CAREGIVER PERCEPTIONS OF STRESS AND BURDEN

THE ROLE OF THE RELATIONSHIP IN THE ASSESSMENT PROCESS

A SOCIAL EXCHANGE MODEL

by

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ABSTRACT

The overall purpose of this research is the creation of a home care related assessment approach that includes the recognition of the perceptions of the primary caregiver, as well as an increased understanding of the quality and nature of the relationship between the caregiver and the recipient. A framework of gerontological social exchange theory was employed in the analysis of data obtained from thirteen interviews containing both structured and unstructured components. General findings indicate that, with the necessary increase in informal caregiving due to aging populations and shrinking public resources, enhanced knowledge of how the nature of relationships affect the perceptions of need, stress, and burden will be pivotal in the successful provision of limited support services in the future.

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No project of this magnitude can be completed without the untiring faith and support of many. My husband, David Weintraub, has been remarkable as my sounding board, computer guru, and right hand man. Jeanette Auger and Ann Marie Powers have understood the unique complications of life as a mature student, and the privilege of working with these wonderfully talented women has been my pleasure. Finally, I could not have written this thesis without the cooperation of thirteen caregivers, fifteen care recipients and a number of third party ‘middle-people’ who assisted with referrals. I was given gifts of time, honesty, candor, enthusiasm, and friendship. It has all been remarkable.

DEDICATION

This thesis is dedicated to the memory of
Harry Robertson
1926 - 1997

Gertrude
It's not the work, you know, the cleaning or the running
around that's stressful. It's having to be here all the time,
like being on call twenty-four hours a day.

Mim
It seems I'm the one who has to make all the big decisions.

Emma
I love her just like she were my mother. I don't want
to ever see her go to a nursing home as long as
I am here.

Abby
I don't think she is nursing home material yet, but I
don't know how long I can go on - being so tied
down and not having a life. When the kids are
home, every visit is ruined.

Joy
By now, I was getting really depressed and I went to
see my own doctor for some chemical help. I told
her that I was going downhill fast and that I was
suicidal; that I was thinking of killing both of us
and she believed me.

Dawn
It's hard to do but you keep going because you
know how hard it is for them.

CHAPTER 1

INTRODUCTION

This paper will begin with the sharing of a recent past experience. I was asked by Nova Scotia Social Services to assess the living circumstances of Mrs. Chester, who lives alone. Members of the community had expressed concern regarding her safety and well-being. Mrs. Chester, at age ninety-three, lives in a house some ten kilometers from any discernible grouping of buildings one could reasonably identify as a village. Her house consists of two rooms - a bed chamber and a main room containing a wood stove as well as a hand pump at the kitchen sink. There is electricity, but no toilet facilities in the immediate vicinity. Mrs. Chester has trouble walking, so uses an indoor commode chair rather than attempting to navigate to the privy with her cane. It was surprising to see her looking clean and comfortable, considering the details of misery supplied in the referral. She reported having more than enough help from her neighbour, Jane, who lives on the next property down the road. This woman not only carries wood and does errands, but she attends to much of Mrs. Chester's personal care as well - including the task of emptying the commode. Mrs. Chester was quite emphatic about Jane being her friend and it took the process of a rather lengthy interview to uncover exactly what Mrs. Chester contributed to the relationship. "I don't pay Jane, but I help them out when they have money troubles". This woman maintains her independence and dignity by exchanging her friendship and financial support in times of distress for personal care not likely to be willingly done by just anyone. Mrs. Chester and Jane are only one of many examples of caregiver/recipient relationships where reciprocity and balance play a significant role in determining exactly what constitutes burden.

My interest in this subject has grown from my experiences as a social worker and hospital discharge planner. It has never ceased to amaze me how families seemingly unable to cope with the increasing burden of caring for an elder continue to rise to the challenge, while others who appear to have more than sufficient resources to manage well, look at institutionalization as their only option. Why do some people provide care above and beyond the call of duty while others walk away at the first sign of complications? Blended into these extremes are the interventions of publically funded home care agencies attempting to provide support services to desperate families and an ever increasing elderly population. Assessments are task-oriented and focus on the absolute needs of the care recipient without recognizing the strengths and weaknesses of kin and neighbour caregivers - who happen to be contributing in excess of 80% of the care currently provided to our senior citizens (Brody, 1985). This thesis will detail the nature of caregiver/recipient relationships within the framework of social exchange theory, and provide home care assessors with options to enhance their interview skills as they make determinations regarding needs of both recipients and families. Providing housekeeping services has been the single biggest home care intervention to date. Dollar for dollar, it is also the cheapest service to provide, comparing the wage of a homemaker to a personal care worker, certified nursing assistant, or registered nurse. The question remains as to whether housekeeping services are the most effective use of precious resources. Keating et al. (1994) correctly point to government policy gradually increasing the emphasis on family-based care as opposed to institutional care, but if we expect kin caregivers to continue to supply this service, support of a higher order than twice monthly vacuuming is going to be necessary.

Chapter 2 is divided into two distinct parts. The first addresses the historical foundations and concepts of social exchange theory, employed as the framework for this paper. Linda George argues the need for research to make unique contributions to the field of caregiver study. She states we must generate new information, not simply reiterate that which already exists. This new information must be grounded with a theoretical interpretation:

> ...we run the risk that policy makers will conclude that interventions are not sufficiently beneficial to merit implementation when, in fact, we simply have not yet developed interventions based on firm knowledge of the phenomenon of interest (1990:581).

As stated by Bengtson et al.(1997) and discussed in Chapter 2, theoretical frameworks have not been actively embraced in caregiver research to date. As a result, this review covers the areas of theory development, exchange theory in caregiving research, and the use of this theoretical framework as an assessment tool.

In Part II of Chapter 2, I explore the myriad of research about caregiver stress and burden. Attention is given to four main, although overlapping, areas - the direction of research, foundational observations in the field, typical stress and burden research examples, and the evolution of assessment and policy. Since the majority of caregivers are women (Brody, 1985), the nature of caregiver/recipient relationships is explored using Carol Gilligan's book, *In A Different Voice* (1982), framing the concept of women's 'ethic of care', as a focal point in understanding the nature of relationship exchange.

Chapter 3 discusses the methodologies employed. Both structured and unstructured interviews were conducted with thirteen caregivers of fifteen recipients. The basis for the questions asked in the structured interviews are explained in detail covering the major perceptual themes of relationship quality, physical tasks, caregiver well-being, strain, determination of mental impairment of the recipient, impact, and ability to cope. Questions relating to the personal circumstances of the caregiver, coupled with those about outside assistance utilized, were also obtained (see Pages 114-120).

Unstructured interviews were taped and analyzed. The major emergent themes were history, obligation, activities other than caregiving, and attitudes towards institutionalization (see Page 121). Shulamit Reinharz, in *Feminist Methods in Social Research* points to the "feminist ideal of letting women speak for themselves" (1992:228). This methodology of allowing the 'voices' of the caregivers to be heard is incorporated into the body of my work. Much of caregiver research, although detailed and statistically sound, does not speak directly to the reader of the lifestyle being studied. Voice-centered work illustrates similar results, but in a more personal and identifiable way.

Chapter 4 contains the results and analysis of the data obtained from both sets of interviews. In Part I, I use the information from the unstructured sessions, coupled with 'theme of meaning' (Noonan et al., 1996) interpretations and 'entitlement to leisure' (Bedini and Guinan, 1996) perceptions to create thirteen individual caregiver profiles. The method of interviewing, followed by the resulting analysis, create a process by which additional caregiver interviews can be modelled. Part II contains the numerical results of the structured interviews (See Table I) quantified for comparative and experiential rather than statistical purposes. The group is similar to related study groups in the literature (Schulz, 1990; Elliot et al., 1996) and the numbers permit contrasting of caregivers depending on which particular perception is being examined. Assessors must constantly be aware of how their own perceptions may not be the same as those of the interviewee (be they caregiver or recipient). In addition to assessing a current situation, exploring perceptual areas like relationship quality, impact, and ability to cope afford the interventionist the opportunity of examining the relationship and its ongoing repercussions within the theoretical framework of social exchange. This opens avenues of enhanced understanding as to the reasons why some situations manage to have different needs than others.

Chapter 5 concludes the thesis, summarizing the findings, making recommendations for assessment options/alternatives, and exploring potential future work. Based on the literature review, general results were as expected. Positive relationships and social activity both decrease the level of perceived burden and stress expressed by the caregiver. Gerontological social exchange theory is a focused and valuable theoretical framework for the analysis of caregiver/recipient interaction. Current public home care initiatives are oftentimes less than adequate having little to do with expressed need. Institutionalization decisions depend, to a large degree, on the availability and abilities of the caregiver, rather than the disabilities of the recipient. The use of the 'voice' proved to be a powerful tool in illustrating the personal drama in the lives of the former. The familiarity created by hearing the 'voice' elicits understanding and identification from the reader.

Recognition of relationship quality and caregiver needs would go far in streamlining a publically funded home care service currently struggling with hospital closures, fiscal restraints, and an aging population.

CHAPTER 2

LITERATURE REVIEW

PART I - EXCHANGE THEORY

Barry McPherson (1990), in his book *Aging as a Social Process,* notes that few studies of aging actually use a theoretical framework. Vern L. Bengtson, Elisabeth O. Burgess, and Tonya M. Parrott (1997) completed an extensive study (between 1990 and 1994) which analyzed the theoretical content of articles from journals focusing on social gerontology. Their conclusions were similar to those of McPherson. Out of 645 articles cited, only 28% (127) referenced a specific theory. Of these 127, 18 employed exchange theory. The authors argue for more attention to be paid to the inclusion of a conceptual framework in research, enabling a clearer examination and explanation of findings. Following their advice, and recognizing the act of caregiving as involving relationships requiring a particular level of intimacy, I determined exchange theory to be a theoretical framework suitable for this research. It has the necessary characteristics to be advantageous in explaining relevant interactions between caregivers and care recipients. The following review of the literature relating to social exchange theory covers the areas of theory (and gerontological theory) development, exchange theory in caregiving research, and the use of this theoretical framework as an assessment tool.

Understanding exchange theory involves putting it in an historical perspective. The following is a summary of the development of the theory of social exchange. Peter Blau (1964) and George Homans (1974), are thought to be the first social exchange theorists, although discussions were taking place long before this. As a matter of fact, Blau recalls the work of Marcel Mauss (1954) who wrote *The Gift,* calling attention to the significance of gift and service exchange in simpler societies. Blau best describes social exchange as follows:

> The basic principles underlying the conception of exchange may be briefly summarized. An individual who supplies rewarding services to another obligates him. To discharge this obligation, the second must furnish benefits to the first in turn. Concern here is with the extrinsic benefits, not primarily with the rewards intrinsic to the association itself, although the significance of the social "commodities" exchanged is never perfectly independent of the interpersonal relation between exchange partners (1964:89).

Social exchange differs from economic exchange, in that there is no specific contract and the existence of the exchange is not stipulated in advance. There is an expectation of exchange but one cannot bargain in advance for a reciprocal act. Social exchange requires trust that obligations will be discharged. Feelings of obligation and gratitude are created in a way not found in economic exchanges where the act of exchanging money for service is the bottom line. Blau goes on to say:

> In contrast to economic commodities, the benefits involved in social exchange do not have an exact price in terms of a single quantitative medium of exchange, which is another reason why social obligations are unspecific. It is essential to realize that this is a substantive fact, not simply a

> methodological problem. It is not just the social scientist who cannot exactly measure how much approval a given helpful action is worth; the actors themselves cannot precisely specify the worth of approval or of help in the absence of a money price. The obligations individuals incur in social exchange, therefore, are defined only in general, somewhat diffuse terms. Furthermore, the specific benefits exchanged are sometimes primarily valued as symbols of the supportiveness and friendliness they express, and it is the exchange of the underlying mutual support that is the main concern of the participants (1964:89).

It follows that establishing a relationship involves both trust and commitment - trust that exchanges will be appreciated/reciprocated and commitment for the same. There is benefit to a stable exchange, but the greater commitment of the one leads to an advantage for the other. Conflicting interests tend to occur for the one making the greater commitment.

George Homans (1974) describes exchange theory as behavioural psychology applied to the interaction of humans. He brings the passage of time into the equation by suggesting the understanding of repeated interactions is foundational in comprehending how the past can affect the present throughout the life of a social exchange relationship. Positive and rewarding relationships pave the way for the likelihood that repeated incidents of a similar nature will occur. There is also the possibility of satiation whereby the exchange is neither rewarding nor stimulating anymore. Homans details his perspective of the long-term characteristics of exchange relationships by noting that impersonal exchanges are governed by the reward at hand, while personal exchanges involve a history of rewards over time. In the latter, the overall relationship may have value while certain individual exchanges may be ambivalent or actually punishing. Finally, familial relationships create the accumulation of a wide variety of exchange experiences. Observations from one generation to the next establish social norms of familial exchange. For example, some elders expect their children to provide necessary care when needed while others assume they will hire assistance.

Homans (1974) presented a comprehensive picture of social exchange theory in his diagrams of the four examples of relationship triads (see Figure I). Homans begins by asserting that over the life of couples or adult children and their parents, a multiple of exchanges are experienced and long-term relationships result in the establishment of an understanding as to attitudes towards life. He also supports the concept of successful long-term exchanges being more likely when agreements outweigh arguments. A totally balanced exchange occurs when two people have a positive relationship and they also discover they have similar views about Issue X (Triad 1). This reinforces their already positive history of exchanges. The second triad is also balanced in the sense that the relationship has a history of negative exchanges, the two people disagree about Issue X, and this reinforces their negative exchange relationship. Triad 3 illustrates a history of positive exchanges with a negative component regarding Issue X. This might not be important enough to affect the whole relationship, or it might actually serve to undermine future exchanges. The final triad exemplifies a negative relationship with agreement regarding Issue X. Again, the influence of this experience could be two-fold. The players might ignore their agreement due to its unimportance, or they might be inspired to reflect on their relationship as a whole, causing the pendulum to swing from negative to positive in overall perspective.

Nancy Hooyman and H. Asuman Kiyak, in their book *Social Gerontology: A Multidisciplinary Perspective* (1996), summarize the four basic premises of social exchange theory as purported by Homans and Blau:

(1) Individuals and groups interact with the purpose of maximizing rewards both physical and psychological. The principle of reciprocity is implied in that individuals tend to help those who have helped them, and they tend to avoid hurting others in the implicit fear of retaliation.

(2) Past experiences are used to determine potential exchange outcomes. For example, whether or not the person reciprocated in the past?

(3) People will remain in an exchange relationship as long as they perceive themselves as getting a benefit.

(4) One individual can obtain power by having another dependent on them. These imbalances can change over time.

With the concept of social exchange explained, the next step is to give the theory a gerontological perspective. Passuth and Bengtson (1988) and Bengtson et al (1997) have written extensively about the development of gerontological theory. Exchange theory is considered by them to be at the second level of theoretical development. First level theories include disengagement and activity theories, as well as modernization theory and the subculture theory of aging. Major contributions to these theories occurred between 1949 and 1969. The second stage of theoretical development , in addition to exchange theory, encompasses continuity theory, social breakdown / competence theory, the life course perspective, age stratification theory, and the political economy of aging. The authors view third level theories as being recently conceived multi-disciplinary attempts that tend to be either micro or macro-social in their focus, but not both.

As the theory of social exchange has developed from 1970, the focus in gerontological interpretation has been the gradual lessening of exchange commodities possessed by elders and the inevitable reduction in power as a result of this loss. Dowd wrote 'Aging as Exchange: A Preface to Theory' in 1975. He sees the first level theories of disengagement and activity as missing the mark when it comes to explaining the concept of aging. He describes disengagement theory as the often voluntary act of an aged person in pulling back from society for the purpose of maintaining personal autonomy in those areas where still able. This theory accounts for the aging individual's deteriorating health, possible loss of spouse, likely lower income, and most probably lack of social status due to mandatory withdrawal from the workforce. Activity theory argues that disengagement is forced withdrawal and successful aging can be accomplished via voluntary withdrawals in some areas where warranted by the aging process, coupled with increased social interaction in other areas where excelling can be achieved. An example often cited is giving up participation in community organizations but increasing time spent with family and friends. Dowd suggests the concepts of disengagement and activity seem obvious at first blush - certainly one must face the fact that deteriorating health means less physical participation - but beneath the surface is a more complicated relationship of social exchange that over time has the potential of rendering the elder less powerful and more dependant. Dowd explains:

> In the case of the aged, decreased social interaction is the eventual result of a series of exchange relationships in which the relative power of the aged vis-a-vis their social environment is gradually diminished until all that remains of their power resources is the humble capacity to comply (1975:587).

He continues by observing how the aged offered much more to society prior to the Industrial Revolution when knowledge and experience were valuable resources. In today's society, skills are often obsolete long before the person is ready to stop using them, leaving little to offer society in exchange for services rendered. Without resources, the aged are without power. Dowd agrees with Emerson (1962) suggesting elders have four options that will enable successful aging:

(1) Withdrawal (disengagement) - the elder will avoid relationships where they are no longer able to contribute

(2) Extension of a power network (activity) - the elder will focus on areas

where they see their exchanges as having more value, or where they feel they have already invested and can comfortably accept favours in return.

(3) Emergence of status - the elder regains some kind of status when a formerly unused skill regains some value.

