services prove to be economically attractive in a time of government restraint.

B. Need to Take Supplemental Role:

Families were recognized as the central support and that government services such as Long Term Care were described as a supplement to the efforts of informal networks. The need for both family and formal supports reflected the limitations seen in each system.

"I think that we need a combination of both... and I think it is wise to ask family what they can do as a family...It is fine to say that we want to support you at home as long as possible but again financially we know our limits."
This supplemental relationship between the two sources of support for elderly persons was also presented as complementary.

"I think the strengths for the family is the emotional support....because they are often off to work, LTC can do this housework stuff. I really think that families carry the bulk of caregiving. I see us supplementing what the families can do."

This case manager reflected the belief that families and formal services may find themselves better suited to providing different kinds of support and assistance.

In addition to physical and resource limitation impacting on the relationship between Long Term Care and families, there is the issue of co-operation and responsibility. The responses of the case managers indicate that they do not intend to replace family, but rather, place a high priority on a kind of cooperative team work that leaves the family with some control.

"We are home support, not home takeover. We are going to help but we aren't going to take it all away."

"It benefits both parties....to let families feel that they have their part and we are not just walking in there and ordering them around."

Given the reassurance of support services it was believed that families would be more willing to continue their role as caregivers.

C. The Need to Balance Client and Caregiver Needs

One of the difficulties faced by case managers when
assessing the need for service or support is the task of balancing different individual needs and perceptions of the situation. Case managers find themselves wondering who their client should be.

"The client is supposedly your focus and you want the best things for the client, but it really depends. In some situations it is biased and I am equally if not more concerned about the wife (as caregiver)."

The case manager may act as an advocate for the client or the caregiver. Several respondents commented on the difficulty they faced when attempting to prioritize needs.

D. Benefits of Supporting Family Care

Behind the efforts of these LTC case managers, a basic belief in the benefits of family involvement and control in the caregiving situation emerged. It was felt that family caregiving involves an emotional attachment and commitment that is difficult to duplicate with institutional services.

"My goal is always to keep that person at home as long as they are able to. I generally find that they don't do as well once they move out of the home and they don't have that family support."

Several respondents saw family care as important to the caregiver who is very committed to providing care and does not want to give up this role or control that it offers them.

"It is important for him to be the caregiver because he doesn't feel that anyone else can do it as well as he can."
While the benefits of family care are many, the respondents felt it was important to realize that "often one family member is getting the total responsibility". It was felt that LTC needed to focus on increasing the strength of the informal system through developing the resources available to individuals. Education, increased awareness of available resources, emotional support and counselling were all areas where case managers identified the need to intervene. As the following quote reflects, people often have the resources to help themselves but need support and encouragement to develop and use this potential.

"People are beginning to accept the idea of needing some psychological support....that maybe there are other means of getting over what the current problem is."

"Some families are just not creative. They don't think about it or because they have not talked to a professional and don't know what they can do to lessen the load on themselves."

People often need support and education to identify and deal with their own needs. Respondents were alert to the family's view of the situation and the need to recognize and validate the stress caregivers experience. One case manager said, "We are always looking at the stress of the caregiver. It is there all the time and needs recognition."

In summary, the case managers identified the need for respite care services to respond to the resource limitation of
families and to address the balance between formal and informal care. These case managers clearly saw LTC as a service that supplements the existing high level of support from families. The program needs to continue to recognize limitations and weaknesses of caregivers and target services to strengthen these areas. It is especially important to recognize the fact that most of the responsibility for care falls on one individual and the emotional and mental stress that this can cause.

2. Benefits of Respite Services

This section outlines what many case managers saw as both present and potential benefits of respite care services. The discussion is divided under categories of general impressions, benefits to the caregiver, the dual benefits of respite services, education and transition benefits, system stimulation and emotional support provided by many respite services.

A. General Impressions:

When discussing respite care services, most of the case managers felt that the present program worked well and was able to meet most community needs. Their comments were often qualified by recognition of cost restraints and comparison to other health care systems.

"I think that given the framework of finances that they have to work under, they have got a really good program."

"At the same time you need to appreciate what is available to seniors when you look at the United States where the cost is dear or third world countries where there is
nothing."

One of the main strengths of the LTC program was identified as its ability to meet needs through a variety of respite services. Homemaker supports, adult day care, respite beds in facilities, live-in companions and caregiver support groups were all seen to provide respite and support to caregivers. It was believed that a variety of services meet different kinds of need and respond to individual family preferences.

"I have one lady whose husband is quite demented and I have sent her information repeatedly on the caregiver group but she was not accepting. She was comfortable with the idea of her husband going to a day program...That gives her respite and she feels OK with that."

Where one service was not acceptable to the caregiver, another was able to provide her with the relief that she needed.

B. Benefits to the Caregiver:

Many of the benefits of respite services are directed at the caregiver. Respondents saw respite as an opportunity for caregivers to pursue their own lives and interests. It was perceived to provide some freedom and reduce possible feelings of isolation and resentment.

"The caregiver at least feels that they have something that is their own time. They can do whatever they want to do instead of always being at the beck and call of the client."

It was believed to provide emotional support and renewed
"They would feel resentful if they weren't able to get out and lead their own lives. I think it probably refreshes both parties...it rejuvenates."

C. Dual Benefits of Respite Services:

While the focus was on the caregiver, many of the respite services were seen to benefit both parties. Adult day care as well as other services were identified as providing stimulation and socialization to the client while enabling the caregiver to have a break.

"The obvious benefit for the caregiver is that it gives them a few hours break...For the client the day cares are very creative and try to provide programs that work at improving skills. They don't look at it as a lost cause but see it as a challenge."

The services were seen as a positive experience for the client. As respite services give the caregiver a chance to pursue life goals, it gives the client a chance to develop skills and independence both emotionally and physically.

"It is therapy for the client who is going off for their social outlet and program. For a lot of them that is the only time that they get out."

Again the focus here was on providing stimulation to the family system and working to strengthen supports within that system.

D. Education and Transition Benefits:

Education and transition functions for both the client and
caregiver were specific benefits that many of the case managers referred to in the interviews especially in relation to institutional respite beds.

"Families could use respite as a way to let the client know what it would be like if they went into an intermediate care facility. They might enjoy it. I am sure that clients sometimes feel that they are being pressured (into a care facility)."

Case managers felt that both the client and the family were able to learn more about services and options and that this information would ultimately enable them to make more informed and appropriate decisions.

E. System Stimulation:

As other sections of this chapter have alluded to, one of the primary ways that the respondents saw respite services benefiting families was through the stimulation and new energy that they bring to the situation.

"The mere fact that there is someone there and listening and the fact that they are now a part of our system begins to alleviate the stress...the homemaker respite or any service brings another person into the home who can relate to the spouse and client so there is a sort of vitality that comes in and generates some newness in that house."

This case manager described how adding a new person to the family caregiving system or by extending the family system boundary through the addition of a support service can open up
the system and allow new energy and ideas to enter. The system can then become less rigid or closed and open to change and adaptation.

F. Emotional Support:

Several comments of the case managers reflected how respite services often indirectly provide emotional support to clients and caregivers. Being connected to the formal health care system offers reassurance to people. As one case manager stated, "if they know they have a safety net they feel better". Another respondent believed that the provision of companion respite services was a recognition of the need to provide emotional support.

"God forbid if we didn't have respite. It sends a loud message to the public that we don't have to have things to do...we recognize the psychological aspect of long term illness and the stress that that puts on families...there is that recognition of the need to consider one's mental health."

This section has summarized comments that reflect the benefits of respite care services as seen by these case managers. While caregivers were the primary focus, services often benefited the client as well. A systems model perspective was evident in this section in the discussion of energizing and revitalizing the family system through expanding resources and boundaries. Increasing the resources and ability of the caregiver to cope and adjust to their situation was identified
as the major benefit of respite services.

3. Barriers to Meeting Need in the Informal System:

Throughout the interviews there was considerable discussion addressing the lack of fit between services and what is acceptable or utilized by families. This section focuses on the barriers to meeting need from within the family. It becomes the third major theme arising from the interviews with case managers. This discussion of barriers is presented under the following categories: the reluctance of caregivers to seek help; their role expectations; cultural and economic influences; resistance to change; conflict within the informal system; and the limited skills and knowledge of many families.

A. Reluctance of Caregivers to Seek Help

Caregiving responsibility was described as often being carried by one person and shared only to a limited degree. The case managers felt that parents are very hesitant to seek help from children recognizing the other family demands their children face. They commented that caregivers "feel guilty about using up time of these very busy younger people". Having family available or willing to help does not ensure that the caregiver is receiving support. Case managers also identified culture and history as playing major roles in determining how receptive caregivers are to involving their children. As immigrants, it was felt that many caregivers place a strong value on independence. They neither expect nor want to impose demands on their family. One case manager described this
attitude as,
"They have done a lot for their family and have not got the expectation of help being returned when they need it".

Related to this reluctance to ask family for help, respondents noted a hesitation to seek help from the formal system. Role expectations and guilt were described as barriers to involving outside services. One case manager stated that people believe "you are private and independent and you don't seek help from others". Families attach a stigma to government help and were described as having a "reluctance or anxiety about involving the government". Pride and a fear of losing control were believed to prevent many people from seeking out help. "That means that you haven't coped and you don't want to admit that."

B. Role Expectations:

Role expectations were also discussed as a barrier to effectively meeting need. The strong sense of duty and responsibility felt by many of the caregivers and, for women, the expectation that their lives focus on caregiving were noted by the case managers.

"It is hard for some of these seniors to see that they need to go (into a care facility)--it is their duty. It was a bargain set at the time of the marriage."

In the interviews, case managers presented the role of caregiver as very important to the caregiver's sense of self and purpose and that to give it up would involve feelings of guilt and
abandonment. As one respondent noted, "It is important to be needed".

C. Cultural and Economic Influences

The case managers interviewed deal with a broad variety of cultural, ethnic and economic differences. Need and demand may vary with culture and economic status.

"We do get a lot of people with different ethnic backgrounds who present with similar problems and yet they are much more complex simply because of the ethnic origins."

These values are also changing between generations. The issue of culture and economic status was a variable that was seen to have significant impact on acceptance of services.

D. Resistance to Change

Respondents discussed the reluctance to seek help and support as leading families to the point of crisis where their perspective and ability to consider alternatives is constrained.

"They wait until they are at the end of their rope because they don't want to interfere or ask for extra service. But, when they have reached that point, they are not willing to try anything else."

Most of the case managers expressed strong concerns about the impact this delay in seeking support has on their ability to intervene and provide assistance. The stress of a crisis and the caregiver's overinvolvement in the client's care were noted as further barriers to acceptance of change.
"I would say it is almost the more heavy the client gets, the more the caregivers get overwhelmed and can't accept much change."

Case managers expressed frustration over their perception that people are somehow not aware of services or that the services are not reaching them in an acceptable way.

E. Conflict Within the Informal System:

Earlier sections have identified gaps and conflict between formal and informal systems of care. There were also comments about the dynamics within each system. Within families, conflict, communication barriers, value differences and historical events were identified as having an impact on family attitudes about providing care and involving outside supports. The case managers made comments like, "if it has not been a good past history, it exacerbates it (the family stress) and makes it even more difficult to work with these people" and "people can withhold things from family members" that relate to the need to consider family dynamics. Generational differences exist and "elderly people find it very difficult to understand that the children have different values."

Other respondents felt that the lack of understanding and ambiguity regarding what the caregiver role should be can make family members reluctant to get involved.

"People are very upset by that process (alzheimer's) and they often distance themselves from the parent."

Given the presence of conflict and value differences, case
managers commented on family members experiencing disagreement on how to deal with the situation.

F. Limited Skills and Knowledge:

The belief that families may have limited skills and knowledge to enable them to effectively meet the needs that they are faced with was reflected in comments such as,

"Even if there are a lot of family members, they often don't have these skills.....They have had no exposure or education to deal with a difficult situation. So, they feel that something we find is a minor problem is a major problem for them".

The present bureaucracy and maze of services and programs was described as very complicated. Case managers believed that families often need to act as liaisons and advocate for the coordination of informal and formal care. Their comments reinforce the need for a certain level of education, awareness and self assurance in order to fill this role. Several respondents noted the difficulty faced by immigrant and less educated families when dealing with formal care systems.

This section has outlined some of the barriers within families that hinder their ability to provide adequate care and to accept and link with formal care services. While some of these barriers arise out of limited personal resources, many are related to role expectations, values, and cultural expectations. These are important factors to be considered in the development of any program that hopes to transcend some of these barriers.
4. Impediments to Meeting Respite Need in the Formal System

During the interviews, case managers discussed barriers to meeting respite needs that originate within the formal system of health care services and LTC in particular. The system of formal services, the way that it is organized and delivered also offers many obstacles to effectively meeting need. Impediments discussed included limited access and availability of services, job restrictions, the low priority of mental health, staff qualifications, cost and funding restraints and service gaps.

A. Limited Access and Availability of Services:

Many of the present services that case managers identified as providing respite care such as respite beds, adult day care, homemakers, both short term and live-in, were described as having limitations that restrict their access to the target population. Respite beds were identified as being in short supply and difficult to access due to long wait lists.

"It isn't always easy to access a respite bed at the time that the family most needs it. Respite beds are usually booked by people who are very aware of what the system can offer them and are well organized and are able to book well ahead."

For those with immediate needs or without the information or organizational skills to plan well in advance, respite beds were seen as a restricted option.

Time factors and wait lists also emerged as an issue in the use of adult day care for respite. One respondent noted that
for clients already reluctant to get involved with something new, a delay can increase their anxiety.

"When people are shy about accepting these things, it is nice to be able to...follow up with it immediately so they don't have time to get more anxious about it."

The program (day care) organization and lack of flexibility decreases its usefulness to many people. Case managers discussed the inflexible time schedules, the language barriers faced by some clients and the inappropriateness and disruption of providing service outside the home for some clients.

Live-in homemakers were pointed out as a needed resource that is in short supply. When needed they are often not available and if available, the system was described as reluctant to use this option due to cost concerns.

While the variety of services that are available increases the chance of something suiting the client and caregiver situation, some case managers identified a tendency to overload the family. Often families have a limited ability to take in new information and make decisions when they first connect with LTC.

"I think one of the dangers of our job is that we tend to overload them with a number of options rather than giving them the information and giving them time to study it and think it over."

This statement identified a fine line where putting in an extra service may cause more stress to the family system than it
provides support.

B. Job Restrictions:

Respite has been identified as encompassing both 'time out' services as well as counselling and education services that have the potential to strengthen the caregiver's ability to cope with ongoing care responsibilities. Many case managers expressed frustration over the lack of time to do adequate assessments, to develop a rapport with their clients or to give any kind of emotional support or counselling.

"The main thing that I find frustrating is the amount of work you have. You have so many clients, you really have to put a lid on the amount of involvement that you give each family...you have to be hard on yourself and sometimes hard on the client and say that this is all that there is." Time limits affect the depth of assessments and understanding of the clients and their families. One case manager stated, "we probably don't know an eighth of what it is like for them".

Although emotional support and counselling were identified as major needs, case managers felt unable to address these areas in any depth.

"We are skimming the role of counselling. If you need counselling you are not going to be able to do it in one visit."

They described their jobs as reacting to crisis situations. They admitted that they often have infrequent and brief contact
with most families.

C. Low Priority of Mental Health:

One case manager identified the lip service that is paid to emotional and mental health needs.

"I don't know how you can juggle a case load and concentrate on anything else. They (administration) may be telling us, yes, feel free to do that but the pressures and expectations to keep up the work load is not in support of that kind of attitude."

The low priority given to emotional and psychological needs was reflected in the separation identified between LTC and mental health. No professional positions or programs exist in LTC that are focused on counselling or mental health. One respondent noted, "Long Term Care doesn't have a social worker or counsellor role." Funding and jurisdiction issues were also raised as a factor.

"Mental health in the health department is non-existent...Because people are tied into the health department it is somewhere where they should receive help."

