

SUPPORT GROUP FOR WOMEN CAREGIVERS
OF THE ELDERLY: A FEMINIST APPROACH

BY

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A Practicum Report
Submitted to the Faculty of Graduate Studies
in Partial Fulfillment of the Requirements
for the Degree of

MASTER OF SOCIAL WORK

Faculty of Social Work
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ABSTRACT

Caring for the increasing numbers of elderly persons is a growing concern in our Canadian society. The State's policy of "Community Care", however, delegates most of the responsibility for caregiving to families. This "caring labour" is disproportionately carried out by women, and is often not valued or recognized. A Feminist groupwork intervention strategy was used in this study to provide support and to empower women caregivers toward positive change in their own lives. The group, conducted for eight weeks, in Portage la Prairie, Manitoba, had four participants, and had as its objectives to help reduce caregiver burden, increase social support networks, and increase self-efficacy of participants. The practicum found the group helped to decrease burden, improve the quality of social support, and increase self-efficacy through the process of empowerment. Therefore, this form of group intervention was found to be an effective modality for counselling women caregivers. Implications for social workers working with women caregivers are outlined, and suggestions for future study are offered.

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INTRODUCTION:

This author chose to implement a practicum in order to fulfil the requirements for her Masters in Social Work Degree. This document, referred to as the practicum report, encompasses the rationale for the practicum, as well as a summary of results. It is organized in the following format: the introduction, the objectives of the practicum, the literature review, the research question and conceptual framework, the methodology, the results, the discussion, and the conclusion.

Within the scope of this practicum, the author examined the issue of female adult children (daughters, daughters-in-law) as caregivers to their elderly parents. The practicum utilized a feminist analysis of caregiving as a women's issue, not solely because women do indeed provide the bulk of caring labour, but because, caregiving is, within a patriarchal context, a source of exploitation and oppression for women. The intervention proposed was a support group for women caregivers focusing upon the development of mutual support, sharing of emotional experiences, problem-solving, and empowerment of women participants to cope more effectively and to make positive changes in their lives where feasible. The effectiveness of the group was measured by reduction in subjective feelings of burden, and increase in self-efficacy and mastery, and development of social support networks. The evaluation was comprised of both qualitative and quantitative

data collection through pre/post interviews, monitoring of group interactions, and data derived from self-anchored scales.

One possible final outcome may be a continuation of the group in the form of a social action group, where participants would lobby the government for changes in the system of care provision currently in place. However, it was beyond the scope of this practicum to recommend or implement alternatives for care provision.

Although a great number of studies have been conducted and the literature is vast in the area of family caregiving, only a few studies have explored the gender issue of caring within the context of a patriarchal society. The feminist literature on the topic has provided an excellent critique of state policies, but few authors have focused upon supporting and raising the consciousness of women caregivers in practice.

The feminist approach to social work intervention analyzes the underlying societal assumptions and resulting policies regarding the gender division of labour and provision of formal vs. informal care. These policies serve to marginalize women's position in society, delegating primary responsibility for unpaid caring labour to women, despite their greater participation in the paid workforce. In practice, women need to become aware of their oppression and to be empowered to advocate for positive changes.

Previous to the 1980"s, the literature on caregiving was not gender-specific and caring was thought to be a "family" duty. E. Brody (1981) introduced the concept of "Women in the Middle"--these women were facing various stressors, including the competing demands of job, family and caring for elderly parents, the ramifications of which are important for social work. In order to define and organize the variables which must be studied, the author chose a framework developed by Pearlin, Mullan, Semple and Skaff (1990) which included such factors as intergenerational family dynamics, changing roles, job-caregiving conflict, feelings of burden and stress on the part of women caregivers, loss of self-esteem and feelings of mastery, depression and declining physical health as issues impacting upon the caregiver and the care being provided. This framework has been modified to meet the specific parameters of this study and will be discussed further on in the report.

In summary, this practicum attempted to explore an old issue (women caregivers) from a new perspective. By examining the context in which caregiving occurs and relating this context directly to the experiences of women in the group, my intention was to make some connections between policy and practice, between public and private, between political and personal, which are both meaningful for the field of social work and the clients themselves. As indicated by the results, the group members increasingly became aware of the political

implications of their role as women caregivers as the group intervention progressed and did begin to make these important connections relevant to their personal situations.

OBJECTIVES OF THE PRACTICUM

PRACTICUM OBJECTIVE:

The overall objective of this practicum study was to design, implement and evaluate the effectiveness of a short-term Caregiver Support Group for daughters and daughters-in-law caring for elderly parents in its ability to meet the needs of this population in terms of reducing feelings of burden, increasing support networks and increasing subjective feelings of self-efficacy as related to coping with the caregiving demands. My objectives for my own learning from the practicum were more specific and are detailed in the list below.

LEARNING OBJECTIVES:

The following are broad learning objectives I endeavoured to meet through the development and implementation of this practicum study.

1. To develop and implement a Women Caregivers' Support Group targeted at daughters and daughters-in-law caring for elderly parents.
2. To develop an understanding of female adult children as caregivers, utilizing a feminist perspective to analyze both policy and practice issues.
3. To develop skills and experience in short-term group counselling techniques, utilizing a feminist framework as a theoretical base.

4. To develop a thorough knowledge of the difficulties associated with provision of care to the elderly, and their effect on female adult children caregivers.

5. To develop knowledge in analysis of policy issues and their relationship to social work intervention.

CHAPTER I -- LITERATURE REVIEW

The following chapter explores a variety of relevant literature to the issue being studied in this practicum, providing a thorough understanding of previous work on the issue of women's caregiving, the variables that need to be considered and their impact on the proposed study.

WOMEN AS CAREGIVERS:

Most of informal care for the elderly is provided by women, often spouses, and in their absence, daughters, daughters-in-law and other female relatives (Qureshi & Walker, 1989; Lewis & Meredith, 1988; Brody, 1981; Finch and Groves, 1980). Just as the majority of caregivers are women, so too are the majority of care recipients (Aronson, 1986). Caregiving is, therefore, an issue of primary concern to women.

Historically, society had relied upon the unpaid labour of women to care for children, disabled persons, and the elderly. Care by the community equates to care by the family, which, in turn, equates to care by women (Finch & Groves, 1980). The movement to de-institutionalize the elderly and maintain this population in the community has resulted in a shift of responsibility from the public to private sector, from formal to informal care.

CARE RECIPIENTS AND CARE PROVIDERS:

Qureshi and Walker (1989) explored the relationship between care recipients and those who provide the care. They

asserted that there exists a conflict between the needs evidenced by these two groups of people arising out of the state's failure to meet these separate and yet, equally critical needs. For the most part, elderly persons are not consulted regarding their preferences for care. Aronson (1990) described the phenomenon of "compulsory acquiescence" in her qualitative study of older women, where these older women felt compelled to accept family care as the alternative is institutionalization. Thus, in order to maintain some level of independence and dignity, older people accepted assistance from the same children they have raised and cared for. In fact, Aronson (1990) viewed the elderly, particularly elderly women, as having been relegated to a passive status with respect to determining their care preferences. Influenced by the forces of ageism and sexism, older women have been marginalized into subordinate economic and social status. The older women in Aronson's study considered themselves fortunate to have daughters to care for them, but repeatedly emphasized that they did not want to become a burden. Those women experienced great conflict between the desire to maintain independence and the need for care.

The re-entry of women into the paid labour force has threatened the stability of the state's "family" policy as there is a diminished "pool of unpaid labour" upon which to draw. However, the result has been even more oppressive for women: women are still ultimately responsible for provision

of care, and thus, they are forced to balance paid work in the labour market with unpaid caring labour. Brody and Schoover (1986) found that working daughters caring for their elderly mothers provided as much affective support, housework, laundry, transportation, grocery shopping, and financial management assistance as their non-working counterparts. When conflicts between paid labour and caring arose, caregivers often quit their jobs, reduced their hours of work, or took early retirement in order to maintain their caregiving functions (Lewis & Meredith, 1988).

Ungerson (1983) described further the oppressive nature of the sexual division of labour:

The tensions for women between paid work and unpaid domestic labour can, at an individualistic level, be described in terms of 'opportunity costs'--that is, if women 'choose' to spend their time in paid work then one of the perceived costs of doing so is loss of time to carry out domestic tasks at home; similarly, if women 'choose' to spend their time at home then the perceived costs consist of loss of earnings and possible companionship at work (p.34).

The basic assumption with this concept is that women make these choices freely, and that whatever their choice, women still maintain primary responsibility for domestic labour.

The economic consequences for these women who "choose" to give up employment are significant: not only do they become dependent upon their spouses, or in some cases, their elderly parents in losing their immediate source of income, but they forfeit future pension benefits and job opportunities (Finch & Groves, 1980).

WHY DO WOMEN CARE?:

Given the obvious disadvantages experienced by women as a result of providing care, why do these women continue to care for elderly family members?

Socialization practices dictate appropriate roles and behaviours for women which are, in turn, internalized by women as they are developing their identities. Lewis and Meredith (1988) explained:

Women's decision to care is made within a framework of widely held assumptions that caring is women's work and that, in the end, caring should take precedence over other types of work (p.5).

The caring ethic is a key component of women's psychological development as further illustrated by Gilligan (1982):

Women not only define themselves in a context of human relationships but also judge themselves in terms of their ability to care. Women's place in man's life cycle has been that of nurturer, caretaker and helpmate, the weaver of those networks of relationships on which she in turn relies. But while women have taken care of men, men have, in their theories of psychological development, as in their economic arrangements, tended to assume or devalue that care (p. 17).

Whereas caring and nurturing provides for the development of a sense of identity for women, it is also a strong component of socialization. Society, through its main transmitter of information, the family, has reinforced a gendered division of labour in terms of work that is ascribed to men and that which is ascribed to women.

The decision to care may result from feelings of both obligation and affection at the same time. Because of this

ambivalence experienced by caregivers, caring often becomes a "labour of love". In Lewis and Meredith's qualitative study completed in 1988, only a small percentage of their sample of women caregivers consciously decided to take on the labour of caring.

The remainder either "drifted" into caring or felt that it was an expected part of life, not something about which they could choose.

DEFINITIONS OF CARE:

One of the major critiques of the caregiving literature is the lack of consistency in the definition of caring. "Care" can range from a single instance of assistance to long periods of commitment, with varying demands and burdens (Barer & Johnson, 1990). Feminist scholars Lewis and Meredith (1988) provided useful definitions that they utilized as a reference point when interviewing caregivers.

"Full Care" occurred when the care recipient requires personal care to the point where he or she cannot be left alone without a substitute carer. "Semi- Care" was defined as the period where the care recipient should not be left alone for extended periods, but little or no personal care is required. "Part-time full care" was defined as a situation where the care recipient actually requires full care, but the caregiver provided the care while also carrying on with work and family commitments. These distinctions between different types of care allowed for greater understanding of the differing

demands and provided a useful framework to compare women caregivers.

Brody (1990) categorized the types of assistance older people require as including emotional support, mediation with organizations, financial support, assistance with activities of daily living such as bathing, shopping, meal preparation, laundry, transportation, dressing, etc. The amount of assistance required is, of course, based upon individual need, but in many cases is varied and quite demanding of both time and emotions.

Sometimes, women caregivers become so immersed in the caregiving role that they find it impossible to take a break as nobody else could provide the same quality of care. These women become "professional caregivers" or have "caregiving careers" where they care for several relatives either sequentially or sometimes simultaneously (Lewis & Meredith, 1988; Brody, 1990).

For the purposes of this study, the author chose to incorporate the definitions outlined by Lewis and Meredith in their 1988 qualitative study of daughters who were providing care to elderly mothers. In using an in-depth interview format to glean qualitative data, my study was similar to that just described. It was possible to utilize these definitions as a guideline and to ask participants expand upon the meaning of "caring" in their own lives.