(4) Coalition formation - in recent years, elders are likely to group together and seek to influence society by the power of numbers.

Dowd also suggests a majority of elders choose none of the above and the result is a situation where they lose power to family or society. It is important to note that Dowd wrote 'Aging as Exchange: A Preface to Theory' over twenty years ago. Since then, elders are often categorized into two different groups - the "young-olds" (normally seen as those aged 65 to 75 years) and the "old-olds" (those over 75). The former tend to retain power while having both health and wealth. The latter have run out of both, in many cases.

By 1980, Dowd was exploring potential power resources for the aged. He comments about how the continuous use of power by one individual over another creates imbalance, but the powerful player needs the weak one in order to obtain the reward of feeling powerful. Oftentimes, an elder will play a passive / aggressive role in order to retain some power. This can happen in caregiving situations, for example, where the care recipient is dependent on the caregiver to do errands and make small purchases. The power position occurs when the elder remembers other chores once the caregiver has completed the original tasks, thereby controlling the caregiver's time. Dowd also talks about mutual disengagement in his book *Stratification Among the Aged* (1980), suggesting this occurs when perceived rewards are deemed unsatisfactory or perceived power is seen as too overwhelming. Both parties seek more balanced exchanges elsewhere. An example of this is oftentimes seen in decisions regarding institutionalization of an elder.

Hal Kendig (1986) agreed with much of Dowd's work when he wrote the chapter 'Intergenerational Exchange' in the book *Aging and Families*, which he edited. He takes familial relationships one step further by suggesting younger generations see helping elders as an obligation rather than an exchange - that they are repaying previous benefits. Of course, this is simply a matter of delayed exchange as noted earlier, where obligations are built-up and discharged over time. Kendig also adds the concept of interdependency to exchange theory when he suggests interdependency with reciprocity would increase morale whereas total dependency could lead to depression and/or insecurity. Kendig accurately points out: "Family, and the norms and emotional ties which underlie it, provide the primary arena in which informal assistance is exchanged over the life course" (1986:109).

Two books published in 1990 included chapters dealing with exchange theory in relation to aging and caregiving. Toni Antonucci wrote 'Social Supports and Social Relationships' in the *Handbook of Aging and Social Science*. Antonucci successfully explains the subtle difference between exchange and reciprocity. The concept of exchange is viewed as a valuable commodity for trade. Reciprocity is the act of returning, in kind, that which has been given. Until this point, the distinctiveness between the two have been somewhat vague in the literature. Antonucci also provides a workable definition of successful aging:

> ...although there seem to be cultural differences in the rules of exchange, the concept of reciprocity, even within American culture, is not clearly understood...It is suggested that in the United States deposits are made early in one's life course in anticipation of future needs or withdrawals. The ability to avoid feelings of over-benefitting or indebtedness from this life course investment in social exchanges may be a mechanism of successful aging (1990:213).

The second work, *Aging and Caregiving: Theory, Research, and Policy,* includes the chapter 'Theoretical Perspectives on Caregiving: Concepts, Variables, and Methods', written by Richard Schulz. He explores the motives caregivers have for helping. Years ago, many generations lived in one household and caring for elders was a part of daily routine. He observes that, with the aged living longer, and the majority of households being separate, caregiving has become a far more demanding issue than it once was. Although some of Schulz's social assumptions may be arguable, his list of the social norms of helping easily relate to the theory of exchange. He claims the role of social norms in caregiving are threefold:

(1) reciprocity - repaying that which has already been given

(2) equity - focusing on a cost/reward balancing in the relationship

(3) social responsibility - avoiding feeling guilty and wanting to do the 'right' thing

All of these roles involve exchange. The adult child exchanges caregiving for a childhood of care given. The elder may exchange acts such as babysitting or compliance for support from an adult child. An adult child may expect an inheritance or enjoy the feeling of being more powerful. The spousal caregiver may exchange care in payment for a lifetime of partnership. Finally, the caregiver provides care in exchange for not feeling guilty; or to feel good about him (her) self. Schulz also notes the difficulty researchers have in obtaining true data on the negative effects of caregiving and it is suspected the reason for this has to do with the balance coming from the positive effects of feeling useful, having control, or perhaps finally being able to reciprocate.

In the following year, Victor Cicirelli (1991) focused on the concept of attachment in an attempt to explain why adult children provide support and care to their aging parents. The author is convinced a positive attachment relationship in childhood does not fade in adulthood but takes on different characteristics. There are changes in the simple proximity-seeking model of infancy as the nature of attachment to parents in adulthood is reflected in behaviours like psychological support or advice-giving. Part of this theory purports that once attachment is established in the child, a complimentary system of protective behaviour develops in which the child wants to protect the attachment figure from harm. The question becomes what role does attachment play in the motivation of adult children to provide care? It would seem logical for rewarded proximity-seeking behaviour (the child feels secure) from childhood to be repaid to the parent in adulthood. Cicirelli phrases it thus:

> Probably the best conclusion at the present time is
> that adult children's help to elderly parents is
> universally motivated by attachment and simultaneously
> influenced by cultural conditioning regarding a
> sense of equity and / or obligation (1991:36).

This argument is followed by William Berman and Michael Sperling , in their book *Attachment in Adults: Clinical and Developmental Perspectives.* They believe that: "the caregiving system is an integral component and direct outgrowth of the attachment system" (1994:9). Antonucci (1994), in the same text, speaks about close relationships occurring for an individual throughout their life, but how the majority of exchanges come about between those who would be considered primary attachment figures. In following this argument, successful aging would mean having provided secure attachments for one's children who, in turn, provide care that is free from demands of compliance or dependency in one's old age. This may well be true in the ideal, but the creation of strong positive exchange relationships outside the family circle as well, may more likely secure successful aging for childless elders and those whose children live far away, have died, or have ceased supportive contact.

Returning to our chronology, by 1992, Buunk and Hoorens were using social exchange theory as a vehicle in explaining the complexities of social support and stress. They point to research appearing to show a high need for reciprocity in business related affairs, but a lower expectation in familial-type situations. Nevertheless, overall balance (as perceived by the actors involved) is considered important over time. They also note how unbalanced helping / support relationships can lead to feelings of unfairness and resentment by the person who sees themselves as giving more, and guilt or shame by the person who thinks they are giving less. They suggest unbalanced relationships do not affect all people to the same degree. We return to Figure I noting the history of the relationship as playing an important role. This characteristic can be added to individual, personal attributes like flexibility or rigidity possibly being reflected in the exchange outcome. Their observations were supported by Hendricks, as early as 1981, and by Dwyer in 1994. The authors observe personal perception as a major key in exploring supportive relationships, illustrating that how we see ourselves is not necessarily how others see us. One caregiver may report wishing to be able to do more while the recipient is overwhelmed with the support given. Another caregiver may report excessive burden when the recipient complains of lack of support. By this time, the concepts of exchange and reciprocity in caregiving to the aged were beginning to surface as keys to understanding and assessing caregiver/care recipient relationships.

In summary, we can revisit the work of Bengtson et al. (1997), who suggest current interpretations of the social exchange theory of aging are more likely to focus on interactions based on emotion (altruism or guilt) than on straight-forward costs and benefits. They go so far as to caution researchers not to be overly simplistic in the use of social exchange, encouraging them to look to the underlying emotions inevitably present. They also propose the interpretation of social exchange relationships to be far more valuable in the long run than merely predicting what commodities will be exchanged and what values they may have.

Research using exchange theory as it relates to caregivers has proven as varied as the caregivers themselves. Major themes, or areas of focus, include cultural comparisons; stress; burden; support; benefits and costs; as well as familial relationships. For example, Hiroko Akiyama, Toni Antonucci, and Ruth Campbell wrote about exchange and reciprocity between generations of both American and Japanese women. Their data show both concepts playing vital but different roles in the two societies. In their work, they define reciprocity as:

> ...equal or comparable exchanges of tangible aid, emotional affection, advice, or information between individuals or groups (1990:128).

Part of Japanese culture involves every individual's limitless debt to their parents for previous favours granted. The authors claim Americans to be more pragmatic in equating exchanges, so when reciprocity cannot be maintained (in the case of the old-old), imbalance occurs. Studies comparing cultures help formulate a better understanding of our own society.

Caregiver stress and burden have been topical subjects in gerontological research for decades. Authors are increasing their use of exchange as a theoretical framework, or referencing the existence of reciprocal relationships as affecting both caregiver and care recipient perceptions. Pearlin et al. define "ordinary exchange" (1990:583) as assistance between people and suggest stress and burden are created when these ordinary exchanges become imbalanced where one player is gradually more dependent on the other. The authors see a direct correlation between increased impairment of the recipient and increased perceived burden and stress of the caregiver.

Exchange also involves issues of familial support. By 1991, more research was focused in this direction. Gottlieb discusses different dimensions of support, suggesting when caregivers are faced with a recipient's deteriorating cognitive status, rewards such as verbalized appreciation or the recipient's attempts to assist the caregiver are soon missing. Familial support is necessary to help fill the reciprocity gap or an imbalance is likely to occur. Walker, Martin, and Jones (1992) examine the consequences of caregiving for both elderly mothers and their caregiving daughters, stating social exchange theory as underlying much caregiving research. The authors point out the potential for a number of rewards available to the caregiver that may well not be easily seen in an initial assessment. It is often amazing to the outsider when caregiving continues long after observable rewards cease to exist. Their study examined both the benefits and costs of intergenerational caregiving. They found the costs for caregiving daughters included frustration, anxiety, and insufficient time. They observed daughters with less experience at caregiving to be more anxious. They found a poor relationship history between parent and child resulted in greater strain and therefore higher costs. Positive relationships were reported as enjoyable and not demanding, whereas negative ones yielded feedback about less time for family and friends. Benefits of interaction in a positive relationship appear to be exchanged for the time and energy spent to give care.

Betty Kramer, in her paper 'Marital History and the Prior Relationship as Predictors of Positive and Negative Outcomes Among Wife Caregivers' looks at the relationship history of couples (where one eventually becomes a caregiver to the other) with much the same results as Walker et al. (1992). She says her research confirmed the findings of others:

> ...caregivers who reported a close relationship with the care receiver before illness onset felt less burdened than those whose relationship had been distant... past marital adjustment was the best predictor of subjective burden (1993 a: 373).

Both Hogan et al. (1993) and Dwyer et al (1994) examine the role played by reciprocity and exchange within the family, suggesting support and relationship quality are far more important players in predicting caregiver stress than might be assumed. Carruth concurs, in her paper 'Motivating Factors, Exchange Patterns, and Reciprocity Among Caregivers of Parents With and Without Dementia' when she states:

> Restricting the examination of reciprocity to a dyadic relationship without also examining balance in other patterns of exchange among family members limits the understanding of how other relationships may complement or compensate for exchange patterns within the adult child - parent relationship (1996:411).

She also noted in her research how family members who are not as emotionally attached to the recipient are more likely to see day-to-day exchanges as unfair or unreciprocated.

Recent research has taken a variety of courses, including Johnson's (1996) examination of possible risk factors associated with long term caregiving balanced with little, if any, reward. Schaufeli, vanDierendonck, and vanGorp (1996) relate the lack of balanced exchanges in professional caregiving to burn-out in the workplace. Finally, this year, Crispi, Schiaffino, and Berman (1997) take another look at how attachment affects perception of burden in adult children of institutionalized dementia patients. They repeat what we are coming to know and understand - securely attached (close and positive) relationships are less likely to produce adult children caregivers who perceive themselves as stressed or burdened.

In summary, social exchange theory is becoming more influential in the wide field of gerontological research focusing on caregiving. Policies and assessments relating to the assistance of kin caregivers must find a way to examine/define/explore the relationships within the family circle. A short review follows.

Elaine Brody's work, 'Parent Care as Normative Stress' is a good starting point as she emphasizes the need to link research with both policy and practice. She reflects:

> Given the reality pressures, given the interpersonal and intra psychic tensions, it is not surprising that the emotional aspects of caregiving have been a consistent theme in research reports. Nor is it surprising that some adult children relinquish tasks of parent care before others think they should. What is remarkable is that so many transcend the strains and take so long to reach their limits of endurance (1985:23).

Now that we are better able to assess the effects of the existence or lack of existence of reciprocity in a caregiving relationship, the next step would be the creation of programs and policies to supply needed support. Kramer agrees:

> When relationship histories are difficult and caregivers are forced to deal with situations they find intolerable, clinicians must be aware of alternatives and provide the necessary information, referral, and support to alleviate the distress (1993 a: 373).

Bedini and Guinan (1996) encourage interviewers to assess the amount of leisure time caregivers have and take. The analysis becomes complicated as each caregiver's own 'ethic of care' (Gilligan, 1982), described as the degree to which one willingly puts the needs of others ahead of one's own, must be taken into account.

Finally, Noonan, Tennstedt, and Rebelsky (1996) studied predominant emerging themes of caregiving, as taken from interviews with forty-eight caregivers. Major general themes included gratification and satisfaction, responsibility and reciprocity, friendship and company, and a commitment to doing what needs to be done. In Chapter 4, these themes of meaning will be explored in greater detail to illustrate their potential value to the assessor of a caregiver/care recipient relationship.

One final point must be made before turning our focus to a review of caregiver stress and burden research. Both Peter Blau (1964) and George Homans (1974) suggest social exchange occurs in all relationships excluding coercion (ie: your money or your life) and the act of conforming with internalized norms. Gilligan (1982) refers to this as the 'ethic of care', referenced earlier. It would seem the decision to conform to internalized norms is made in exchange for the positive feelings the act of conforming elicits (pleasure, feeling good about oneself) and the avoidance of negative feelings (guilt, personal condemnation) that could result from exhibiting nonconformist behaviour. During analysis of the interviews in Chapter 4, social exchange of this 'internalized ' variety will be included as a part of the overall equation.

PART II - CAREGIVER STRESS AND BURDEN

Examining gerontological literature relating to various aspects of caregiver stress and burden can become a challenging endeavour, sometimes daunting, and seemingly endless. The following review is divided into four separate parts, in an attempt to organize overlapping and often contradictory information. The first part deals with the editorialization of certain researchers as they struggle with explanations of directions being taken in the field. The second presents some basic postulations now accepted as foundational in caregiver research. The third exemplifies what appears typical in the field of stress and burden study, while the final focuses on the areas of assessment and policy, noting the evolvement of these issues.

We begin with an editorial written by Steven Zarit for *The Gerontologist* in 1989. He reflects on the fact that ten years earlier, there were few researchers interested in the area of caregiving, and at the time of his writing he mused about the field being overrun with caregiving studies. He correctly points out how the population is aging, families are continuing to provide the majority of care to their elders, and current research so far has been adequate; but he questions where the field is going. He asks if we need additional stress and caregiving studies while pointing out all the still unanswered questions. One of the most significant observations in his editorial is as follows:

> In a study of stress and coping, for example, we usually presume that coping mediates the effect of stressors, but coping may also change the stressor. The caregiver who is coping in effective ways (e.g., able to calm down a disruptive patient) will report fewer behaviour problems, while the less effective coper will report more (1989:147)

We get one of the first indications of how future research will begin to take the perception of the caregiver into account.

Linda George (1990) answered Zarit's editorial one year later with one of her own. In it, she bemoans the lack of quality of work in the field and chastises those who research without the foundation of a supportive theoretical framework. George emphasizes the need to generate new information about caregiver stress rather than simply continuing to reiterate that it exists.

By 1994, research focus and discussion was changing from exploration to measurement. Researchers like George and Stull et al. attempted to fine tune measurements of burden and well-being. Interest stems from assumptions made about caregivers being seen as burdened, but various objective measures (e.g., number of trips to their personal physician and use of prescription medications) show them to be no different than control groups of non-caregivers in the population. George's argument says policy makers are not likely to recognize caregiver burden as distinct if their scores for burden are no different than the norm. She feels objective and subjective measures must be clearly separated and studied with more focus put on their differences. Stull et al. go one step further in suggesting burden and well-being are not diametrically opposed. A caregiver can report themselves as being burdened because of the time and energy they devote to their role, but this level of burden may not necessarily affect feelings of well-being. The authors continue, noting how society considers caregiving to be a burdensome task. As a result, a meaning may well be attached to the role without the caregiver losing their sense of well-being.

Rhonda Montgomery, in an editorial in the *Journal of Gerontology*, notes sixty-one papers written for that journal plus *The Gerontologist*, over the previous three years, dealing with caregiving issues. She points to the emerging concept of the caregiver as individual and unique, with a culmination of beliefs, values, and experience; no longer perceived as a generic job description. In a review of the literature she concludes support services for caregivers must be designed in recognition of individual needs. They must be flexible, in order to understand the fluidity of circumstances. She says:

> Consequently, there is a minimal likelihood of a single service program effectively relieving psychological distress or other negative consequences for large numbers of caregivers in a heterogeneous sample (1996: S110).

Judging from this editorial and current research, it would seem a gradual change is taking place whereby it is becoming clear that an all encompassing ‘program’ assisting caregivers will not be found and will not provide the magic pill solution to the ongoing problems of stress and burden. By 1996, the emerging theme is programming designed to assist individuals in meeting specific needs.