This case manager felt that continuity of care required a comprehensive and holistic approach to health from LTC. She felt that people should not be sent away to other services in order to receive mental health support.

Time and job restraints limit the use of counselling skills that exist in the department.

"I don't think that they get the full benefit of our
training and professional skills, particularly in the social work area in regards to caregivers. Group dynamics and how to communicate and being an advocate for these people are skills that they don't get to access very much."

D. Staff Qualifications:

The limited flexibility of services as well as limited access and time were all noted to impinge on the ability of the LTC program to meet the respite needs of its clients and their families. In the case of home based respite services, the qualifications of the homemaking staff was another concern raised by the respondents. The bulk of the respite care services are provided by homemakers with limited training and low wages. Many of these homemakers were described as dealing with complicated and stressful situations. Several of the case managers interviewed felt that homemakers were often providing service beyond what can be expected given their training and salary.

"The ladies will get attached to the homemaker and it therefore is supportive for them. As long as we have these kind of relationships with homemakers and clients that is all very good, but we shouldn't see homemakers as providing that...it is the emotional support. I don't know if the government in actual fact recognizes that...I don't know if they want to pay for that."

For the heavy care client or those with multiple problems the case managers commented on the difficulty they encounter when
trying to find suitable homemakers, especially on short notice.

E. Cost and Funding Restraints of Respite Services:

Many of the case managers attributed the short comings of LTC's respite services to cost constraints and continually prefaced comments and recommendations with concerns over what would be financially acceptable. It is, in one person's words, "all in terms of the almighty dollar and where they decide to spend it". The assessors found their jobs constrained by cost concerns.

"I think that money always has to be an issue.... administration needs to trust that the assessor knows what needs to be done and trust that in the end it is going to be equal or less (in terms of cost)."

Decisions must be justified on a cost basis. Many felt that individual circumstances were not given full consideration and that there was an over emphasis on short term costs. Respondents identified the need to consider cost from a personal, program and societal perspective, both past and present.

F. Service Gaps:

All of the barriers discussed lead to a situation where despite the variety of services, there are still large gaps in the LTC program's respite services. As one case manager summarized,

"There are lots of resources but they just don't fit in sometimes. You just can't plug people into these slots and
say that this person should be doing really well because they are hooked up...It still doesn't mean that the problem is solved. Maybe that is a negative feeling, but there is still something missing."

For people with multiple problems, emotional needs, or a lack of family support the gaps were seen as especially evident. Workers questioned the purpose and mandate of LTC and to what extent this formal system should be involved and take responsibility for meeting needs. Questions were raised with comments such as, "When we talk about support, I am not sure what we truly mean. It is ambiguous at times" and "It is as if I don't know if LTC is the be all and end all either".

In summary, barriers to meeting respite needs emerged as a strong and central theme. While some of the impediments related to family characteristics, many were associated with resource limitations, values and priorities of the formal system itself. The shortage of funding, time constraints, limited training and lack of mental health supports may be related to values associated with ageism and economic worth of recipients. Support services are provided out of a system based on a medical model of intervention which can have a negative influence on the priority given to chronic needs of elderly persons and their families.

5. The Need for Change

Having reviewed what the case managers see as the need for respite services, the role that LTC should take, and the
barriers seen within families and formal services, this next section outlines the areas where it was felt the program needed to change and develop in order to be more efficient and responsive to family support needs. The suggestions are presented under the following headings: expansion of existing services; education and counselling for families; increase in the community base of services; the soft sell of service delivery; and the re-evaluation of respite service priorities.

A. Expansion of Existing Services:

The suggestions made for change by the case managers focused on expanding and rearranging existing services. This included having more respite beds available in facilities especially for higher care levels and allowing families to use the service for longer than the allotted 30 days if needed. By expanding the flexibility and availability of respite beds, it was felt that the service could provide ongoing regular relief instead of being restricted to vacation relief.

"I just really think that it has to be individual. If they (the family) need more than thirty days, if they need two months...I would hope that the system would be able to accommodate that."

Emergency and short notice respite were identified as areas where respite beds could expand. This would involve a change in focus and a new way of administering respite programs.

"I think you need respite care services available at a drop of a hat. I don't know how that could be set up and I
don't know whether the government would find that financially feasible because if it wasn't financially feasible they wouldn't even look at it."

Within existing services other programs were pointed out as needing expansion and more flexibility. Suggestions included more adult day care spaces, more flexible hours and creating specialized day care programs for groups such as the demented. Case managers felt that better funding would improve the ability of the program to attract more qualified homemakers.

B. Education and Counselling for Families:

Education and counselling were two new areas that case managers felt that the program should develop in order to support family caregiving.

Case managers described families with knowledge and information about resources and options as better equipped to identify their own needs and request appropriate services.

"I think that there needs to be more information for those people who are reluctant. These are the people who really need it but aren't using it. People who are informed ask for it and book it (respite) every year."

A worker needs to be sensitive to how much new information the family can take in at that time. Suggestions were made for the development of comprehensive written material to be given to families.

"I have never seen anything that we can hand out to a family showing what resources are available to caregivers
from the health department, how to access them and what the rules are. They need to have something concrete because I just find that people can't maintain all that information that you load on them."

Counselling was another area where suggestions were made for the program to develop more resources so that support to families would include mental and emotional support as well as instrumental assistance.

"We could use a counsellor that we could tap into. You could give some relief emotionally to someone if you had access to counselling."

C. Increase the Community Base of Services:

Comments made by case managers supported provision of respite services in a local and familiar environment. Caregiver support groups would be less alienating and better utilized if based at local health units and run by case managers familiar to the caregivers.

"they might feel more comfortable coming to talk to me in a group when they know someone. At VGH they walk into a room full of strangers."

It was felt that having services unit based would add to continuity and improve access as families became more familiar and comfortable with a variety of services from a single source. Transportation difficulties faced by many elderly further limit their use of services outside their local community.

Respite beds and adult day care are other services that are
often provided outside the local community. Respondents' comments noted that this separation from familiar environments can make a service stressful and reduce its acceptability to client families.

"Everyone in the health department agrees that service needs to be community based because that is where people spend most of their lives."

Several statements supported the belief that community based services could be more flexible and responsive to local demand and circumstances.

D. The Soft Sell of Service Delivery:

To this point discussion has focused on the need to expand and add services but suggestions also addressed the need to change the way respite need is assessed and services introduced. Case managers try to be sensitive to the unique stresses faced by individual families.

"I think that we need to be innovative about what we do in the way of offering respite. It needs to be tailor made for each situation. We have to take into account how they perceive things."

Family involvement and limitations were recognized.

The way that services are introduced was another important factor in creating acceptable and individual care plans. It was felt that services can be perceived as invasive and overwhelming and can lead to the caregiver withdrawing. As one case manager commented, it is important not to "bombard them with options so
that they feel that their lives have been invaded". It was recommended that services be introduced gradually as the case managers gather more information about the family and the family becomes more comfortable with the involvement of services. Intervention should begin with suggestions not prescriptions

"I like to give them options and let them ask for what they need...I won't push it on them. They need to make their own decisions."

One case manager summarized the way she felt she works in marketing terms.

"If you were to look at some situations in case management and look at a course in selling, in some situations it is related. If you are trying to sell an idea there is the soft sell and the hard sell. A hard sell is where the 'shoulds' come in and people are completely put off by that."

The product here is described as support services and this product must respond to consumer demand. A hard sell or imposed definition of need was seen as inappropriate.

E. Re-evaluate Service Priorities:

A common thread that ran through many of the recommended changes was the need for increased flexibility in the way need is assessed and the way that respite services are organized and delivered. "Everything has to bend to meet the need of the clients and families." Case managers would like to see "more flexibility in the times and variety of services" and more
"innovative people and money".

In order to achieve this kind of flexibility and maximize innovative planning, it was felt that job requirements and time priorities needed to be reevaluated. Case managers wanted to spend more time with high risk and heavy care situations.

"I really wonder if they shouldn't look at the issue of personal care on the program. I just don't think it takes a qualified person to do most of these annual reviews...I think our time would be better spent out doing some counselling to families."

Many felt that much of their time is spent trying to meet deadlines and time requirements.

A concern with cost and restrictions of the program seemed to be present throughout most of the discussions of needed changes in the program. As one respondent stated, "I think the system is pretty good but I would hate for it to ever become more restrictive". These concerns further reinforce some respondents' feelings that the program can at times be inflexible and unresponsive to client and family needs. These case managers felt that one of the major criteria and determining factors of how programs are designed and delivered is their cost.

In summary, this section has focused on many of the criticisms of respite services and recommendations for change. It is important to note that most respondents expressed positive overall impressions of the program. There was a general feeling
that services were adequate and available to those in need. A certain level of dissatisfaction was accepted as present in any system and necessary to keep a program alert and self-examining.

"I think the system works out well...in every system there are faults but the approach used here is well thought out."

A focus on shortcomings may encourage growth but it is also "good to look at the positive". The program can also learn from what works.

Most recommendations focused on reorganizing or expanding existing services in order to improve accessability. The concern with cost factors may have constrained the recommendations put forward. Nevertheless, many of the suggestions presented were aimed at giving the family more control over their situation by increasing personal resources and ability to choose appropriate and flexible service options.
Caregiver Interviews

The second group of people interviewed were the family caregivers. This section summarizes some of the comments and themes that emerged from the analysis of these focused interviews with the sample of wives, daughters and a daughter-in-law. Once again, the data have been grouped into broad categories that include stresses faced by caregivers, their perception of their role, informal supports, the effects of caregiving, background factors, the benefits and shortcomings of services and the need for change.

1. Stresses

Caregivers identified a great number of stresses in their lives. The perception of stressful factors varied between respondents. However, despite these individual differences there were some common themes or shared difficulties. These themes include the stress of total responsibility, coping with confusion, lack of control, emotional strain, family conflict, and role expectations.

A. Stress of Total Responsibility:

Most caregivers found the total dependency and constant responsibility of caregiving one of the most mentally and emotionally draining aspects of their role. Their comments often reflected unrealistic expectations that families should be able to meet all possible needs. Comments such as, "I look after him 24 hours a day" and "I have to get everything ready for him" reflected the caregivers constant responsibility for
ensuring that their family member's needs are met. One respondent summarized the stress of caregiving as,

"I think that providing care for your family member is more stressful than abandoning them in a care facility".

Related to the issues of constant responsibility and the client's confusion were various physical and emotional strains. Sleep patterns, safety concerns, and medical conditions were all perceived to add to the stress of the respondents. The caregivers described themselves as 'night attendants', 'supervisors' and 'medical officers' of the home.

Proper sleep and rest had a significant impact on the caregiver's ability to cope.

"She goes to the toilet at all hours. You're up all night and don't get much sleep. It is the most stressful thing I have ever done."

The responsibility for care was portrayed as inescapable even at night. There was no break or relief.

If the client was confused, as many of the care receivers in this study were, the caregiver felt that he or she must constantly supervise the client and ensure that he or she does not act in a way that is harmful to himself or others. Wandering, getting lost and concerns about the unsafe use of stoves and heating appliances were all raised as major issues for these caregivers.

The ill and infirm client often suffered from multiple medical conditions. The caregiver faced the responsibility of
monitoring these serious and sometimes life threatening situations. The stress on the caregiver was increased by this added task.

"He keeps getting these infections. He is on antibiotics and then off them again."

"I'm scared. She has to take those pills for epilepsy"

These caregivers feel responsible for identifying problems and seeking proper help.

B. Coping With Confusion:

Mental confusion or disorientation of the client was seen as another common stress. The caregivers presented themselves as taking responsibility for the relative, anticipating their needs and protecting them from harming themselves. Discussions addressed communication impairment that leaves the caregiver "wondering just much he is aware of". Many caregivers described their schedules as responding to the client's actions and need for orientation. They found that the confusion can lead to aggressive or embarrassing behavior by the family member that can be difficult for them to deal with.

"Sometimes his mood is good and sometimes bad. When bad he locks the door and yells for help. I am very scared about that because if the neighbors hear."

If the client was confused, the caregiver felt that he or she could not leave the client alone. The feeling of being trapped and totally responsible was reflected in statements such as "I can't leave him alone. If I go, I have to rush" and "We
cannot leave Dad on his own here for 10 minutes".

C. Lack of Control:

The inability to escape the situation or seek other options left the caregiver feeling trapped and out of control. One caregiver stated "Actually we have no choice" when describing how they choose to deal with caregiving.

Unpredictability was a major factor that contributed to the caregivers' lack of control. The caregivers described themselves as subject to constant changes in the client's situation and needs. These changes could be unpredictable and the caregivers felt it necessary to anticipate and adjust to continual fluctuations.

"One week something happens so you figure out a way of getting around it. But, you no sooner start implementing the new way then have to change because something else has happened. It is this constant change."

The caregivers related attempts to encourage routines and some predictability that were often quickly negated.

The clients can increase the stress felt by the caregivers by resisting changes or acceptance of help. They may not want to go to adult day care or use a respite bed. They may not want someone else coming into the home. Exposure to change can be very upsetting for the confused client. Some caregivers identified this kind of resistance and the impact it had in further reducing the options available to them.

The caregivers related that the pace and schedule of the
day was set by the clients and their needs and that the caregivers must continually adjust to the clients. One caregiver stated, "everything must be very leisurely for her". Another respondent stated "I hear the same story for 47 years and I have to pretend that I haven't heard it before...He is very stubborn". Patience was identified as a necessary trait to enable them to deal with their role.

D. Emotional Strain:

Faced with the constant responsibility, unpredictability and lack of control, many caregivers experienced a great deal of mental stress.

"I was scared to go to bed. So I was awake and sleepy and tired and cranky with mama. I hated to be cranky with her."

When outbursts or negative reactions occurred, the caregiver responded with feelings of guilt and reproach.

Isolation can be stressful and even lead to physical symptoms. One caregiver was able to relieve high blood pressure problems through the use of respite.

"It is just the boredom of being around him all the time. He thinks I should be sitting here with him all the time...It gets to the point of irritation."

Many found the lack of stimulation and monotony difficult to cope with. Caregivers admitted that "emotionally, it is quite draining".
E. Family Conflict:

As this section has indicated, caregiving can be a very stressful experience. For some respondents, this stress was exacerbated by pre-existing family conflict and conflicting demands. Respondents identified long standing family conflicts that were heightened by the demands of caring for their relative. Other families experienced conflict and differences of opinion regarding how care should be provided.

Multiple family demands were described as competing against each other. One family could not care for both mother and father at home and had to make a choice. For middle generation caregivers with children of their own, the demands of being a parent competed with a sense of filial responsibility.

F. Role Expectations:

Role expectations and role changes can be a cause of stress. The caregivers found themselves assuming new responsibilities and duties that were previously handled by the client or having to complete tasks that they felt were not appropriate for them to carry out. This caregiver felt that she was being forced to do things that she was not comfortable.

"When I give him a shower, that to me is something. I am a woman and he is a man. If you like or not you have to do it and you feel some kind of repulsion."

In summary the role of caregiver is varied and as individual as the stresses and demands that it entails. What people perceive as within their ability to deal with and what is
seen to be stressful is often closely connected to their perception of their role and what it entails. This section has outlined a number of physical and task related sources of stress as well as stresses related to emotional and interpersonal factors. These caregivers often face multiple demands with limited resources. The gap between what is perceived as a demand and the ability to deal with that demand results in a stressful and high risk caregiving situation.

2. Caregiver's Perception of Their Role

This section provides a more detailed examination of how many of the respondents perceived their role as caregiver. Most caregivers saw themselves as the primary support for the client. Although the discussion of their role focused on physical and instrumental tasks, there was some recognition of the mental or emotional aspects of being a caregiver. This section is divided under headings of obligation, role responsibilities, high personal expectations, functional aspects of role for caregiver, identified limitations and positive concern for the client.

A. Obligation:

A strong sense of obligation was fueled by cultural and value influences. Respondents referred to filial responsibilities and marital vows reinforcing their feelings of duty.