INTERGENERATIONAL FAMILY RELATIONS:

Contrary to society's popular misconception, the family still cares for its elder members, as has been proven by various studies (Moore, 1987, Troll, 1986). Who provides this care within the aging family? Brody (1990) explained that one person, generally a daughter, is appointed "primary caregiver" in a family. Who takes on this role depends on a variety of factors including geographic proximity, gender, place in the sibling order, being an only child, and the death of other siblings. In many families, there does exist some conflict around caregiving responsibilities, but most families fall between the extremes of severe conflict and the "ideal". Old patterns of interrelating resurface and are played out as the "favourite" child, the "rejected child", and the "responsible" child all may react differently to their interactions with aging parents.

Siblings who are not the primary caregivers often feel guilty for not providing more care to their parents. This guilt may be self-inflicted or may result from deliberate attempts on the part of primary caregiver and/or parents to make that person feel guilty (Brody, 1990). Elderly parents sometimes compare their children and may only "accept" care from the primary caregiver. Unfortunately, caregiving daughters often feel such immense responsibility that they will not leave their parents alone, and thus, cannot carry on a normal life of their own (Lewis & Meredith, 1988).

In Lewis and Meredith' (1988) study, they found that married women attempted to "shield" their husbands and children from the caring process. They tried to keep life as "normal" as possible and thus, shouldered the burden of care for both mother and family themselves. Many respondents felt guilty if their husbands participated in caring or, in some way, took on more responsibility for other household tasks or family responsibilities.

Despite these attempts to "normalize" life, the caregiver's family likely experienced interference with lifestyle, privacy, patterns of socialization, plans for vacations, and plans for the future such as retirement or relocation (Brody, 1990). Competing demands on the caregiver's time and energy often lead to emotional strain which Brody (1990) characterized as including depression, anger, anxiety, frustration, guilt, sleeplessness, feelings of helplessness, irritability, lowered morale and exhaustion.

Shifts in the hierarchy and power relations between the generations within a family occur as the parents age, and coping with these changing patterns is perhaps one of the most difficult tasks facing the older family. The term "role reversal" is often used to describe these changing patterns by professionals and lay people alike. However, recent research questions the validity of that term in reference to the elderly parent-adult child relationship. Seltzer (1991)

differentiated between "change" and "reversal":

. . . Change is not synonymous with reversal. Placed within the life cycle perspective, late life changes in the care/receiving balance are viewed *within* role changes rather than changes of roles (p.6).

The concept of role reversal has tended to oversimplify a complex relational interaction between parents and children. It has equated the care provided to an elderly parent as "repayment" for the care received as a helpless child. One major difference between the two processes is that young parents have generally chosen to care for children, and see the gradual progression towards independence with increasing maturity. Caring for an elderly parent is often not chosen, nor is it associated with progression, but rather deterioration. The inner meaning for both caregivers and care recipients is quite different as is the experience of caring (Brody, 1990).

Another related concept is that of "second childhood" which is often used to refer to decreasing cognitive abilities and increasing dependence on the part of the elder. Brody (1990) revoked this concept as a superficial resemblance, not taking into consideration life experiences of the elder, physiological and psychological changes that account for the changes in behaviour and functional ability.

Although the term "role reversal" is not accurate in this instance, there does exist some dramatic changes in the dependency/interdependency/independence relationship between

adult children and their elderly parents. Greene (1989) stated that " . . . a primary issue with which therapists working with the aged and their families must deal centres around the theme of dependence-independence" (p. 64). Resolution usually involves realistic acceptance of limitations as well as strengths by the elder, thus allowing oneself to be dependent when appropriate. For the adult child, he/she must be accepting of some responsibility, while at the same time, able to realize one's limitations.

In a study of personal autonomy within the context of family caregiving relationships, Horowitz, Silverstone and Reinhardt (1991) found that the major barriers to autonomy in later life stemmed from mental or physical disabilities. The elderly want to remain as independent as possible, on the whole, and generally adult children respect their autonomy, except when deteriorating health puts the elder at risk by exercising his/her autonomy. Further, this study viewed the provision of support services by family members (transportation, advocacy with formal care system) as enhancing the elder's autonomy.

There usually exists an exchange of services between the elderly and their children. Children provide personal care, assistance with financial management, emotional support, housekeeping, laundry, meal preparation, administering medication and transportation. In return, elderly provide financial assistance to their children, child care (if able)

and housing in some cases. As the elder deteriorates physically and mentally, the balance is weighted in terms of demands or dependency needs of the elder. Berman (1987) concluded that

older people . . . are at a great disadvantage in terms of exchange. They have little to exchange and the less they have to exchange, the more powerless they become (p.29).

It is interesting, however, that the recent research in the area of elder abuse suggests a different set of interactions where abuse is present within the adult child-elderly parent relationship. Pillemer and Finkelhor (1989), in a review of studies on elder abuse, concluded that most adult child perpetrators of abuse were dependent on their victim for financial resources, and for housing. These authors explained that these dependent adult children felt powerless, and compensated for their perceived lack of power by abusing the elder. Of course, this explanation is oversimplified as a number of other contributing factors trigger the abuse, but the reverse dependency issue was relevant to this discussion. Although it was beyond the scope of this report to delve into the dynamics of elder abuse in detail, it is interesting to note that dependency is a mutual, and very complex phenomenon.

Talbott (1990) found in her study of elderly widows that the widows feared becoming a "burden" to their children. This author related this fear to feeling unappreciated by their children and feeling emotionally dependent upon their

children for support, encouragement, and as confidantes:

Feelings of emotional dependence, if they are not mutual, produce a power imbalance in a relationship. Mothers who feel they need their relationships with their children more than the children need them worry about annoying or displeasing their children, make concessions to their children, and settle for what they can get from their children (pp.599-600).

The emotional dependence often resulted from the multiple losses (vision, mobility, memory, loss of home, death of peers) that the elderly experience.

Lewis and Meredith (1988) found in their study of caregiving daughters and elderly mothers, that problems within the intergenerational relationship usually arose out of a power imbalance, where one person was overdependent, dominant or manipulative. Relationships were mutually supportive if both daughter and mother gained from the relationship and valued the contributions and competencies of the other.

The elder sometimes uses guilt to increase their power in the relationship with their adult children or conversely, they may become compliant if they feel powerless to utilize any alternative strategy (Berman, 1987). Compliance was found to be particularly prevalent in cases of elder abuse and neglect.

What prompts adult children to take on caregiving responsibility often at substantial cost to their own well-being? Selig, Tomlinson and Hickey (1991) provided the following explanation:

It is well recognized that feelings of filial obligation affect an adult child's decision to

take on the care of an aged parent, and that strength of these feelings also has an impact on the caregiver's perceived level of stress, burden and role conflict (p. 625).

In intervening with family caregivers, the therapist can accept the perceived obligation as a given and devise strategies to decrease the stress associated with that obligation (such as respite care and acceptance of other formal services). The therapist can, as an alternative, help the caregiver explore the basis for their feelings of obligation and to adjust their expectations of self. Caregivers often need to be given "permission" to expect less of themselves (Selig, Tomlinson & Hickey, 1991). Unrealistic self-expectations is a phenomenon particularly critical for women due to the strong socialization norms directing women into caregiving roles.

These same authors described three views about the basis for filial obligation. Some caregivers follow the moral precept "Honour Thy Father and Thy Mother" which has a long history as a traditional Christian ethic. However, in reviewing history, many families in pre-industrial England did not necessarily care for elderly parents, or if they did, the burden of care was possibly not as great as life expectancy was shorter and many older people died of acute, rather than chronic illnesses. Making caregivers aware of these factors may decrease their unrealistic sense of obligation and alleviate their sense of guilt.

Secondly, some adult children feel indebted to their

parents for the love and assistance associated with raising them as children. Again, it can be clarified that the love of a parent for their children cannot be repaid in full.

Thirdly, another motive for filial obligation arises as an expression of love and friendship on the part of the adult child. Selig, Tomlinson and Hickey (1991) suggested that the elder can relieve unrealistic feelings of obligation by clarifying what their expectations are of their children in an interaction guided by the therapist. Most elderly people do not expect such an extent of sacrifice on the part of their children; in fact, they often express their fear of becoming a "burden" to their children.

As a result of experiencing both feelings of obligation, as well as love and affection, Lewis and Meredith (1988) found caregiving daughters held a great deal of ambivalence toward their elderly mothers and the changes in their relationship with that person, which relates to the physical and/or cognitive changes associated with the aging process.

THE ROLE OF POLICY: PUBLIC VS. PRIVATE

A Feminist analysis of caring as a women's issue encompasses policy analysis at both a societal and personal level. A number of authors have explored "caring labour" and provide a useful framework in which to examine this issue.

Pascall's (1986) "Caring Labour Theory" makes connections between micro and macro-level policies and practices: the personal becomes political, the private, public. Pascall

explored the meaning of caring in women's lives, but also made explicit the exploitation women experience as carers where their labour remains largely unpaid and unrecognized. Further, Baines, Evans and Neysmith (1992) asserted that "an appreciation of the centrality of caring in women's lives focuses attention on social relations and, in so doing, challenges social work's traditional separation of the micro and macro perspectives" (p.35).

By maintaining "caring labour" in the private sphere, the state in effect supports a gender-based division of labour and reinforces women in marginalized economic positions.

The division of labour in the public sector or social policy rests on the broad base of caring by women at home. The care of dependents is a relationship and a labour involving women and taking place largely in the domestic sector. Contrasting the private world of home and family with the public world of paid work and 'economic activity', it is possible to show how social policies have manipulated the boundaries between private and public . . . However incoherent 'family' policy may seem in certain respects, there is some consistency in social policy's tendency to preserve--at considerable cost to many of the very old, the very young, and the very handicapped--women's availability and readiness to care for family members within the family, without pay. Such preservation results in keeping women dependent in the family and weak in the public sphere (Pascall, 1986, p.102).

Finch and Groves (1980) viewed policies around "community care" as a justification for decreased state support, resulting in increased informal support. Whereas institutional care requires extensive "formal" resources

within the public sphere, community care allows for a reduction of state input under the pretence of providing a healthier, more independent environment for care recipients. The family thus becomes the first line of defense. These assumptions are quite explicitly stated by the government in the Philosophy Statement for the Continuing Care Programme, Province of Manitoba:

Individuals progress towards and remain in a state of high level wellness in the familiar environment of their own home. It is preferable for individuals to remain at home to the extent that needed resources can be made available. Care in a facility is appropriate where resources of person, family, community and program cannot sustain an individual in the home. (Policy Guidelines, Continuing Care)

The Continuing Care programme has a policy that governs eligibility for the programme based upon the availability of a primary caregiver (family, friend, neighbour, or possibly a professional) in the immediate area of the care recipient who can act as a "back up" in case the care plan breaks down for some reason or paid workers are unable to provide the care. A primary caregiver also may take on responsibility for decisions regarding client's care should a client be unable to make those decisions him/herself. The implications of such a policy often means that the elderly who most need the care of the state, those who have no family or friends, are not eligible for the services.

Furthermore, the Policy Guidelines state that services in the community are not to exceed the cost of institutional

care, except in certain situations of a short-term nature. These circumstances include: 1) while awaiting placement in a Personal Care Home, 2) the temporary absence of a primary caregiver, and 3) in the case of a terminal illness (Policy Guidelines, Continuing Care).

For the purpose of this study, my sample selection targeted caregivers whose care recipients are currently receiving the formal care services offered by Continuing Care so as to gain further insight into the benefits and limitations of the formal care system and its effect upon informal support provided by family members.

Within the group setting, we discussed the split between formal and informal care, and its impact on the lives of caregivers. We spent some time also looking towards alternatives for a more equitable sharing of care responsibilities, to lessen the burden of responsibility currently on informal family caregivers, and to recognize the contributions these women are making in their role as caregivers.