In the same journal, Jon C. Stuckey and his colleagues (1996) respond to Stull et al. (1994) regarding their attempts to decipher the differences and similarities between burden and well-being. For the first time, they explore the role played by the relationship of the giver and recipient, suggesting how a positive relationship can enhance reports of well-being and cushion the negative effects of burden. Research, by this point, is becoming less interested in the measurement of independent variables and more focused on the reports of the caregivers' sense of self and their interaction with the recipient. This notion is reinforced by Miller and Lawton when they note current research as "highlighting the integration of caregivers' lives, rather than the fragmented interpretations so often found in research literature" (1997: 216). The authors make an interesting observation regarding the gradual change in focus from burden to well-being in research over the last few years:

> The emphasis on caregiver burden had a policy-relevant dimension by drawing attention to the need for additional service resources to mitigate family burden and prevent early institutionalization. A new emphasis on positive aspects of family care may be used to support policy makers who believe that families should shoulder the care of impaired elders without additional societal resources (1997: 217).

In these days of fiscal restraint coupled with a focus on family values, current authors provide much food for thought at the table of policy and planning.

In summary, caregiver research has proliferated since the late 1980's, moving from detailed studies measuring the determinant variables of stress and burden to a recognition of the significance of both individual personalities and relationship quality.

Our second step is the acknowledgment of basic foundational information generally accepted under the umbrella of caregiving research. To begin, the population is aging. By the year 2012, that cohort born between 1947 and 1967 (known as the 'baby-boomers') will begin turning sixty-five years of age. We know most countries (Olson, 1994) are struggling in an attempt to balance fiscal and political realities with populations where the numbers of frail elderly continue to increase. The number of mentally impaired elderly is climbing as well (Olson, 1994). At present, only 7.5% of Canadians over age sixty-five and 35.6% of those over eighty-five are in institutions (Neysmith, 1994). It follows, then, that 92.5% of those over age sixty-five practice self-care or have some form of support given, and 64.4% of those over eighty-five similarly are fending for themselves or get help from the community. As life expectancy increases, so does the number of frail elderly (defined as those over 85 years and mostly women) with health issues. This cohort is growing at the fastest rate (Biegel and Blum, 1990). Elaine Brody (1995) earlier dispelled the myth of Canadians dumping their elderly into institutions and homes for the aged. It has become clear that, for the most part, those in institutions are more likely to be people with no money and no family.

It is generally accepted that the majority of care being given, whether professional or by family, is provided by women. Neysmith states:

> The importance of home care is underscored in virtually all federal, provincial, and municipal documents, yet the quality and content of these services continue to be an issue; service delivery depends heavily on the labour of poorly paid female health care paraprofessionals and volunteers (1994:164).

She goes on to say:

> A forecast of minimal expansion in formal services means that the Canadian model of home-based care will continue to depend heavily upon the informal services provided by kin (1994:165).

Biegel and Blum (1990) reinforce the significant role played by kin caregivers, noting the preference of a majority of elders for family members to be the ones supplying their support. In their introduction to the text *Aging and Caregiving: Theory, Research, and Policy*, they summarize societal changes as seen in studies to that date. The average woman in today's society spends seventeen years caring for her children and eighteen years caring for a parent or parent-in-law (Preston, 1984; Select Committee on Aging, 1987); these same women are also balancing involvement in the workplace at ever- increasing rates (Biegel et al., 1984; Doty, 1986; Select Committee on Aging, 1987); married couples often have more parents than children for whom to provide care (Preston, 1984; Select Committee on Aging, 1987); and increased institutionalization costs are causing policy makers to focus on in-home care, often downloading on to families, especially women (Arnett et al., 1986; Marcus, 1987; Waldo et al., 1986).

Schulz (1990) details the caregiver profile (Horowitz, 1985; Select Committee on Aging, 1987). He says most American caregivers are women, their average age is fifty-nine years, 70% of them are married, one third are employed, more than half are defined by him as being poor, their self-assessed health status is likely to be lower than normal, and 75% live with the recipient of the care given. Pat Armstrong, in her paper 'Caring and Women's Work', adds the ominous statistic that families in Canada receive little public support and "when intensive home care is provided, it is usually provided from five to thirty-five hours a week and women 'volunteers' must do the rest" (1994:116). All of theses profile trends are further supported in the document *Facts on Aging in Canada*, written by Gail Elliot, Melanie Hunt, and Kim Hutchinson. It was funded and published in 1996 by the Office of Gerontological Studies at McMaster University, paralleling earlier American work suggesting the increased burden of women and the continued expectation of unpaid kin support in the area of elder care in the future.

It is now generally accepted in the field that caregivers who have outside interests and obtain support from those interests, tend to cope better with their role as a caregiver. Interaction 'just for fun' (Thompson et al., 1993) and additional role rewards like strong personal relationships or a fulfilling occupation (Litvin et al., 1995) can result in reports of less stress and burden.

Finally, in exploring established truisms in the field of caregiver research, it is generally recognized that distinctions must be made between spousal and other kin caregivers (Bass et al., 1996). The former tend to be older, in poorer health, more likely to want to keep the recipient at home, and more likely to provide more care. In summary, an overall profile of the caregiver is beginning to emerge from the literature - a profile underscoring the common threads of the occupation while still recognizing the unique characteristics of each caregiver and each relationship.

Although research about caregiver stress and burden covers a host of subjects, overlapping and often contradictory, in this third focus area, I have attempted to organize the literature and provide examples in each of eight major categories - the role of women; adult children caregivers; spousal caregivers; support options; overriding health issues; stress; the positive aspects of caregiving; and caregiver perceptions. Issues relating to theoretical frameworks and methodologies are discussed in Part I of this chapter.

I have chosen four papers to exemplify the research focus relating to the role of women, all published in 1994. Sheila Neysmith and Barbara Nichols examine the similarities between formal and informal caregiver working conditions, suggesting the exploitation of women in both arenas. Government policies appearing to encourage the provision of paid care based on the lowest common denominator of education and pay scale, coupled with an overriding encouragement of increased familial responsibility, are soundly criticized by the authors. Irene Hoskins complicates this issue by reminding the potential policy maker of the fact that more women today, are employed in the workplace. She asks for clarification as to who is expected to provide the preferred in-home care (over institutionalization) if women are working. She asks if employers will become more flexible in allowing employees (women informal caregivers) the needed time to absorb this additional workload. Keating et al. ask: "Who's the Family in Family Caregiving?", suggesting governmental policy emphasizing family does not recognize that 'family' tends to be one primary caregiver, usually a woman - perhaps with a job and most often with a family; or a spouse who is as old as the recipient, with health issues of her own. Pat Armstrong completes this discussion by warning us of the current policies focusing on the positive aspects of in-home care, and how they may lead, without adequate community support, to downloading on to the shoulders of women.

Adult children as caregivers has long been a topic of study under the headings of both burden and stress. Elaine Brody (1985) dispelled the myth of today's children not providing care for aging parents. Ten years later, Brody, together with Litvin, Albert, and Hoffman (1995), explored the competing roles held by daughter caregivers as the stress factors associated with marriage, children, and employment were juggled. The multiple roles of adult children caregivers is a recurring theme. Other research focuses on elder abuse (Johnson, 1996) as well as adult/child relationships (Crispi et al., 1997). As noted earlier, the latest research examples oftentimes have giver and recipient interaction issues as their base.

The spousal caregiver usually has different burden and stress issues than the adult child. Zarit, Todd, and Zarit recognized this as early as 1986 in a longitudinal study comparing subjective reports of burden with times of institutionalization. Hooker et al. (1992) went one step further, examining the role played by personality in both mental and physical health of spousal caregivers. They conclude personality traits of neuroticism and optimism both play significant roles in ability to cope. A more recent study by Liora Navon and Nurit Weinblatt (1996) delves into the reasons why spouses, in many cases, continue to care for loved ones long after the general consensus of opinion would support institutionalization. They contend caregiving spouses to be satisfying themselves more than the recipient as they rely on old habits and familiar routines in a futile attempt to prolong the inevitable. The authors argue the caregiver to be so entrenched in the scenario of their lives that recognition of the actual status of the situation is highly unlikely - they cannot see the forest for the trees, even though they would probably advise a friend to institutionalize their spouse, seeing little or no comparison with themselves. Finally, a recent article by Norm O'Rourke (1996) returns to the theme of subjective burden, exploring attitudes of hopelessness and the effect this may have on a caregiver's ability to cope.

Throughout the literature are found innumerable examples of studies exploring the impact of various interventions - the termination of in-home services (Hooyman et al., 1985), needs assessments (Abraham, 1992), the exploration of social support networks (Bass et al., 1996; Bourgeois et al., 1996 b; and Thompson et al., 1993), the consequences of negative familial interaction (Bourgeois et al., 1996 a), and placement delay (Mittelman et al., 1996). Researchers look for consistency in need as well as reliability in outcome after satisfying that need. Results tend to be as varied as the caregivers themselves.

Health issues are often embedded in studies about support as well as those about stress. Long-term caregiving has the potential to cause profound effects on the primary caregiver. Skaff and Pearlin (1992) and Schulz and Williamson (1993) discuss the concepts of loss of self and of isolation, both situations possibly preceding perceptions of elevated stress and/or psychological symptomatology. Lieberman and Fisher (1995) found spousal health to be directly related to the severity of the illness of the recipient as well as its duration. Whitlatch et al. (1997) endorse these findings and conclude caregivers who delay the employment of respite services run the risk of compromising their own health over the long term.

The concept of stress is elusive at best. Chiriboga, Weiler, and Nielsen (1990) created a stress paradigm to exemplify the issue. The paradigm consists of three parts. Stressors are defined as life events that can be both positive and negative as they always involve change. Mediators are social supports or personality characteristics like coping abilities and self-esteem. Responses can be physical (as in the deterioration of one's own health) or psychological (as in the experiencing of anxiety or depression, stressing one's mental health). Simply put, one experiences life changing events, and the response made depends on the support tools at one's disposal. A person cannot avoid the event, but there are a variety of ways in which to respond - learning to manage one's stress becomes a valuable tool when facing personal challenges of any kind. Research about stress is a highly criticized area of the caregiving literature. Raveis et al. (1990) note problems with sampling as well as design. Pearlin, Mullan, Semple, and Skaff , in the same year, review the concept of stress in the search for more measurable issues. Confusion and complication often prevail. Just last year, Vitaliano et al. (1996) completed an extensive study for the *Journal of Gerontology*, focusing on the metabolic variables at work surrounding caregiving and distress. Their results confirm long-term caregiving takes its toll.

Lately, research has taken a different route, beginning to explore the positive aspects of caregiving. It is being suggested caregiver burden may well stabilize over time, if the recipient's condition does not continually deteriorate. If stabilization occurs, the caregiver is able to adjust and focus on the positive aspects of the relationship. Miller and Lawton (1997) review recent research, concentrating on the positive.

Lastly, we will look at work relating to caregiver perception. All three papers to be cited were published in 1996 and the relative newness of this perspective is being noted. Noonan, Tennstedt, and Rebelsky explore seven 'themes of meaning' among kin caregivers. These will be examined in greater detail as part of the analysis in Chapter 4. Perception is in the spotlight as the authors illustrate:

> Our findings make it clear that caregiver meaning
> is strongly connected to why caregivers persevere
> in their roles (1996: 325).

Bedini and Guinan assess caregivers based on their responses as to whether or not they feel entitled to spend leisure time away from caregiving. This second study, like the former, relies heavily on qualitative interviews and the individuality of the caregivers - emerging trends in the research. Finally, the concept of the perceptions of care recipients is noted, as seen via the work of Cox and Dooley. Again, relationship and personality take centre stage in the attempt to understand the caregiving process.

Now, how does this myriad of research, with its multitude of themes and methods, affect the creation of policy and the process of assessment in the field of home care for the elderly in our communities? We begin by recognizing, as encouraged by Elaine Brody (1985), the importance of attempting to link research with both policy and practice. She points to uninformed policy as being worse than no policy at all. Just this year, *The Gerontologist* published a symposium of articles, introduced by Baila Miller and M. Powell Lawton (1997), the purpose of which was to remind the reader of the necessity for integration of both positive and negative aspects of caregiving and to provide hints as to how policy can be directly affected by research.

Certain research encourages policy relating strictly to the care recipient. Neysmith and Nichols (1994), as well as Cox and Dooley (1996), suggest future

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policy focusing on the care receiver instead of the caregiver and both explore universal support systems independent of familial input. Other articles, like 'Working Women and Eldercare', written by Irene Hoskins (1994), predict necessary workplace adjustments, better permitting women to absorb the caregiver role. Hoskins encourages policy changes in the areas of flexibility and time off, as well as the addition of support services for workers who are experiencing added stress.

Much of current research underscores the need for more comprehensive assessments of families. Recognizing the limitations of the primary caregiver (Abraham, 1992; Keating et al., 1994) and assessing the physical and mental health of caregivers (Hooker et al., 1992; Mittelman et al., 1996; O'Rourke et al., 1996; Schulz et al., 1993) are major areas of focus. Policies advocating a thorough assessment and follow-up with balanced programs of respite; counseling; long-term support; recognition of isolation factors; and intervener understanding are encouraged in one form or another in the majority of written conclusions.

As early as 1985, Hooyman, Gonyea, and Montgomery were suggesting the need for research in the area of intervention outcome. It was gradually becoming clear not all programing was benefitting all caregivers in the same way. This observation was reiterated by Zarit, Todd, and Zarit (1986) as they saw the time of intervention (early in the onset of caregiving versus later) and the gender of the caregiver as having an effect on intervention outcome. Thompson et al. (1993)

provide us with an example of intervention measurement where they conclude policies and programs designed to permit caregivers to avail themselves of positive outside activities lead to less feelings of burden and stress. By this time, in the literature, interventions are being seen as having more potential for success if less global and more individual - calling for heightened assessment skills on behalf of professionals who can no longer assume all interventions will benefit all caregivers. Rhonda Montgomery sums up this refocus:

> The utility of future research findings will be enhanced by new efforts to implement and assess the impact of health and support services on caregivers. These efforts, however, must contend with the challenge of giving sufficient attention to careful description and delineation of services, targeted populations, and caregiver outcomes while at the same time, resisting the temptation to focus on resource-intense services that have little feasibility for widespread implementation (1996: S110).

Bourgeois, Schulz, and Burgio (1996 b) conducted a review of interventions for caregivers of patients with Alzheimer's Disease and they see the field as evolving from a profession driven perspective to a caregiver response perspective, following the trends first noted above. Recent research, as exemplified by Noonan et al. (1996) and Bedini and Guinan (1996) illustrate this most recent approach. Interview analysis, in addition to structured questions, is used to explore caregiver personalities and assess expressed needs. The voice of the caregiver is just beginning to be both heard and understood. The study of caregiver stress and burden continues to evolve. We have come so far as to understand that each situation is different; that we must listen first. We know assessors and interventionists must focus on the family; the needs and strengths of one case cannot be extrapolated to another. This thesis provides the reader with an avenue by which to take advantage of all that has gone on before, assessing with respect, understanding, and knowledge by listening to the voices of those who provide the care.

CHAPTER 3

METHODOLOGY

This chapter describes the processes employed for collection and analysis of the data. It is divided into three sections. Part I focuses on general descriptions of the subjects as well as the selection and referral process. Part II discusses the two methods used for the accumulation of data as well as the rationale behind the particular techniques employed. Part III clarifies the methods by which the collected information was analyzed.

PART I - SUBJECTS

Acceptance as a participant into the study depended on three factors. The person must have been caregiving for at least one year. They had to be considered as the primary caregiver (family member or friend), defined as the first person called upon in the case of any problems in the recipient's life. Finally, they had to be unpaid.

Although there are no doubt a great many caregivers in our communities that meet these criteria, finding willing participants proved to be a relatively daunting task. Richard Schulz (1990) and Raveis et al. (1990) criticize current recruitment processes. They say the direct approach of soliciting subjects via support groups or media campaigns is biased and leads to the increased likelihood of obtaining subjects who are distressed, or perceive themselves as so. A more indirect approach is via a third party referral. This option, along with word of mouth and direct personal knowledge possessed by myself as the researcher, were the recruitment methods employed. Of the thirteen participants, four were third party referrals through a family physician. She told the individuals about the study and received permission to provide their name and telephone number to me. Three of the referrals occurred in a similar fashion, but the third party in each case knew the caregiver, as well as myself, personally. Six of the caregivers were known to me prior to commencement of the study and were either approached directly or volunteered their time when they became aware of the need for participants.

Initial contacts were made via telephone and the research was explained. Interviews were scheduled with each caregiver for a time and place that was convenient for them. Two interviews took place in my own home, one in a coffee shop, and ten in the homes of the caregivers themselves. The caregivers resided in Annapolis Royal, Kentville, Windsor, and Halifax, Nova Scotia as well as Sackville, New Brunswick. Letters of appreciation were sent to each woman.

This interview pool of thirteen cared for fifteen recipients. One person was caregiver to both her parents while another looked after her aunt and uncle. All participants were women, eight being between 40 and 59 years of age and five being between 60 and 74. Nine were married and five were separated or divorced. Six of the thirteen had some college or university education, two had completed highschool, and three had not. Two had university degrees, one graduate and one undergraduate. Eight interviewees categorized themselves as retired, five worked full or part time, and one considered herself to be unemployed by choice. In response to the question of how they personally perceived their own health, eight said good, four said fair, and one considered herself to be in poor health. Personal perceptions of happiness varied as well. Five participants saw themselves as very happy, six said they were fairly happy, and two stated they were not very happy. Eight of the caregivers lived with the recipient and five did not. Five were adult children, four were spouses, three were relatives, and one caregiver was a friend.