"If I would leave him I would feel guilty because I feel that if I took on looking after him, I should be here. A lot of it has to do with whether you want to look after
them—whether it is something that you want to do or you feel that it is a duty."

This caregiver felt that she had made a commitment and must now struggle in order to be comfortable with sharing any of the responsibility. For other caregivers, the choice was perceived less voluntary but still tied to a sense of duty.

"I have ended up with this not so much voluntarily but because of the situation...I knew that my parents would be happier here than in a nursing home."

Feelings associated with filial responsibility and a belief in reciprocity of caregiving were reflected in some of the caregivers' comments about obligation. One caregiver described herself as "a product of the old ethic. You repay what you get". She felt that her mother had made many sacrifices during her life and was deserving of the care she now received.

Some of the respondents associated their sense of obligation with the absence of anyone else to take the responsibility. They feared that if they did not provide the care no one else would do so. "If I don't do it who is going to do it?"

All of the caregivers felt some sense of obligation, either voluntary, culturally influenced or forced upon them. Guilt and resentment were some of the negative outcomes of this sense of duty. Many wished other family members would share the obligation and thus make their situation less restrictive and more bearable. However, most caregivers admitted that they were
providing care out of much more than a sense of obligation. A strong sense of caring and affection was identified in many of the relationships.

B. Role Responsibilities:

When asked to describe the responsibilities of their role as caregivers, most focused on the physical and instrumental tasks. Long descriptions detailed the events and routines of the day and the tasks that had to be performed.

"I give him a sponge bath every day but usually I get him to go into the bathroom. It is a small room so he has to sit on the toilet while I give him a sponge bath. Then I bring him out and he has his breakfast. I feed him his porridge because he can't manage anything like that. Toast he can manage. Lunch time I give him soup and a sandwich. I will feed him the soup."

This kind of task by task description was common.

The caregivers tended to take personal responsibility for identifying and meeting all needs.

"Last night after dinner I wasn't quick enough getting him in there (to the bathroom). He just couldn't make it."

This caregiver was blaming herself for not responding and recognizing the client's need quickly. The caregiver seemed to accept a kind of total, all-encompassing responsibility for the welfare of the client that was not always clearly identified in their description of instrumental tasks. Caregivers saw their responsibility involving all aspects of the clients care and
well being.

C. High Personal Expectations:

This kind of total care that the caregivers saw themselves responsible for was discussed in relation to the high expectations that many of them had of themselves. These expectations were often associated with affectionate ties and a belief that families should be self-sufficient.

"We love them. It hasn't been bad yet. We can still handle it and as long as we can handle it and cope, we will do as we have...It is a great help (LTC services) but not the main line. The main line is the family."

"I think that we have it too good in this country. All I have to do is phone up to get help."

Many of the caregivers had low expectations of help from the formal system of services. They felt that the family had primary responsibility and should be grateful for any assistance that made their job easier.

Expectations also varied within families and had an impact on the caregiver's ability to cope.

"I think that when people are living together, everyone have to give up something to make it easier."

This family expected and was prepared for many changes in their life. Other respondents described themselves as less prepared for the adjustments they had to make. In one situation a husband and wife disagreed over how much they should sacrifice for the care of a parent.
D. Functional Aspects of Role For Caregiver:

Comments of the caregivers often pointed to the stake they had in the role they were filling and their reluctance to give up responsibility or separate from the client. Many put the needs and wishes of the client above their own.

"My mother was on the waiting list for a nursing home, but when the time came I asked my mother and she said she wasn't ready, so I said OK. I am not going to force her." For caregivers who had been involved with the client and their care for many years a fear was associated with separation. One caregiver became very emotional when asked about leaving her mother alone, even for a few hours. She felt that much of her purpose in life was tied up in the role of caregiver. She described the difficulty that she was experiencing making a decision about facility placement for her mother. This caregiver's desire to maintain her role as long as possible was shared by many of the respondents.

Continuing as caregiver has many benefits as well as stresses. Companionship, affection and a sense of purpose were noted as very important by many of the women interviewed. As one wife said, "I want to keep him around as long as I can. I need some one to talk to, too".

E. Identified Limitations:

Most caregivers were able to identify some kind of limitation to their ability to provide care for the client. Physical limitations were more readily identified than mental or
emotional capacities. Difficulty with bathing, heavy housework and the caregivers' own aging were some of the limitations identified.

"When it comes that I can't do it anymore, when I have to feed him in bed, look after him night and day...if I can't make it, they can't force me."

Despite strong cultural dictates, this woman was able to identify the limit of her ability to cope and the point when her own needs will override those of the client and other family members. In most of the interviews, however, the women were generally reluctant to identify their own limitations.

F. Positive Concern for Client:

Caregivers in this study were closely attuned to the client's needs and desires. They described themselves taking on responsibility for the quality of life experienced by the client. Their comments showed an appreciation for the personality and individuality of the client both past and present. This close concern with the perception and needs of the client also limited what the respondents viewed as acceptable care options.

"It is threatening to him and I don't like to put him under that pressure. I know that it would break him up if I forced him to go. So I stick it out. It isn't worth it to me. I'd rather put up with what I am doing now."

Many of the caregivers believed that it was in the client's best interests to be cared for at home.
"I felt she would never walk or do anything. I felt she had a better chance to do that at home."

In summary, this section has touched on several ways in which the caregivers perceived and reacted to their situations as caregivers. Many of the factors discussed in relation to the caregivers' roles impacted on the control that they were able to exercise in their own lives and the lives of the clients. Some felt very trapped and imposed upon while others felt the role had been assumed voluntarily. The caregivers also varied in their ability to exert influence on their environment. Some were ruled by their values, culture and expectations of themselves as well as the client's needs. Other's were able to take control through establishing routines and support systems that enabled them to expand their lives beyond the caregiving relationship.

3. Informal Supports

Support available from informal networks was mentioned by all of the respondents however, friends and neighbors were seldom mentioned as a source of assistance. For these families, informal support seemed to mainly consist of family members. This discussion of findings in this section is addressed under the headings of availability and limitations, types of support received and reluctance to seek support.

A. Availability and Limitations:

The availability of family support varied amongst the caregivers interviewed. Some had extensive family networks
close and involved while others described themselves as more isolated and receiving very little assistance. Some of the families showed a strong commitment to be supportive and involved despite other demands in their lives. Even when a lot of family support was involved, the primary caregiver usually assumed the coordinating role. One daughter described her situation as "I am the head office and when I need help, I call for help".

Those without family support felt isolated.

"Well if you had a sister. It is not good being an only one at a time like this. If I had a sister, she could take her sometimes at least to help me out."

This daughter felt that her role as caregiver would be made easier if she had family to share the responsibility.

While family was often nearby and attempted to be supportive, respondents described limitations to how involved relatives could become. Some of these limitations related to distance, competing demands, role expectations, and limited personal abilities. Some of the respondents identified networks that were aging and facing health and illness concerns of their own. In some families it was the ill and infirm caring for each other. One caregiver stated,

"My son lives in Delta, my daughter in Calgary. My brothers and sisters are older and one sister has arthritis really bad and a brother had a heart attack. I can't ask them. Three of my girlfriends all moved away."
For younger caregivers, there were often competing family and work demands that limited the time and effort that they could contribute.

"If I wasn't working it would be different. But, it is impossible to live with one person working and so many people to look after."

Voluntary time available for family relationships, especially those outside the nuclear unit was perceived as limited. Middle generation caregivers described themselves caring for both children and parents. The older generation saw their children spending most of their resources on meeting the basic needs of the nuclear family with little left over for the needs of elderly parents.

Those who were involved and caring identified physical and emotional limits to their ability to cope with the needs of the client. This caregiver admitted that one person is often unable to deal with all the demands involved in caring for an elderly person.

"There isn't one of us, even though she is as capable as she is, there isn't one of us alone that can look after her."

Family history and conflict were other factors noted to limit the support offered to the caregiver. While in many cases family are supportive, there were situations where family relationships were described as dysfunctional or conflictual. For some caregivers the conflict had a long history and was
exacerbated by the stress and demands of caring for an elderly relative. This respondent tells us how the conflict affects the support offered and received from her family.

"He don't like me and I don't care because as soon as ma goes I never want to see him again....won't do anything because he figures that he is helping me and he hates me."

B. Types of Support Received:

For those with family support, the nature of that involvement and assistance varied. Although there was some discussion of emotional support, the interviews tended to focus on the instrumental tasks performed by family members. Families were described as helping with housework, shopping and errands and providing relief by staying with the client and enabling the caregivers to get out for a while. Some of the caregivers felt that the support that family members gave was based on an understanding and emotional attachment to the client that was difficult for others to duplicate.

"The fact that she (caregiver's daughter) is here is very good. At supper time she says 'you are going to have cold tea again--sit down and have your supper' and then she takes over and looks after her dad."

Other caregivers had limited expectations of their family. "There is only them two brothers of mine and how much help can they give you. They can't bath mama."

Role expectations have an impact here on the duties or roles assumed by family members. This caregiver sees providing care
as primarily a female task.

Regular informal contact and emotional support were portrayed as unique aspects of family involvement. Caregivers found that contact with family can provide stimulation and mental support.

"Yes, a lot of emotional support because she is forgetful and asking questions over and over. It is nice to be able to have someone to ask questions of and talk to."

Having someone to turn to who knows the client and the caregiver intimately was seen to be a major advantage of the input provided by family members.

Many of the caregivers would have liked to have had more support from their families but recognized the demands and constraints faced by their families. When asked if she would like more family help, one caregiver typically responded, "Oh, yes, but I know that there is no one that is able to any more".

C. Reluctance to Seek Support:

Given the limitations faced by family networks, many caregivers were reluctant to seek more help from their relatives. Statements of the respondents repeatedly reflected an underlying desire to maintain independence and some separation between the lives of parents and grown children.

"The fact that I have a daughter living here helps a great deal. But, I don't like to encroach on her time too much. She is working all day every day."

The caregiver often felt it was necessary to deal with the
burden alone and not to shift it to others in any way.

"I think that we all have problems and I don't think that we should force them on other people, unless you absolutely have no choice."

For this daughter, caregiving was seen as something reciprocal and she felt that she had no right to ask for assistance from other relatives. She believed that it was unfair to ask people outside the immediate family to provide assistance without some form of reimbursement. "You can't expect somebody to do something without some reimbursement." This caregiver could not afford to pay privately for help.

The clients were also described as offering resistance to many service options. Some clients refused to have strangers in the home or refused to participate in programs outside the home that could offer the caregivers some relief. Caregivers felt that a fear of institutionalization was the basis for much of the clients' resistance to formal programs.

In summary, this section has outlined many of the benefits and limitations of family support. Given the caregivers' reluctance to seek help, the amount of family support that does occur is surprising. In all of the situations included in this study, it was still one person, however, that assumed the bulk of caregiving responsibility. Reference to informal support and caregiving can be misleading as caregiving responsibility is usually assumed by one primary caregiver.
4. Effect of Caregiving on the Family Member

When trying to understand the kind of supports that people need, it is important to look at more than stressors, demands and available resources. This section addresses the perceptions and personal reactions of individual caregivers to their situation. Although each caregiver in this study reacted in an individual way to her situation, there were many shared responses. These shared responses have been organized into the following themes: lack of freedom; emotional responses; and effect of caregiver physical health.

A. Lack of Freedom

A feeling of being trapped and lacking freedom was expressed by many of the caregivers. The responsibility of their role as caregiver was seen as inescapable.

"I don't have any weekends or evenings off and I sometimes don't have any days off. It is every day around the clock."

There are no holidays or breaks and little time away from their home and duties. All the caregiver's time and effort was spent meeting family needs. As one daughter-in-law stated, there is "no time for our selves or friends, just for family".

Some of the caregivers felt that the impact on their lives was total and beyond their control. One woman described her situation as "my life is finished. I am time up". Another woman spoke of the feeling of being confined against her will.

"Sometimes I just feel, just like ma says when she can't
get out that it is like being in jail. I feel that I am in jail sometimes."

This woman felt bound by a sense of duty and responsibility to care for her mother. She saw herself having no options and trapped in a situation that she would like to escape from.

Feeling that they had no choice or options in their situation was another factor that contributed to the feeling of being trapped by their circumstances. One woman stated, "If I want to or not, I have to do it. Until when? How much can I take?". Family members described how immediate needs and outside forces such as available formal supports ruled their lives.

"You focus the entire day on what you have to do and working that around when the homemaker will be here."

Many of these caregivers perceived themselves as reacting to circumstances beyond their control.

A lack of hope expressed by some caregivers exacerbated their feelings of being trapped.

"You can't see an out. I remember that my mother used to say she didn't mind listening to me if I was sick for two days, but if I was sick for longer than that she got fed up with that...When they are old, you can't see any hope...Now, it seems that it is all down hill. You can't look to things getting better."

The future was seen to hold only greater dependency and need for care. The lack of a positive future created a sense of
hopelessness for this daughter.

Many caregivers began to give up social contacts and felt unable to pursue activities that they found enjoyable.

"It is one year we have him. We go to only one party. We go somewhere, we take him. My husband is worse. He don't want to leave him for even one minute...My life is very cut down."

Having some personal and free time was seen as very important. The lack of this opportunity was perceived to have an effect on the caregiver's ability to cope on an ongoing basis. One caregiver admitted, "I couldn't cope with it if I didn't have help coming to let me out free once in a while".

Along with social lives, personal and family relationships were also affected by the demands of caregiving. For some families the changes involved in caring for an elderly relative were expected and adapted to but for others the effect was more negative.

"Since I have my father-in-law, my life with my husband is not the same. We are just two people together and I am the maid for them...I am not free to go out and enjoy a few hours with my husband."

The stress and isolation felt by some people affected their personal lives. This caregiver felt that her marriage had suffered and that her life was now totally task oriented. She felt powerless to change any of this.
B. Emotional Responses:

Given the lack of freedom and hopelessness perceived by many caregivers, a range of emotional responses emerged in the interviews. For many respondents, anger and resentment were the result.

"After a while you feel bitter, resentful and you don't do everything you should...It ties you down and you can't lead your own life."

For other caregivers, the anger is directed at family for being unsupportive.

"I am mad too at my sister for being tied up the way she is when there is not need for it."

For some, depression arose from the constant stress and hopelessness they felt. One woman commented "I used to get so depressed or whatever with everything". Psychological responses to their situations affected the caregivers' ability to work and provide care. Caregivers interviewed commented that in the end it is often the emotional limitations and the inability to cope psychologically with the demands of caregiving that leads to breakdown and placement.

"Everyone seems to come to the point where they have to resort to a care facility because their psychological shape is out of whack."

While caregivers admitted to their limitations and sought help at a crisis point, strong guilt feeling were expressed by most of the women interviewed. A daughter described herself
as,

"much more selfish than my mother. I have a conscience that I hate. I have so much guilt. Sometimes when I lose patience with her I feel guilty".

This caregiver felt guilty for being human, making mistakes and experiencing justified emotional responses to her situation. Guilt increased the feeling of being trapped as the caregivers deemphasized their own needs and continued to take on total responsibility for the client.

"If I go out for one hour, my feeling is like I am stealing this hour from him because if I am not there, I don't know what will happen."

Many respondents questioned their ability to provide adequate care. They focused on the gaps and negative aspects of their abilities. One daughter tried to encourage her mother's independence but was left wondering "whether I make her do more than she should". This constant self criticism and high expectations contributed to the feelings of guilt and inadequacy.

The stress and lack of predictability affected many caregiver's attitudes towards their future. The caregivers were "just sort of going at it blindly" and "living from day to day to keep things going". They often felt capable only of planning from day to day. To plan further was believed to be beyond their control.
C. Effect on Caregiver Physical Health:

Many of the caregivers in this study were elderly and had health limitations of their own. The constant demands and stress of caregiving can have further negative effects on the health of the caregiver. Physical injury and high blood pressure were two physical effects identified in the interviews. Given the age of many of the caregivers and their reluctance to identify their own needs and limitations, the physical effects of the burden they face may have been under-represented.