Baines, Evans and Neysmith (1992) concluded that:

Caring must be viewed as a source of both women's oppression and women's strengths. Although feminists recognize how women have been vulnerable to exploitation, social work practitioners must also pay attention to the ways in which women clients have learned to be flexible and creative in dealing with life's contingencies. A feminist perspective in social work practice reframes many of the deficits attributed to women clients as strengths (p.34).

CAREGIVER BURDEN:

There exists a good deal of literature on the factors contributing to caregiver stress and subsequent feelings of burden, much of which has focused upon caregivers of dementia patients. Ory et al. (1985) defined burden as "the impact of the changes in cognition and behaviour of the Alzheimer patient on the family, and the patient's subsequent need for care and supervision" (p. 623). Burden appears to be quite a subjective reaction: various studies found that feelings of burden are related to the caregiver's perception that his/her life has been negatively affected by the caregiving task (Novak & Guest, 1989a; Ory et al., 1985; Zarit, Todd & Zarit, 1986). Further, Novak and Guest (1989a) found no significant correlation between feelings of burden and length of time that caregiving had been ongoing. They found a significant, moderate correlation ($r=0.38$, $p<0.05$) between caregiver burden and the functional status of the care recipient. However, Novak and Guest concluded that subjective feelings and needs were the best predictors of feelings of burden.

For the purpose of this study, the author chose to measure burden through application of a self-anchored scale developed by Novak and Guest (1989), the Caregiver Burden Inventory (CBI). However, in keeping with the subjective nature of perceptions of strain and burden, qualitative data gathered through the interview process supplemented the data gathered through administration of the CBI.

SELF-EFFICACY:

The concept of self-efficacy was explored in detail by Albert Bandura in his numerous studies on the topic. Bandura (1982) described self-efficacy theory as based upon the assumption that all processes of psychological and behavioural change operate through change in an individual's sense of personal mastery or efficacy. Self-efficacy is composed of three major tenets: 1) self-efficacy expectancies--beliefs about one's ability to execute certain specified behaviours, 2) outcome expectancies--beliefs concerning the probability that this specific course of action will lead to certain outcomes, and 3) outcome value--the subjective value placed on certain outcomes (Maddux, Stanley, & Manning, 1987). Self-efficacy expectancy has been demonstrated to be a good predictor of behaviour in a variety of studies and are derived from four major sources: performance experiences, vicarious experiences, verbal persuasion and emotional or psychological arousal (Maddux, Stanley, & Manning, 1987).

A relevant example of research data to this study is the relationship between self-efficacy and depression. Bandura (1982) found that depression is predicted under conditions of high outcome value, high outcome expectancy and low self-efficacy expectations. When people believe strongly in the value of certain desired behaviours (high outcome value) and that these behaviours are attainable through certain

behaviours (high outcome expectancy), but believe that they are incapable of performing that behaviour due to lack of skills, confidence (low self-efficacy expectations), then they will display a lack of motivation, self-devaluation and depression.

In this study of women caregivers, this author attempted to identify behaviours (eg. acting in an assertive fashion) which were important to achieve certain desired outcomes (eg. reduction of stress), and to assist participants in increasing their perceived ability to achieve these desired behaviours (increase self-efficacy expectancies). The concept is closely tied to that of empowerment which this author has defined as the process of realizing one's personal power to make choices, and respond to situations based upon a sense of our own needs, values and goals.

The group process assisted members in identifying which skills they needed to actualize their sense of personal power and sense of mastery. The variable of self-efficacy was measured through the use of the Self-Efficacy Scale developed by Sherer et. al (1982), as well as through group and individual progress reports.

SOCIAL NETWORKS:

The literature in the area of social networks and their importance in terms of provision of support is vast. For the purpose of this practicum, the aspect most pertinent is the buffering effect of social support against stress. In a

review of the literature, Hobfall (1986) found that a number of studies which concluded that social support had a positive effect upon mental and physical health. Further, Hobfall (1986) summarized that

women are more sensitive than men to social interactions, they develop closer and more extensive social networks, and are more giving in these relationships (p.6).

Women's need for social support in coping with life stressors is well documented by Feminist writers, and is often seen as a strength of women's therapy groups, in decreasing women's isolation. (Butler & Wintram, 1991; Hartman, 1987).

Various researchers have found that, although women are more apt to seek help than men, they also give support to others more often than they receive it in return (Abel, 1991).

The research on the development of social support within the context of caregiver groups has produced mixed results (Goodman, 1991). Goodman (1991) found that some members of caregiver groups developed relationships within the group which became part of their informal helping network, but that many of the relationships were limited to the group context.

One objective of the Women's Caregiver Group in this practicum was to increase social support for women participants. The facilitator hoped that mutual support provided to members within the group context would translate into members seeking support from their own social networks, and that members would expand their networks in order to meet their need for support. It was also the aspiration of the

facilitator that some relationships developed within the group might be sustained by members.

The changes in the social networks and perceived support received was measured on a pre/post basis using the Lubben Social Network Scale (LSNS), as well as qualitative data.

THE USE OF A GROUP FORMAT:

For the purpose of this study, this author chose to utilize a group format as the most appropriate form of intervention to meet stated objectives and attain treatment goals. The group had a dual purpose which included a social action component to its content, consistent with the feminist techniques of analysis and empowerment, as well as a focus on treatment. Toseland and Rivas (1984) defined treatment groups as meeting members' socioemotional needs through open communication, high self-disclosure, high levels of interaction within a group of people with common concerns. Within this typology, this Caregiver Support Group can be further categorized as a "growth group", providing "a supportive atmosphere for individual members to gain insights, experiment with new behaviours, get feedback and grow as human beings" (Toseland & Rivas, 1984, p.23).

The use of a group format for counselling women was consistent with the feminist approach to practice which emphasizes the importance of support amongst women to reduce their alienation and to raise their consciousness about the oppressive nature of patriarchal society and its institutions.

Schubert Walker (1987) expanded on the value of groups for women:

Groups provide a unique opportunity for participants to assess themselves, validate their experiences and perceptions, attempt personal, behavioral, and attitudinal changes, express feelings, and receive feedback . . . Therapy groups for women eliminate the unconscious sexism that is present in mixed groups and provide a supportive environment in which participants can discover and experience the commonalities of being a woman (p.3).

One important component of the group's purpose was to empower participants. Smith and Siegel (1985) define "empowerment" as

helping women to gain awareness of power they already have but have not recognized as such (p.13).

Butler and Wintram (1991) define "feminist groupwork" as

enabling women to meet and identify both their common and their diverse dissatisfactions and needs and to translate these into wants. The group process facilitates the exploration of ways in which these wants can be met (p.17).

The intention of the group was not only to raise the participants' awareness of the oppressive nature of the gender division of labour and the societal forces that support this division, but to realize the internal and external resources available, both individually and collectively, to make changes in their lives, and to explore alternatives to the current system of care provision.

SUMMARY:

In conclusion, much of this review of relevant literature has focused upon the writings of Feminists researchers and it is evident that the Feminist Perspective has a great deal to

contribute to the study of women as caregivers.

Reinharz (1992) provides the following definition of "feminist research", which by its broad nature, appropriately describes the approach utilized in this practicum:

1. Feminist research methods are methods used in research projects by people who identify themselves as feminist or as part of the women's movement.
2. Feminist research methods are methods used in research published in journals that publish only feminist research, or in books that identify themselves as such.
3. Feminist research methods are methods used in research that has received awards from organizations that give awards to people who do feminist research. (p.6)

As a result, the author chose to utilize a Feminist Perspective as a framework for analysis of the issue of women caregivers. The intent of this review was to outline important variables relevant to the study; these variables will be further defined within the conceptual framework in the following chapter.

CHAPTER II -- FRAMEWORK FOR INTERVENTION

This chapter focuses upon structuring a framework for research inquiry and for group intervention. The research question and conceptual framework which follow form the basis for the study's methodology, both in terms of its research and practical components.

RESEARCH QUESTION:

This study has addressed and attempted to answer this research question:

Is short-term group counselling based upon a feminist perspective an effective intervention in assisting women caregivers in reducing feelings of burden, increasing feelings of self-efficacy and social support, thus improving their ability to cope as caregivers?

The measurements and data analysis which need to be completed in order to answer this question are outlined in the section which follows. The conceptual framework provides some parameters in which to organize the variables which relate to the question under study in this practicum.

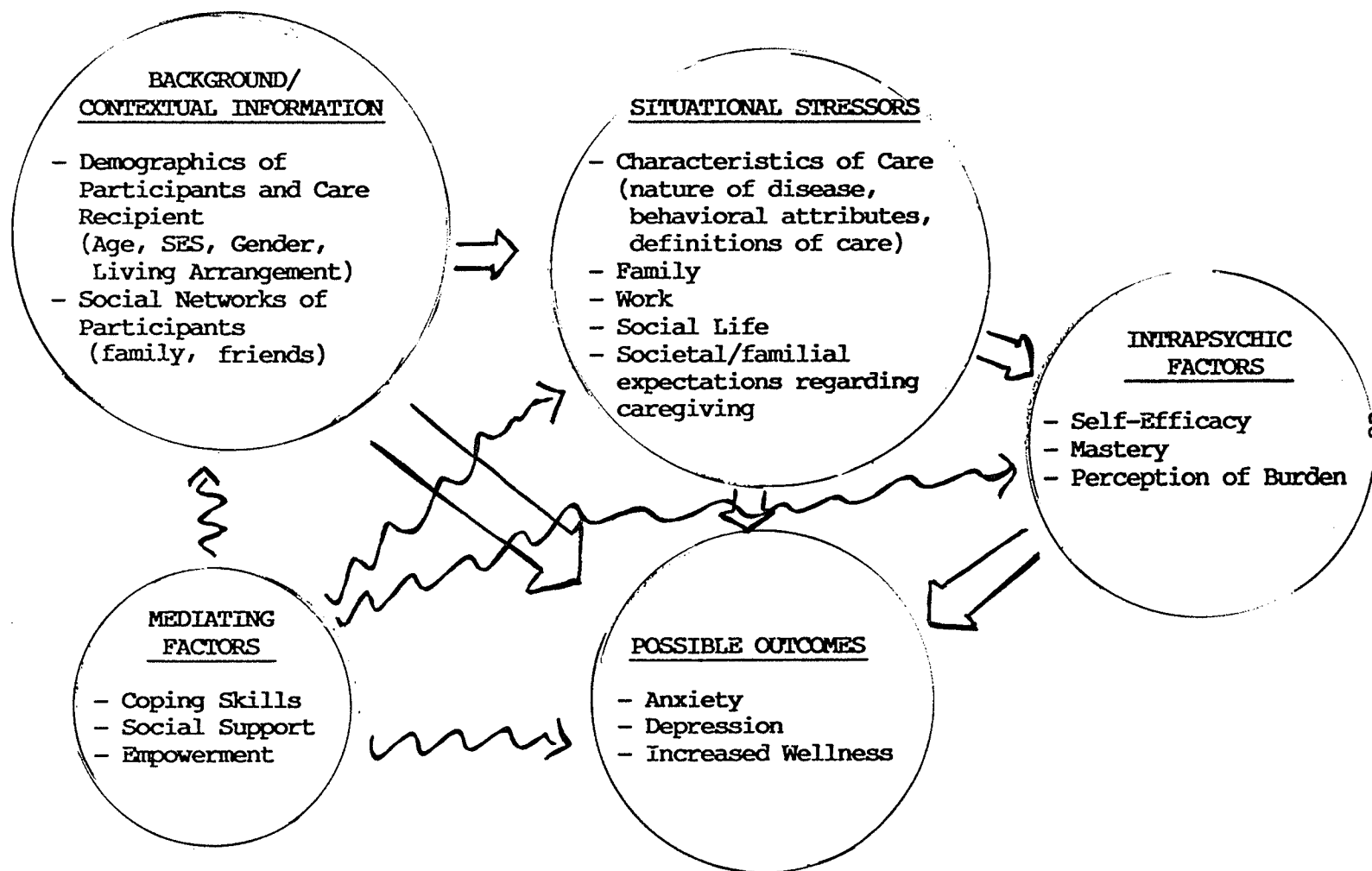
CONCEPTUAL FRAMEWORK:

As the contributing factors to the stressors and possible outcomes for caregivers are both numerous and complex, this author chose to utilize a modified version of a framework developed by Pearlin, Mullan, Semple and Skaff in 1990. This conceptual model was originally developed from a sample of caregivers whose care recipient was a victim of Alzheimer's Disease. However, from this author's experience, many of the variables influencing the caregiving experience are similar

for caregivers of elderly persons with other diseases or disorders. As this study is based upon a feminist perspective, the societal context in which women are expected to provide care must be examined further; thus, the author made some additions to the framework including the analysis of societal expectations of women with respect to the gender division of labour and its perpetuation in the policies of the formal care system.