Although the participant number is not large, the characteristics of the group reflect research result averages as noted by Schulz in 'Theoretical Perspectives on Caregiving: Concepts, Variables, and Methods' (Horowitz, 1985; Select Committee on Aging, 1987) and *Facts on Aging in Canada* (Elliot et al., 1996). They note the majority of caregivers are women (all interviewees are women in this case), the average age is 57 years (this reflects the current sample), 70% are married (in this case, 69% were married), one third are employed (30% were employed in this group), and three quarters of caregivers live with the recipient (61% of this group lived conjointly). Schulz also says more than half of caregivers, as reflected in current research, are poor and the majority tend to self-assess their own health as being poorer than normal. In this case, only two out of thirteen, or 15%, reported experiencing stress regarding finances and 61% of the sample considered themselves to be in good health. These final numbers may well reflect the third party selection process. The participants were not selected from a core group, and therefore did not reflect a specific need for assistance in the areas of physical/mental health or finance. The group was as random as possible under the conditions of third party referral.

PART II - DATA COLLECTION

The research session consisted of two parts - a structured interview followed by an unstructured interview. They were held in the homes of the caregivers (with three exceptions, as noted earlier) and lasted fifty to ninety minutes. Prior to commencement of the structured interview, time was devoted to getting acquainted, signing the consent form (see Page 113), choosing pseudonyms to be used in the written document, and clarifying the particular caregiver situation. Subjects 1-W and 5-W took part in split structured interviews, where certain sections were answered twice, reflecting different relationships with each of two care recipients. The separate results can be seen in Table I.

The purpose of the structured interview is three-fold. First, it is a vehicle whereby basic information can be elicited quickly and efficiently. Second, it delves into subject matter that may well not be a conscious focus in the day to day life of a caregiver. Finally, it permits the generation of descriptive statistics for comparison purposes (Bethoux et al., 1996).

The structured interview consists of ten separate sections (see Pages 114-120). Section 1 asks basic questions (Cantor, 1983; Rankin, 1992) and allows caregivers to be compared as to age, employment status, etc. Section 2 relates to the caregiver's perception of the quality of their relationship with the recipient. It was adapted from Marjorie Cantor's (1983) study, "Strain Among Caregivers: A Study of Experiences in the United States", because of both its simplicity and its directness. Section 3 is called a Physical Support Measure. It is part of the Home Care Nova Scotia assessment tool, and is designed to determine the recipient's needs. It was chosen because of its detail and inclusiveness regarding household and personal care tasks. Section 4 deals with caregiver well-being (George and Gwyther, 1986) and includes the caregiver's perception of their own health coupled with their assessment of the amount of social activities in which they take part. Section 5 is about caregiver strain (Robinson, 1983) and I found it to be balanced in terms of both the physical and emotional components involved. Section 6 examines the subjective perceptions of the relationship (Robinson, 1983) and works in balance with Section 5. Section 7 deals with the dimensions of mental impairment (Pearlin et al, 1990; Poulshock and Deimling, 1984) and is designed to illustrate the associated dysfunction difficulties as they are perceived by the caregiver. Section 8 is called 'Impact' (Pearlin et al, 1990) and it focuses directly on the feelings of the caregiver documenting any resulting lifestyle changes, as well. Section 9 measures coping strategies (Kramer, 1993) and explores the related skills employed by the interviewee. Section 10 looks at what assistance is provided to the recipient besides that of the caregiver. It was not taken directly or indirectly from Kosloski and Montgomery (1995), but was inspired by their work. This series of questions not only stimulates thought and personal experience evaluation, but is able to be scored in a way that permits description as well as comparison.

Open-ended, unstructured interviews make up the second part of the session (see Page 121). They were each taped for later analysis. Shulamit Reinharz (1992), in her book *Feminist Methods in Social Research*, lauds the format because it permits the full use of information received from each individual. She points out how it differs from survey research and structured interviewing because open interchange is encouraged between the participant and the researcher. Although guided and supported by the interviewer, the subject is free to follow an idea or train of thought towards its logical conclusion. Voice-centred, open-ended interviewing employs as many actual quotations as possible, in order for the reader to hear and appreciate the message as it was originally presented. Carol Gilligan (1982) was a pioneer in the area of voice-centred interview research and she underlines the importance of presenting the actual words spoken by the subjects interviewed.

Robert Weiss (1994) wrote *Learning From Strangers: The Art and Method of Qualitative Research*. In it, he itemizes the reasons for conducting qualitative interviews. The open-ended interview allows for the development of detailed descriptions so the interviewer is able to gain as much information about the personal circumstances of the interviewee as possible. The method permits the integration of multiple perspectives, in that no single participant can present an all-encompassing picture of particular circumstances or services. Open-ended interviews give full descriptions as well as histories. They also provide holistic information, since they can be blended with other documentation to create a complete picture of an issue under study. Personal interviews reveal insights into how particular events are perceived by the interviewee. Quotations provide a vehicle whereby the reader is in a position to identify with the speaker. Finally, Weiss suggests qualitative work can fill a gap left when details are lacking in the identification of issues and variables, or in the development of an hypothesis.

Weiss also explores the options available as the researcher determines the framework of the lead questions. To begin, it is necessary to define the problem. In this case, as it relates to the enhancement of assessment in the arena of provision of public home care services, questions must be formulated to reflect caregivers' perceptions. Second, a determination is made of the depth and breadth of information to be collected. This research focused on the amount of care given, the respondents perceptions of their role, their attitudes towards obligation and reciprocity, and their assessment of the value of help currently received. Third, the researcher must take their awareness of their own level of understanding from previous work, study, and knowledge of the current literature into each session. In this case, past interview and work experience proved invaluable. The fourth area of focus is in pilot work, as Weiss suggests preliminary interviews are needed to fine-tune the process. A pretest was carried out for this thesis and the result was certain alterations in the process for additional interviews. Finally, the author notes good open-ended and unstructured interviews result from the researcher having a well-defined sense of what areas need to be addressed in order to give substance to any final report. Lead questions must allow for deep and creative response opportunities on the part of the interviewee.

Weiss reminds the researcher of the "implicit contract" (1994:65) between the interviewer and the respondent, and his suggestions are summarized below:

(1) They will work together to produce useful information.

(2) The researcher will define the major topics while the interviewee will respond with guidance as needed.

(3) Questions will be asked with respect and without curiosity, although it is understood by the interviewee that some areas of discussion may be subjects that are not normally talked about in general conversation.

(4) The respondent's integrity will be respected.

(5) The researcher will insure the protection of the participant's identity.

As noted by Reinharz (1992), trust is one of the most important criteria in the creation of an atmosphere producing a successful open, unstructured interview. In this research experience, the first step in creating trust was established via the method of third party referral. In all cases, a trusting relationship existed between myself and the third party, as well as between the third party and the participant. An element of trust was given to the interview experience because of this established network. The result was an atmosphere whereby I could use interpersonal skills to build additional trust within the relationship. Feminist researchers tend to invest more of themselves into personal interviews, leaving behind the more formal characteristics of distance and efficiency for an informal atmosphere of selfdisclosure, attentiveness, and belief in what is said by the interviewee (Reinharz, 1992). This method describes a tool used by myself throughout a professional career as a social worker and mediator. It comes as no surprise that the creation of an atmosphere of trust, coupled with a sincere attentiveness and desire to believe, yield successful and bountiful unstructured interviews.

One final point needs to be made regarding the process of conducting open, unstructured interviews. All of the participants in this research were women and the topics discussed were about their roles as caregivers. Reinharz (1992) supports the notion that women may need to be interviewed by women in order for a true depiction of the truth of women to be portrayed to the reader. Although men and women feel they speak the same language, there appear to be mistranslations and misunderstandings that curb communication and lead to problems with the interpretation of acts of cooperation and caring, according to Carol Gilligan (1982) much earlier in her book, *In A Different Voice*. In interviews, such as the ones presented here, the recognition of the existence of women's 'ethic of care' (the tendency for women to put the issues of others ahead of their own) as they describe individual dilemmas, concerns, and rewards is tantamount to the overall understanding of perceived stress and burden. The fact that this study represents a woman interviewing women is a methodological element noted for its expected advantageous position in the areas of interpretation and analysis.

PART III - METHODS OF ANALYSIS

The structured interviews (see Pages 114-120) were scored (see Table I) according to the ranges shown below. The analysis conducted is intended to be of a descriptive nature and not statistically significant in any way. What is important is to explore, individually, the areas of burden (amount of work done), reciprocity and exchange (perceptions of the relationship), and stress (coping strategies and perceptions of strain). The figures are guideposts, only.

Section 1	demographics	comparison only
Section 2	relationship quality	14=good 0=poor
Section 3	physical support	120=heavy 0=light
Section 4	caregiver well-being	20=well 0=not well
Section 5	caregiver strain	26=high 0=low
Section 6	relationship perceptions	14=very involved 0=not involved
Section 7a b	recipient mental impairment	14=good(#1-7) 32=poor(#8-23)
Section 8	impact	28=high, 0=low
Section 9a b	coping strategies	28=good (#1-6, 13-20) 20=poor(#7-12, 21-24)
Section 10	assistance	comparison only

In specific terms, Section 1 asks basic descriptive questions - age range, gender, marital status, relationship to the recipient, and living circumstances (with the recipient or in a separate domicile). All of these questions are asked in order to provide the researcher with introductory information about the subject. The answers also permit the generation of overall comparisons of the participant pool. For example, all of the interviewees were women. Two additional multiple choice questions were asked at the outset. The former requested the respondent to describe their current health status as good, fair, or poor. The latter asked each to rate their present level of happiness as very happy, fairly happy, not very happy, or not happy at all. The purpose of these two questions was to increase the interviewer's awareness of the subjects' personal perceptions from the outset.

Relationship Quality is the title of Section 2 of the structured interview. The questions all relate to how the caregiver and care recipient get along, as seen through the eyes of the former. There were seven questions and each could be answered with 'yes', 'some', or 'no'. A 'yes' response received two points, a 'some' was given one point, and a 'no' was scored as a zero. The higher the total (maximum 14), the higher the quality of the relationship, and the more evenly balanced the two are seen to be by the caregiver.

Section 3 is a straight forward physical support measure, taken from Home Care Nova Scotia's (1995) assessment portfolio. The caregiver was asked to weigh an extensive list of tasks that they may or may not do with/for the recipient. A score of three points indicated the heaviest chores - done exclusively by the caregiver who has total responsibility for them. A score of zero indicated a task not done by the caregiver at all. This point range gave the interviewee the opportunity to score an item with a one or two point value depending on how heavy they perceived their workload to be. The heaviest physical support score, in this case would total 120 points and the lightest would be zero. The perceived workload of each caregiver can be specifically analyzed rather than simply noting (in the case of home care assessors currently) exactly which tasks are not getting done.

Caregiver well-being is explored in the fourth section of the structured interview. It combines requests for self-assessments of both physical and mental health as well as financial status, with an examination of time spent in social activities and pursuing hobbies. Responses were to be high, medium, or low, with scoring of two, one, and zero points respectively. A score of twenty would indicate a high rating for sense of well-being and a score of zero would suggest a caregiver with no feelings of well-being whatsoever. These questions cast light on areas generally not the focus of home care assessments - whether or not the caregiver is becoming isolated or finding themselves giving up personal pursuits.

Section 5 focuses on the concept of caregiver strain and asks the interviewee to assess the level of strain they may experience in areas like sleep disturbance; plan changes; lifestyle adjustments; and finances. Response options were 'yes' - two points, 'some' - one point, and 'no' - zero points. A score of twenty-six would indicate a caregiver experiencing the highest level of strain and would alert the assessor in planning interventions. An analysis of caregiver strain in comparison to relationship quality and perceived well-being create a more balanced picture of the participant's perceptions of their own circumstances.

The sixth section relates to the respondents' subjective perceptions of their role as a caregiver in the relationship. It is scored in the same fashion as Section 5 and a score of fourteen indicates the interviewee feels they have a heightened understanding and are deeply involved. A score of zero would suggest no understanding and little involvement. This particular section serves as a verification for other sections of the structured interview, in that it addresses a blend of issues covered elsewhere.

Section 7 explores the amount of mental impairment suffered by the recipient as assessed by the caregiver. Scoring was the same as the previous two sections. A score of fourteen on the first seven questions (Section 7a) shows the interviewee seeing the recipient as having no mental impairment. A zero would suggest high impairment levels. A score of 32 on the remaining questions (Section 7b) illustrates a high degree of impairment and a score of zero means the caregiver sees no indication of mental impairment at all. Analysis of this data assists the assessor in becoming aware of the potential for relationship quality deterioration due to increasing mental impairment of the recipient, as perceived by the caregiver.

The purpose of the eighth section is to ascertain the impact caregiving has had on the interviewee. Queries focused on areas like anger, strain, manipulation, and feeling tom between the recipient and others. Scoring was the same as above with a total of thirty-two showing maximum impact and a total of two meaning maximum pleasure with no other impact. A score of zero indicates the role of caregiver has not impacted on the participant, but has provided no pleasure, either. An assessment of impact is valuable in determining long-term caregiver effects.

Coping strategies are the focus of the ninth section, divided into two parts and scored in the established fashion. Section 9a has fourteen questions and a score of twenty-eight indicates a high level of coping skill while a zero shows no ability to cope, as perceived by the subject. The second part (9b) has ten questions where twenty points would suggest poor coping skills and zero suggests high skill level. Analysis of this section enables a comparison of the interviewee's perceptions of their ability to cope, with unstructured interview data where the need to cope is discussed.

The final section looks at existing assistance available for each caregiver. An analysis of this section would compares the amount of support actually provided with the interviewees perceptions of the amount and quality of help received. Oftentimes, someone who gets a lot of help in comparison to others, still feels overwhelmed and this may well become an assessment issue as it relates to long-term impact or coping skills. Information gained here was incorporated, as in Section I, into overall descriptions of situations.

A summary of themes and scoring measures for Sections 2 - 9 can be found at the bottom of Table I.

Unstructured interviews followed the structured session. The intent was to allow the informant a free and informal atmosphere whereby each could discuss their position as a caregiver. The lead questions (see Page 121) were guidelines only focusing on the areas of how the person became a caregiver and the nature of the illness of the recipient; the elements of reciprocity, balance, and obligation; the roles played by other family members; other areas of interest pursued by the caregiver; community resources and experiences; the concept of institutionalization as an option; and best and worst case scenarios. Although each focus area was addressed, interviewees were permitted to speak for as long as they chose on any particular subject. For example, while certain individuals wanted to present detailed explanations regarding their relationship with the recipient, others talked at length about familial interaction or lack of community resources.

Each interview was taped and transcribed. Interview analysis has involved examining the caregivers' attitudes and perceptions as determined from the transcript contents. Bedini and Guinan's (1996) four typologies of 'entitlement to leisure' and Noonan et al.'s (1996) 'themes of meaning' for caregivers were modified and employed as assessment tools. Comparisons were made between the assessed scores of the structured interview and the information related in the unstructured interview for individual respondents. In addition, individual caregiver's perceptions were compared . For example, a particular interviewee may report they have a heavy workload and score 40 points in Section 3, whereas another may describe their physical support as being minimal, but score 70 points. Elements such as this were analyzed for the purpose of creating awareness in assessment issues.

The following chapter provides detailed profiles of all the participants, a description of their caregiving styles, and an analysis of the interview results in Part I. The structured interviews are utilized to compare interview experiences in Part II. Listening to what a caregiver is saying and recognizing their perceptions of their own situation can be valuable assessment tools.

CHAPTER 4

RESULTS AND ANALYSIS OF DATA

PART I - CAREGIVER PROFILES

As noted in Chapter 1, the purpose of this research is the creation of an overall assessment process better able to serve home care assessors and interventionists as they determine needs and allocate ever-shrinking resources. Thirteen interviews were conducted and each is profiled. They include a brief history of the situation, along with an assessment of the caregiver's overall 'theme of meaning' (Noonan, Tennstedt, and Rebelsky, 1996), an examination of each participant's perception of their 'entitlement to leisure' (Bedini and Guinan, 1996), and an exploration of the giver/recipient relationship as assessed in light of a social exchange theory perspective.

Noonan et al. (1996) found a number of 'themes' or reasons as to why caregivers do the job they do. These themes help explain the differences in levels of perceived stress and well-being reported; differences appearing to have little to do with the health of the recipient or the amount of actual physical work done to give care. Four primary themes categorized by the authors and incorporated into this analysis are as follows:

1. **Gratification and Satisfaction** - caregiving is reported as making the caregiver feel good.

2. **Responsibility and Reciprocity** - caregiving repays for past actions and/or is a moral duty

3. **Friendship and Company** - the recipient is interesting, good company, and someone with whom to talk

4. **Doing What Needs to be Done** - caregiving is described in reality-based phrases like, 'there was no one else', or 'we just go day to day'.

Leandra A. Bedini and Diane M. Guinan explore four types of caregivers that emerge from their analysis of perceived entitlement to leisure time. They are:

1. **Repressors** - caregivers who claim they have no need for leisure, or they have put that need on hold.