In summary, this section has touched on the impact that family caregiving can have on the primary caregiver. Many of the effects were related to the emotional and psychological well-being of the caregivers. Feelings of hopelessness and lack of control were major themes throughout all of the interviews. These comments further reinforce the need for services to address the resources and limitations of the caregivers when attempting to support community care.

5. Background Factors

The caregivers' history and context are important factors in determining the strengths and needs of aging families.

A. History:

Many caregivers have a long history of providing care for the clients and other family members. Spouses have lived with the clients for many years and several of the daughters had spent most of their lives living with their parent. Often other family members had been cared for in the past. Many of these
women have spent most of their adult lives as caregivers.

Along with a long history, many caregivers related that the caregiving relationship had evolved gradually. The caregiver had often adjusted to slowly increasing needs over a long period of time.

"He started with this seven years ago. It has been the last two years that we have had the homemakers and the nurse...Up until four years ago he was bike riding...It comes on very gradually."

In the beginning the situation was perceived as manageable. As it gradually worsened, the caregiver was sometimes unaware of the increased stress and effect the situation was having on them.

With this long history and large investment in caregiving some caregivers offered resistance to outside support. Some respondents were reluctant to give up a role that had been an important part of their lives for many years.

Most of the caregivers seemed to be very closely attuned to the desires and needs of the client. Being intimately familiar with the client was felt to enhance their ability to respond to needs.

"Others were less used to our parents. It took less adjusting for me. I was used to their idiosyncracies. I have grown old with them."

These caregivers believed that the best care would come from someone who knew the client well.
B. Other Factors:

Other issues such as past family crises, commitments, war and immigrant experiences, and cultural expectations were raised as factors influencing the present day responses to caregiving and the inclusion of formal supports.

These were just some of the background factors that emerged as important considerations. The limited information gathered in these single interviews points to the enormous need to consider the full present and past context of the client and their family in order to understand their needs and how to support them.

6. Benefits of Formal Services

Many of the respondents expressed an appreciation for the support they received. Some were reluctant to express any discontent and qualified comments with concerns regarding limitations of the service and possible unrealistic expectations. Those benefits identified included instrumental assistance, freedom, stimulation, and emotional support.

A. Instrumental Assistance:

Most caregivers quickly identified the instrumental aid received through LTC. Assistance included, "come and give him a bath and something to eat", "comes and cleans up here once a week", and "came to help me give him a shower". Taking over household tasks and assisting with physically difficult duties were regarded as helpful roles by taking away some of the burden and giving the caregiver more time and energy to deal with other
issues.

For some caregivers it was the combination of family and formal efforts that relieved the burden. For one woman, the homemaker gave personal care while the family did major housework and provided social support.

"When Elsie comes the men wait in bed until she gets here. She helps them with breakfast, gives them a bath, and gets them dressed. When Elsie is not here, Mom has to do that." Assuming some of the daily tasks eased the constant strain. The caregiver got a small reprieve from total responsibility.

B. Freedom:

Besides the instrumental assistance, services allowed the caregiver a little freedom. Homemaker respite, adult day care and facility respite all gave the family members some time to pursue personal interests and escape from the responsibility of caregiving. One daughter stated that her mother can "shop, relax and she doesn't have to think about what is happening to them". Confidence in the service was pointed out as essential in order for the caregiver to feel any real relief or freedom.

"Giving me four hours twice a week--that means more than anything. This girl is very good with him. I don't have to worry in the world when I go out. I feel so free and easy because I know that she is so good to him."

While holiday respite was mentioned as helpful and allowed a more complete break, caregivers referred to the weekly and regular respite as most important.
C. Stimulation:

Services were often seen as helpful due to their provision of some stimulation, new input and information.

"It is some new people and a new voice for him, not all the same....at least she (the caregiver) can talk with someone. we see each together everyday but at least she can see someone and talk about different things."

Clients and caregivers were often isolated and had limited access to other people. Services were perceived as providing social contact and emotional support.

Another caregiver described the new motivation and energy she felt after being able to get out once or twice a week.

"They did tell me that I should have two days at least and I was glad of that because you have a different attitude when you come back after being away from him for a few hours. It does make a difference. You don't think it would, but it does. It just has sort of a new energy about it."

By separating herself for short periods this wife was able to feel revitalized and able to continue as a caregiver.

D. Emotional Support:

Although more difficult to identify and articulate, most caregivers did identify ways in which the services they received provided emotional support. In an earlier section of this chapter the emotional burden of caregiving was identified as a major source of stress.
"Oh it is the emotional. Since we have had the help from the government it is not that bad. Before it was very very bad and Mom was at the breaking point."

Services gave this caregiver emotional support by easing the burden and providing her with some freedom and something to look forward to. For others, the services helped improve self-esteem and reduce feelings of depression.

Consistent and reliable services were seen as essential in developing confidence and trust in formal supports.

"We were fortunate to have a homemaker come that has been coming for two years. She really knows him and he knows her."

Many clients and caregivers developed close positive relationships with homemakers. They were able to provide companionship, positive reinforcement and new stimulation in addition to the instrumental tasks that they performed.

In summary, this section has outlined the varied benefits of formal services. A single intervention may have several spin-offs for the caregiver and the client. What this theme begins to reveal is that what provides respite or relief to the caregiver is not necessarily determined by the service itself, but by the family member's reaction and receptivity to the intervention.

7. Limitations of Formal Services

This section includes a discussion of inappropriate or inadequate services, resistance to formal involvement and cost
limitations.

A. Inappropriate or Inadequate Services:

For many of the people interviewed the services being offered were in some ways perceived as either inappropriate or inadequate for their situation.

Time restraints related to hours of homemaker service and adult day care days were felt to limit the benefits to the caregiver of these services.

"Five hours makes you race around to be home again. Five hours is a nuisance."

Short afternoon respite left some caregivers with few options and inadequate time to do necessary tasks outside the home. The service was seen by some respondents to be inflexible and unable to respond to irregularities or individual situations.

A lack of consistent and dependable homemakers contributed to some caregivers' negative experiences with services. Family members found it difficult to develop confidence in the service when the homemaker was often changing.

"the first lady that came, I wanted to get to know her and tell her a little bit about my mother and orient her to the house...By the time that happened, then the next week there would be another lady and I would think, oh god, just when I was ready to take off for the four hours, I have to go through this reeducation process again."

Without the opportunity to develop trust in the homemakers, this daughter felt that she was unable to benefit from the service.
Other concerns related to the quality of care and training especially of the homemakers.

"You don't get the same standard of care from each worker. Some have more savvy or have more experience. They don't seem to match the patient with the person's experience."

Client needs can vary and it was seen as important to match the situation with an appropriate homemaker. Some family members felt that homemakers lacked the proper experience and training that would enable them to provide an acceptable standard of care. In some situations the services increased the burden faced by the caregiver when those services were perceived as inadequate or inappropriate.

"What kind of help is that. I have a few hours off then I have to clean up after him. That doesn't help. Then everyday it was a different person."

For this woman, her experiences with homemakers were found to be stressful and the source of more work for her rather than providing any kind of relief. In other situations, adult day care and services outside the home failed to provide relief for the caregiver.

"This was supposed to be of assistance to me but it wasn't. It meant that I had to get up earlier, get her dressed, make breakfast and be available for her until the bus came to pick her up at 10:30. Then by that time I was already exhausted....but the next day she was completely out. She was over tired and I ended up with double duty."
The adult day care disrupted this family's routine and created more work and hassle for the caregiver.

One family clearly identified the lack of consistent and comprehensive information as a major inadequacy of the present service system.

"All the information you need, you often don't get. Some of it you get, but you have to seek it out. No one takes the initiative."

This family was frustrated by the effort that it took to get the information they needed to plan and have some control over what was happening to their mother. Many other families showed a need for information through their lack of knowledge about existing services and options available to them.

The bureaucracy of formal services was seen as very inflexible.

"They have fixed the hours of care at five hours a day. If you want to change that it is a big hassle. If you have an emergency and the homemaker stays an extra hour or two you get in a big kafuffle. It has to be authorized in advance. That is silly. I keep track of the hours. It seems to cause confusion if there is any change or irregularity."

This family felt that they were not being trusted as capable to plan organize the service needed for their mother.

B. Resistance to Formal Involvement:

For some caregivers, involving formal services and outsiders in a family situation was regarded as unacceptable.
As discussed earlier, this reluctance is related to culture, values and role expectations but it also influences the benefits obtained from formal services. Strong cultural expectations left this caregiver with few options.

"I can't do anything because my husband does not want. My husband want to keep him here till he dies."

The husband viewed accepting services as an insult to his ability to care for his father. The wife stated her belief that the situation will end in a crisis. Is there any way to avoid this?

Many caregivers were reluctant to seek services.

"I just don't like asking for more time because I found they have been very good at giving me these two four hour days."

This caregiver did not see herself as having a right to support. She looked at the service as a gift that she must be grateful for. She continued to see herself as having sole responsibility for the care of her husband.

Many caregivers reflected negative attitudes and beliefs about facility care. For some this was viewed as an unacceptable option for either permanent or short term placement.

"I don't like care facilities. I don't think that they are good places for anyone human to be. To them it is just a job. They have no desire to see the person get better."

Several respondents felt that an institution would be unable to
understand and respond to the varied and intense needs of their relatives. It was felt that limited resources and staff time coupled with confused or uncommunicative residents created an atmosphere where the client would have "limited chance to talk and be stimulated". These caregivers felt that an institution could not replace the personal committed care that was provided in a family environment.

C. Cost limitation:

The final issue related to the limitations of formal care addresses the cost of several respite services. Many elderly have low and inflexible incomes. Even when highly subsidized, services can be out of reach for clients living at subsistence levels. For one immigrant client who had no income, his family was unable to access needed facility placement due to the cost. Encouraging caregivers to take a holiday may be impossible for those with low incomes.

Some caregivers priced private homemaker agencies for live-in respite. This option, however was expensive and unavailable for most families. They saw LTC services as their only practical option.

This section has outlined some of the limitations of the formal care system as seen by the caregivers. Many programs fell short of adequately meeting need due their lack of flexibility and responsiveness to individual family situations. The caregiver's own attitudes and beliefs limited the benefits to be derived from many programs. Addressing these gaps raises
several questions. Do we adjust the service to the client perception or do we target interventions at changing attitudes?

8. Service Needs and Changes

Caregivers were less articulate than care managers in identifying unmet needs and ways service should change. The intense involvement that many of these women had in their own situation may have limited their view of how things could have been different. These families generally had had little prior involvement with the health care system or other large bureaucracies. Despite this lack of experience and possible intimidation, some suggestions did emerge from the interviews. These suggestions include education and information, family support, flexibility, expanded facility respite, emotional support and assessment of 'family' needs.

A. Education and Information:

Many of the respondents identified the need for more education and information. They had several questions about what kinds of services were available and how to access them. Others expressed frustration at the difficulty they had when trying to seek out information. One daughter complained about "the lack of a central information center".

People noted the need for more information about care facilities and other services in order to be able to make informed decisions. Training and education on direct care practices were seen as helpful to the caregiver in facilitating their ability to provide care at home and reduce the need for
outside intervention.

"It is like when my husband had cancer. I always felt too busy to go and phone and ask for help. I didn't find time until after he died when I didn't need it so much."

This caregiver discussed how a crisis and ongoing stress limited her ability to take in and use information. She went on to discuss the need for centralized information and increased awareness of services before people reach a crisis point.

B. Family Support:

While most caregivers were reluctant to seek help from their families, some did identify the need to expand this area of support. As one caregiver stated,

"the help I need should come from my husband...Their father should be looked after a little bit by everyone."

This woman was seeking both emotional and instrumental support from her family. Without family support, it was seen as a difficult burden for one individual to carry alone. The caregiver made the suggestion that families needed to look at their own potential for becoming more involved and supportive in the caregiving relationship.

C. Flexibility:

When discussing services that were presently being utilized, most identified a need for the hours and schedule be more flexible.

"they're not flexible...If you need 14 hours in a day you shouldn't have to fit it into a 5 hour slot as long as it
doesn't add up to more than 120 hours. I don't know how they determine how much care someone needs."

Flexible hours were seen as necessary for the service to be able to respond to changes in the family situation. An example often cited was the need for homemaker respite hours to be lengthened on occasional days to permit the caregiver to do special tasks or visit friends and relatives outside the immediate area.

Regulations and lack of input into to what homemaking agency was used further reduced the control families felt that they had over who provided the care to the client.

"If it didn't come from (a certain agency) could it not be transferred so that another person could get so much for doing this."

Caregivers recommended shifting care provision to a broader range of careproviders and allowing families to have a voice in the choice of homemaker for their relative.

It was also suggested that flexible adult day care hours be introduced to make the service useful to a broader range of need and reduce the disruption to the family. Respite bed use should also be flexible. As one respondent stated, the health department should "judge it on the basis of how much you need, not just a flat 30 days".

D. Expanded Facility Respite:

Facility respite was an area in which many of the caregivers made suggestions for the reorganization and improvement of service delivery. Short notice, emergency, and
short term institutional respite were among the recommendations made.

Present facility respite is often booked months in advance. Many caregivers found this very frustrating and felt that it was very difficult for them to plan so far in the future.

"It would be useful, especially if you didn't have to make arrangements six months ahead. Who is to know in the future. Sometimes it is right now."

To be responsive to need, the caregivers believed that the service should be available on shorter notice. Caregivers found it difficult to plan when they would next reach a crisis or need the opportunity for a complete break.

Emergency respite was another area where it was felt that increased access to service would be beneficial. Caregivers often felt that they "can't afford to get sick". They wanted the reassurance of knowing a service would be available when needed. This reassurance would enable them to plan for and feel less anxiety about their future.

At present, facility respite is available in weekly blocks. Some families felt that shorter term, frequent respite would better meet their needs.

"What I think would be good would be if they could take the person into a home for say two days a month for example. This would give you a couple days each month to get away or rest."

Through periodic short breaks, the caregivers felt that they
would be able to enjoy a variety of opportunities throughout the year. Some respondents saw a year as too long between respite occasions.

As an alternative to institutional respite, in-home respite where a homemaker comes into the home and stays with the client while the caregiver goes away was seen by many to be more acceptable than using institutional facilities. This option was perceived to offer less disruption for the client and reassurance to the caregiver who would know that the client was in a comfortable environment.

"I wouldn't have to worry about anything happening here and she wouldn't have to be upheaved out of her home and go into a strange place with strange people."

Comments of the respondents revealed their belief that this form of respite would be seen as less threatening and alienating to the client who would be maintained in a familiar environment with a familiar routine.

One caregiver discussed the need for more specialized separate respite facilities.

"What I am looking at is if only they could have some kind of extended care place even if it was sort of strictly a respite place."

She felt that a specialized facility would be better equipped to meet the unique needs of her mother.

E. Emotional Support:

Emotional and mental strains have been identified as a
major stresses faced by caregivers. Caregivers reinforced the need to include supportive services that address these stresses. As one daughter stated, this can be simply "a matter of being here, talking to them and keeping them company that helps a lot". The caregiver was often socially isolated. While much of the emotional support that people needed came from family, there were limits to the involvement and support available from within this network. One family asked,

"if someone is struggling with the emotional side of care, is there someone at the health department that they can talk to?"

F. Assessment of 'Family' Needs:

For some of the families in this study, especially where there were multiple generations involved, it was felt that assessment and assignment of service needed to be based on more than just the client's care needs. One caregiver had requested help with housework but was denied that because of her age and physical ability to complete the task herself. She felt that the fact that she had many other responsibilities and demands on her time was not taken into consideration. The caregiving situation was being faced by the entire family, not just the client.

"They said at the center that if my mother-in-law need help they could send someone here to look after her. But, for my mother-in-law it doesn't make sense. My father-in-law need more care. If someone come to look after her, I
rather to have more hours to look after him."

This caregiver had been offered more help with her mother's care, not with the housework where she felt there is a need.

In summary, this section has outlined several changes recommended by the caregivers interviewed. These recommendations ranged from expanding existing services to creating entirely new and specialized services.