The conceptual framework can be divided into different clusters, each describing a different phenomenon or contributing factor in the caregiving process. These broad categories include the "Contextual Information", the "Situational Stressors", the "Intrapsychic Processes", the "Mediating Factors" and the "Possible Outcomes". Specific variables to be studied in this practicum fall under these broad categories. The diagram represented on the next page will serve to clarify the interaction of these categories and the variables within them. Furthermore, specific operationalized definitions of the variables will follow Figure 2.1 (p.33).

Figure 2.1 CONCEPTUAL FRAMEWORK



DEFINITION OF VARIABLES:

The following section attempts to provide operationalized definitions of the variables found within the conceptual framework in order to clarify how they will be measured within the context of this study.

Independent Variables:

1. Demographic characteristics of participant and care recipient

- Age

- Gender

- Socioeconomic Status: this variable will be measured by questions with respect to income bracket (upper, middle, lower income), education level and occupation.

- Living arrangements: does the caregiver live with care recipient, if so, whose home?

2. Characteristics of Care

- Characteristics of the disease or condition of care recipient and its behavioural manifestations.

- Amount of care required: this variable will be operationalized by Meredith and Lewis' (1988) definitions of care. Full care is described as the care recipient requiring extensive personal care, to the point where he/she cannot be left alone without a substitute carer. Semi-care is described as the period where the care recipient should not be left alone for extended periods of time, but little or no personal care is required. Part-time full care is defined as a

situation whereby the care recipient requires full care, but the caregiver provides the care in addition to other work and family commitments. Questions will focus upon caregiver's perception of their caregiving responsibilities and the amount of stress or burden they experience as a result.

3. Possible Sources of Stress

-Family: changes in interpersonal relationships between caregiver and care recipient, conflict vs. support between primary caregiver and other siblings, conflicting demands from caregiver's own family responsibilities, as described by participants.

-Work: Possible conflicts between demands of caregiving and demands of job or career, how flexible is the workplace, one's colleagues, one's employer, as described by participants.

-Social life: effect caregiving has upon caregiver's ability to take time for herself, maintain social contacts. Do social commitments place additional strain upon the caregiver rather than being a welcome diversion?

-Societal expectations and the response of the formal care system: what is the participant's perceptions of society's/community's expectations regarding provision of care to the elderly? Do they find the formal care system helpful, in what way, and where could they see improvements?

Dependent Variables:

1. Social Network of Participant

-Family network composition and perception of support: questions will focus upon who is in the family and the participant's perception of how supportive they are in terms of provision of care to the care recipient.

-Friendship network composition and support: questions will focus upon who are the participant's friends and can she gain emotional and/or practical support from these friends.

-In addition to qualitative data, changes in social network composition was measured by the Lubben Social Network Scale (LSNS).

2. Intrapsychic Factors

-Self-Efficacy: this variable is measured by participants' perception of their ability to master certain behaviours, their own competence to cope and effect the change they strive for. Changes in self-efficacy will be measured pre/post group by the Self-Efficacy Scale (SES), as well as selected questions in the pre/post interviews.

-Perception of Burden: this variable is measured by participants' perception of the stress or negative consequences that the caregiving has upon their lives. Changes in perception of burden will be measured pre/post group by the Caregiver Burden Inventory (CBI), as well as qualitative data through interviews.

3. Possible Outcomes

-Anxiety: the participant's perception of their fears, or psychological dis-ease associated with caregiving.

-Depression: the participant's self-report on whether they feel despondent, and to what extent, as a result of caregiving.

-Increased Wellness: the participant's self-evaluation of changes in their overall health, physically, mentally, and emotionally.

Mediating Factors

-Coping ability: the participant's perception of their skills for coping with stress, ability to solve problems and cope with the emotional aspects of caregiving.

-Social support: the participant's perception of the nature and quality of support gained from their networks. The buffering effect of social support serves as a mediating factor in coping.

-Empowerment: the process of realizing one's personal power to make choices, and respond to situations based upon a sense of our needs, values, and goals. Development of a sense of empowerment will be assessed by participant's report post-group.

CHAPTER III -- METHODOLOGY

The overall purpose of this practicum study, as stated in the Objectives section of this report was to design, implement and evaluate the effectiveness of a short-term Caregiver Support Group targeted at daughters and daughters-in-law caring for elderly parents in its ability to meet their needs in terms of assisting in the reduction of feelings of burden, building social support networks and increasing subjective feelings of self-efficacy, as related to coping with caregiving demands.

As related to the overall purpose of the study, the following more specific intervention objectives were set as guidelines for the evaluation of the intervention:

The group:

- 1) Attempted to lessen the subjective perception of burden and stress experienced by women caregivers who are participating in the study through mutual support, sharing of emotional experiences and development of internal and external resources.
- 2) Strove to empower women participants to cope more effectively and increase their sense of self-efficacy through problem-solving, assertiveness-training, and stress management techniques.
- 3) Began to raise the level of awareness of women participants about the oppressive nature of the gender division of labour sanctioned by the state through a feminist analysis of the issues.
- 4) Explored alternatives for change in the private and public spheres based upon a vision of a more egalitarian division of caring responsibility.

Based upon the literature review and her own professional knowledge base, the author proposed the following hypothesis:

that the differences found between participants in the areas of amount of perceived burden, changes in feelings of self-efficacy and social support, are related to the "stage" of caregiving, as defined by Lewis and Meredith's (1988) definitions of care, as well as to individual differences.

This study attempted to meet the above objectives through the use of a group intervention as described in the following section.

GROUP FORMAT:

Group interventions have been reported to be an effective manner in which to counsel caregivers. The mutual support that develops in a group (high levels of rapport, cohesiveness, and trust) makes personal disclosures around feelings and experiences possible. As well, there is a reduction of isolation as the participants share similar feelings and experiences (Toseland & Rossiter, 1989). However, Toseland and Rossiter (1989), in a review of effectiveness of caregiver support groups, suggested that composition of the groups should be targeted for spouses or adult children, as well as by gender, as there were significant differences between these groups of caregivers.

The author bases her approach to groupwork practice on the Feminist Perspective, while also utilizing concepts from ecological practice, family systems theory, and cognitive restructuring. Some unique characteristics of feminist groupwork include recognition of issues of primary importance

to women: women's isolation and invisibility within the societal context, the oppression of women within the patriarchy, and the psychological effects of that oppression, as well as the need to empower women to become aware of the oppression and their personal power (Butler & Wintram, 1991).

In women's groups, the facilitator needs to be acutely aware of the relationships between women participants and between the facilitator and the women in the group. There is a power differential between facilitator and members, but feminist groupwork recognizes this fact, and makes attempts to minimize these differences by recognizing the women as their own experts and validating their experiences. Schubert Walker (1987) reported on the advantages of female therapists treating women:

Female therapists are more sensitive to the issues facing women, are better able to empathize with feelings, provide a positive role identification model, and may be able to facilitate the resolution of role conflicts by using their own experiences (p.7).

Feminist writer Schubert Walker (1987) described the process of group development in women's groups as having four stages: 1) "opening up"--the revelation of inner feelings and experiences, 2) "sharing"--the recognition of commonalities amongst group members, 3) "analyzing" --the combination of subjective feeling and thinking objectively to analyze the position of women in society, and 4) "abstracting"--the examination of existing institutions and possible changes to the status quo.

Toseland and Rivas (1984) provided a more traditional and yet useful framework for understanding group development which they divided into four main stages: the planning phase, the beginning phase, the middle phase and the ending phase. This author chose to incorporate this framework into a feminist approach to groupwork.

The Planning Phase included establishing the purpose of the group, recruiting members, composing the group, orienting members to the group, contracting, and preparing the group's environment.

In composing a treatment group, these authors suggested that members should have common concerns and goals, but can be heterogeneous in their coping abilities, life experiences, and learning. Small groups generally range from 5-8 members, and a closed membership promotes enhanced cohesion and mutual sharing amongst members.

The initial group meeting involves discussing the purpose of the group, contracting with respect to ground rules for the group and setting group goals.

The Middle Phase involves the preparation, structuring and evaluating of group process. In planning group sessions, the facilitator creates a plan of weekly topics and structures, to a certain degree, the process of group interaction. In the context of the Women Caregivers Support Group, the weekly agenda involved a round-table sharing as an ice-breaker, followed by a mini-lecture, and an open group

discussion of the topic. The group facilitator also assisted members in meeting their goals through enabling, brokering, mediating, advocating, and educating. Toseland and Rivas (1984) suggest that intrapersonal intervention in a treatment group should utilize cognitive restructuring, thought stopping, reframing, and relaxation techniques such as creative visualization and progressive relaxation to assist members in changing thoughts, beliefs, and feelings about life's stressors. Environmental interventions focus upon connecting members with resources, expanding members' social networks and creating a positive group climate.

The Ending Phase focuses upon both a formal written and informal verbal evaluation of the group in terms of participants' learning, meeting stated goals, and looking toward the future.

The group was a small group, composed of five participants initially and was closed to new referrals after the initial interviews were completed. Potential candidates for the group were interviewed for the purpose of sample selection and to gain in-depth case study data prior to the initial group session. Where the candidate was agreeable to partake in the group and appropriately met stated criteria, she then became a group member.

The group had a dual purpose including a social action focus consistent with the feminist techniques of analysis and empowerment, as well as a focus on treatment. As outlined in

the "literature review" section of this proposal, the group was characterized as a "growth group", providing mutual support, sharing experiencing, gaining insight into behaviours and actions of self and others, raising the consciousness of women to their common experience as caregivers.

The group was composed of eight sessions, which is a common time frame for short-term group interventions, according to Toseland and Rossiter's (1989) review of groups for caregivers. The intervention also included pre and post group individual interviews to provide additional background and contextual information. In addition to enriching the data base, these interviews were used to evaluate the effectiveness of the group as described further in the evaluation section.

GROUP EVALUATION:

The process evaluation of group sessions coincided with the overall data collection and methodology of the study. In this case, the variables to be measured, both qualitatively and quantitatively included perception of burden associated with caregiving, amount of social support, and feelings of self-efficacy and mastery.

The quantitative measures were performed on a pre/post basis with the use of standardized scales. The qualitative data was gathered through the in-depth interviews conducted pre and post, as well as the group process evaluation.

The practitioner wrote a progress report for each group session to note changes in the group's climate, leadership,

cohesiveness, and goal achievement, as well as other clinical observations. Videotaping sessions allowed for detailed evaluation of sessions wherein the practitioner noted changes in members' behaviours and verbalizations which relate to the variables being measured. For instance, members may have discussed changes in the way they cope with stress, or how helpful they found the group in terms of providing mutual support. The worker noted increasing interaction and cohesiveness between group members such as contacting one another between group sessions, discussions over coffee, making plans for continued contact after the group ended.

The worker allowed time at the end of each session for evaluation and feedback from members about the helpfulness and effectiveness of the intervention within that session. The Client Satisfaction Questionnaire (CSQ) by Attkisson et al. (1989) was administered in the termination session to evaluate the overall effectiveness of the group.