2. **Resenters** - those who say they would like more leisure time, and are displeased at their inability to access it.

3. **Consolidators** - people who finds ways to include the recipient in their plans, in order to do what they want to do.

4. **Rechargers** - those caregivers who manage to make time for themselves.

Each of the above eight assessment categories can be examined in the light of social exchange theory. All four 'themes of meaning' create positive feelings for the caregiver - gratification, knowing one has taken responsibility and repaid a debt, the comfort of friendship or companionship, or relief at knowing one has 'done the right thing'. Carol Gilligan (1982) speaks at length about women's 'ethic of care' saying responsibility is at the center of their moral concern. She says women tend to anchor themselves in a world of relationships and these are likely to give rise to activities of care. If one's moral ethic involves taking responsibility for others, enjoying their company, and feeling good about doing what is considered 'right', then in exchange for caring for a loved one (or anyone, for that matter), a woman feels good about herself.

Three of the four typologies examined by Bedini and Guinan (1996) follow the same logic. Repressors convince themselves they have exchanged leisure time for doing the right thing. Consolidators find ways to combine their leisure time with caregiving, trading their companionship for the recipient's agreement to inclusion. Rechargers exchange any feelings of guilt or selfishness they might have with a belief that the care they give will be of a higher caliber if they have been able to get away. Resenters have not learned to exchange personal time for more quality caregiving. They may end up demanding compliance from the recipient in exchange for leisure time lost.

For a summary of each caregiver, recipient, and situation please reference the Subject Outline on page 122 throughout this chapter.

The analyzes begin with Participant 1W, Vicky. She is fifty-four years old, married, and caring for her parents, Mr. and Mrs. Jones. They do not live with her. Vicky and her husband, Mel, lived for most of their married life in British Columbia. They have four grown children, three of whom remain there. They returned to Nova Scotia to semi-retire and build their dream home on a piece of inherited property.

Vicky chooses not to work outside the home. Her husband is employed as a mechanic. Mr. Jones is a single leg amputee as a result of diabetes complicated by heart disease. Mrs. Jones is a depressive, chronically 'ill' woman who oftentimes refuses to eat. Vicky and Mel were only back in N.S. for a couple of years before Mr. Jones had the amputation and Vicky began helping out in earnest. She describes herself as fairly happy and in good health. Vicky tells how she became a caregiver:

> Home care was coming for awhile. The girl that was coming, she would spend three hours on the phone and a half hour doing work and I thought 'this is kinda' ripping things off' and so I called the person that hired her and then she quit. So anyway, I ended up doing it.
>
> When Dad has his leg amputated, they [D.V.A.] hired someone to come and do his personal care because I won't do that, but I kept on doing the housework. So...I just fell into it over time. Now they are dependent on me. I feel suffocated sometimes. They want to know where I am at all times.
> Even though they are dependent on me, I am like a child. They have to know everything I do. It causes problems with my husband sometimes. We try to keep our Saturdays and Sundays free, but it's hard.

(D.V.A. is the Federal Government Department of Veterans' Affairs, and provides services to qualified veterans).

Vicky falls into the primary theme category of **responsibility and reciprocity**, along with a certain amount of **doing what has to be done.** She says: " If I don't do it (caring for her parents), no one else will". In discussing obligation, her feelings of being torn are obvious:

> I almost feel obliged not to go (on a trip to see her children out west). They have such a short time left, and I feel I should stay home and not go, but then I know I will feel resentful. I don't know if I will go or not. I just get this twinge of guilt every time I think of it. I really don't know who will do for them if I go.

Vicky is also a **resenter** when it comes to allowing herself leisure time. She has managed to obtain a certain amount of compliance from her mother, in exchange for her loss of personal time for herself and Mel. Vicky perceives her relationship quality with her mother as low. They have never gotten along.

> I have told her, you control it [mother's tongue] around me or I will not come. I will not take any more, the abuse I took all my life. I will not take it and she knows it.

She enjoys her relationship with her father, showing clearly that dealing with her mother has a greater negative effect on her emotions. She often expresses her frustration with her mother.

In assessing Mr. and Mrs. Jones and their caregiver, Vicky, the interventionist must recognize Vicky's resentment at feeling suffocated and be aware of the differences in the quality of the relationships between each of the parents and their daughter. Currently, the system takes advantage of Vicky's 'ethic of care' - her moral course of providing care and doing the right thing. It may well leave Mrs. Jones in a position of exchanging compliance for care while Vicky and Mel continue to feel resentment about their lack of time to pursue semi-retirement activities.

Participant 2W is sixty year old Elizabeth Jean married to, and caring for, husband John who suffers from advanced muscular atrophy, a disease similar in characteristics to Lou Gehrig's Disease. His present status is that he is still able to drink using a bent straw, and eat (although not when others are around because his head and hand are both just about in the plate and it is, he feels, unpleasant for anyone besides Elizabeth Jean to see). He can push the button for the speaker phone. He is able to talk relatively clearly and has no mental incapacities whatsoever. His disease was first diagnosed some forty-four years ago. As a progressive disease, symptoms were gradual in presenting themselves. He was in the armed forces for a time and carried out duties in municipal government until his retirement ten years ago. Elizabeth Jean, with the advantage of a nursing background, slowly took on more and more responsibility for John's care until a bladder tear and back problem made it impossible for her to continue and maintain her own health. D.V.A. now provides almost all of John's personal care.

> In the beginning, it was devastating. We had one baby and another on the way. We were so afraid we would pass it on to the children.
>
> Like so many other things, you live with something every day, it becomes normal.

Elizabeth Jean and John live in a restored and exquisitely decorated Victorian home that has been in John's family for three generations. It is Elizabeth Jean's pride and joy - no detail has been overlooked. She describes herself as fairly happy and her health as good, now that she is no longer doing the heavy lifting.

This caregiver speaks with great admiration of her husband and his contributions to their life together.

> He has always been wonderful and understanding. There is nothing you could ask him that he would consider trivial.

It seems obvious that Elizabeth Jean's theme of meaning combines **friendship and company** with **responsibility and reciprocity** as she goes on to say:

> I feel obliged to be at home most of the time. to see that things are going right.
>
> He has really done everything - the running of the house - the business end of things. I have just started taking over the writing - the paying of the bills - anything that demands writing.

As the assessment relates to leisure. Elizabeth Jean shows characteristics of both a **repressor** and a **consolidator.** She has given up certain things as inconvenient. focusing on more home centered activities where John may or may not be involved depending on his condition at the time. She describes leisure pursuits:

> I used to enjoy parties, bridge. I gave it up a few years ago. It became an effort. It disturbed him. I used to golf, curl - getting older. I might have given those things up anyway. I like walking, reading, watching television. We entertain the family every holiday. It has always been easier for us to do it here. This is a family home. We used to entertain a lot.

Although Elizabeth Jean has ample help to assist her husband in coping with his extreme physical disabilities, an assessment must recognize her status as a case manager as well as her ever increasing role in the matter of household affairs. She has put many areas of her life on hold balancing against a partner who struggles to cope with a degenerative disease. John decided early after diagnosis that it would be unfair to take his frustrations about his condition out on his family. Elizabeth Jean reciprocates daily for all that he has given in a lifetime of suffering.

Caregiver 3W is Moriah, the daughter of Mrs. Dow. Moriah is in her mid-sixties. She is a divorced, retired school teacher with three grown daughters. Her mother lives a short distance from her in a seniors' complex, and her brother lives in a nearby city. He is considered, by her, to be a big support. Moriah describes herself as very happy and sees her own health as being good. Her mother suffers from Parkinson's disease coupled with transglobal amnesia. She talks about the time when it was decided her mother should move closer to her:

> I was very concerned about her in an apartment alone in Halifax. She began to have attacks of amnesia where she would go for hours not knowing where she was or where she had been. She had been having these attacks for some time, but my brother and I started talking after I found she had fainted one day. The GM Apartments are here and they are for seniors, so there are other people around. We talked to her and looked at several places here and in Halifax. I was very impressed with the GM Apartments and had my mother and brother come to see them.

Moriah's theme of meaning, as assessed by this interview, is very much **responsibility and reciprocity**. The following excerpts explain this conclusion:

> My brother had taken responsibility for Mum when she lived in Halifax and I worked, so I felt it was my turn now. My mother has given so much to both of us over our lives. I feel it was my opportunity to give some back.
>
> Indeed I do feel obliged. I feel very responsible. She looked after my grandmother who had Alzheimer's disease when I was just a little girl. My mother had a very difficult life. She ran the farm, but then she went back to university after my father left and got her degree and taught school. She was a very strong woman.

Moriah is a **recharger** when it comes to allowing herself time for leisure. She states:

> Church makes a big difference to me. It helps me stay focused and it relieves stress.

In assessing Mrs. Dow and the care she receives from her daughter, an understanding of the element of exchange is critical. Moriah describes the changes that have occurred:

> She has always called the shots. She has always been very capable, very domineering, always in charge. She expects people to dance to her tune, even though she always put our interests first. Things have changed a little bit in that now I have more power - the balance of power has changed a little (she smiles).

This caregiver has exchanged caregiving for an opportunity to feel like she is in control, instead of 'toeing the line' as she most certainly has for most of her relationship with her mother. Recognizing this, an interventionist would be better equipped to assist the family in dealing with Mrs. Dow's deteriorating health, perhaps changes in living circumstances, and decisions regarding long-term care.

Gertrude is participant 4W. She is forty-five years old, married, a retired certified nursing assistant, and caring for her Aunt May and Uncle Fred who live next door. She considers herself to be fairly happy but in poor health. Her aunt and uncle are 89 and 91 years of age respectively, and Gertrude worries about them all the time:

> It's not the work, you know, the cleaning or the running around that's stressful. It's having to be here all the time, like being on call 24 hours a day. They don't get along with my sister-in-law and my brother works away a lot. They say they'll be fine, but I worry like crazy and it's not worth the trouble [to go on a holiday].

Gertrude's 'ethic of care' demands she take as much responsibility for May and Fred as she is able. She falls into the theme category of **responsibility and reciprocity**, saying:

> They're wonderful people. I owe my life to them. When I was four and my brothers were six and two, our parents left us in their dooryard with a letter, and took off for Ontario. It wouldn't matter what I did for them, it would never be enough.
>
> The biggest problem is that they are too independent. They won't ask for help and I am always trying to second-guess them. If I weren't on the ball, Aunt May would be up on a ladder cleaning out her cupboards. She's 89 and I get so flustered when she tells me she can manage when I know she can't.

This caregiver could well be perceiving the needs of her aunt and uncle as being higher than what they actually are. An awareness of this issue is paramount in doing an assessment.

Gertrude reveals herself as a **repressor** when it comes to her leisure time. She manages to put everything on hold, including a long overdue visit with her daughter in California.

> I could handle everything if I just had some back-up, you know, someone I could trust to be on call and help them when I'm not here. Then I could take a holiday...Aunt May and Uncle Fred just say they would be fine and not to worry - right!

The difficulty in this case is not for the assessor to assist with finding back-up for Gertrude, but to recognize her feelings of obligation and reciprocity - only the best will do, and more than likely that is herself and no one else. This caregiver's stress stems predominantly from her overwhelming need to make up for all this couple has done for her. No one else can repay them; it is not their debt. Gertrude will do whatever it takes:

> If I died, I guess a [nursing] home would be their only option, but I'm a C.N.A. and can handle just about anything as long as my health is okay.

Even if an assessor were to suggest that the time for institutionalization is near and resources are not available to assist Gertrude, it is unlikely this option would be chosen. Home care agencies, in recognizing certain caregivers' needs to continue 'above and beyond the call of duty', must understand and attempt to provide what assistance they can. Currently, home care is often withdrawn when needed the most, because assessors determine a recipient can no longer be cared for at home. In many of these cases, the commitment of the caregiver and the strength of the relationship with the recipient are not factored into the decision-making equation.

Participant 5W is Lezah, a married, retired draftsperson, about sixty years of age. Her mother, Mrs. Denson, lives with Lezah and her husband. This caregiver describes herself as very happy and in good health. The circumstances leading to her becoming a caregiver to her mother are somewhat unique:

> My mother has always been with me. My husband and I were married less than a year when Dad had a very bad heart attack. We moved both of them in with us so that I could help her care for him. They were here for ten years before Dad died and my mother has stayed. She helped me raise my kids and has been a part of my life. I have no idea what life would be like without her here.

Lezah combines **friendship and company** with **responsibility and reciprocity** in her caregiver role.

> Mother is really no trouble. She's bright and interesting. Okay, she's forgetful and needs a bit of help with the stairs but she manages fine, considering she's 83.
>
> I owe my mother a lot. She helped with my children so that my husband and I could travel a bit. She has made a contribution, you better believe it. I would never turn away from her now.

In relation to leisure pursuits, Lezah is a **consolidator** and a **recharger**. She goes regularly to the local fitness club. When she wants to go away, she includes her mother, hastening to mention the design of her vehicle, chosen for the ease with which her mother can get in and out.

An assessor must recognize the important role played by Mrs. Denson in this family. No burden is likely to be too heavy, and this needs to be understood. As her care demands increase, the family may well ask for assistance, and interventionists must look for creative options so this family will be able to continue care at home.

> There is nothing that would happen, even to me, that would result in her being institutionalized. My husband and the children would rally round and care for her. I know it.

As mentioned in reference to Caregiver 4W, we must assess situations based on the perceptions of the family, not from the point of view of our outside experience. What we may consider to be more than a family can handle, may well be perceived by them as the recipient's 'just due'.

Caregiver 1AR is Betty, age seventy, caring for husband, Bob, who has been suffering from congestive heart failure and chronic obstructive pulmonary disease (COPD) for the last ten years - since experiencing his first heart attack. Caregiving includes most personal care as well as the running of the house and managing a myriad of medications and machines. Bob is on oxygen twenty-four hours a day. He sleeps with another machine to prevent apnea (he stops breathing spontaneously). Betty manages all of the equipment herself. Her help consists of a young woman who comes to do her vacuuming once a week. Betty had a heart attack, herself, three years ago, and she suffers from high blood pressure. Despite this, she describes herself as very happy and in fair health.

Betty's primary theme of meaning as a caregiver is **friendship and company**, although **responsibility and reciprocity** play a role in this balanced spousal duo. She speaks of her forty-two year marriage:

> Since we've been married, everything's been hunky-dorey. He says I spoil him and I say he spoils me. I don't think we've ever had a bad fight. He's a wonderful father. He's been awfully good to me, very supportive. Never complains. When we got married, my cousin told me it would never last. I guess I showed her!
>
> He's very sociable and interesting. He knows everybody and lots and lots of things. We have lots of company. There's always someone dropping in, even if it's only for fifteen minutes. We have wonderful neighbours who are often over just to check on us.

This caregiver manages by being a **recharger.** Betty's greatest joy is her membership in a local dance band. She plays the fiddle and sings. It results in lots of outings and much company.

> The dances are usually from 8-11. It's not that long and I usually call [home] a couple of times. I play at least one night a week. Sometimes on Sunday. It gets me out. I love it.
>
> I wish I had someone who could stay with Bob while I go out with the band, but Home Care won't do medications, so if he needs his puffer, or, well, they don't like the oxygen machine. I have friends that I can call if I'm scared to leave him. They're pretty good.

Betty is completely aware of how her participation in the band serves as a vehicle whereby she can relieve stress and feel like she is more than only a caregiver. Bob is totally supportive of her, and this makes all the difference. An assessment of this family is likely to reveal a caregiver who is working to her maximum. Recognition of the need for flexibility of services provided is paramount.

Caregiver 2AR is an extraordinary woman. She is seventy-one year old Mim married to fifty-eight year old Dick. Only her own words can describe how she came to be a caregiver:

> I'm a caregiver because when I married Dick, he was already a diabetic. In four years, he had a heart attack, and two years later he had another one. Since I'm twelve years older, I ended up retiring when he went into renal failure. We did dialysis in the house and I never missed a day. He could only shower every five days and believe me, that was a big thing - he had to be all bandaged up to cover the catheter. His skin would be dry and we would rub him down. Fortunately, he got the kidney and we thought that was the most wonderful thing of our whole life.
>
> Exactly three months to the day, they took out the catheter, and he said he had a terrible headache. Sent him to the pain clinic. Dick wasn't in the best of health. Through all this, it ended up that he was diagnosed with throat cancer.
>
> He had thirty-three radiation treatments. We stayed in a trailer park. It was expensive but we got over that.
>
> In August of the next year, he wasn't feeling great again. They sent us to a lung specialist. We only had two meetings and they did surgery and took out the right lobe of his left lung. It wasn't cancerous but terribly infected. He would get so nauseous he would bring up cupfuls of blood. It scared the life right out of me.
>
> We were only home four or five days and they called us back. The doctor said the cancer had spread and he had to have a laryngectomy. They lost him twice. Oh, God!

> No wonder I'm not reasonable for what I say or do sometimes. I mean, I live these things so vividly. I have missed one doctor's appointment in all these years and that's all.