Most of the caregivers wanted to have more input and control over the frequency, access and form of the services being offered to them. Services suggested would offer the client and the caregiver the opportunity to increase their physical and psychological ability to cope with their situation. This must be done by increasing the resources available to them, not by imposing external solutions. These suggestions do not necessarily involve a gross increase in cost or resources, but do involve a change in approach and control. One caregiver summarized this belief by saying,

"I know the government is spending all kinds of money on different support services. I am saying do it direct--do it directly with us".

This caregiver wants to see the consumer dictating the nature and content of services and how they are delivered. She makes the basic assumption that families are the best ones to assess need and plan for appropriate care. Given the resources to do this, the outcome for both the client and caregiver would be positive. There are many barriers to accomplishing this
kind shift in control, the most significant one being the bias our society and medical model show towards the elderly and their needs.

"Most medical professionals don't think old people are as important. They see disability for a young person as a great tragedy. For the old person, they have lived their life--they don't need to have a better life."

This person articulated the pessimism felt by many others towards the likelihood of significant change. The low priority given to the aged and chronic health care needs impacts on the funding and attention support services receive. A traditional medical model continues to compartmentalize need and gives clients and families little control over the content and delivery of services.

Summary

This chapter has outlined the themes and content of the findings of this research. The data are rich in detail and scope. The categories are not mutually exclusive but relate to and impact on each other. These findings, like the individual situations they reflect, cannot be compartmentalized. The data gathered from case managers and caregivers revealed many similar themes, but the content and emphasis did reflect the different perspectives and positions of the two groups.

The next chapter presents a more detailed discussion of the implications of this data along with a presentation of the core
categories that connect much of the data that have been presented. The theoretical implications for practice and program development will also be addressed.
CHAPTER 5

INTERPRETATION OF FINDINGS

Introduction

This chapter focuses on the interpretation of the data gathered in this research project. This analysis must be considered in the context of the original objectives of this research. The primary objectives identified were:

A) To conceptualize 'need' for respite from the perspectives of case managers and caregivers, and;

B) To identify program objectives and service recommendations that address the need identified by the two respondent groups.

The discussion of the findings has been divided into two main sections. The first section addresses needs identified from the data. The second section deals with recommended objectives and interventions in the area of respite care. A final section will explore the barriers within the formal and informal system that impede the development of effective and complementary care networks.

Two central organizing concepts are used as the core categories of the data. These core categories unify the numerous themes of the presented data and relate to both need and service delivery objectives of the study. These core categories are discussed under each of the first two main sections of this chapter.
The first of these two concepts will be referred to as system stimulation. Here a systems model of interpreting need and planning intervention is used to understand how caregivers experience their situation and how services can support the caregiving relationship. The second core category to emerge from the data relates to locus of control in the caregiving relationship. Discussion of this concept touches on understanding who controls the system of supports and services available to family caregivers and how a complementary relationship between formal and informal sources of care may be developed.

Most of the interpretation and discussion of concepts in this chapter is done at the level of their theoretical and philosophical underpinnings. While some specific program recommendations will be presented in the concluding chapter of this thesis, it is important that these ideological and value issues be addressed and understood first.

Conceptualizing Need

The findings of this research reveal a broad spectrum of needs related to respite care. These needs are now organized and discussed as they relate to the need for stimulation in the system and the need for the caregiver and family system to develop and maintain control in their situation.

1. System Stimulation:

Many of the needs identified by both case managers and
caregivers relate to the lack of resources available for meeting the responsibilities and duties involved in caring for an infirm elderly relative. Both groups of respondents discuss the need to increase resources available within and outside the family system.

A. Case Managers' Perspectives

Case managers feel that many caregivers have limited personal and family resources. The isolation of the caregivers, their lack of education and awareness, and absence of role models for their situation create a gap between the needs being faced by the caregivers and their ability to cope with these demands. The caregivers are unable to plan or exercise options as a result of being overwhelmed by their situation. Often personal resources and coping strategies are constrained by culture, socialization and a fear of becoming involved in unfamiliar situations. They may face conflicts between the needs of the elderly relative and the need to care for themselves or attend to other family responsibilities. All of these needs and resource limitations point to a need to increase the resources available to the caregiver.

It has been demonstrated that it is usually one individual who assumes the bulk of caregiving responsibility. Defining need should focus on this individual as a central part of the system, but the entire caregiving relationship and context must also be considered. The availability of other informal supports, the
history and status of the relationship with the caregiver and the personal and cultural values held by the family members must be considered when assessing what kind of support people need and what will be perceived as acceptable and beneficial.

Education, counselling, increased personal time, and freedom for the caregiver are some of the areas where needs were identified. These suggestions are based on an assessment of what the caregivers need to maintain their role in the system. The case managers validate the caregivers' right to receive support for their own needs. In the case of respite, need is being defined on the basis of the caregivers' needs within a system of family and formal supports.

The identified client is seen in the context of a caregiving system. The center of this system is shared with the primary caregiver. The system experiences many limitations and gaps between resources and demands. The need is for the formal system to intervene in a way that increases the resources and energy available in the caregiving system. While respite care services are usually targeted directly at the caregiver, other interventions may provide equal benefit. A service that intervenes with the client and provides the caregiver with a new perspective and contact may be as beneficial as a service that provides more direct relief to the caregiver.

Case managers see formal supports as a part of the caregiving system. These supports also face limitations in their ability to meet needs especially when the supports are
unavailable, unknown, or unacceptable to the family. To be able to work effectively as part of the caregiving system, formal supports need to understand the primary relationship between the client and caregiver and work to strengthen this relationship when it is seen as positive for both parties. Formal supports are not seen as something divorced from the primary caregiver. Services must aim to become part of the caregiving system by providing input and stimulation within the caregiving relationship.

B. Caregiver Perspective

The caregivers identify many of the same needs as did the case managers. They describe the multiple stresses that they face and the limits they experience to their own ability to cope. These caregivers admit to being isolated and lacking information or understanding of how to adjust to their situation or deal with the necessary outside resources and services. They are usually the sole source of support and have high expectations of themselves to be able to meet most needs within this confined system. Their long history and intense involvement in the caregiving relationship contributes to their isolation and reluctance to involve or seek out outside resources.

For these caregivers, the caregiving system is a very small and closed network. Formal supports are either unknown or seen as unacceptable. Family support is often unavailable. Limited information or stimulation comes into the family system.
Depression, hopelessness and other negative emotional reactions occur along with physical exhaustion. These caregivers are asking for help through increased information, awareness of options and some freedom or flexibility in their lives. Their need is not defined in terms of specific resource deficits or interventions, but focuses on the need to make a connection and increase their ability to plan and cope with the situation. They do not want to give up tasks or responsibilities, but want to connect with a service in a way that will strengthen their motivation and ability to continue in the caregiving role.

For the caregivers, the caregiving system consists primarily of the client and themselves. Formal services are seen to be outside and separate from this system. They want resources such as the LTC services available for them to tap into and bring new energy and relief into their system. Access to such services will enable the caregivers to expand their options and revitalize the caregiving relationship, both physically and emotionally.

The issue of how connected formal services are to the caregiving system is the major difference between how case managers and caregivers view the need for system intervention. The case managers, as part of the formal system, are likely to see its role as more central than families who are already providing the bulk of care.
Matrix I

NEEDS RELATED TO SYSTEM STIMULATION

<table>
<thead>
<tr>
<th>Case Manager Viewpoint</th>
<th>Caregiver Viewpoint</th>
</tr>
</thead>
<tbody>
<tr>
<td>-limited personal and family resources to meet high degree of stress and burden</td>
<td>-multiple stresses related to confusion, medical concerns, mental stress and unpredictability</td>
</tr>
<tr>
<td>-gap between demand and resources</td>
<td>-demands outweighing resources</td>
</tr>
<tr>
<td>-isolation and limited perspective of caregiver</td>
<td>-social isolation of the caregiver</td>
</tr>
<tr>
<td>-lack of education, socialization and role models</td>
<td>-lack of information</td>
</tr>
<tr>
<td>-value gaps and conflict</td>
<td>-sole responsibility for care</td>
</tr>
<tr>
<td>-fear of the unknown</td>
<td>-high expectations of self</td>
</tr>
<tr>
<td>-negative emotional reactions and mental stress of caregiving</td>
<td>-long history of burden</td>
</tr>
<tr>
<td>-caregiver's need for freedom</td>
<td>-constant responsibility and lack of freedom</td>
</tr>
<tr>
<td>-caregiver's right to support</td>
<td>-depression and hopelessness</td>
</tr>
<tr>
<td>-need for LTC to supplement family involvement</td>
<td>-stress and conflict within the family</td>
</tr>
<tr>
<td></td>
<td>-limited family support and availability</td>
</tr>
</tbody>
</table>
2. Need for Control in the Caregiving Relationship:

The second major and related theme that emerges from the discussion of need for respite is a need for control. Some of these needs appear similar to those discussed in the first section, but their source and interpretation take a different perspective. Case managers and caregivers identify many similar issues in this area along with some differences. Their perceptions and an interpretation of the issues that they raise will now be presented.

A. Case Manager Perspective

Case managers see family caregivers as having limited control over their situation due to their limited personal resources and all consuming demands of caregiving. This situation is exacerbated by shortages and restrictions associated with formal care services.

Many of the shortcomings identified expose a need to expand formal resources, improve service access and increase service flexibility. These services should be targeted at the family and not be provided on the basis of one individual's care level. The caregiver's situation needs to be recognized and validated as an essential and stressful position in the family.

What case managers are identifying through these suggestions is the need to involve the caregiver as a central actor in the assessment and delivery of services. They discuss the need to adopt a team approach to care that involves the collaborative efforts of both family and formal services.
Continued family care is seen as beneficial to the client, caregiver and the formal system. They feel that it is necessary to leave the family with control as the primary source of care but that an attitude of shared responsibility should be adopted by both formal and family networks.

Case managers describe the need to provide support within the caregiving relationship rather than imposing external solutions or taking away roles from the family and caregiver. By strengthening the personal resources and ability of the caregiver to control and organize his or her own situation it is felt that the outcome will be positive for both the client and family. Many of the negative emotional responses such as depression, anxiety and hopelessness stem from the caregiver's experience of lacking control. The case managers describe caregivers who have limited opportunities to develop skills or knowledge of how to deal with caregiving responsibilities and the complicated formal bureaucracy that claims to offer assistance. These caregivers are left feeling that their lives are controlled by needs of the clients and the schedule of available external supports.

This discussion points to the need for family caregivers to increase their influence and control in order to maximize the care provided to the client and improve the caregivers' own mental and emotional health. Through increased personal resources and greater input into the involvement of external services in their situation, caregivers will be better equipped
to develop and maintain a complementary relationship between formal and informal sources of care.

B. Caregiver Perspective

Caregivers echo the need for increased personal and formal resources to enable them to deal effectively with their situation. They see a need for more information and education about resources. Existing services need to become more flexible and accessible.

Many of these respondents perceive themselves with few choices. Their feelings of obligation, duty and cultural values contribute to their sense of being trapped in their situation. These caregivers often feel uneasy and lack confidence in the ability of formal services to provide quality care for their relative. Their own high personal expectations and assumption of total responsibility for the care and comfort of the client contribute to a resistance to many formal interventions. The judgement of many services as unacceptable further limits the choices available to the caregiver.

The comments of the caregivers in this study reflect their desire for consistent and reliable services. They need to have increased input and influence in the content and delivery of support services in order to feel comfortable and accepting of these interventions.

Without addressing the resistance these caregivers feel to existing services, formal supports will continue to provide limited choices to families. There is a need to validate the
physical and emotional stress of caregiving. The values and perceptions of the caregiver must become part of the assessment of need.

The needs identified by family members often relate to their sense of hopelessness and lack of control over their situation. These people need more than instrumental services. They need supports that increase their ability to cope with their situation without threatening to take away their control of the caregiving relationship. They need to feel that their experiences are valid and their responses legitimate. They must be given the opportunity to define their own needs and how those needs are best met. This involves increasing their confidence, skill level and knowledge.

In summary, this discussion has focused on understanding need from two perspectives: the need to provide stimulation to the caregiving system; and the need for the caregiving system and the caregivers in particular, to develop control over their circumstances.

From a systems model approach, respite care services are needed in order to provide new energy into the caregiving system. Intervention that provides physical or emotional relief can act to revitalize the system and strengthen the caregiver's ability and motivation to cope with the caregiving demands that he or she faces. The need for intervention must be assessed on the basis of an understanding of the caregiving system and its strengths and weaknesses. The impact of a particular
intervention must be considered in terms of its influence on connected parts of the family system. Respite is defined by the benefit perceived by the caregiver, and not by the type or point of intervention.

Respite care services are designed to provide relief and support to the caregiver. From the perspective that considers the locus of control, these services need to involve consultation and collaboration with the caregiver. The need for respite should be defined in consideration of the caregiver's strengths, limitations and receptiveness to intervention. If respite is to provide relief and support to the caregiver, his or her personal reaction to the service must be the focus of assessment. Without experiencing some control over the definition and delivery of supports, the caregiver will derive restricted benefits from any service.
Matrix II

NEEDS RELATED TO LOCUS OF CONTROL

<table>
<thead>
<tr>
<th>Case Manager Perspective</th>
<th>Caregiver Perspective</th>
</tr>
</thead>
<tbody>
<tr>
<td>-shortage of personal and formal resources</td>
<td>-inadequate resources to meet care demands</td>
</tr>
<tr>
<td>-limited access to resources</td>
<td>-need to improve access and increase flexibility</td>
</tr>
<tr>
<td>-time and cost restraints</td>
<td>-need to increase choices available to the caregiver</td>
</tr>
<tr>
<td>-need to expand services and increase flexibility</td>
<td>-need to address caregiver resistance to services</td>
</tr>
<tr>
<td>-need to focus on family, not individual needs</td>
<td>-need to increase comfort and trust in services</td>
</tr>
<tr>
<td>-need to accept shared responsibility</td>
<td>-need to improve quality and consistency of supports</td>
</tr>
<tr>
<td>-need to adopt team approach to care</td>
<td>-need to address high personal expectations</td>
</tr>
<tr>
<td>-need to leave family with primary role as caregiver</td>
<td>-need to increase caregiver's input in service delivery</td>
</tr>
<tr>
<td>-need to recognize and validate role or caregiver</td>
<td>-need to increase awareness of formal services</td>
</tr>
<tr>
<td>-need to provide support within the family</td>
<td>-need to validate physical and emotional stress of caregiving</td>
</tr>
<tr>
<td>-need to adopt soft sell approach to service</td>
<td></td>
</tr>
</tbody>
</table>
Planning Interventions

In this chapter, the topics of need and intervention have been artificially separated. In reality these two areas are closely connected and overlap. In consideration of the needs identified in the first section of this chapter, this section explores the implications for intervention.

1. Intervention Based on System Stimulation:

Many of the recommendations for change or program development that arise out the interviews in this research project are direct responses to the need to fill gaps in the existing system of formal and informal supports. Addressing these needs through support programs for caregivers involves more than adding resources. The following is a discussion and interpretation of the recommendations made by both case managers and caregivers.

A. Case Manager Perspective

The strengths of existing services and the need for further development focus on expanding the resource base of the family. This includes providing education to maximize the caregiver's own abilities and skills as well as developing knowledge and information about existing services and options to further enhance the caregiver's access to resources. Counselling and emotional support need to be incorporated into the formal health care system. To accomplish this, case managers must be given the time and flexibility to identify high risk situations and provide mental health supports as well as instrumental services.
The goal of increasing the energy and commitment of the informal support network is accomplished through providing services that are incorporated into the system, not imposed from outside the caregiving system. Services such as education and counselling give the caregiver the opportunity to develop his or her own personal skills and coping abilities. Respite services that provide caregivers with personal time and flexibility in their lives give them the chance to make connections outside the family. Whether respite allows the caregiver to join an organization, escape from constant the demands, or adds a new person or activity to her life, the boundary of that system is expanded. The caregiver's role is expanded, not constrained, by the services that are offered.