The section which follows outlines the purpose, goals, ground rules, and agenda for the eight-week duration of the group.

PURPOSE OF THE GROUP:

The overall purpose of the Women Caregivers Support Group was to empower participants to cope more effectively with caregiving demands through a variety of techniques, including providing mutual support, problem-solving skills, assertiveness-training, stress management skills, emotional

validation, and information about community resources.

Through these interventions, the aim of the group was to assist in reducing subjective burden, in developing social support and in increasing feelings of self-efficacy.

GROUP GOALS: (to be shared with group and modified with input)

1. To provide a safe environment in which women caregivers can share common experiences and feelings, as well as gain support and validation.
2. To provide education regarding self-care (stress management, assertiveness-training, problem-solving) and community resources.
3. To utilize cognitive restructuring techniques to assist in changing possible negative outcomes such as depression and anxiety.
4. To assist participants in making changes in their own networks and in the larger systems context to gain further support and recognition for their caring labour.
5. To form the basis for future advocacy and expansion of support services, both formal and informal.

GROUND RULES OF GROUP:

1. All discussions within the group are kept confidential in order to respect the privacy of participants.
2. All members have the right to express themselves and to be heard by the group.
3. Feelings or opinions expressed by members are respected and accepted.
4. Decision-making is done as a group.
5. Members are expected to bring up concerns to the group so that they can be dealt with.
6. If a member should be unable to attend a session, or continue with the group, she agrees to notify the group facilitator.

OUTLINE OF GROUP SESSIONS:

Session #1

Introduction of Group and Members

- Introduce facilitator
- Review purpose and goals of group
- Solicit input from members
(what they hope to achieve)
- Review ground rules
- Have members introduce themselves and "tell their story"

Session #2

- Sharing of issues with group members

Topic for Discussion-- "The Aging Process and Stresses Associated with Caregiving"

- Mini-lecture on interpreting what is normal and what's not/Fact Sheet on Aging and Retirement

-Stressors Associated with Caregiving/ Changing roles/characteristics and behaviours associated with diseases (ie. dementia)/burden, stress associated with daily care, competing demands.

- Group discussion

- Session Evaluation

Session # 3

- Sharing of issues with group

Topic for Discussion-- "Self Care and Stress Management"

- Mini-lecture on assertiveness-training, problem-solving skills, self-esteem, self-efficacy, relaxation/ "time out"/ balancing work and leisure time

- Group Discussion

- Session Evaluation

Session #4

- Sharing of issues with group

Topic for Discussion-- "Emotional Responses to Caregiving"

- Mini-lecture on losses associated with aging parents/ how to

cope with feelings of anger, guilt, frustration/family dynamics--abuse and neglect/factors contributing to depression and anxiety.

-Group Discussion

-Session Evaluation

Session #5

-Sharing of issues with group

Topic for Discussion-- "Women as Caregivers"

-Mini-lecture on gender division of labour/is caring labour recognized?/looking towards a more equitable sharing of caregiving responsibility between family members.

-Group Discussion

-Session Evaluation

Session # 6

-Sharing of issues with group

Topic for Discussion--"Formal and Informal Care"

-Mini-lecture on what resources currently exist and are they adequate/is the state contributing enough?/a vision of shared care

-Group Discussion

-Session Evaluation

Session #7

-Sharing of issues with group

Topic for Discussion-- "New Ways of Coping and Achieving Increased Wellness"

-what has the group learned?/review stress management techniques/sharing of care--does it work?

-Group Discussion

-Session Evaluation

Session #8

-Sharing of issues with group

Closure of Group

-verbal evaluations

-written evaluations

-follow-up procedures

-Looking toward the future (follow-up meeting?/ advocacy re. issues of concern to women caregivers)

-Wind-up with coffee and dessert at restaurant

SOURCE OF REFERRALS:

Referrals were made through the Continuing Care Programme in Portage la Prairie. Case co-ordinators agreed to identify potential clients who were family members of recipients of the services of this programme on the basis of the above criteria. As the focus was upon families currently receiving formal services through Continuing Care, open cases were surveyed for potential clients. The case co-ordinators contacted potential clients and requested permission to release their name to myself for the practicum. As well, a notice outlining the selection criteria was forwarded to the Alzheimer's Society of Manitoba whose staff agreed to include this notice in packages of information from the Society requested by appropriate individuals from the stated catchment area.

The initial referral list consisted of twelve names of potential candidates, all of which had been identified through Continuing Care as no response came through the Alzheimer's Society. I began by writing a letter of introduction which explained the scope and purpose of the practicum. Approximately one week later, I contacted each individual by

telephone to determine their interest in the group. Of the twelve individuals, six women were recruited for the pre-group interviews.

Pre-group interviews were scheduled within the last two weeks of April, the purpose of which was to pre-screen candidates for suitability, to gather contextual and baseline information, and to further discuss the potential benefits of the group process. All six women interviewed were suitable for the group. Just prior to the first session, however, I received notification from one candidate that she would be unable to attend due to her husband's very poor health. Another women, Sarah, did attend the first session, but was unable to continue due to a time conflict with her regularly scheduled leisure activity. Therefore, the group stabilized at a rather small, yet cosy number of four women.

SAMPLE SELECTION CRITERIA:

The following are the criteria which delineated the sample for this study:

1. Subjects are to be female adult children caregivers (daughters, daughters-in-law) of elderly parents experiencing physical and/or cognitive impairment.
2. Their care recipients are to be receiving the services of the Continuing Care programme.
3. Residence within the City and Rural Municipality of Portage la Prairie, Manitoba.
4. Subjects are to be primary caregivers of the elder.

5. Subjects should be able to speak and understand English.
6. There should be no apparent major psychiatric or social problems with the client.

SETTING:

The setting was within the Manitoba Health office space in Portage la Prairie as access to space with videotaping facilities limited use of other community space. This office space was most appropriate as it was confidential and had facilities for disabled persons.

DATA COLLECTION:

Data collection involved both qualitative and quantitative techniques, as described more extensively in the "evaluation" section of this report. Pre/post in-depth interviews with participants gathered important descriptive data in a case study format. Many of the variables studied around the issue of caregiving could not be measured by quantitative methods, and thus, questions in the interview format attempted to gain information around type of care provided, the burden and stress of the caregiving process, characteristics of the caregiving situation which factor into the coping abilities of the caregiver. As well, possible outcomes experienced by the caregiver in coping with caregiver stress may well be more accurately measured by self-report and practitioner assessment. For instance, depression scales, in this author's clinical experience, are often biased by respondents and thus, do not measure depression in a valid

manner. These scales can also be quite obtrusive and do not contribute to the therapeutic relationship. In clinical research, the gathering of data should not override the importance of providing treatment.

Data collection also took the form of some quantitative measures of burden, self-efficacy and social support networks. These self-anchored scales are described in greater detail in the "evaluation" section which follows.

Finally, the group sessions were videotaped and analyzed both for the purpose of data collection and for clinical supervision. A record of practitioner observations of group development, as well as individual treatment progress reports, also provided additional data.

EVALUATION:

The evaluation section outlines in greater detail the variables and methods of evaluation. To reiterate, the basic question that should have been answered by this study is as follows:

Is short-term group counselling based upon a feminist perspective an effective intervention in assisting women caregivers in reducing feelings of burden and increasing feelings of self-efficacy, as well as social support, thus improving caregiver coping?

The research methodology utilized in this practicum combined both qualitative and quantitative evaluation methods. Qualitative evaluation was defined as:

Qualitative approaches may seek to comprehend subjectivity through 'indwelling' or the empathic understanding of another's experience. The observer projects him or herself into the life of the other in order to appreciate what that individual is expressing (Neimeyer & Resnikoff, 1982, p.77).

Quantitative research attaches numerical components of frequency, magnitude and duration to human behaviour, thus providing insight into the causes and correlates of behavioural phenomenon (Neimeyer & Resnikoff, 1982).

Combining aspects of both research methodologies is referred to as "triangulation". Triangulation between research methods "allows one type of data to *elaborate* the findings of the other. Elaboration provides richness and detail" (Rossman & Wilson, 1985, p.632).

Jick (1979) described the benefits of using triangulation as: increasing confidence of results, assisting in an integration of theories, and providing a context in which the behaviour can be understood. Patton (1990) stated that methods triangulation through use of both qualitative and quantitative data derived from different research methods is a form of comparative analysis which strengthens reliability of data obtained.

In this study, the qualitative data was gathered from in-depth interviews conducted pre and post group, as well as observations and data gathered about individuals in the group process. This data was compiled in the form of comparative case studies. Although the case study has been criticized as

lacking in validity, various authors have countered that the use of triangulation can increase internal validity, and that we can generalize (external validity) more confidently if the findings apply to a number of cases (Stoecker, 1991).

The quantitative data gathered in this study was derived from the use of several scales including:

- 1) Caregiver Burden Inventory (CBI) (Novak & Guest, 1989)
- 2) Self-Efficacy Scale (SES) (Sherer, Maddux, et al, 1982)
- 3) Lubben Social Network Scale (LSNS) (Lubben, 1988)

These scales were administered to group participants on a pre/post test basis--the basic "AB" model of Single System Evaluation. Measurement before the intervention was introduced provides a baseline and the "post" measurement provides data on any changes that may have occurred. Attributing these changes to the intervention may not be accurate due to threats to internal validity as we are not able to control all alternative explanations for the change. However, the qualitative data gathered through interviews and observations of group members served to strengthen the validity of the findings as contextual information was available for evaluation.

THE SCALES:

The following were the self-anchored, standardized scales used in this practicum:

1) CAREGIVER BURDEN INVENTORY

This standardized, empirical measure was developed by Dr.

Mark Novak and Carol Guest, based primarily on the work of Guest (1986) as well as an incorporation of items from previously published scales. The Caregiver Burden Inventory was originally developed in 1987, but was revised and expanded for a study in 1989. The CBI is a multi-dimensional, 24 item questionnaire designed to measure burden in specific areas of the caregivers' lives. It is relatively easy to administer and is classed as a self-anchored rating scale. The scale consists of five factors: time dependence, developmental burden, physical burden, social burden, and emotional burden. Scoring for each factor ranges from 0-20, except for Factor 3 (physical burden) which ranges from 0-16 (scores are mathematically adjusted by multiplying by 1.25 to adjust score to an equivalent out of 20). The Mean Scores for each factor, with Standard Deviations follow:

Factor 1: $x = 6.98$ (s.d. 5.89)
Factor 2: $x = 7.08$ (s.d. 5.89)
Factor 3: $x = 5.47$ (s.d. 5.9) (adjusted)
Factor 4: $x = 2.54$ (s.d. 3.54)
Factor 5: $x = 2.02$ (s.d. 3.04)

Total: $x = 22.14$ (s.d. 16.30)

The five factors accounted for 66% of the variance in the data set. Internal consistency reliability (Coefficient Alpha) was high at .89 for the overall scale. A breakdown of Alpha for each factor provided the following results: Factor 1 and 2 = .85, Factors 3, 4, and 5 = .86, .73, .77 respectively. (Novak & Guest, 1989)

McKean (1989) found a strong correlation between the

Caregiver Burden Inventory and the Burden Inventory (Zarit & Zarit, 1987) which is a well-established scale. Alpha scores for the Burden Inventory (BI) range from .88 to .91 in various studies. The test/retest reliability is reported at .71 for the BI (Zarit & Zarit, 1987). Schallman (1990) also found the BI and the CBI were highly correlated ($r = .83$, $p < .001$) in her study of caregiver burden with spouses and adult children. These two studies establish concurrent, criterion-based validity for this instrument.

In my research on the validity and application of the CBI, the primary advantage that this measure has over other measures of its kind is the multi-dimensional measurement it provides. Other inventories only provide "total" scores, which does not allow for distinctions between dimensions of burden (Novak & Guest, 1989; McKean, 1989).

The CBI has been utilized primarily in research on caregivers of demented elders, but further research with caregivers of elders in poor physical health, for example, may broaden its applicability.