Mim is totally involved, researching each surgery and every medication. She has been proactive, writing letters and seeking support as they are financially stretched to the limit. Dick is not a senior, so the burden of his care falls totally on them. The situation is complicated because they live in a community suffering from the closure of its local hospital. Despite some recent heart problems of her own, Mim sees herself as very happy and in fair health. This couple has a close relationship, so it would appear **responsibility and reciprocity**, coupled with **friendship and company**, would be the major themes of meaning for her, however, a deeper analysis may reveal her to be one who is **doing what needs to be done.**

> There's never a day goes by that he doesn't tell me he loves me and he thanks me for whatever I do. You can't blame anybody, but sometimes you wonder why it happened to you. He had a good job. We would have been sitting pretty, but this is not what has happened so we have to make the best of it.
> I don't feel obligated to look after him.
> We made a commitment.
> We love one another dearly.
>
> They talk about the elderly, elderly, elderly. Alright now, if Dick was elderly and I was fifty-eight, the shoe would be on the other foot. That's why I'm in the mess I'm in. [She has had a heart attack recently]. It's stress and strain, and worry. I know you're not supposed to worry but I can't help it.

On top of the stress of financial concerns as well as the burden of being a great distance away from medical support. Mim is clearly a **repressor** when it comes to her attitude towards time for herself, even in the face of a recent suspected heart attack. She made it clear to me that her life revolves around Dick:

> I'm not used to coffee clutches. I'm not used to people dropping in. I just don't fit in here. I'll always be from away because I left when I was young. I depend on <u>nobody</u> but myself.

Mim has a great deal of difficulty managing the stresses associated with Dick's precarious health, their financial worries, her own health, and the perceived feelings of isolation associated with their physical distance from urban medical facilities. Caregivers oftentimes benefit from support groups and/or stress management advice in one form or another. An understanding of her absorption in her role is tantamount in assessing the needs of this couple.

Emma is participant 1NB. She is the primary caregiver of Mrs. Heinz, the mother of her common-law spouse, Fred Heinz. Mrs. Heinz lives with the couple. Emma also assists with the running of their in-home business by answering phones and talking to customers. She is forty-five, divorced, and the mother of a learning-disabled son. Emma sees herself as being very happy and her health as good. Mrs Heinz has Alzheimer's disease. She lived in her own home until about three years ago. The family began to notice her as being disoriented and ill kempt. Emma succinctly describes how she became Mrs. Heinz's caregiver:

> We brought her home. Ever since then, she's been at our place.

Emma exhibits all four themes of meaning regarding her role. She said at one point in the interview: "We never know when it will be us needing help", suggesting **responsibility and reciprocity** are part of her motivation, feeling that she will help someone now to pay for help she may well need for herself later in life.

> I love her, just like she were my mother. I don't want to ever see her go to a nursing home as long as I am here.

Emma and Mrs. Heinz have become friends and allies. She talks about the increasing memory loss, illustrating how **friendship and company** are part of the mix:

> But she will ask over and over, 'Did I bring my purse?'. Then she'll poke me and say, 'If I ask about my purse one more time, you tell me to shut up - I left the damn thing home'. So she knows when she's confused. She just can't help it.

Apparently, when Mrs. Heinz first moved in, Fred took the majority of responsibility for his mother, but as Emma puts it:

> You know what a man's like. He was doing the best he could. After awhile, I started to do for her.

She was doing what she perceived as **needed to be done.** Finally, it appears this caregiver simply gets a great deal of **gratification and satisfaction** out of her role.

> We get along great. Fred says I have more patience... But I feel sorry for her.

Emma is a **consolidator** and a **recharger** when it comes to leisure time. The couple often take Mrs. Heinz with them, or get a sitter if they are going out together.

> We can't go anywhere unless we have someone to stay with her. I like to go out with Fred - to dinner or a show. Just being with him I really enjoy. He has a heart of gold.

Emma also hastened to mention the use of a respite bed at a local nursing home when Mrs. Heinz had to be left for a few days.

An assessor must be aware of the status of the relationship between Emma and Fred, in this case, and how a change in quality here could have ramifications on Emma's role as a caregiver to Fred's mother.

Caregiver 2NB is Abby who cares for Mrs. Allison, her mother, who has Alzheimer's disease. Abby lives with her husband in half of a house, while Mrs. Allison lives in the other half. There is a connecting doorway. Abby manages all of her mother's personal care, her finances, her meals, and her outside appointments. She describes how she became a caregiver to her mother:

> We took her to Florida about five years ago...and she had no idea where we were on the map at all. She continued to live alone for a couple of years, but in the third year she started getting really bad, forgetting things, appointments and stuff. She had an old wood stove in the basement and she was burning garbage. I took her to her doctor that she had been going to for thirty years, and he said she shouldn't be alone. We talked to my brother and decided to move her into the flat upstairs.
>
> Anyway, she has always been in our life and my

> brother agreed but I got no help from him. He didn't encourage her or help us in any way. Although I needed him, he had his own burdens, so I didn't expect his help. He's very good about taking her, though, if we want to get away.

There is no doubt about Abby's theme being one of **responsibility and reciprocity**.

She talks at length about obligation and sacrifice:

> I feel obligated to look after her. I resent it day after day. Then there are days that I don't. I guess that's just natural.
> I know there is help out there but I just haven't gone after it yet.
> It has made a big difference since I retired.

This brings us to an assessment of Abby's attitude toward leisure. Although she and her husband hire a housekeeper and get away for a week, two or three times a year, she remains a **resenter.**

> Yes, I feel obligated. I don't think she is nursing home material yet, but I don't know how long it can go on - being so tied down and not having a life.
>
> We don't have people in to dinner or entertain because she interferes so. No one can have a conversation because she interrupts and is very childish.

It is important that an assessment not miss the resentment felt by Abby towards her mother in relation to her four children, especially a daughter recently diagnosed with multiple sclerosis.

> When the kids are home, every visit is ruined. They see my burden better than I do. The minute they come home, she thinks they are

> using her. She is generous and the next minute she is hostile. Her routine is upset and she is losing her place. Especially when Maya comes home. Maya needs to find her way in life, and she can't come home. When she was first diagnosed (with MS), we had to find her a place to live nearby, because she couldn't stay with us. Mother got it all confused and didn't want Maya in the house because she was afraid she would get AIDS. She doesn't like Maya and it has been really hard.

There is far more to this relationship than initially meets the eye - retired nurse, convenient duplex, and a mother with AD who is healthy and ambulatory. An assessment must thoroughly examine the losses being experienced by this caregiver and her family. A current home care assessment would likely see this as an ideal arrangement where little, if any, intervention would be necessary, leaving the caregiver with no option but to eventually choose between her mother and her family by examining the choice of institutionalization.

Interviewee 1H is Joy, the wife and primary caregiver of Max, an Anglican minister, aged fifty-six, who has had two very debilitating strokes along with numerous complications. Joy is fifty and considers herself to be retired. She describes her health as fair and sees herself as not being very happy. Joy told me about Max's second stroke and the inevitable aftermath:

> He had the second one downstairs and I didn't find him for at least an hour, maybe more. We knew it was really bad. He couldn't speak to me or anything. I think he knew what had happened when he was on the floor. I kept talking to him until the ambulance got there.

> For the next six months I just went on automatic pilot, I guess. I dealt with everything, everyone. For the first five days we stayed at the hospital twenty-four hours a day. We did not know if he would live. This was a really massive stroke, affecting his entire right side - total paralysis down his right side including the right side of his mouth. It took a while for him to realize he could no longer read, write, or speak.

Max had many complications including undiagnosed injuries from a fall out of his wheelchair, while still in hospital. Joy went through months of anguish, not knowing where it would end. The family finally involved politicians in order to get the go-ahead for a more thorough investigation of Max's condition.

> In the end, we went through four surgeries and each time they told us his chances weren't good and he survived all four. They tried and I don't blame them. They did all they could to save the leg, but eventually the leg had to come off.

During this period of crisis, Joy was a **repressor**, giving little thought to herself and her own needs. She describes bringing Max home from hospital:

> The first time we came home from hospital on a day pass, we had a blizzard and I couldn't get him back. I was by myself and he was totally helpless. It gave me the first inkling of what I was in for. The social worker at the hospital came and talked to me about home care. I was less than enthusiastic about getting help, but she insisted and am I ever glad she did.
>
> When we first came home for good, we only had four to six hours a day of help. By now, I was getting really depressed and I went to see my own doctor for some chemical help. I told her I was

> going downhill fast and that I was suicidal; that I was thinking of killing both of us and she believed me and prescribed two medications. I never told this to anyone else. I could see no point to our lives and no future.

Joy was totally involved in Max's care management, trying to sort out mounting financial issues, facing the possibility of losing their home, and dealing with the whole crisis alone as she attempted to shield her husband from the details. Joy finally negotiated increased home care hours which permitted her to become a **recharger**, rather than continue as a **repressor**. She belongs to a doll collectors club, a clergy-wives support group, and a cystic fibrosis parents network. She reactivated all of these outlets once she got adequate help at home with Max.

For the most part, Joy would have to be assessed as a caregiver **doing what has to be done.** Although she loves Max dearly and would hate to see him go downhill and have to be institutionalized, their relationship is not easily characterized as **responsibility and reciprocity**, except in a strictly religious sense. Joy is very responsible to her beliefs and this must be understood by the assessor of her situation. Joy describes herself:

> I have always been a caregiver, so that hasn't really changed.

They adopted a child with cystic fibrosis, have four children of their own, and are now raising a grandchild. Her religious focus supports her in dealing with the additional burdens added to her already overflowing plate.

> One of the things I am really glad about is that I've never felt resentful. I've never thought, 'Well why did God do this to us?'. It has been easier not having those thoughts - more an issue of hopelessness and not having purpose anymore.

The assessor, in this case, must be aware of how financial constraints can affect the functioning abilities of this caregiver. Leisure time is a necessity, as she is stretched to the limit of her responsibilities. As Nova Scotia Home Care continues to gradually withdraw service to fewer and fewer daily hours, and the money continues to trickle away, Joy's stress level is bound to rise again. Awareness of the need for balance is the key to management in this case. There is a break even point after which she will become depressed if assistance is further downsized.

Participant 2H is fifty year old Dawn, mother of thirty year old William who is very ill with complications arising from AIDS. William was first diagnosed in 1989, but symptoms did not begin to manifest themselves until eighteen months ago. Dawn is divorced and currently lives with a friend and colleague. She has a full-time job but has been on and off disability since William became ill. Presently, she is again on long-term disability. She describes her own health as fair and says she is not very happy, taking anti-depressants and seeing a psychiatrist regularly. William has his own apartment but sometimes moves to Dawn's when ill.

This caregiver describes herself in terms of being a **repressor**. She feels she must put off all personal issues to focus on her son, as he does not have much time. She is **doing what needs to be done**, in her eyes.

> I'd be lying if I said I wasn't totally exhausted but why do they have to become very ill or close to death before we realize how important they are? I won't have him for that much longer so it doesn't matter right now about me. I don't care if I spend all my money on him or if I don't have time for myself. I'll have lots of time and money when he's dead and what good will that be?

Much of Dawn's stress and burden relate to her 'ethic of care' - **doing what needs to be done.** She has convinced herself that William must have her assistance as an advocate and care manager since the majority of agencies, doctors, and professional caregivers are incompetent.

> Home Care doesn't listen to what you need. It's easier to just do it myself 'cause they are so inflexible. When you need help, you need help, but you have to be on their schedule.
>
> The Family Benefits are so far out in left field, they have no idea what is really going on.
>
> You could spend days and days trying to find him a place to live that is wheelchair accessible. I thought it would make sense for me to go to an association that deals with disabilities so that they could point me in the right direction. She told me she had a list but it was from 1992. Now, what good is that?
>
> I couldn't get through to these people who have degrees up the ying-yang, that he needs his dog. People told me that there would be no trouble finding him a place if he got rid of his dog. I couldn't believe how ignorant they were.
>
> Would you believe that the social worker told me we couldn't get him a walker unless he gave up his wheelchair? I tried to tell them that some days he needs his wheelchair, but the walker will help

> when he's up to it. They just won't budge. I went and bought him a walker myself.

One of the biggest issues in assessing a case such as this one relates to the actual condition of the patient at the time of the assessment. An AIDS patient can present as quite capable on one occasion and at death's door on the next. Any interventionist must be aware of the perceptions of the caregiver. Even if the recipient can manage right now, the caregiver has probably experienced the worst of the worst many times in the past.

Dawn expressed her difficulty in pulling back from the situation:

> The hardest part is trying to get away. Once last year, I tried to go to an AIDS conference. I had everything all organized with the V.O.N. and everything, but I had just gotten to Toronto and he called that he was being evicted from his apartment. It wasn't him. The guy who owned the place went into receivership and they started changing the locks. That was when I had so much trouble finding him a place. I just had to get on the next plane and come home.
>
> You can't spend every day thinking about what could happen next because pretty soon you're waiting for him to die. Now that's stress! On the other hand, I can't spend the day with my head in the clouds, either.

As can be seen from her remarks, Dawn continually struggles with her own perceptions, trying not to let herself swing too far one way or the other. The fact that she is no longer able to concentrate at work, that she sees a psychiatrist twice a week, and that she takes anti-depressants all point to a caregiver who has far more stress and burden than even she, herself, is willing to admit. Assessments must recognize issues such as this one, and not simply write her off as an over-protective mother and an aggravation in the system, as oftentimes happens. Many kin case managers, like Dawn, have valuable skills if provided with the simple luxury of being able to focus on a few issues at a time. It is important to note her anxiety in making up for lost time, in exchange for what has been missed and what will never be.

> I'm on Paxel. What does that tell you? Paxel is an anti-depressant.

This was the initial response from Participant 1K - Lesley - who cares for her father, Mr. Garland. Lesley is fifty-two and practices nursing full-time. She is divorced and lives with her widowed father. She describes herself as being in good health and fairly happy.

> I've been a caregiver since I was seventeen - I'm a nurse. I started with Mum and Dad in 1988. I moved in when Dad was having trouble coping with Mum and my husband had left me and the girls.
>
> He is eighty-seven and has Parkinson's. He's fairly under control. He's had a triple bypass and a couple of strokes. The man is a wonder. He's trying to stay alert and do for himself.

Lesley's 'ethic of care' involves **gratification and satisfaction** coupled with **responsibility and reciprocity**.

> I've always felt valuable, needed, whatever, looking after Dad. He always said that the place was mine, so there I feel responsibility in that he has deeded the place over to me, and I feel obligated to honour his

> wishes 'cause he doesn't want to go to a nursing home.
>
> Dad's provided me with a home, and I love him, and he's my dad. There's a lot of stuff there. Mum and Dad were always of the old school that you looked after your own family. I guess that was instilled in me.

As a nurse, Lesley has always reaped rewards from caregiving. As an adult child caregiver, these rewards are lessened somewhat by the change of status from nursing supervisor to child. Lesley worries about money, as well, and this puts additional strain on the relationship.

> I worry sometimes because he gets me to fill out cheques so he can get some money. I worry that the family will think I'm taking the money out for myself. That really bothers me. There's only one person that would kick up the dust (sister-in-law), but she would give me a lot of grief.
>
> If I had to give up my job, I couldn't afford to take care of Dad.

Even though she is under stress because of the double burden of caregiving both at work and at home, Lesley has succeeded in finding time for herself. She could be classified as both a **consolidator** and a **recharger**. Both she and Mr. Garland love to go to yard sales and auctions together. In addition:

> I have my rug hooking and I belong to a sewing circle. I do a lot for the community hall. I like to do that. We have a garden club - just the people on our road. There are so many different people, you can learn a lot.

An assessment of this situation must not take advantage of Lesley being a nurse who automatically feels it is her responsibility to provide care. Understanding how she overburdens herself, and respecting the bargain she has made with her father to avoid placement in exchange for the deed to the homestead, assist in determining how to fill in gaps without it appearing she is negligent, incapable, or unrealistic in her expectations of keeping him at home and working, too.

The last interviewee is Molly, a forty-five year old married woman who sees herself as the primary caregiver to Miss. Sloan, a retired and childless school teacher who lives across the street. Molly has a small business that she considers to be part-time. She describes her health as good and herself as fairly happy. Molly explains her ongoing relationship with Miss. Sloan:

> She moved in across the road twenty-five years ago at age sixty and from then on if there was ever a problem, she called us. When she was younger, it was house stuff like changing a light bulb. She's eighty-five now, and in the last two years she has really failed a lot.
>
> She's never been married. She has one brother who is seventy-one and a sister who is eighty-seven and they fight like cats and dogs. Since she got really sick in January and they know she almost died and they're going to get her money - now they're all there. The nephew, who has the power of attorney, says she can't afford all the care she needs. This is a lady who worked all her life and has done everything to take care of herself - she had money - now she doesn't have a cent to her name.

Molly's 'ethic of care' is based on a foundation of **friendship and company**, coupled with present circumstances involving **doing what needs to be done**. Molly has watched Miss. Sloan deteriorate from a ‘young-old’ woman who took care of herself and was in control of her own finances, to an ‘old-old’ person who has lost power as she has lost her health and turned over the control of her money to someone else. She sees herself as an advocate for this woman who no longer is able to stand up for herself.

> I used to take her dinner every night when we ate, or have her over when we had a special meal. Now, I've started doing the same thing because they [family] have canceled her help, except overnight. My worst fear is going in the house and finding her dead.

With the passage of time, Molly's role has changed from one of supportive neighbour to caregiver and advocate. She is the first number to be contacted by Lifeline (a telephone emergency call system) and she perceives the family to be interested only in Miss. Sloan's estate.