A holistic definition of health and well-being that incorporates physical, emotional, psychological and social adjustment is a necessary component of this kind of intervention. The needs of the caregiver cannot be separated from the client and the caregiving system. Mental health needs are closely connected to physical health and the need for instrumental support. The interconnectedness of the caregiving system, both within the caregiving relationship and between individuals in the system must be recognized in the development and delivery of respite services.

Services must be community based, responsive to the interrelated parts of the caregiving relationship and flexible in order to be able to provide service that is targeted at the
part of the caregiving system where the intervention will be the most effective. For some caregivers, homemaker respite is able to provide significant support due to the trust the caregiver develops in the service and the stimulation and new energy that is presented to the isolated client. While adult day care may be very supportive for some clients, for others the service is perceived to be alienating and stress producing. The key to providing a service that is able to strengthen the core caregiving relationship lies in developing flexible supports that are sensitive to the perceptions, strengths and limitations of the caregiving system.

B. Caregiver Perspective

In order to increase the resources and coping ability of the family caregiving system, caregivers recommend that services be provided that increase the personal time and freedom available to them. Education and information are other areas where they feel that programs should be developed. These recommendations focused largely on expanding existing services. It is often easier for people to ask for 'more of the same' than to identify new ideas. This tendency may create a bias in the recommendations presented by both groups of respondents.

For many of these caregivers, instrumental services are the focus of many recommendations. This is an area where the family members seem to feel more comfortable admitting to their limitations. Emotional and mental health needs are difficult for some to identify and articulate. Physical limitations are
perceived to be more socially acceptable than psychological weaknesses. This bias is an important consideration in the early stages of involvement with formal services. Caregivers may need to develop comfort and trust with services geared at instrumental tasks before they will accept intrapersonal supports.

Both caregivers and clients are often isolated. Their self-esteem and confidence in their ability to provide adequate care are often damaged by the constant burden, hopelessness and feelings of guilt that they experience. The mental stress that these caregiving systems endure reinforces the importance of including counselling and mental health supports in an attempt to strengthen the caregiving system.

In the interviews, caregivers identified the benefits of the stimulation that a service and respite opportunity brought to them. Again, the positive outcome of introducing a new person, input, or information into the caregiving system is identified as a major benefit of respite services. The family's perspective is broadened when its system boundary is expanded to include this new source of energy and stimulation.

Intervention, however, cannot be assumed to be beneficial just by its existence. The service must be consistent and reliable so that the caregivers will trust and incorporate the support into their field of options. The service must be provided on the basis of an assessment of the family's need. Strict program and eligibility criteria negate any attempts to
provide flexible and responsive services.

As was noted earlier, caregivers perceive a sharp division between the formal care system and family caregiving. Services are generally seen as external and foreign to the family unit. This may be a result of value differences and a gap in the formal system's understanding of the caregiver's experience. To be able to reach caregivers in a way that is acceptable to them involves shifting attitudes and control of the situation. This issue of control is dealt with in detail in the next section, but is closely linked to how successful a service is in providing energy to the caregiving system.

Caregivers generally want to maximize their ability to provide care for their relative. They want to feel that they are meeting the client's needs as best they can. By providing a service to the caregivers that enables them to maximize their own energy and motivation, the service may begin to break down the barriers to a complementary relationship between formal and informal supports. Whether that service is one that gives the client the opportunity to pursue personal life goals and reduces his or her resentment or feelings of being trapped, or one that stimulates the client and brings a new perspective to the relationship between the client and caregiver, the common theme is the revitalization, the opening up of the system boundaries. The caregiving system is still seen as separate from formal services, but more open to accepting new energy and resources from its environment.
This discussion has provided an interpretation of the need for intervention from the perspective of a systems model that defines intervention in terms of the stimulation and energy that it injects into the caregiving system. Case managers and caregivers shared many similar values although the case managers were able to articulate their suggestions in system terms more clearly than caregivers. This difference points to the need for service to be aware of the perspective and insight of the caregiver. Self awareness is the first step in being able to define one's own needs and to plan for appropriate care and support.
### Matrix III

**INTERVENTIONS BASED ON SYSTEM STIMULATION**

<table>
<thead>
<tr>
<th>Case Manager Perspective</th>
<th>Caregiver Perspective</th>
</tr>
</thead>
<tbody>
<tr>
<td>-expand system boundary through introducing services</td>
<td>-increase personal time and freedom from burden</td>
</tr>
<tr>
<td>-increase resources within the family system, not take away roles</td>
<td>-provide education and information</td>
</tr>
<tr>
<td>-focus on education and counselling</td>
<td>-provide stimulation through a new service, person or input into the family that broadens their perspective</td>
</tr>
<tr>
<td>-increase priority on emotional and mental health needs</td>
<td>-begin with services based on acceptable instrumental aid</td>
</tr>
<tr>
<td>-adopt holistic approach to health needs and reduce compartmentalization of needs</td>
<td>-provide emotional support to increase self esteem and reduce isolation</td>
</tr>
<tr>
<td>-increase awareness and present options</td>
<td>-provide more flexible, consistent, reliable services</td>
</tr>
<tr>
<td>-focus on dual benefits of services</td>
<td>-provide services based on family need, not strict program criteria</td>
</tr>
<tr>
<td>-develop community-based, responsive and flexible services</td>
<td></td>
</tr>
</tbody>
</table>
2. Intervention Based on Locus of Control Issues:

It is difficult to separate the discussion of intervention objectives related to the two core conceptual categories of this research. There is much overlap and interconnection between these issues. This section expands on the interpretation that began in the previous section by developing the concept of locus of control in more detail.

A. Case Manager Perspective

In the development of any social service, especially when geared at less powerful consumers, the issue of control over content and delivery is important. Case managers make many suggestions that involve empowering caregivers. They feel that intervention has to begin with validation of the caregiver's experience and legitimating services targeted at the caregiver. Program objectives must reflect the caregiver's own right to support separate from its impact on the client.

Education, counselling and mental health supports are again raised as essential to increasing personal and family resources. The primary role of caregivers in meeting client needs is recognized. In order to maximize the care provided to the client and simultaneously provide personal support and reinforcement to the caregiver, services must not threaten to take away control or functional roles involved in the caregiving relationship.

A holistic definition of health plays an vital role in shifting the locus of control as well as addressing the need to
provide a systems-based intervention. Services must reduce the compartmentalization of needs. Caregivers must feel that they have access to comprehensive, reliable and trustworthy services. Without the opportunity to develop confidence in the services being offered, the only way that caregivers may feel able to exert control over the care that the client receives is by refusing to accept external supports.

Professionals such as the case managers in this study, need to consider all aspects of supports and resources. Attempts to encourage or facilitate increased family involvement or control must take the form of a mutual explorations of options rather than the imposition of expectations on families. While it may be advantageous for families to become more involved in some situations, this approach runs the risk of pushing already overburdened families beyond their limits. What is appropriate or functional in terms of family involvement must be defined by the family and not imposed by an outside service or professional. The power of definition is central to this issue of control.

The case managers feel their influence is restricted by the high case loads, limited time, job restrictions and paper work requirements of their jobs. For these professionals, locus of control is also an issue. They feel powerless to work to empower families when they experience limits to their own control over their job situation. These case managers feel that they can be more effective if they are given more autonomy and
flexibility in their jobs. They see a need to reevaluate the priorities of the program and focus more effort in the area of prevention. Until they can become proactive in their jobs, instead of simply reactive, they will not be able to provide the kind of service to families that will increase the ability of this informal network to cope and prevent a crisis from developing.

Increasing the control that caregivers have over the involvement of formal services necessitates an acceptance of the concept of shared responsibility. The findings of this study contain repeated mention of cost constraints. The short term, cost benefit basis for determining services as perceived by the case managers restricts the ability of the program to consider long term costs and benefits. The concept of shared responsibility is not integrated into the formal health care system. Accepting payment for a service is held to be synonymous with accepting responsibility for meeting the need. The family continues to be seen as the system with primary responsibility for meeting care needs of elderly persons. While the informal system does provide the bulk of care for this group, there are limits to its ability to meet all needs. The state and formal care system need to accept a supplemental and complementary role to the family. Rather than providing crisis and safety net provisions, this sharing of responsibility should be incorporated into the mandate of formal services. The responsibility for care belongs to the society as a whole and is
not something that is transferred from one group to the other. As long as the values and philosophy of the formal system dictate the role of family, caregivers will continue to feel that they have no choices in the way that they provide care.

B. Caregiver Perspective

Family members interviewed in this study express several ideas that relate to the concept of locus of control. As has been discussed, many of these caregivers perceive themselves as having limited control over their circumstances, daily routines and their future. Given that the perception of need can vary according to cultural beliefs, service providers are faced with the dilemma of choosing whether to intervene in an attempt to change values or to provide different levels of support to different groups. It may prove to be futile to take on the task of intervening to change people's cultural and value expectations. One may also question the ethics and value biases involved if intervention is targeted at cultural beliefs. While it may be difficult to become directly involved in personal expectations that limit the perception of choice and control, formal services can become involved in developing options and resources available outside of the immediate family unit.

Information and education reemerge as ways of increasing the caregiver's ability to plan for her own situation. Increasing the flexibility and loosening the criteria associated with existing support and respite services would give the caregivers the ability to fit the services to their needs rather
than always feeling that they must suit their needs to the available supports.

Most caregivers want more input into the types of services that are offered to them, especially in terms of the timing, schedule and access to these supports. Both the client and the caregiver can perceive formal supports as threatening if these services fail to address the values and emotional needs of the family. As noted earlier, resistance to services may be an attempt to exert continued control over their life situations. For clients who already feel vulnerable, services that involve removal from the home or introduction of strange routines may be interpreted as threatening to their lifestyle.

If the client and caregiver have control over the involvement of LTC and other formal services, the likelihood of those services being rejected due to their threatening nature is reduced. In trying to understand where and how to intervene in the caregiving system, understanding where individuals feel vulnerable is a necessary first step. Interventions must address these fears by increasing comfort through education and public awareness. Programs must be sensitive to cultural and value differences. It is impossible to design specific supports that suit all constellations of need and values, therefore the services that are developed must be flexible.

What this discussion has attempted to present is the importance of locus of control as an issue in designing program interventions. If respite is seen in terms of the benefit it
provides, then the perception of the recipient becomes the central determining factor in service planning. In order for clients and caregivers to appreciate some form of relief, the service must be presented in a way that does not alienate or threaten. The caregivers must feel that they have some control over the service— that solutions are not being imposed external to the caregiving system. It has been demonstrated that services must be provided from a perspective that involves a holistic approach to understanding need and intervention and consideration of a caregiving system. Respite involves introducing new energy into the system by providing the caregiver with some form of relief or stimulation. These respite services must also permit the caregiver a continued and increased sense of control over her own life and over what kind of input enters the caregiving relationship.
## Matrix IV

### INTERVENTIONS BASED ON LOCUS OF CONTROL

<table>
<thead>
<tr>
<th>Case Manager Perspective</th>
<th>Caregiver Perspective</th>
</tr>
</thead>
<tbody>
<tr>
<td>-validate family experience</td>
<td>-provide better information and access to services</td>
</tr>
<tr>
<td>-provide education and counseling to increase personal and family resources</td>
<td>-increase the flexibility and choices included in formal services</td>
</tr>
<tr>
<td>-accept concept of shared responsibility</td>
<td>-provide counseling and support to help caregivers accept limitations</td>
</tr>
<tr>
<td>-provide counseling and mutual exploration of limits and options for family support</td>
<td>-loosen strict criteria of service eligibility</td>
</tr>
<tr>
<td>-recognize supplemental role of formal services</td>
<td>-allow family input into the content and delivery of services to reduce threat that can be perceived</td>
</tr>
<tr>
<td>-target services at caregiver and reinforce their right to support</td>
<td></td>
</tr>
<tr>
<td>-use holistic definition of health in assessing need</td>
<td></td>
</tr>
<tr>
<td>-re-evaluate priorities of program re: prevention</td>
<td></td>
</tr>
<tr>
<td>-advocate for more trust and flexibility to be given to case managers</td>
<td></td>
</tr>
</tbody>
</table>
Barriers to Meeting Need

Having presented the two core categories of the research as they relate to need and objectives for intervention, this section provides an interpretation of the barriers that are faced by families, formal care providers, and program planners in operationalizing intervention objectives that support family caregiving and a complementary formal/informal relationship.

1. Barriers Within the Informal System:

The findings in this research demonstrate that families are often reluctant to involve formal care services. This resistance constitutes an obstacle to the formal system in its attempt to provide support.

A. Case Manager Perspective

Case managers discuss many of the values and role expectations held by family members as both positive and negative. The high value placed on self sufficiency and the strong sense of obligation and duty that many caregivers are believed to share reinforces their commitment to provide care. These same role expectations can lead to feelings of guilt, resentment, and a reluctance to seek help or admit to the need to involve outside resources.

All of the caregivers in this study were female. The issue of caregiver role expectations cannot be separated from issues addressing the role of women within families and society as a whole. As personal expectations and the opportunities for involvement outside the family increase for women, the
expectation that they provide care and nurturing within the family has not decreased. The potential for guilt and burn-out increases with the growing gap between demands and resources.

Repeatedly, case managers identify the frustration that they feel when families first seek out help during a crisis. These families have tried to cope for a long time on their own and have often reached a breaking point. The family's perception of a crisis limits its openness to options that involve a change in thinking or family functioning style. These case managers feel that families often come to LTC having already decided that the solution they are seeking is facility placement. The stress of caregiving may have become more than families feel they can cope with and the only solution they see is the total removal of the source of stress. Just as these families were reluctant to seek out help earlier, they now continue to resist changes that may help them cope with the care of the client at home.

Case managers indicated that perceptions of control, as well as role expectations, relate to the barriers created by families. Many caregivers lack socialization or role models for the part that they now play. In our aging society where the elderly can live through long periods of dependency, caregivers are faced with a situation that their experience does not prepare them for. They do not know what their future will be, how they should set priorities and deal with competing demands, or what limits they should set to their sense of spousal or
filial responsibility. There may be conflict within the family if members do not share the same values or interpretation. All of these factors contribute to the feelings of helplessness and lack of control that caregivers can experience.

Case managers felt that formal services may be perceived by the caregiver as another factor in the situation that they are unable to control. This fear of losing further control can reinforce their resistance to accepting the involvement of outside services. This resistance to change and the involvement of supports creates a significant barrier to the development of a functional helping relationship between informal and formal support networks.

B. Caregiver Perspective

Caregivers expressed many of the same values and concerns identified by the case managers. They feel a strong commitment and obligation to remain the primary caregiver. Their role expectations and feelings of guilt reinforce their decision to carry the burden alone. The long history of caregiving and lack of awareness of options heighten their resistance to changes that involve new or unknown services. Change threatens the caregiver who has had a long intense involvement in the care of the client.

Many of these caregivers find it difficult to admit to their own limitations and emotional needs. The acceptance of outside supports is interpreted as a failure to fulfill their role obligations.
over their situation leads many to initially resist services. At the point of a crisis it becomes necessary for the formal system to become involved. Feeling that they have lost all control at that point, caregivers may want to abdicate their role entirely and have the client placed in a facility.

Family dynamics and conflict are issues that some caregivers identified as central. The struggle within a family to define its role and obligation creates a further barrier to the involvement of LTC and other formal services. Family members may resist outside services in reaction to family conflict or as a result of the belief that other family members should provide the support.

The barriers that exist within the family caregiving system relate to and supersede the two core categories discussed in the beginning of this chapter. The family system boundary may be closed to the influence of outside supports for a variety of reasons. The issue of control over one's own role and future of the caregiving relationship can manifest itself as an impediment to involving support services.

2. Barriers Within the Formal System:

The formal system also includes many structural and ideological factors that inhibit effective involvement in the caregiving system.