2) SELF-EFFICACY SCALE (SES)

This scale was developed by Sherer, Maddux, Mercadante, Prentice-Dunn, Jacobs and Rogers in 1982. The scale was based upon the theory of self-efficacy developed by Bandura (1982) which maintained that the process of psychological and behavioural change operates through the alteration of the individual's sense of personal mastery or efficacy. Sherer et

al. (1982) reported good internal consistency with Cronbach Alpha reliability co-efficient of .86 for the general subscale (measures self-efficacy without reference to any specific behavioural domain), and .71 for the social subscale (measures efficacy expectancies in social situations). No test/retest data was reported.

Sherer et al. (1982) also reported good criterion-based validity by accurately predicting that people with higher self-efficacy would have greater success than those who score low in self-efficacy in past vocational, educational, and monetary goals.

The SES further demonstrated criterion-based validity by correlating in predicted directions with a number of established measures such as the Ego Strength Scale, the Interpersonal Competency Scale, and the Rosenberg Self-Esteem Scale.

In this study, this scale was utilized to measure changes in feelings or perceptions of personal mastery and competency pre/post group intervention. One of the components of the group intervention focused upon raising the participants' consciousness about the division of labour around caregiving and its oppression of women as carers. The goal was to empower these women to analyze their own situations and make changes in their personal and political lives where possible. The Self-Efficacy Scale provided a measurement of the group's effectiveness in promoting feelings of increased competency

amongst participants.

3) LUBBEN SOCIAL NETWORK SCALE (LSNS)

This scale was developed by J. E. Lubben in 1988, based on the modification of the Berkman-Syme Social Network Index for use with older populations. The LSNS has a high degree of internal consistency (Chronbach's Alpha = .70). Low scores on the LSNS have been associated with increased risk of hospitalization and lower health status (Lubben, Weiler & Chi, 1989).

As this measure has been developed relatively recently, it has not been used with a variety of populations. In my clinical practice, I have found the scale to be very useful in measuring social networks as it targets family networks, friendship networks and amount of social exchange within networks. As these aspects of network analysis are also important with a somewhat younger population, this author chose to utilize this instrument.

The LSNS was utilized on a pre/post basis to measure any changes participants may have experienced in their networks. As the group intervention encouraged seeking additional support from other family members to share in the caregiving responsibility, as well as development of personal networks for the purpose of gaining support and respite, some changes in network size and contact were anticipated.

DATA ANALYSIS:

The data analysis was divided into two types, based upon

the differences in the data collected. For instance, qualitative data derived from pre/post individual interviews was formulated into a comparative case analysis of commonalities and differences amongst the variables under consideration. This analysis included data collected from participant's self-report, as well as clinical evaluation and impressions of the practitioner and focused upon changes which have occurred throughout the course of the group. Furthermore, the group interactions and process were also tracked by the author and evaluated in terms of progress of individual members and the effectiveness of the group as a whole. Participants provided written feedback in the form of a Client Satisfaction Questionnaire (Attkisson et al, 1989) and rated the effectiveness of the group intervention.

The second aspect of data analysis centred upon the quantitative data which will be presented in line graph format to facilitate comparative interpretation and analysis. Mean scores derived from previous research utilizing these scales provide for a means of comparative analysis as well.

LIMITATIONS OF PRESENT PRACTICUM:

This study was limited by the small sample size and the lack of a comparison or control group in what conclusions can be drawn from the outcome measures as well as the generalizability of findings. However, the richness of qualitative data does provide a perspective that cannot be derived from large-scale quantitative research projects.

Although there were certainly some differences between the participants based upon the nature of the care recipient's illness, and the resulting needs of care recipients and caregivers alike, the limited potential sampling population made it necessary to include caregivers of both physically and cognitively impaired care recipients. These individual differences must account for some of the variation, but the results from this study do suggest some patterns which can be commented upon as valuable research.

CHAPTER IV -- INDIVIDUAL RESULTS

INTRODUCTION:

This chapter begins by providing in-depth qualitative data derived from individual interviews in the form of comparative case studies. As well, quantitative measures derived from the use of three self-anchored scales (Caregiver Burden Inventory, Lubben Social Network Scale, and the Self-Efficacy Scale) will be presented for each group participant. Interestingly, each participant represented a different typology of care provider as defined by Lewis and Meredith (1988), these being "full care", "part-time full care" and "semi-care", as well as one member who made the transition from "part-time full care" to "full care". Following the individual case studies and quantitative results, a process evaluation of the group on a session by session basis will complete the qualitative data.

The case studies which follow are presented in a pre/post interview fashion and categorized by the various factors described in the conceptual framework: 1) contextual information, 2) characteristics of care, 3) social networks, 4) other stressors, 5) social life, 6) expectations re. caring, 7) assistance through formal care, 8) self-efficacy, and 9) outcomes. In conducting the post-group interviews, the author asked participants to assess their own level of change and to describe the factors which contributed to the change.

#1. A Case of Semi-Care: "Ellen"

Ellen classified herself as providing "semi care" which was defined as the period of caregiving where the care recipient should not be left alone for extended periods, but requires little or no personal care (Lewis and Meredith, 1988).

The following information was gleaned from the individual interviews with each group participant:

Contextual Information--

Ellen is of Ukrainian descent, is 75 years of age, and has one daughter who lives in Winnipeg. She lost her son in a motor vehicle accident several years ago. Ellen herself is widowed and is a retired Psychiatric Nurse. Ellen cares for her 95-year-old mother who still lives independently in an Elderly Persons Housing block. She manages with support from family and Continuing Care. Ellen's mother did stay with her for a brief period while recuperating from a fractured arm, but she found her mother soon became overly dependent, and actually functioned better on her own.

Ellen reported no significant changes in the contextual information in the post-group interview.

Characteristics of Care--

Ellen's mother has remained quite well physically, with the exception of the fractured arm, but has deteriorated substantially mentally. She requires supervision and

reminders to carry out all Activities of Daily Living, and even must be reminded to eat. Ellen has been caring for her mother for over five years, providing transportation, assisting with grocery shopping, paying bills, banking. Although Ellen telephones her mother at least twice a day and visits her daily, her mother does continue to live independently.

Ellen described their relationship as a good one, but felt it became strained when her mother was living with her. Ellen carries sole responsibility for her mother's care as her siblings are not geographically close, and she described feeling burdened by the responsibility at times, as well as restricted in what choice she could make in her own life. For instance, she has to arrange for respite care if she wants to leave home, even for a day.

Ellen noted the changes in her mother as she is not capable of carrying on conversations or of making decisions. Ellen was saddened by her mother's mental deterioration and increasing dependency.

At the time of the post-group interview, Ellen had noted a deterioration in her mother's condition, both physically and mentally, which contributed to increased caregiving demands. For a period of time, Ellen was receiving calls from her mother in the middle of the night and had to rush over to her mother's apartment to check on her. However, the situation seemed to have stabilized by the time of this interview.

Ellen still had a difficult time with feelings of guilt and inadequacy as a caregiver which was, in part, a response to her sister's criticisms. Ellen described this conflict within herself as increasing as her mother's health deteriorated. She reported, however, that her level of burden had remained stable.

Ellen reported that the Caregiver Support Group helped her to identify and deal with her feelings of guilt. She indicated that her relationship with her mother had not changed noticeably since the pre-group interview.

Social Networks--

Ellen had three siblings, but one brother is deceased. She has another brother who currently resides in Arizona and a sister in Nevada. Although they are unable to share caregiving duties due to distances, Ellen sees her brother as a good support. However, her sister is often blaming as she finds it difficult to realize her mother's deterioration. She has often berated Ellen for not providing more care or for the decision to apply for a personal care home bed. Ellen has several close friends and activities in which she is involved.

In the post-group interview, Ellen was still struggling with her sister's lack of acceptance of their mother's decline and need for placement in a personal care home. However, Ellen did seem more resolved that the decision had been a sound one.

Ellen felt her friendship networks had remained stable,

but she hoped to build new friendships with other group members outside of the group context.

Other Stressors--

As Ellen's own family lived relatively nearby, she made visiting with them a priority and felt that her caregiving responsibilities did not interfere with family contact. As Ellen was retired, she did not have to cope with balancing paid work with her caregiving labour.

In the post-group interview, Ellen reported finding little change in her ability to balance family/work commitments with caregiving, but she had not identified this issue as being problematic in the pre-group interview.

Social Life--

As mentioned before, Ellen had a very busy social life, with many commitments to choirs, bands, etc. Ellen did share that she often felt guilty or "torn" for not spending more time caring for her mother. She described herself as feeling "tired" as she tried to meet all of her commitments.

At the time of the post-group interview, Ellen's level of involvement had remained about the same, but she reported feeling more "tied down" to her mother's care than previously.

Expectations re. Caring--

Ellen agreed that women were seen by society as the "traditional caregivers". In her family, Ellen was "appointed" as the primary caregiver as she was nearby, but

she felt her brother would have shared the responsibility if he had been able to. Ellen hoped her daughter would not be forced into caring for her in her old age; rather, she saw herself living in a personal care home when no longer able to live independently.

In the post-group interviews, Ellen felt that changes in caregiver roles would occur slowly and she did not foresee men as active participants in caregiving. She felt that women's caregiving was "taken for granted" and that increased awareness of the issue was necessary to increase recognition. Ellen further commented that she felt recognized for her caring efforts within the group setting.

Assistance Through Formal Care--

Ellen's mother received Continuing Care Services which include medication monitoring, morning care, supper preparation, and a bedtime check. She also attended an adult day programme and received Meals on Wheels daily at noon. Ellen was satisfied with the care provided by Continuing Care, although she found the inconsistency of different workers exacerbated her mother's confusion.

Ellen reported in the post-group interview that she was very satisfied with the assistance she received through Continuing Care. Because of her participation in the group, she felt increasingly entitled to the services available and how to access them. Ellen felt the state should provide more adequate housing for the elderly to meet the range of needs.

Self-Efficacy--

Ellen reported feeling "rushed and tired" and even "exhausted" when trying to meet competing demands on her time. She felt that she may have to rely on hired assistance to relieve her of the burden of caregiving if the demands increased. Ellen found going to Bingo, talking to friends, and knitting helpful in coping with the stress.

In the post-group interview, Ellen reported coping quite effectively with caregiving demands which she attributed to the group intervention as the Group had helped her to put her own situation into perspective and to realize how fortunate she was. Furthermore, the Group assisted her in asking for help and in dealing with her siblings more assertively. Ellen did feel empowered* by the Group, and although she had been able to realize some choices previously, she felt she had gained self-confidence through the Group process.

Outcomes--

Ellen reported feeling anxious at times "when things piled up". She felt well most of the time, however, and did not feel her health had been adversely affected by caregiving.

At the time of the post-group interview, Ellen's anxiety has increased as she worried about her mother living alone.

* The author defined "empowerment" as the process of realizing one's personal power to make choices, and respond to situations based upon a sense of our needs, values, and goals.

She found that talking about her feelings of anxiety often helped and that the Group provided a medium for that type of sharing. In spite of her increased worry, Ellen maintained that she felt well most of the time.