In terms of leisure, Molly is a **consolidator** as well as a **recharger**. Over the years, she included her friend in outings, taking her grocery shopping and to appointments. Despite her faithfulness to her caregiving responsibilities, she continues to be deeply involved in Eastern Star (a service organization) and she teaches her ceramic classes on a regular basis. Nevertheless, Miss. Sloan is always in her thoughts:

> I worry any time I am away because I am the first one to call on the Lifeline. On Saturday, she called twice when I was at a meeting.

After meeting and sharing the experiences of thirteen caregivers, overall assessment themes incorporating an holistic perspective can be established, creating a blueprint for future interviews. The amount and kind of care being given must be balanced with the perception of stress and burden expressed by the caregiver in performing tasks. The quality of the relationship, a thorough history, and an examination of current exchanges will assist in the identification and understanding of problem areas. A recognition of the value of outside help (other family or community), as perceived by the primary caregiver, will aid the assessor in obtaining a complete picture of the circumstances. Recognition of relationship differences and the awareness of the perceptions of others are invaluable additional tools necessary for holistic interviewing.

PART II - COMPARISONS / CONTRASTS

Assessing circumstances and relationships cannot be done in a vacuum. With interest and experience comes the innate ability to ask the questions able to elicit necessary information about perceptions. These caregiver perceptions are a foundational component in the overall evaluation of the caregiver/recipient relationship. The following analysis is simplified by employing Table I as a reference and the Subject Outline on page 122 as a guide.

Section 2 in the structured interview examines the caregiver's view of the quality of their relationship with the receiver. Of the fifteen relationships, twelve were rated at a level of twelve points or more out of a possible fourteen, indicating a feeling of quality interaction between the players as seen by the interviewee - getting along, understanding one another, and having similar views on life. The three with the lowest scores (1W, Vicky and her mother; 2NB, Abby and her mother; and 1K, Lesley and her father) all reflect the result of a history of negative interaction as seen in the profiles. Vicky has never gotten along with her mother. Now, she exchanges caregiving for compliance in issues regarding behaviour towards herself as well as other family members. Abby gives care so as not to feel guilty about her resentment and dislike for her mother. Finally, Lesley has traded care for the deed to the homestead, getting emotional stress and financial worries in the bargain. Even though we, as assessors, may see a stressful relationship of lesser quality as expressed by the participants themselves, they are often prepared to continue on for reasons that only a thorough assessment will uncover.

Section 3 explores actual physical support given by a caregiver to a recipient. A score of 120 would indicate the highest possible level of care. Each of thirty tasks was weighted by the caregiver as '0' - not done at all, to '4' - a task totally their responsibility. It was left up to the participant to value a task performed occasionally as '1' or '2' points, allowing the process of perception to be employed. Caregiver 2H, Dawn, saw herself as carrying the heaviest load of all the interviewees, with a score of 79. She assists her son who is stricken with AIDS. Three others scored over seventy - Caregiver 1K, Lesley, whose father is ambulatory and stays alone all day; Caregiver 2NB, Abby, whose mother is physically healthy but has AD; and Caregiver 2W, Elizabeth Jean, whose husband has muscular atrophy and full-time hired nursing support. On first examination, one would expect those caregivers with maximum care and minimum outside support (1AR, Betty; 2AR, Mim; and 1NB, Emma) would register the highest point totals. In the case of these thirteen caregivers of fifteen recipients, perception of the amount of care given is related to the difficulties experienced with care management (Dawn and Elizabeth Jean) or stresses within the relationship (Abby and Lesley). The need to recognize the importance of the perception of the amount of workload, as seen by the caregiver, rather than as perceived from the outside, cannot be emphasized enough. As the assessor attempts to determine actual circumstances and unmet needs, an awareness of the quality of the relationship and its effect on perceptions is invaluable.

Section 4 measures caregiver perceptions of well-being - their physical and mental health coupled with the amount of outside activities in which they engage. A score of twenty is optimum. Four of the thirteen caregivers scored below ten points, suggesting they see themselves as being in some form of difficulty and lacking in activities outside of their primary role. Caregiver 2W, Elizabeth Jean, has total professional care for her husband, but she has given up most other pasttimes except those of care management, saying she must be available even if others are doing the physical tasks. Caregiver 4W, Gertrude, looks after her aunt and uncle. She expresses the feeling of being on call twenty-four hours a day, even though the task levels she reported in Section 3 are both below twenty- five out of a possible 120. Caregivers who verbalize an overwhelming sense of responsibility, even if their actual physical chores are few, most often see themselves as burdened and tied down. The caregiver with the highest score (18) is 1AR, Betty. She has no formal help with her husband but manages to play in a band on a regular basis, making all manner of complicated arrangements with neighbours and friends so she is able to do so. Assessors need to be aware of the perceived isolation of many caregivers who have cut themselves off from the outside in order to be available at all times.

Section 5 deals with the concept of strain, as seen by the interviewee. Questions relate to sleep disturbance, emotional adjustments, financial pressures, work complications, and the like. A score of twenty-six points suggests the highest indication of strain whereas a zero means there is no perception of strain at all. The results point to extremes that may well not be observed unless specifically assessed. Caregiver 5W, Lezah, whose mother has always lived with her, scored a one. Caregiver 2H, whose son has AIDS, scored a twenty-five. Seven additional participants scored more than thirteen. What actually constitutes strain for the caregiver can never be assumed by the assessor. While one person may cope exceedingly well with a parent under the same roof, another may be totally overwhelmed. A relationship history often can indicate the reasons behind present strain perceptions.

Section 6 addresses a number of issues discussed in other sections, serving as a verification in many ways. A score of fourteen suggests a caregiver who sees themselves as aware and involved. A score of zero would point to problems of giving or getting help. Only one caregiver (1NB, Emma) scored below the half-way mark in this section - one of the two non-related caregivers. Most scores were in the eight to ten point range, indicating involvement and understanding, but with a need for additional help or support.

Section 7 looks at the caregiver's perceptions of the recipient's mental impairment. A recipient with no impairment whatsoever, as seen by the interviewee, would have a two part score of 14/0. The totally impaired recipient would receive a score of 0/32. Of the fifteen recipients, only two had formal diagnoses of mental impairment - the receivers of care from 1NB (Emma) and 2NB (Abby), both with Alzheimer's disease. The former gave her recipient the benefit of the doubt when describing behaviour, resulting in a 14/9 score. Emma sees her charge as 'not impaired' because Mrs. Heinz tries so hard and is aware of her affliction. Abby sees her mother as getting steadily worse and reports this with a score of 8/16. Most interviewees made allowances for memory lapses or difficult behaviours, with the exception of Caregiver 1W (Vicky). She does not get along with her mother and her scoring (6/10) illustrated her frustration with Mrs. Jones' behaviour. Oftentimes, caregivers have trouble quantifying the degree of mental impairment exhibited by a recipient. They have been making allowances, concessions, and adjustments for so long, even the most bizarre behaviour to an outsider may seem normal to the caregiver. Anyone assessing a family who cares for a mentally impaired individual must understand this and recognize how the quality of the relationship may well affect the caregiver's reports of impairment.

Section 8 discusses impact and covers area of emotion like anger and resentment. It also explores social life and feeling torn between the recipient and others. A score of thirty indicates the greatest impact while a score of two means the only impact is one of pleasure. One point suggests some pleasure with no negative impact. The scores of caregiver 1W (Vicky), who cares for both her mother and father, reflected a big difference in impact perceived as caused by the two. With her mother, she scored a sixteen, while with her father she scored a three.

The negative relationship she maintains with her mother is clearly reflected in her perception of negative impact. Caregiver 5W (Lezah), whose mother has always lived with her, sees no impact save pure pleasure. Caregivers 1NB (Emma) and 2K (Molly), the two caregivers unrelated to their recipients, both scored a one, suggesting the interactions they experience provide some pleasure and, at the same time, do not negatively impact on their own lives. The highest score (29) was from caregiver 2NB (Abby), whose mother has AD. It is clear how a shaky history coupled with a difficult mental impairment can negatively impact on a caregiver.

The final section of the structured interview, scored for comparison, is about coping strategies and the caregiver's perception of their ability to cope. It is divided into two sections so a score of 28/0 indicates high ability and 0/20 shows poor ability. All interviewees scored themselves at eighteen or above in the first section, indicating they all felt themselves to be fairly good at coping. Three of the thirteen scored themselves greater than ten points in the second section, suggesting some problems. The two caregivers scoring eleven both care for two people, which could well produce a different perspective in ability to cope. The third was Abby, whose mother has AD. Her ability to be very candid and her critique of her own behaviours are reflected in her score.

In summary, every caregiver (no matter what the experiences of the assessor) is different. A functional assessment boils down to a clarification of relationship history, interaction as a function of that history, and perceptions as reported by the participants. Issues such as 'theme of meaning' (Noonan et al., 1996) and 'entitlement to leisure' (Bedini and Guinan, 1996), coupled with a recognition of the concept of 'ethic of care' (Gilligan, 1982) can be positioned within a framework of social exchange theory in order to increase understanding of the caregiver/recipient relationship. In addition to actual physical support tasks, an assessment must include attention to perceptions regarding relationship quality, well-being, strain, mental impairment, impact, and ability to cope. A balanced view of the caregiver's strengths and weaknesses coupled with a clear profile of the relationship will lead to a greater likelihood of needed resources being partnered with appropriate receivers.

CHAPTER 5

CONCLUSION

PART I - SUMMARY AND DISCUSSION

The direction of my thesis has been the presentation of a home care related assessment approach which includes the recognition of the perceptions of the primary caregiver as well as an increased understanding of the quality and nature of the relationship between the caregiver and the recipient. A thorough explanation of social exchange theory and a review of the extensive literature pool on the subjects of caregiver stress and burden both reflected evidence of reciprocity and balance of relationships playing significant roles in determining what already constitutes stress and burden on the part of the caregiver. Taking into consideration the profound changes having recently occurred in our medical system, recommendations are made that would, if implemented, create a climate of flexibility and choice for those individuals who informally care for elderly or disabled members of our society.

Thirteen caregivers of fifteen care recipients (see Page 122) were interviewed for this thesis. Each interview consisted of both structured and unstructured components (see Pages 114 - 121). The structured portion permitted information to be elicited quickly; it delved into subject matter most likely not the conscious focus of daily life for the interviewee; and it became the basis for the generation of descriptive and comparative evaluations. The unstructured and open-ended sessions were voice-centred in their presentation and concentrated on areas of importance as perceived by the subjects. Analyses created individual profiles exploring caregiver perceptions and relationship balance as fulcrums to understanding each particular case. Interviewees were compared, illustrating clearly the different perceptual values and foci depending on circumstances, personalities, and relationship qualities.

Individuals who have not been either personally or professionally touched by the recent changes in our medical system may well not be completely aware of how profound these changes actually are. Patients are admitted to hospital when they need 'acute' care or when they are in an 'acute' condition. They are not discharged when they are well, but when they are no longer 'acute'. For the majority of families and informal primary caregivers, this presents a critical circumstance demanding the rallying of support in one form or another. For those who live alone, without reliable familial or neighbourly help close by, the problems are exacerbated.

One final example will illustrate the current situation and resulting complications, as well as provide a platform whereby my recommendations can be presented. Mrs. MacLeod has been in hospital for over three weeks. She had surgery on both her knees some ten years ago but they are now deteriorating quickly, giving her a great deal of pain. She is no longer able to walk but for a step or two with the aid of a nurse. She is ninety-two years old, lives alone, and has a married daughter who resides an hour away by car. She is sixty-eight and her husband has medical problems of his own. Mrs. MacLeod expects to return to her own home, alone, once she is able to walk again. Nova Scotia Home Care is willing to provide daily personal care and household assistance. They will arrive at 8:AM to help her out of bed, give her a bath, and prepare her breakfast. They will return at 4:PM to make her supper and help her into bed. Her daughter is willing to drive the two hour return trip every day at noon, but Mrs. MacLeod would be alone through the night. She is unable to get from the bed to the chair or to the commode without assistance. The chances are highly likely she will not improve. Although no longer 'acute', the physician is nervous about discharging her home without night supervision. This, of course, causes pressures in a hospital with a limited number of beds, constantly filled with acute care patients.

An assessment of this situation is far more complicated than might be assumed at first blush. Nova Scotia Home Care does not do either over night or standby care. Even if the family is willing and able to cover the other bases and the recipient financially qualifies for support, the mandate of the current service is task-oriented and does not include more than a few hours per week of respite, if deemed absolutely necessary. Mrs. MacLeod's daughter will not have the flexibility in management of her mother's care to choose to stay with her all day in exchange for someone else to come to the home at night. Mrs. MacLeod has no resources to pay for private care. She and her daughter do not have a history of getting along. Living with an adult child and her ailing husband, or having them move to her house, are unwelcome (and most likely unwise) options that would probably precipitate the complete breakdown of a relationship operating out of filial responsibility with a kin caregiver who resents losing what little free time she has to a disabled mother who refuses to go to a nursing home.

The hard answer here is placement for Mrs. MacLeod. Her daughter does not feel she can do more than daytime care. She would most certainly go home at risk of falling, and her choices are few. In this particular case, Nova Scotia Home Care has offered to satisfy the need for morning and suppertime care seven days a week. This is generous support when translated into a dollar figure of $50.00 per day (a nursing home costs double this). Their recommendation is for the family to provide additional required care, not taking into account the potential risk involved if this relationship is stretched beyond the limits already expressed by the players.

In assessing both Mrs. MacLeod's and her daughter's needs, and understanding the relationship characteristics, the alternative lies with a public home care system based on a financial rather than a task oriented framework. If each recipient situation were entitled to a particular dollar figure translated into service where it is needed the most, then primary caregivers would be able to take part in the assessment and see their needs being met by management in areas where they are most vulnerable.

So in the end, we are left to wonder about the fate of Mrs. MacLeod, sitting quietly in her chair and reading her paper at the local community hospital. Her bed has a per diem value in excess of $400.00, acute patients are in holding beds, and she refuses placement. She will go home at risk, with whatever services home care will provide. The chances are she will fall in the night and be re-admitted to hospital in an acute state again.

Most home care service providers started as home makers, public health nursing, and/or Victorian Order of Nurses. As our population has aged and families have become increasingly involved in care support and management, we have seen how these task-oriented supports are not necessarily the complete answer any longer. In order to assist recipients, assessors must recognize relationships and the perceptions of caregivers. Programs must become more flexible, filling in the gaps with such services as respite, standby, and overnight support, thus freeing caregivers for much needed breaks. I had a woman tell me once that if she just had one night in the week when she could sleep without having to get up to attend to the needs of her mother, she could manage everything else. Her request for overnight care was denied.

PART II - FINAL REMARKS

There are three major avenues towards which this work could branch. First, it would be only fitting to follow up with a second study of male caregivers. The two works could then be combined for comparison. Second, Nova Scotia Home Care generates an incredible variety of statistics about their caseloads. Their data base could be used to access information about unmet needs and ultimate reasons for institutionalization. This could be the beginning of the redesigning of a system that would be more flexible and cost effective. Finally, home care assessors in Nova Scotia are hired, for the most part, from the professional arenas of nursing, social work, physiotherapy, and dietary. Each profession, with its own area of expertise, has an assessment approach. It is time to recognize the home care assessor as a specific professional with a particular focus. Training workshops need to be designed that will enable the interviewers to assess holistically - eliciting information about well-being, strain, perception, impact, and coping so as to expand the task-oriented approach to one of understanding and flexibility. Gilligan's 'ethic of care' (1982), Noonan et al.'s 'themes of meaning' (1996), and Bedini and Guinan's 'entitlements to leisure' (1996) are just three of many tools able to be accessed in the creation of an improved care management assessment approach.

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CONSENT FORM

I,____________________________, agree to participate in the research on "Caregiver Stress and Burden" being conducted by Suzanne Atkinson. I understand that my real name and identifying information will not be used in the write-up of the project and that any drafts, notes, diaries, or tapes will be destroyed following the completion of the study.