A. Case Manager Perspective

Structurally, many of the services that are available have limited access due to staffing, time restrictions, cost,
transportation problems or long waiting lists. Case managers feel that they have limited time to properly assess need and provide families with adequate information. People are not aware of options nor provided with the education that would allow them to advocate for appropriate services on their own. Even when a need is identified, long waiting lists and concerns about the relative cost of services can delay or prevent that service from becoming available.

There are gaps in the services that are appropriate especially for families with special needs related to culture or type of disability. The staff that provide care receive limited training and low wages. The program and families may expect more from these workers than is realistic.

The program is geared to assessing need on an individual basis. The assessment forms clearly relate to the identified patient and refer to the family support in later pages only. The low priority given to the needs of the family and the emotional and mental health of the caregiver contributes to a compartmentalization of needs. The case managers often perceive the need of one member of the family in conflict with the needs of another and are faced with the dilemma of prioritizing these needs. The whole idea of supporting caregivers may be a lip service paid to an intervention that is believed to provide cost efficient care to the identified client. The case managers repeatedly noted the benefits that respite services have for the client as well as the caregiver. It is left to be
questioned if this same consideration for the needs of the caregiver is so prominent in the assessment of services directed at the client.

What the case managers have identified is the structural limitations and inflexibility of formal care services. The objectives of the program continue to relate to physical care needs of the identified client. Mental health supports and the assessment of system needs play a minor role in many formal supports.

B. Caregiver Perspective

Caregivers see many of the supports available through LTC as either inappropriate or inadequate. They are concerned about the quality of the care, the program fit with family schedules, time and access difficulties as well as the inability of inflexible services to meet constantly changing needs. Many services are seen to produce more stress than they relieve. The caregivers find it difficult to access the information they need or want in order to maximize the benefit to both the clients and themselves. The lack of flexibility is a major factor that impedes the ability of the LTC system to meet the needs of older families. There is a need for specialized services to address the unique circumstances of respite clients. In-home respite is seen as advantageous for a number of reason, but this resource is in short supply due to low salary levels and a concern for comparative cost with other services.

Caregivers feel that they must organize their needs to fit
the schedule of available homemakers or respite beds. The program is perceived to have limited responsiveness to the caregiver's needs. Criteria for eligibility is not always synonymous with need. Caregivers have identified the inflexible nature of the program as a significant barrier to its ability to adequately meet the needs of caregiving families.

The formal care system is part of a large health care bureaucracy. Both case managers and caregivers touched on factors within this bureaucracy that inhibit its ability to respond to the needs of clients and their families in the community. The inflexibility inherent in such a large system along with its focus on individual needs constrain its ability to provide effective services. Limited access due to time and cost exacerbate these barriers.
Matrix V

BARRIERS TO MEETING NEED

<table>
<thead>
<tr>
<th>Case Manager Perspective</th>
<th>Caregiver Perspective</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Barriers in the Informal System</strong></td>
<td></td>
</tr>
<tr>
<td>-values of self sufficiency</td>
<td>-commitment to remain primary support</td>
</tr>
<tr>
<td>-reluctance to seek help</td>
<td>-guilt, obligation and role expectations</td>
</tr>
<tr>
<td>-sense of obligation, guilt</td>
<td>-fear of loss of control</td>
</tr>
<tr>
<td>-role expectations</td>
<td>-resistance to change</td>
</tr>
<tr>
<td>-lack of socialization</td>
<td>-reluctance to admit limits and emotional needs</td>
</tr>
<tr>
<td>-fear of loss of control</td>
<td>-family conflicts</td>
</tr>
<tr>
<td>-resistance to change</td>
<td></td>
</tr>
<tr>
<td>-conflict within family</td>
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**Barriers in the Formal System**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td>-lack of information or public education</td>
<td>-inappropriate or inadequate services</td>
</tr>
<tr>
<td>-limited access to services</td>
<td>-time restraints and limited access and lack of information</td>
</tr>
<tr>
<td>-time and cost restrictions</td>
<td>-stress creating services</td>
</tr>
<tr>
<td>-low priority to mental health</td>
<td>-lack of flexibility or specialized services</td>
</tr>
<tr>
<td>-qualifications of staff</td>
<td>-lack of in-home services</td>
</tr>
<tr>
<td>-gaps in services</td>
<td>-criteria, not need based services</td>
</tr>
<tr>
<td>-focus on individual needs</td>
<td></td>
</tr>
<tr>
<td>-compartmentalization of needs</td>
<td></td>
</tr>
</tbody>
</table>
3. Barriers to Formal/Informal Complement:

This last section looks at the ideological barriers that function to impede the development of a supplemental and complementary relationship between family caregiving and the formal care system.

A. Case Manager Perspective

The LTC system is seen by the case managers in this study as a positive and supportive program. They recognize the many benefits and strengths of the program along with the shortcomings of its present organization. There seems to be a consensus that formal supports should function to supplement the already high degree of support that is provided by informal networks. The problems that are faced in trying to create this kind of relationship relate to the values and medical model basis of community health care programs.

As a large bureaucracy, LTC is uncomfortable with ambiguity and flexibility, yet these are seen as essential elements in the creation of responsive services. Cost factors and the focus of the health care dollar on acute and institutional care limit the development of community based services. There is often a conflict between the benefits of the service to a family and the system's assessment of the cost of that benefit. Ageism continues to be pervasive in our society's values. A low priority is assigned to the needs of the elderly and their families. Seen as unproductive members of society, this population must deal with a limited commitment to providing
A traditional medical model of defining need and delivering service underlies the objectives of the health care system. Need is determined by objective criteria and services recommended by experts outside of the family system. There is a strong resistance to consumer control. The creation of a flexible, responsive program where control rests with families receiving the service is contrary to a traditional paternalistic, individually-based medical model approach to health care. While some feel that community based services move away from this traditional view, policies supporting family involvement in care planning may be viewed as justifications for a cost effective service delivery system.

B. Caregiver Perspective

For this group of respondents, the issues related to cooperation between formal and informal networks are less clearly articulated. These people are less familiar than case managers with the formal system of supports and find it difficult to develop an understanding of its values and ideological underpinnings. Nevertheless, their experiences do raise concerns about cost limitations, the resistance to consumer control and the bias of the medical system against devoting resources to the chronic needs of elderly people.

Caregivers are frustrated by the resistance that they face when trying to alter schedules or influence service content. The formal system at times presents as an antagonistic force
rather than an ally. The formal organization and maze of bureaucratic regulations make it difficult for families to feel comfortable with health care services. A cooperative and complementary relationship requires a degree of familiarity and comfort that does not always exist in the contact between families and formal supports.

The barriers discussed here have a pervasive impact on the respondents' views of the role and limitations of formal supports. Developing an understanding of community need and translating that into program objectives and strategies requires analysis at both micro and macro levels. The barriers within the family and the LTC program must be regarded in the context of larger structural and ideological factors. The values and philosophy of a medical model impact on program content and personal biases.

**Summary**

This chapter has presented an interpretation of the research findings as related to need and objectives for respite interventions. System stimulation and locus of control models organize the concepts between categories.

Respite programs address the caregiving system's need for energy and stimulation. Support to the caregiver can expand the resources and boundary of the caregiving relationship. Understanding this system's strengths and weaknesses demands an examination of the locus of control within the family and
between formal and informal networks of support. Empowering the
caregiver is a significant way to strengthen the caregiving
system.

This discussion of energy and control provides a connection
between the caregivers' perceptions and values and their
reaction to supports. If respite is to be evaluated in terms of
its impact on the caregivers and their ability to maintain their
roles, the service must be designed with an understanding of the
family system and power issues.

The last section of this chapter involved an interpretation
of the barriers within and between formal and informal support
networks. This understanding of contextual factors is presented
as an integral part of developing effective support services.
CHAPTER 6
SUMMARY AND IMPLICATIONS

Overview
A summary of the study and a discussion of major conclusions are presented in this chapter. Implications for health care policy and social work practice are also addressed.

The purpose of this study was to gain an understanding of needs as related to respite and family support for the elderly from two perspectives: case managers and caregivers. Respite care services constitute an important step in building a complementary relationship between formal and informal supports but the lack of research on such programs, especially related to the understanding of needs and program objectives, make this study very timely.

A qualitative grounded theory approach was used due to the lack of pre-existing work in the area and the need to develop beginning conceptualizations and hypotheses about what the needs of aging families are and how these may be met through respite programs. Data were collected through open-ended questionnaires and focused interviews (see appendixes C,E &F for questionnaire and interview guides) with a sample of nine case managers in the Long Term Care program and nine family caregivers in the community.

The data were analyzed using a method of open and axial coding, memo writing and the development integrative matrixes
and charts. From this process, core categories were developed and related to the themes and subcategories of the data.

The findings were presented separately for case managers and family caregivers. The questionnaires and interviews with case managers revealed the following major themes:

1) That the need for respite is great in the community and exists across a great variety of situations. Personal and resource limitations, role expectations, and burden, along with program concerns with economic benefits and respite's contribution to a supplemental role with family were factors identified as supporting the need for respite care services.

2) That there are many benefits of respite for clients and their caregivers including stimulation, education, emotional support and the potential to act as a transition to institutionalization.

3) That there are many barriers to meeting need from both the formal and informal system related to personal characteristics, role expectations, resource unavailability or unacceptability.

4) That changes are needed in order to expand existing services, provide education and counselling, increase flexibility and responsiveness to client and caregiver perceptions as well as re-examine the program priorities.

Several themes emerged from the interviews with caregivers that were related to those identified by case managers. These themes are summarized as the following:
1) That the stresses of caregiving are an important factor in their situation; these include constant responsibility, lack of choice and unpredictability.

2) That the caregiver's perception of her/his role is shaped by feelings of obligation, personal expectations and there is often a reluctance to give up the caregiving role.

3) That the informal supports available to the caregiver are influenced by their limited availability, family conflicts, as well as the caregiver's reluctance to seek help from family members.

4) That the responsibilities of caregiving affected the caregivers in a number of ways. This was expressed as lack of freedom and control, feeling trapped, guilt and other negative emotions.

5) That background factors related to history, family functioning and culture are important considerations.

6) That there are many benefits of existing services such as help with instrumental tasks, increased freedom, stimulation and emotional support.

7) That there are also negative aspects of formal service. Services were described as inappropriate or unacceptable in many situations. There was a lack of information and many negative attitudes to institutional care.

8) That there was a need for change and added services. This was addressed through requests for more information, education, flexible services and a broader range of respite
services. There was a concern that the quality of care provided through the formal system be consistent and of an acceptable quality.

These themes summarize the data presented in the interviews. Further analysis revealed two central conceptual categories that related to all of the subcategories and themes. These two organizing themes were: 1) System stimulation and revitalization through respite, and 2) Locus of control as it relates to the caregiver's ability to cope and the benefits derived from services.

A systems model was applied to understanding the needs of caregiving families and ways to provide intervention. The needs of families can be understood in terms of a lack of resources and rigid system boundaries that limit the ability of the family to deal with increasing and changing needs. Respite offers an opportunity for the family to receive some form of stimulation and new energy into the caregiving relationship. The boundary of this system is opened up a little as the service is incorporated into the family's repertoire of resources. This kind of intervention is based on providing resources within the family, rather than removing tasks or roles from the system.

The second model that is central to understanding the needs of caregivers and their families is locus of control. Many of the stresses of caregiving were related to a lack of control and a sense of limited choices in the role as caregiver. Services from the formal system were often rejected due to the perception
that such intervention further reduced the control that the caregiver could exercise over her own situation or the care of the client. Respite care needs to be designed in a way that increases the strengths and resources of the caregivers and thus facilitates their ability to exercise choice and control in their situation.

A third issue was also dealt with in detail in the interpretation of the research findings. The barriers to meeting need from within both the formal and informal systems as well as barriers to the development of a supplemental relationship between these two systems of support were discussed as an important step in understanding the need for intervention and planning services that would be effective and appropriate.

Conclusions

The findings of this study imply that there are both benefits from and limitations to existing respite services. Respite in the form of residential care, adult day care and in-home services does provide rest and relief for the caregiver. It provides a new source of input and stimulation that strengthens the caregiving system. These services, however, are often inflexible and have limited ability to respond to the unique needs of each family.

What can be concluded from the findings of this study is that the need for respite services and programs that provide support and resources for caregivers is great. However, there
is a need for more than instrumental assistance and programs that allow the caregiver time away from caregiving responsibilities. Education, information access, counselling and emotional support must also be incorporated into a system of support in order to address the physical, emotional and social needs of caregiving families. Services need to be responsive to the individual circumstances and the personal perceptions of caregivers. Need must be assessed on the basis of caregiver's ability to cope as well as the client's care needs within the caregiving system.

While the scope, variety and flexibility of services needs to be expanded, it is also necessary to address the underlying values and assumptions of the health care system and society as a whole that have shaped the roles of both the state and the family in providing care.

The conclusions of this study will now be expanded in terms of their implications for program objectives, social work practice and health care policy.

Implications for Program Design and Objectives

This study has led to the recommendation of the following objectives for respite care:

1) To reduce the stress and negative effects of caregiving responsibilities by making instrumental, educational and emotional supports available to the caregiver.

2) To provide support to strengthen the caregiver's
motivation and increase her control over the caregiving situation.

3) To improve the quality of care available to the client by increasing the resources available within the family caregiving system.

4) To help foster a complementary relationship between formal and informal care networks by recognizing the extensive support provided by families and designing services that support, rather than replace or exploit, this involvement.

These objectives are designed to focus on the caregiver rather than on cost savings or delayed institutionalization. Such outcomes may result from a system of support that is able to successfully complement the care provided by families, but short term cost benefits should not be used to justify such services at the outset.

Given these objectives, the following are recommendations that need to be considered in designing respite programs.

1) Expand institutional respite to include more frequent use, more local and community based beds, short term availability and emergency access.

2) Quotas and maximum days of respite need to be expanded and assessed on the basis of need, not a universally set allotment.

3) Adult Day Care programs need to be more accessible. This can be accomplished through increasing the flexibility of space allocations, providing more locally based services, and
expanding hours of operation to respond to family needs and schedules.

4) The need for respite service should be assessed separately from client needs and other services. For example, homemaker hours could be assigned separately for the client and caregiver based on separate assessments of needs.

5) Counselling support needs to be available within local health departments. Case managers need the time and mandate to provide individual and/or group caregiver support.

6) Education and public awareness of services and respite options must be included to develop a connection between families and formal support. In this way, crises may be prevented and the quality of life for both the client and caregiver may be improved through increased knowledge and use of support services.

This study has pointed out the need to define respite in terms of the benefits derived by caregiver rather than the actual form or content of the service. This kind of definition implies that respite services will take a variety of forms and will not be confined to traditional short stay residential care. The Long Term Care Program in Vancouver informally recognizes the respite benefits of adult day care as well as some homemaker services. This broader range of service options needs to be formally recognized, delivered and evaluated as respite care.
Implications for Social Work Practice

The case manager position included in this study is carried out by community health nurses, rehabilitation therapists, and social workers. It is hoped that each profession will bring a different perspective and expertise to the delivery of long term care services. The contribution of social work to the delivery of community based health care services for the elderly and their families is closely connected to the importance of system stimulation and locus of control as addressed by this study.

In the case of aging families where the client and caregiver may experience numerous personal and social losses and perceive themselves to have few options, it is important for service providers and programs to be sensitive to the need for these people to regain some sense of control over their situations. For many elderly and their families, contact with a Long Term Care Case Manager or social worker is the only connection that they have with the formal system. Earlier in this study, case managers were referred to as gatekeepers and as such have an important role in defining needs and linking people with appropriate resources and services. There is a need for social workers in long term care settings to develop an understanding of the aging family systems while at the same time, continuing to be sensitive to individual needs and perceptions.