Quantitative Data:

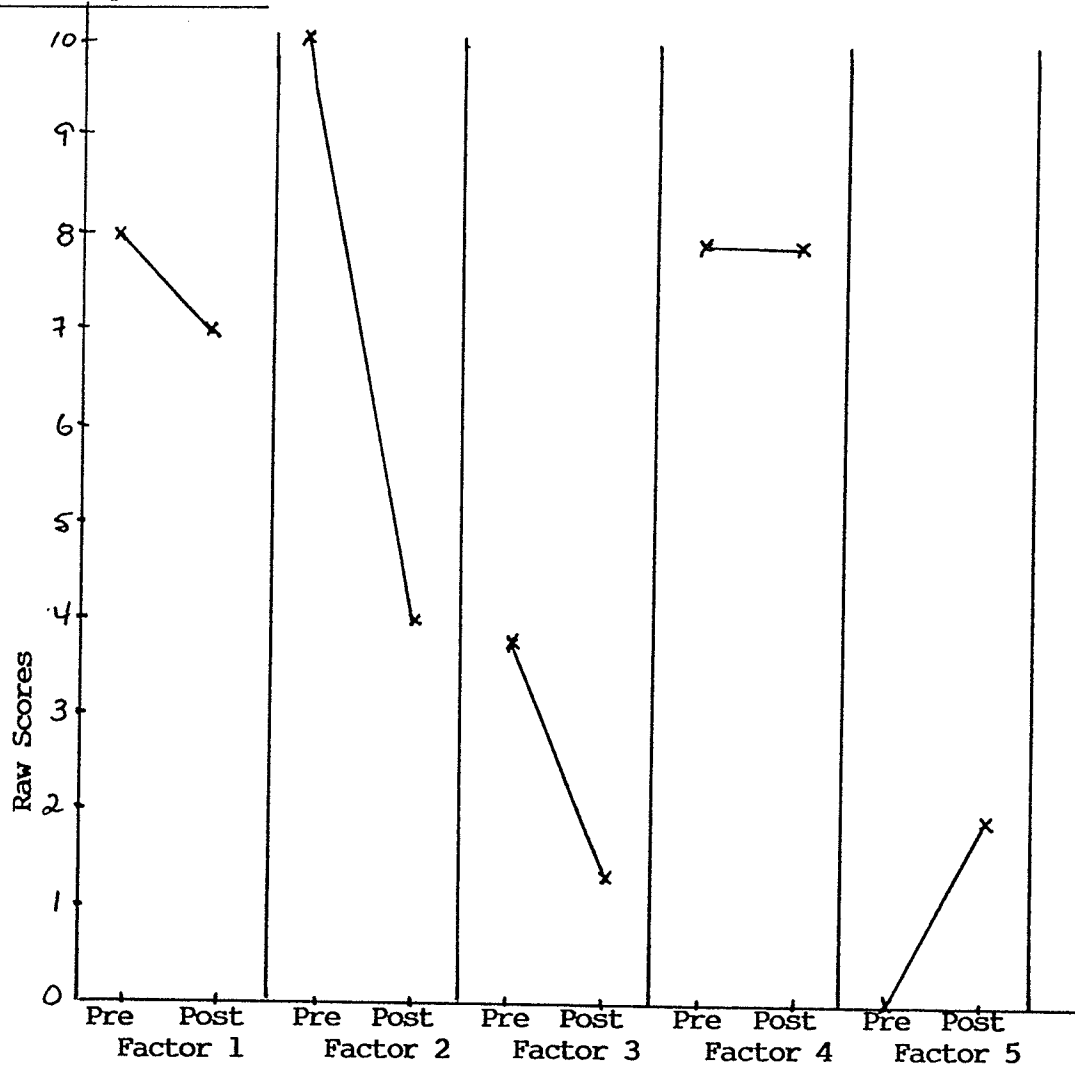
Quantitative measures consisted of three scales which were administered on a pre/post group basis. These included the Caregiver Burden Inventory (CBI) developed by Novak and Guest (1989), the Lubben Social Network Scale (LSNS) developed by Lubben (1988), and the Self-Efficacy Scale (SES) developed by Sherer et al. (1982). These three scales were chosen to gather data on changes in burden, social networks and self-efficacy respectively.

The results for Ellen (Client #1) are presented in Figure 4.1, Figure 4.2, and Figure 4.3. Figure 4.1 (p.68) depicts changes in burden numerically represented by scores from the Caregiver Burden Inventory. This particular graph demonstrates the breakdown by factor which allows for greater interpretation.

Novak and Guest (1989) describe Factor 1 as a measure of "Time-Dependence Burden" which relates to caregiver burden resulting from restrictions on their time. Ellen scored 8 on the pre-test and 7 on the post-test, representing a slight decrease in perceived burden. As the Caregiver Burden Inventory does not have guided scores, the mean scores were

Figure 4.1 CHANGES IN BURDEN BY SUB SCALE

Client #1: Ellen



CAREGIVER BURDEN INVENTORY (CBI)

Factor 1 - Time Dependence
 Factor 2 - Developmental Burden
 Factor 3 - Physical Burden
 Factor 4 - Social Burden
 Factor 5 - Emotional Burden

used to assist in interpretation. This score is comparable to the mean score ($x=6.98$, $s.d.=5.89$) derived for Factor 1 from Novak and Guest's (1989) study of caregivers. Ellen's time commitment to caregiving is perhaps not as high as other group members as she is providing "Semi-Care", thus, accounting for her moderate scores.

Factor 2 relates to "Developmental Burden" which is the caregiver's feeling of being "off-time" with peers and "missing out" on their own stage of life. Ellen scored a 10 in the pre-group result and this decreased to 4 on the post-test, which was comparable to the mean score derived from Novak and Guest's (1989) study for this factor which was $x=7.08$, $s.d.=5.89$. In the pre-group interview, Ellen was feeling overwhelmed with her mother's demands. Through the group, she began to "let go" of her guilt for partaking in her own social activities, which may account for the decrease in score.

Factor 3 measures "Physical Burden" on the part of caregivers (chronic fatigue, damage to their own health). Again, Ellen's scores showed a decrease from 3.75 (adjusted) pre-group to 1.25 (adjusted) post-group. The mean score from Novak and Guest (1989) for this factor was $x=4.37$, $s.d.=4.72$. Once again, Ellen's low score on this factor may be related to her stage of caregiving being "Semi-Care", as well as the acquisition of alternative ways of dealing with the physical stress of caregiving through the group learning.

Factor 4 relates to "Social Burden" which is caregivers' feelings of role conflict, conflict that caregiving creates with family and work commitments. Ellen's scores remained constant on a pre/post basis with a result of 8. The mean score reported for this factor was $x=2.54$, $s.d.=3.54$ (Novak and Guest, 1989) which would indicate that this client's scores were slightly above average values. In addition to providing care to her mother, Ellen maintained several other time-consuming commitments to volunteer work and social events, which could account for her higher score, and the lack of change in her score.

The last factor relates to "Emotional Burden" which is the caregiver's negative feelings toward their care recipient. Ellen scored 0 on the pre-test and 2 on the post-test, both within the range of the reported mean score for this factor ($x=2.02$, $s.d.=3.04$) by Novak and Guest (1989). The increase may be explained by the deterioration of the care recipient in this case, or a greater willingness to admit negative feelings on the part of the caregiver as Ellen gained greater self-awareness.

Figure 4.2 (p.71) depicts changes in social network as measured by the Lubben Social Network Scale (Lubben, 1988). Ellen scored 37 in the pre-test and 36 in the post-test, representing a slight decrease in reported social networks. This result, however, is slightly higher than mean scores obtained through a large study ($n=1,037$) of Medicaid

Figure 4.2 CHANGES IN SOCIAL NETWORK (Pre/Post Group)

Client #1: Ellen

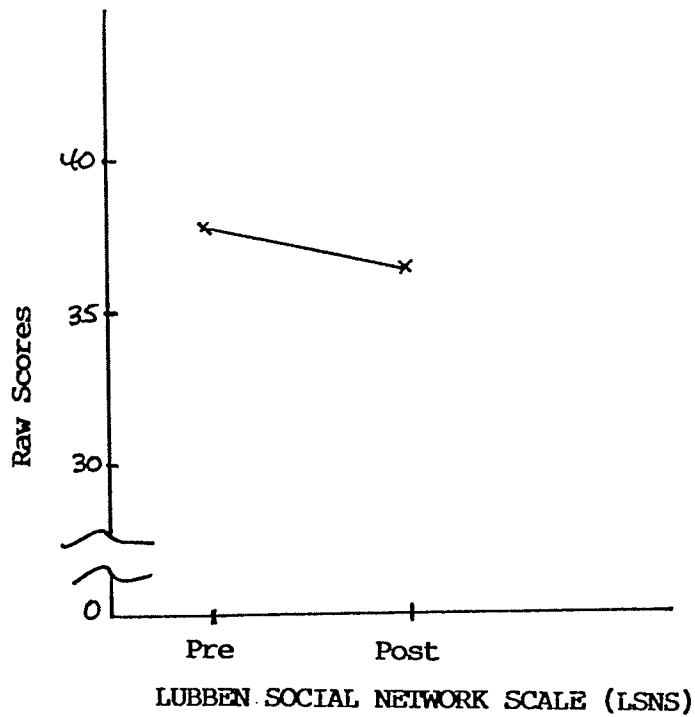
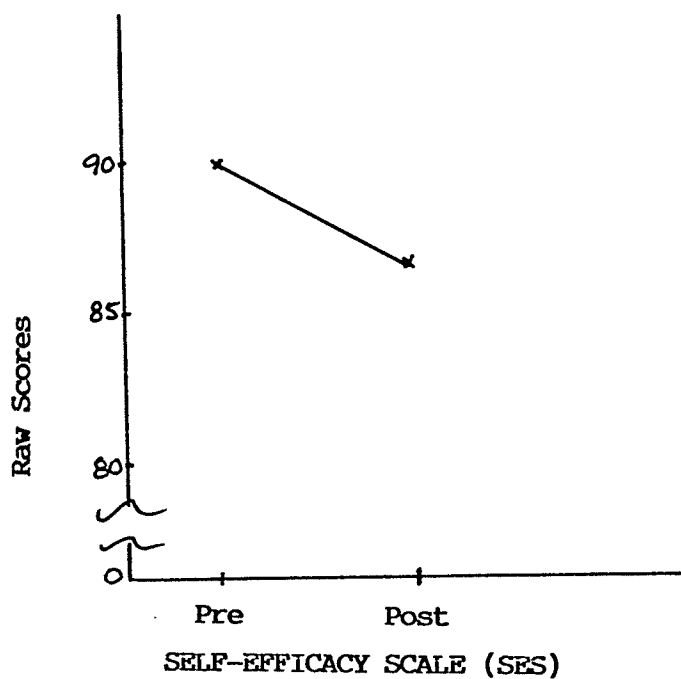


Figure 4.3 CHANGES IN SELF-EFFICACY (Pre/Post Group)

Client #1: Ellen



recipients in the United States which provided a result of $x=25.1$, $s.d.=9.6$ (Lubben, 1988). Ellen's result would indicate above average composition of networks in the three areas examined by this scale: family networks, friends networks, and interdependent social supports.

Figure 4.3 (p.71) depicts changes in Self-Efficacy as measured by the Self-Efficacy Scale (Sherer et. al., 1982). This scale is divided into two sub-scales which examine social self-efficacy and general self-efficacy. On the pre-test, Ellen scored 22 on the social sub-scale and 69 on the general scale, for a total score of 91. Comparatively on the post-test, Ellen scored 18 on the social sub-scale and 68 the general scale, for a total of 86. These scores are comparable to results obtained through a study of 101 college students by Sherer et. al. (1982) which indicate $x=21.20$, $s.d.=3.63$ for the social sub-scale, and $x=64.31$, $s.d.=8.58$ for the general sub-scale.

CASE SUMMARY:

Ellen reported a deterioration in her mother's condition within the time period that the group was running, which may have accounted for some degree of pre/post group changes. Although Ellen was still classified as providing "Semi-Care", there was little doubt that both the care demands and resultant feelings of role conflict had increased. With respect to perception of burden, Ellen reported that feelings

of burden had not increased, and in some areas, had decreased. Ellen also reported that the group had assisted her in dealing with feelings of guilt. The results from the Caregiver Burden Inventory supported Ellen's subjective report in that most sub-scales demonstrated a decrease in burden.

Although Ellen did not report significant changes in the composition of her social networks, she did describe changes in the quality of her relationships with siblings which contributed to increased social support. Results from the Lubben Social Network Scale (Lubben, 1988) demonstrated a small decrease in her score from pre to post group. This inconsistency may be explained as this scale was not sensitive enough to changes in social support.