____________________________________ Signature of Participant

____________________________________ Signature of Researcher

____________________________________ Date

CAREGIVER STRUCTURED INTERVIEW

1. DEMOGRAPHIC CHARACTERISTICS OF CAREGIVERS

Age	20-39 40-59 60-74 75+	
Sex	male female	
Marital Status	married widowed never married separated/divorced	
Level of Education	<grade 12 grade 12> some college/university undergraduate degree graduate degree	
Work Status	working full/part time retired unemployed never worked outside the home	
Perceived Health	good fair poor	
Perceived level of happiness	very happy fairly happy	not very happy not happy at all
Relationship to recipient	adult child spouse other family member	
Living Situation	with recipient separate residence	

2. RELATIONSHIP QUALITY

	YES	SOME	NO
Giver and recipient get along very well			
Giver and recipient understand one another very well			
Recipient understands giver very well			
Giver treats recipient very well			
Recipient treats giver very well			
Giver and recipient have very similar views on life			
Giver and recipient are very close			

3 .PHYSICAL SUPPORT MEASUREMENT

	HEAVY			LIGHT
	3	2	1	0
PERSONAL CARE				
remind to take meds				
stand-by for bath				
bath/shower				
shave				
hair grooming				
care of hands/nails				
care of feet/nails				
oral hygiene				
skin care (moisturizers)				
toilet assistance				
emptying of external equipment				
assist to dress/undress				
MOBILITY				
assist to walk				
assist in/out of bed				
assist in/out of chair				
assist with positioning				
help to maintain posture				
encourage activity				

	3	2	1	0
MEALS				
serving meals/snacks				
cutting up food				
cooking meals				
feeding				
grocery shopping				
meal planning				
kitchen clean-up				
washing dishes				
HOUSEHOLD/FINANCIAL MANAGEMENT				
budgeting				
banking				
bill payments				
transportation duties				
vacuuming				
dusting				
clean bathrooms				
wash floors				
garbage disposal				
laundry				
ironing				
changing beds				
mowing lawns/shoveling snow				
yard work				
ADDITIONAL DUTIES NOT LISTED				

4. CAREGIVER WELL-BEING

	HIGH	LOW
Physical health - self assessment		
Mental health - self assessment		
Finances - problematic		
Social Activities -phone contacts with family and friends		
visits with family and friends		
church attendance		
club/group attendance		
time spent pursuing hobbies		
time spent relaxing		
satisfaction with amount of social activities		

5. CAREGIVER STRAIN QUESTIONNAIRE

	YES	SOME	NO
Sleep is disturbed due to wandering, night calls, etc.			
Helping takes up a large portion of time			
Helping is a physical strain			
Helping is restricting - can't do other things			
Adjustments in lifestyle have had to be made			
Personal plans have had to be changed			
There are also other demands on my time (work, children)			
Emotional adjustments have had to be made			
Certain behaviors are upsetting			
The change in my loved one has been upsetting			
Work adjustments have had to be made			
It is a financial strain			
I feel completely overwhelmed			

6. SUBJECTIVE PERCEPTIONS OF RELATIONSHIP

	YES	SOME	NO
I am very involved in helping			
I find it hard to give help			
I could use some assistance			
I could use some training			
Helping has changed my lifestyle			
I understand my loved ones problems			
I get along well with my loved one			

7. DIMENSIONS OF MENTAL IMPAIRMENT

Recipient is interesting to talk to
Recipient is enjoyable to be with
Recipient is friendly and sociable around people
Recipient is interested in things
Recipient is cooperative
Recipient is clean/neat about self
Recipient is appreciative/grateful for help
Recipient is withdrawn/unresponsive
Recipient complains/criticizes
Recipient interferes with caregiver
Recipient disrespects privacy
Recipient yells/swears at people
Recipient does embarrassing things
Recipient disrupts meals
Recipient is violent
Recipient is confused
Recipient is forgetful
Recipient sees or hears things not there
Recipient wanders
Recipient has unrealistic fears
Recipient talks to self
Recipient repeats self
Recipient does harmful things to self or others

8. IMPACT	**YES**	**SOME**	**NO**
Caregiver feels angry toward recipient			
Relationship makes caregiver depressed			
Relationship is strained			
Caregiver feels resentful towards recipient			
Recipient has negatively affected other relationships			
Caregiver feels manipulated			
Caregiver wishes for a better relationship with recipient			
Relationship gives pleasure			
Caregiver feel recipient makes more requests than necessary			
Caregiver feels torn between recipient and others			
Caregiver feels recipient has no one else			
Caregiver takes part in organized activities less			
Caregiver goes out to entertainment less			
Caregiver visits family and friends less			
Caregiver feels social life has suffered			
Caregiver feels doesn't have enough time for self			

9. COPING STRATEGIES

I come up with a couple of different solutions
I changed something about myself to make things easier
I knew what had to be done so I just did it
I tried not to be too hasty
I changed something so things would turn out
I made a plan and followed it
I criticize or lecture myself
I realized I brought the problem on myself
I hoped for a miracle
I day-dreamed about a better time
I kept my feelings to myself
I tried to make myself feel better by eating, drinking, smoking or taking medications
I imagined myself in recipient's shoes
I tried to understand how recipient felt

	YES	**SOME**	**NO**
I tried to help by listening			
I tried to meet recipient half-way			
I tried to comfort recipient with positive feedback			
I tried to find a fair solution for all			
I tried to get recipient to change their mind			
I express my anger openly			
I withdraw from recipient when I get upset			
I give recipient the silent treatment			
I take it out on others			
I get mad			

10. ASSISTANCE TO PRIMARY CAREGIVERS

Do you use NSHC? Do you use VON?
Do you employ private help?
Do you get help from other family?
Do you get help from neighbours and friends?
Do you make use of nursing home respite services?
Do you admit recipient to hospital when you are overwhelmed?
Do you talk about problems with family? friends? doctor? counselor? other?
Are there other agencies or people that help you - who?
Did you get any training to help you be a caregiver - what?

UNSTRUCTURED INTERVIEW LEAD QUESTIONS

1. WOULD YOU TELL ME HOW YOU BECAME A CAREGIVER - THE NATURE OF '———'S ILLNESS, THE HISTORY OF YOUR CIRCUMSTANCES?

2. CAN YOU DESCRIBE YOUR RELATIONSHIP WITH '———'; BEFORE THE ILLNESS, NOW, ASPECTS OF GIVE AND TAKE, WHAT YOU EACH GET OUT OF YOUR TIME TOGETHER?

3. WHAT ABOUT OTHER FAMILY MEMBERS? WHO IS HELPFUL? WHO IS NOT? WHY? HOW HAS THIS CHANGED, IF IT HAS?

4. TELL ME ABOUT YOUR IDEAS REGARDING OBLIGATION IN YOUR RELATIONSHIP

5. TELL ME ABOUT THE THINGS YOU DO OTHER THAN CAREGIVING? ARE THERE THINGS YOU USED TO DO THAT YOU DON'T ANYMORE? WHY?

6. REGARDING COMMUNITY RESOURCES, ARE THERE THINGS YOU NEED BUT DON'T HAVE? ARE THERE RESOURCES YOU FIND HELPFUL? WHY?

7. WHAT FACTORS WOULD CAUSE YOU TO LOOK AT INSTITUTIONALIZATION AS AN OPTION?

8. MY WORST FEAR IS ....
   IF LIFE WERE PERFECT ......

SUBJECT OUTLINE

CAREGIVER	RECIPIENT
1W - VICKY	Both Parents, Mr. & Mrs. Jones - aged
2W - ELIZABETH JEAN	Husband, John - muscular atrophy
3W - MORIAH	Mother, Mrs. Dow - aged, Parkinson's
4W - GERTRUDE	Aunt May & Uncle Fred - aged, cared for her
5W - LEZAH	Mother, Mrs. Denson - aged, always with her
1AR - BETTY	Husband, Bob - lung disease
2AR - MIM	Husband, Dick - kidney transplant, cancer
1NB - EMMA	Mother, Mrs. Heinz of c/l spouse, Fred - A.D.
2NB - ABBY	Mother, Mrs. Allison - A.D.
1H - JOY	Husband, Max - severe stroke
2H - DAWN	Son, William - A.I.D.S.
1K - LESLEY	Father, Mr. Garland, aged, family homestead
2K - MOLLY	Friend, Miss Sloan, aged, neighbour

TABLE I
STRUCTURED INTERVIEWS
RAW SCORES

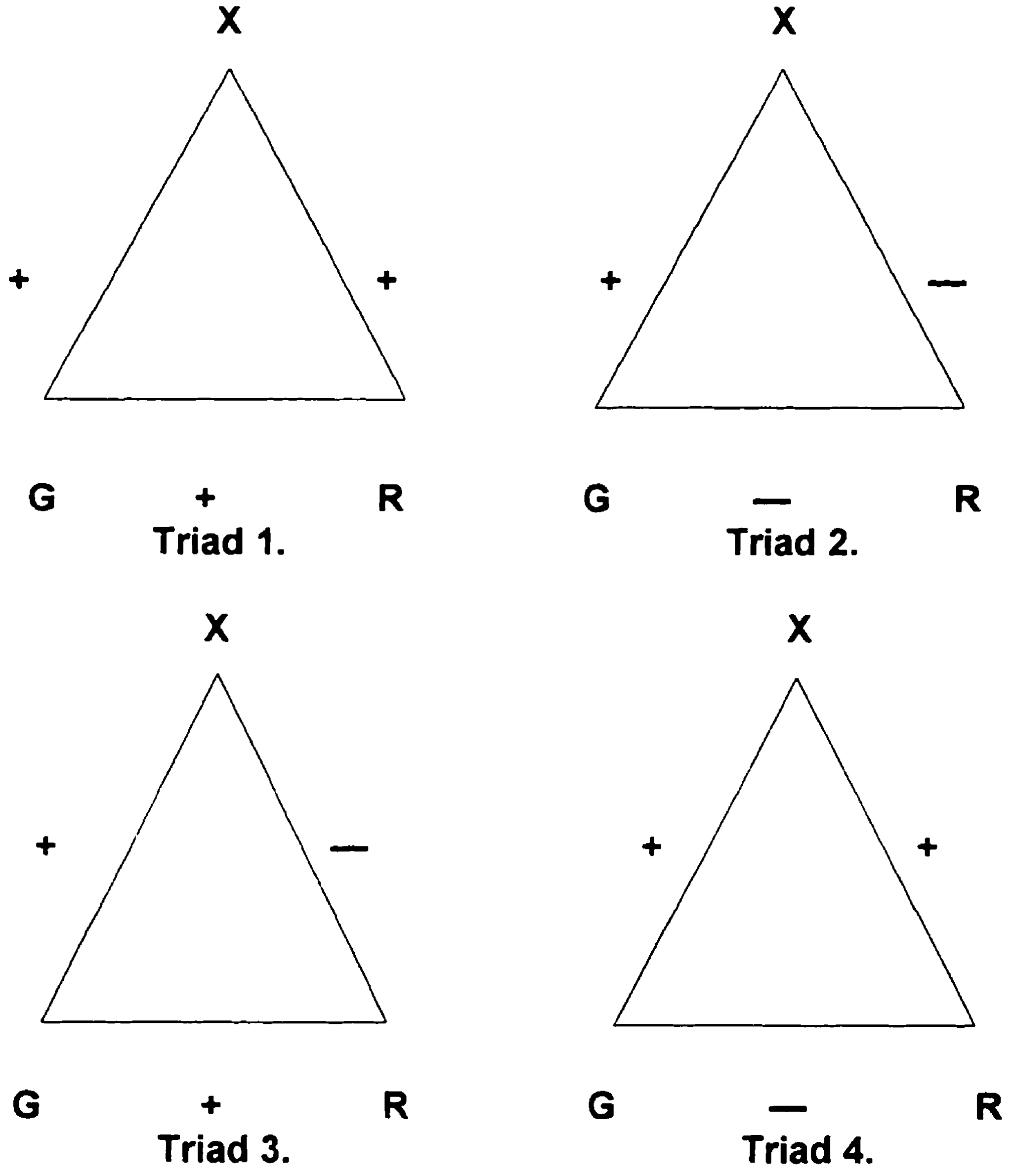
		TOPICS									
		2	3	4	5	6	7A	7B	8	9A	9B
CAREGIVERS	1WM	7	43	12	19	9	6	10	16	19	11
	1WF	12	42	12*	19*	9*	10	11	3	19*	11*
	2W	14	71	8	14	8	12	0	12	27	15
	3W	12	28	17	14	9	14	8	13	21	7
	4WA	14	25	9	16	9	14	1	14	20	11
	4WU	13	22	9*	16*	9*	14	2	14	20*	11*
	5W	14	56	16	1	5	14	6	2	18	2
	1AR	14	67	18	10	10	13	1	5	22	5
	2AR	14	61	12	16	9	12	3	10	22	6
	1NB	12	60	11	14	6	14	9	1	20	2
	2NB	10	77	12	16	10	8	16	29	25	16
	1H	13	60	13	13	10	11	0	9	20	7
	2H	14	79	9	25	7	14	5	11	24	4
	1K	8	75	6	17	7	12	9	18	18	5
	2K	13	5	15	7	7	13	1	1	18	6

LEGEND

2 - RELATIONSHIP QUALITY (14=good; 0=poor)
3 - PHYSICAL SUPPORT (120=heavy; 0=light)
4 - CAREGIVER WELL-BEING (20=well; 0=not well)
5 - CAREGIVER STRAIN (26=high; 0=low)
6 - RELATIONSHIP PERCEPTIONS (14=very involved; 0=not involved)
7a - RECIPIENT MENTAL IMPAIRMENT (14=not impaired)
7b - RECIPIENT MENTAL IMPAIRMENT (32=very impaired)
8 - IMPACT (30=high; 0=low)
9a - COPING STRATEGIES (28=high ability)
9b - COPING STRATEGIES (20=poor ability)

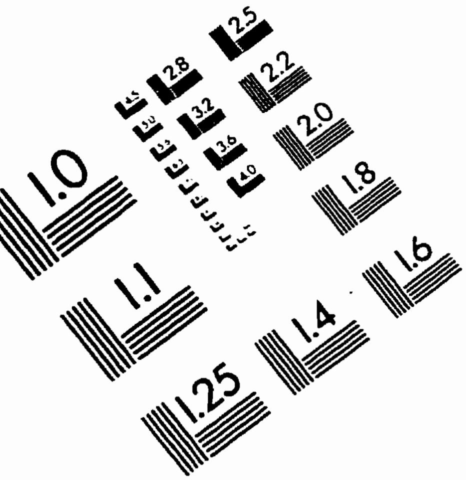
*duplicate scoring

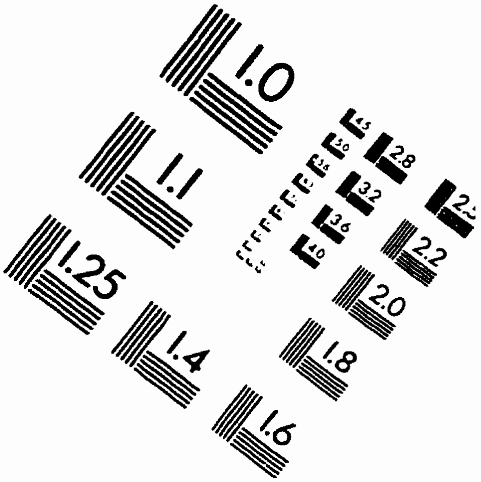
FIGURE I
BALANCED AND UNBALANCED RELATIONSHIPS

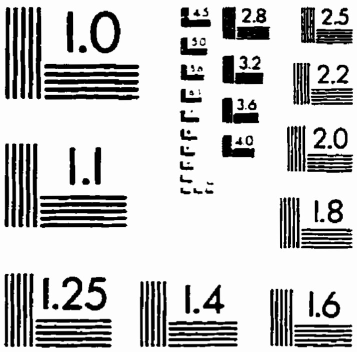


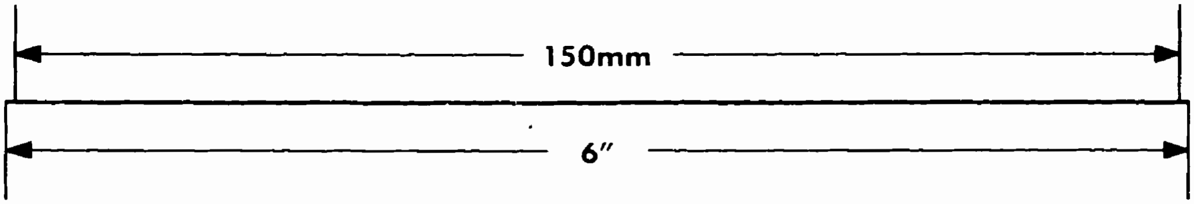
X = Issue
G = Caregiver
R = Care Recipient
\+ = Positive Relationship <u>or</u> Position on issue
— = Negative Relationship <u>or</u> Position on issue
(Adapted from Homans, 1974, p.60)

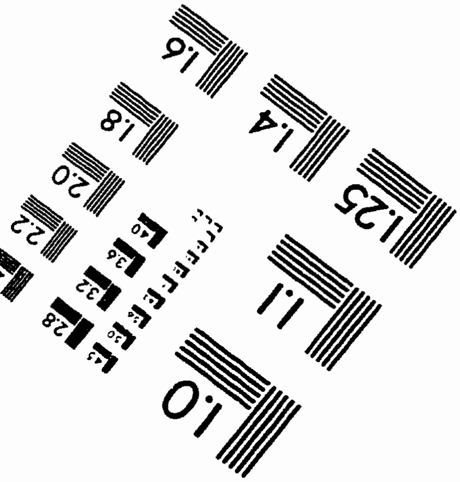
IMAGE EVALUATION TEST TARGET (QA-3)

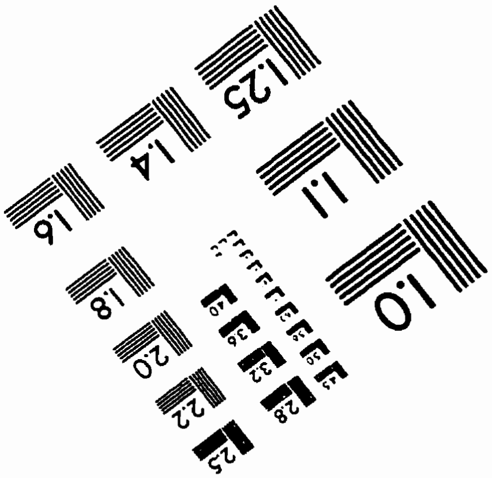












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