Many social work values and goals of practice relate to the issue of empowerment: facilitating individual and group self-
actualization. This begins with a holistic understanding of need and the provision of support that is responsive to individual situations. As members of an interdisciplinary team, social workers can advocate for an understanding of need that incorporates family history, individual coping styles, and social and cultural milieu. The findings of this study have pointed to the need for caregivers to receive validation, support and counselling in order to define and accept the limits of their roles as caregivers. Social workers, given the opportunity, have the skills to provide counselling and emotional support to caregivers. This kind of support provides respite by increasing the personal resources and coping abilities of the caregiver. Planning services must be done in collaboration with the family. The discussion of services and the potential for family involvement must be done as a mutual exploration of options rather than the imposition of solutions. It is through such co-operative and supportive relationships that families may be able to maximize their own potential as caregivers.

The systems model of understanding family networks that has been used by the social work profession has been demonstrated to be applicable to the definition of need and intervention for caregiving relationships amongst the elderly (see Figure 2). This model needs to be continually emphasized in education and practice. Working within a health care system and a medical model of service delivery that defines need on the basis of
individual pathology presents a challenge to social workers (see Figure 1). For the sake of professional identity as well as the needs of aging families in the community, social workers must continue to advocate this approach to service as they work within interdisciplinary teams.

Subtle differences in assessment and the attitude about services mark the line between imposing supports that take something away from the client and caregiver versus providing support within the system. The role of family caregiving must be recognized and appreciated before services will act to supplement, rather than replace families. Social workers can advocate for this recognition within their work place and within families in the community.

This study revealed many personal, political and structural barriers between needs and the ability of support systems to address these needs effectively. Social workers often focus intervention on personal limitations and strengths; however, they must also act at policy and planning levels in order to effect any pervasive or lasting change in the relationship between formal and informal care systems. Within health care systems, social workers must advocate for a more holistic approach to care and become involved in the development of policies and programs that reflect values of interdependency and self-determination.
Policy Implications

This study of the needs of caregivers for respite has raised several issues at a policy level. Many of these issues relate to the values and assumptions of the medical model that has shaped the development of health care services. Others rise from beliefs about the aging process and the role that the state should have in providing support for caregivers. The following policy implications reflect the need to change attitudes and models of intervention in order to create a complementary relationship between formal and informal care systems.

Many of the recommendations made for program changes related to increasing flexibility and giving the caregiver and family more control over the content and delivery of support services. Limiting choices and options available to recipients functions to increase their dependency on the state by further reducing their personal control of their situation. These kind of suggestions reflect a move towards consumer control of service, a concept contrary to the basic assumptions of the medical model. This study supports the involvement of the consumer in the definition of need rather than treating him or her as an object of outside scrutiny. This type of change requires the development of policies that recognize and legitimize the importance of collaboration between family and formal supports. Families need to be given information and choices about services, not treated as passive recipients slotted into programs.
Figure 1

TRADITIONAL, LINEAR MEDICAL MODEL

Assessing Need

Medical Model ↓
Policy Makers ↓
Professionals ↓
Client ↓
Caregiver

Intervention

Policy ↓
Service Programs ↓
Client ↓
Caregiver

This approach to assessing need and planning interventions begins with a medical model and its associated focus on pathology. Independence is highly valued while at the same time the client is seen purely as a recipient of service and has no input or access to the policy process. Need is defined by outside professional and directed at the isolated identified client.
Assessing Need

The center of this system is the caregiver relationship. Policy makers, program planners and service delivery professionals are both directly and indirectly influenced by this relationship as they assess need and target interventions. A holistic understanding of health and acceptance of the value of interdependence impact on the understanding of need and design of formal services. Services are directed at the caregiving system, not at a single individual. Family and clients have access to interaction with professionals and influence on the services thus shifting control away from the upper layers of a health care hierarchy and towards the actors in the center of the caregiving system.
Shifting attitudes and reducing the biases of the medical model necessitates the adoption of a holistic definition of health similar to the WHO definition that incorporates physical, mental and emotional well-being within social and cultural milieus. Health should be defined as more than the absence of disease or pathology, but rather, should reflect maximization of individual potential.

The separation between physical and mental health must be eliminated. Health care services need to be incorporated with mental health and social services. Compartmentalizing need only serve to reduce the effectiveness of intervention and leaves the recipient sensing a further loss of control and confusion concerning the formal care system. The goal of supporting and strengthening informal care networks can be achieved through a variety of interventions and should not be confined to instrumental and personal care health services. Understanding the total context of the caregiving situation and having access to resources that address physical, mental, and social needs is necessary in order to provide effective and appropriate service.

The present health care system focuses assessment and the planning of intervention on the needs of the identified client. Family support and services provided to the caregiver are often justified on the basis of the benefits to the client. In order to realize a supplemental role, formal supports must address the caregiver as a legitimate recipient of support in their own right. This may mean providing services to 'well' individuals.
The role of the state should be seen as more than providing a safety net of emergency services confined to deviant or dysfunctional situations. Formal services must increase their focus on prevention and the goal of self-actualization, rather than just survival.

The common response to demands for increased services and changes in health supports is that cost restraints limit the opportunity for development. While advocacy and policy changes may have to operate within certain fiscal and political realities in the short run, these constraints should not be taken as necessary and unalterable conditions. Our society has made certain choices and set priorities for the allotment of resources. Health services and other social programs must be considered in the context of political and economic policies that affect the funds and resources available.

Implication for Further Research

This study has examined a broad range of needs for a variety of respite services. This exploratory research has supported the importance of further research on needs and the development of support services for caregivers of the elderly. Evaluations and attempts to establish accountability of support programs run the risk of reporting ambiguous or contradictory results if the programs have not been established on the basis of well grounded objectives.

Suggestions have been proposed for defining a broad range
of respite options geared to providing stimulation to the caregiving system and increasing the input of the caregiver in the content and delivery of service. Such services should be established on the basis of careful examination of community need and receptiveness. The evaluation of care outcomes as well as caregiver and client reactions and perceptions should be integrated into the development of respite services only after the development of research based objectives.

The profession of social work must expand its role in research on respite and other issues related to aging families in order to establish effective interventions that meet demands for accountability. The aging of our society is a new phenomenon being faced by our society. Previous models of intervention may not be applicable in this new set of circumstances.

Qualitative research is becoming more accepted in the area of program evaluation due to its ability to provide rich data and reconceptualizations of social relationships. Social workers must become comfortable with the methods of data collection and analysis involved in this kind of approach. Much of the daily work of social workers can be interpreted as small scale qualitative research with client individuals or groups. The assessment skills that social workers have developed have the potential to be applied to larger scale program and policy research. The value of social work knowledge and understanding of community need and program issues should
not be confined to departmental discussions but should be translated into research and policy statements.
REFERENCES


Appendix B

Consent Form

Perspectives on Need: The Issue of Respite Care for the Elderly

The proposed interview is part of a research project being conducted through the University of British Columbia's School of Social Work and the Vancouver Health Department. Lynne Curle, a master's student in Social Work is the researcher.

The purpose of this project is to help us understand the problems that families face in caring for disabled elderly in their homes. To do this, we are interviewing people who work for Long Term Care and families such as you. The goal is to help Long Term Care Better meet the needs of families receiving services.

Your participation in this research would mean that you would be interviewed by the researcher. The interview, occurring in your home, will take approximately one hour at a time convenient to you.

Your participation is purely voluntary and will have no effect on the service that you receive from Long Term Care. If you agree to participate in this research, you may end the interview at any point and you also have the right to refuse to answer any question if you so desire.

All information will be kept strictly confidential.

I have read and understood the project and consent to be interviewed.

Signature: 
Date:
Appendix C

Caregiver Interview Outline

The following is an outline of the topics that I will attempt to cover in the interviews with caregivers. As the interviews are generally non-scheduled, the order, working and presentation of the topics will vary between interviews. I have included samples of questions to probe and elaborate on each topic area, but the interviews will not necessarily be confined to these samples--they are merely included here to give a clearer understanding of how the interview may progress.

1. Describe the experience of providing care for your family member. Eg. What do you have to help your spouse with in the morning? What do your days look like? Do you feel that you can leave your family member alone for any length of time?

2. Why are you in this caregiving role? What is most difficult, most stressful for you? Do you have other family responsibilities? How long have you had to provide care for this person? Do you find the physical care difficult or is the constant need to provide supervision harder for you to cope with?

3. What kind of support or help do you get from friends, neighbors and family? Who comes to visit you? Do they help you with anything? How often does your family visit or help out?

4. What kind of help do you get from Long Term Care or other agencies? Do you get homemaker service? How often? What about Adult Day Care? Does any other agency or service give you help?

5. How do these two kinds of support differ for you? Are there things about homemaker that you prefer over the help of your family? What kinds of things does your family help you best with? In what ways might your family be a better place to get help? Why is Long Term Care the best place for other kinds of things?

6. What would you describe as your need for help or support at this time? What about the future? Do you need services that provide rest of relief from looking after your family member? What do you think will happen in the future? Have you made any plans or thought about how you will keep up your own strength and health in the long run?

7. Have you ever heard of respite care before? What does this mean to you? Have you ever been offered this kind of service before? Would any of the following kinds of help be
useful to you?
   a. placing your family member in a facility for periods of time, eg. one to two weeks once every six months or once a year?
   b. having this kind of temporary admission available more often, eg. every two or three months?
   c. having access to a day facility or adult day care that your family member would attend one or two days a week?
   d. Having a worker from one of the homemaking agencies come one or two afternoons a week to stay and care for your family member while you went out?
   e. having access to a bed in a facility in case of emergency such as getting sick yourself, or any other family crisis?
   f. any other suggestions of services that might be useful in providing rest and relief to you, the caregiver?

8. If any of the above service seemed useful, please expand on how you think that they would be helpful. Do you thin you need such services now? Do any of the services that you receive now sound like these examples?

9. I you had the opportunity to tell the Health Department your opinion about their service, what would you say? What should they keep doing? What should they change or add?
Appendix D

Data Collections Sheet for Chart Review

1. Name:__________________________

2. Client Number:__________________

3. Address:_____________________________________________________

4. Age of Client:_____

5. Client's Gender:________

6. Diagnosis of Client:____________________________________________

7. Care Level of Client:________

8. Date of Initial Referral to LTC:__________________________

9. Primary Caregiver:___________________________________________

10. Location of Primary Caregiver:_______________________________

11. Other People in Client's Home:________________________________

12. References to Caregiver Burden or Stress:_______________________

If Contacted for Study:

Name of Case Manager:__________________________

Acceptance or Refusal to Participate:________

Reason for Refusal if Any:______________________________
Appendix E

Long Term Care Case Manager Questionnaire

This questionnaire is part of a research project entitled "Perspectives on Need: The Issue of Respite Care for the Elderly" being conducted by Lynne Curle, a Social Work masters student at UBC in cooperation with the Vancouver Health Department Continuing Care Division.

The purpose of this project is to provide a better understanding of the need for respite and family supports for the elderly from the perspectives of Long Term Care Case Managers, their clients and caregivers. The goal is to facilitate a better coordination between identified need and available resources. Your participation is purely voluntary and refusal will have no affect on your position within the Health Department.

Completion of this form will constitute your consent to participate in this research project. Information will be kept confidential. Names will only be used to correspond questionnaires with interviews to be held later. Once the interviews are completed, names will be destroyed. This form will take only thirty to forty minutes of your time. After completion of this project, each health unit will receive a report of the findings from the researcher.

Thank you for your cooperation.

Section I
1. Name__________________________
2. Health Unit_____________________
3. Professional Background______________________________
4. Years with LTC____________________

Section II

Please read the following scenarios. In each example you are asked to complete three brief questions.
Example 1: A 69 year old diagnosed with Alzheimer's Disease eight years ago is being cared for at home by his 58 year old wife. His condition has gradually deteriorated over the past few years and he has required constant supervision for the past two or three years. His wife is firmly committed to caring for her husband at home, but the burden of this responsibility is taking an emotional and physical toll. Their two sons live in the city and try to support their mother, but are involved professionals with their own families. They feel that, for their mother's sake, their father should be placed in residential care. To date, their mother has not even agreed to receive in-home supports. Her primary support comes from the youngest daughter aged 22 who still lives at home and attends university. Three times in the last six months, this man has been admitted to hospital in an attempt to monitor his medication and establish some control over his behavior and sleeping patterns. The hospital social worker has recommended waitlisting in her referral, but the wife has continued to decline this suggestion.

1. What are the major issues in this situation?

2. What are the supports and stresses to the caregiver?

3. What would be your recommendations for services in this situation? What would be your care plan?
Example 2: A 75 year old woman has approached Long Term Care requesting placement for her husband. Up until two months ago, the wife reported no concerns of problems. Her husband was admitted to hospital for a TURP and has since been exhibiting confused behavior. For several days, he did not recognize his wife, and then spoke to her about their early days of marriage—apparently re-living his past. When in hospital, he was very pleasant and cooperative with care, but was constantly getting lost on the wards. He recovered physically from his surgery and was discharged the same week that Long Term Care received the referral from the wife. There are two married daughters in the city who have frequent supportive contact with their mother. They are uncertain about what the appropriate course of action should be but feel that the request for placement may be necessary.

1. What are the major issues in this situation.

2. What are the supports and stresses to the caregiver?

3. What are your recommendation, if any, for services? What is your care plan in this situation?
Example 3: Mr. and Mrs. N. have been recently referred to Long Term Care. Mrs. N. was just discharged from hospital after recovering from a CVA that she suffered four months ago. Although still experiencing some weakness, Mrs. N. has regained most of her physical functioning ability. The stroke, however, has left her aphasic. She is unable to communicate verbally and appears to have difficulty comprehending what other people are saying at times. She continues to attend speech therapy as an outpatient, but there has been limited progress. Mrs. N's daughter from Toronto is visiting for two months to help her mother settle in at home. The other two children in the family also live in eastern Canada and visit annually. The daughter has expressed a concern on behalf of the other family members that their father may be unable to cope with the care needs of their mother. They state that their parents have had a very conflictual marriage and have not been 'close' for many ears. Mr. N. states that he is willing to accept responsibility for his wife's care but in the month that Mrs. N. has been home there have been several emotional outburst precipitated by frustration over the difficulty that they have communicating.

1. What are the major issues in this situation?

2. What the supports and stresses to the caregiver?

3. What would be your recommendations for services in this situation? What would be your care plan?
Example 4: Mrs. A. is a 94 year old woman who lives with her 68 year old widowed daughter. They have lived together for thirty years. There are two other sons who also live in the Vancouver area and several grandchildren many of whom seem to have regular contact with Mrs. A and her daughter. Although very mentally alert and bright, Mrs. A. is severely immobilized by arthritis. Her daughter must help her with most of the activities of daily living and transferring from her bed or chair to a wheelchair. The daughter has increasingly become confined to her home in the past year as Mrs. A's care needs have increased. The referral to Long Term Care was initiated by the daughter's family physician who was concerned about the physical toll and signs of depression that were becoming apparent and affecting the daughter's own health. Mrs. A. has suggested to her family that she may consider an application to a nursing facility.

1. What are the major issues in this situation?

2. What are the supports and stresses to the caregiver?

3. What would be your recommendations for services in this situation? What would be your care plan?
Appendix F

Follow-up Interview With Case Managers

1. When you went over these case scenarios, were there any issues or problems that stood out as important to you in assessing each case? Are these issues similar or typical of what you see in the community?

2. What is it about the services that you have suggested that would make caregiving easier for the family?

3. How does this affect the client?

4. Did you focus on one person's need? Was this the client or the caregiver?

5. In your opinion, what are the strengths or positive aspects of the caregiving that families provide? In these scenarios, why are you (if you are) wanting to support the caregiver? Who benefits?

6. Did you base your outline of services on what you see as presently available or on some ideal situation? Would there be any difficulty arranging any of the services that you have suggested?

7. How do you define respite? What kind of services does this include?

8. Why did you recommend or not recommend respite for these cases?

9. In general terms, what do you see as the primary purpose of respite? What are the benefits? Who benefits?

10. Describe what you see as the extent of need for such services in the community.

11. What kinds of actual services do you think would best meet this need you have described?

12. Do you think that the services you have suggested in the scenarios are adequate? What are the gaps?

13. Do you have any recommendations or thoughts about how the present system of respite services should function or maybe be changed?