With respect to self-efficacy, Ellen identified an increase in assertive behaviour and feeling empowered by the end of the group, both components of increased self-efficacy. This result, however, was not borne out by the the Self-Efficacy Scale which demonstrated a small decrease. Again, this inconsistency may be a result of the lack of sensitivity of the measure being utilized.

#2. A Case of Part-Time Full Care: "Joanne"

Joanne classified herself as providing "Part-time Full Care" as defined by Lewis and Meredith (1988), meaning that she was providing a considerable amount of care while still juggling work and other family responsibilities.

The following information was derived from the pre and post-group interviews conducted with the participant.

Contextual Information--

Joanne is of Scottish descent, is 54 years of age, and has one grown daughter. She has been divorced from her husband for a number of years; she works as a professional psychologist for a large social service agency.

Her daughter has two children of her own and just recently moved back home, leaving Joanne to cope with the needs of small children as well as her elderly mother. Her mother, age 94, has lived with her for about four years, having moved from Eastern Canada.

In the post-group interview, Joanne indicated that nothing significant had changed with respect to living arrangements, or other personal data (marital status) for either herself or her care recipient since the pre-group interview.

Characteristics of Care--

Joanne's care recipient (her mother) has some physical limitations, including vision and hearing loss, but remains cognitively intact. She is, however, demanding of her

daughter's time and attention.

Care activities include meal preparation, doing grocery shopping, banking, assisting with bathing, providing transportation to medical and other appointments, laundry, and household cleaning. As Joanne is not comfortable leaving her mother alone for long periods of time, she usually comes home on her lunch hour to check on her mother and hurriedly make some lunch.

Joanne's relationship with her care recipient was characterized by increasing demands, frustration, irritation, quickly followed by guilt. Joanne expressed a desire to learn to care "with more grace".

In the post-group interview, Joanne reported that her mother's health and care needs remained basically the same for the eight weeks duration of the group. However, Joanne indicated a marked change in how she perceived her role as caregiver: she no longer felt a need to "protect" her mother. Further, Joanne stated that the amount of burden she had experienced decreased during the Group. It was her perception that the care was not as "heavy" in spite of her assertion that the care demands had remained the same. When asked specifically if the Caregiver Support Group helped her to deal with the feelings of burden and guilt, she responded positively. Joanne found the group provided her with a new perspective on her situation, and she experienced empathy, rather than sympathy, from other group members.

As a result of gaining a new perspective and hearing how other women cope with caregiving within the group, Joanne experienced a positive change in her relationship with her mother. Her anger and resentment decreased, and she was better equipped to provide care more willingly, and more cheerfully.

Social Networks--

Joanne has two sisters, neither of whom take an active role in provision of care. Her one sister lives in British Columbia and the other in Northern Manitoba. Joanne does have several close friends. Since beginning her caregiving role, Joanne tends to choose friends who also share this experience as they are better able to meet her emotional needs.

In the post-group interview, Joanne reported that she had not experienced any significant change in her sibling relationships. Her sisters did not take a greater role in caregiving unless specifically requested, but Joanne was more aware of her own need for self-care, and anticipated asking for help more frequently from her sisters. Joanne also did not experience any change in her existing friendship network. However, she did feel a "connection" with some group members that might be the basis for the building of new friendships.

Other Stressors--

Joanne often feels "caught" or pulled between the competing demands of her mother, her daughter and children,

and her own needs. The demands on Joanne's time are considerable between her work responsibilities, her "at-home" work, and caregiving.

Although her employer is generally supportive, Joanne does not want to let caregiving interfere with her job, and would never consider giving up her career for caregiving.

At the time of the post-group interview, Joanne indicated that she had learned to "let go" of her need to resolve conflicts between other people in her household and thus, could balance competing demands more effectively. She attributed this change directly to the group intervention. Furthermore, the Group allowed her to step back and to see the effects of being "caught in the middle" on herself. As a result, she began to attend to her own needs, her own self-care. Joanne then found herself saying "no" to her mother's demands without feeling overwhelmed with guilt. In particular, she limited the assistance she provided so that it would not encroach upon work responsibilities.

Social Life--

Although Joanne had little time to go out to socialize, she found that what she really lacks is time for herself.

In the post-group interview, Joanne indicated that she usually found enough opportunities to socialize and to "take a break", but that this respite was often short-lived. She had learned, however, the importance of socialization for self-care from the group process.

Expectations re. Caring--

Joanne felt that she was expected to be a caregiver by her siblings and to carry on the family myth that "their women were strong". She also believed that, in general, men expect women to be the caregivers.

In the post-group interview, Joanne indicated that her expectations regarding women's role as caregivers changed as a result of the group. She now felt that, although siblings should share the care responsibilities, there needs to be a primary caregiver who can make decisions without interference.

She felt that the formal system (the state) needs to recognize women's caregiving efforts through Income Tax deductions (claim elder as dependent) and through employer programmes (job-sharing, reduced hours of work, on site adult day care). These ideas were formulated through group discussion on this topic. On an informal basis in the group setting, Joanne stated that she felt valued and recognized for her caregiving efforts, and that this recognition should be given by greater society.

Assistance Through Formal Care--

Joanne received limited services through Continuing Care, those being periodic respite admissions to Personal Care Home and/or hospital. She felt that the state (government) should recognize women caregivers more formally and provide greater support for them.

In the post-group interview, Joanne indicated that she

was satisfied with the formal care system, and felt entitled to the services available, but not having required many services as yet. Within the group, Joanne developed the opinion that the state's services for the elderly were adequate, but that services directed at the needs of caregivers should be developed further.

Self-Efficacy--

Joanne often felt burdened by the care she provided and isolated in her feelings of stress and frustration. She commented that others often did not understand her feelings of guilt and burden, but that she had a need to express these painful emotions. She also expressed a desire to learn new ways of coping, her current repertoire focusing mainly on problem-solving techniques and taking vacations as respite.

In the post-group interview, Joanne responded that the Group provided her with the strength to deal with caregiving demands differently, limiting the infringement on her own needs and exercising new ways of coping, self-care (ie. saying "no", using relaxation tapes to reduce stress, taking time for herself). She also said the Group helped build her self-confidence and assertion skills. She no longer allowed others to "dump" their problems on her.

When asked if the Caregiver Support Group had assisted in developing a sense of empowerment, Joanne responded positively. She felt that the combination of the Group and her involvement with Al-Anon (which is a self-help group for

family members of alcoholics) reinforced her personal sense of power to make her own choices and to have some control over her own life.

Outcomes--

Many times, Joanne felt anxious or depressed about the interpersonal conflicts ongoing within her household, taking it on as her responsibility to resolve these issues, and seeing herself as failing to be effective. She indicated that she would feel more freedom if she was not caregiving, thus contributing to a greater sense of well-being.

In the post-group interview, Joanne stated that she felt anxious and depressed at times, this occurring when she could not see a resolution to a problematic situation. She indicated that the Group helped her by providing support and an outlet to show her emotions, to talk over the situation. She could then "take charge" of her feelings and cope more effectively.

Joanne indicated that she was healthy and well most of the time, which had not changed since our first interview.

Quantitative Data:

Quantitative data derived from pre/post administration of the three scales for Joanne (Client #2) is presented in Figure 4.4, Figure 4.5, and Figure 4.6.

Figure 4.4 (p.82) depicts changes in perceived burden as measured by the Caregiver Burden Inventory (CBI) developed by Novak and Guest (1989). As each factor within this scale measured a particular aspect of burden, the results are

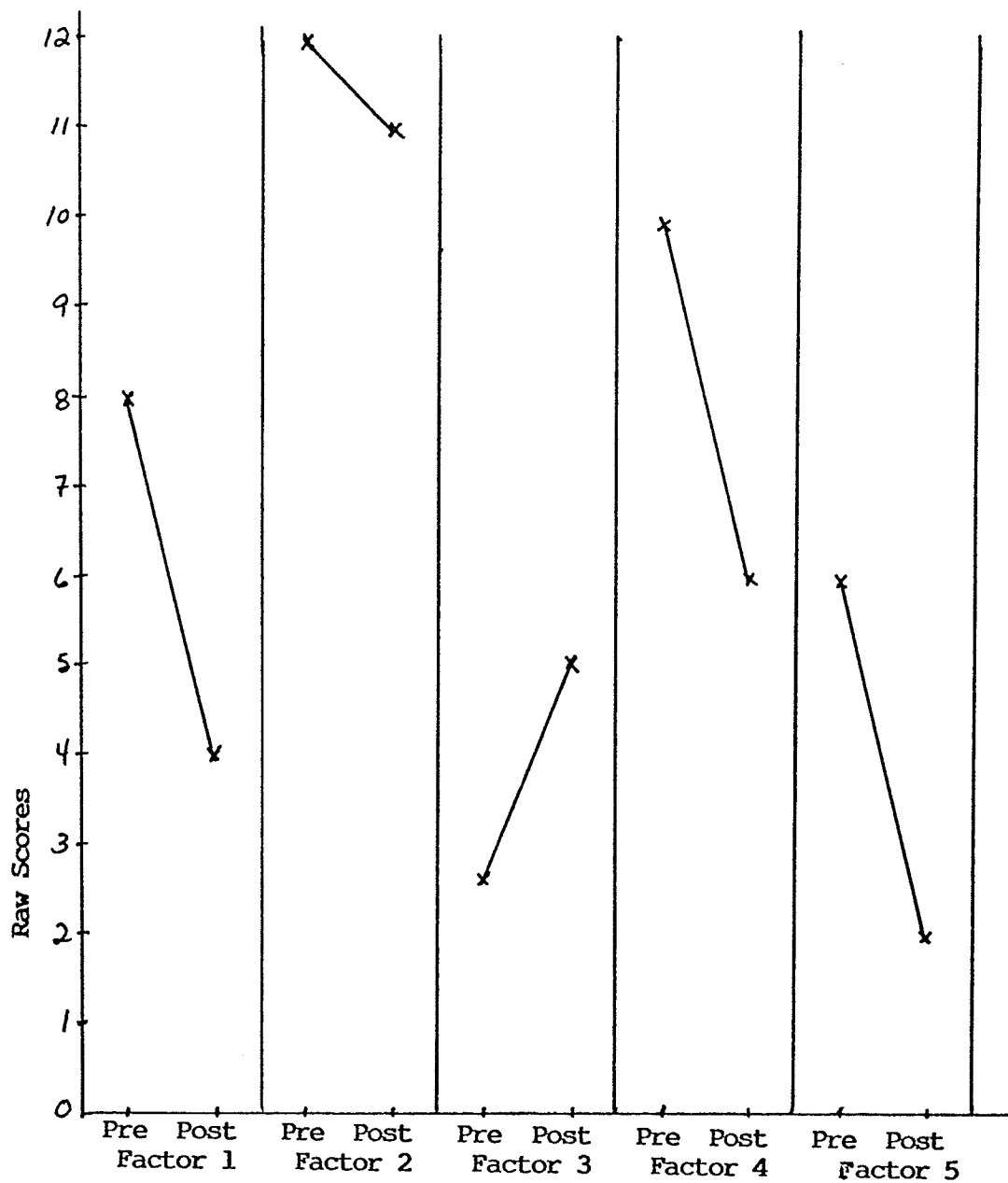
presented by sub-scale to represent these different types of burden.

On Factor 1 describes "Time Dependence" which is burden resulting from demands on the time of the caregiver. Joanne scored an 8 on the pre-test and a 4 on the post-test, indicating a decrease in this aspect of burden. These scores are comparable to mean score results ($x=6.98$, $s.d.=5.98$) derived from Novak and Guest's (1989) study. Joanne found the group particularly helpful in gaining a perspective on how to allow others to care for her mother, and how to set limits on the amount of demands she would respond to. In incorporating these coping mechanisms into her daily regime, Joanne then experienced a reduction in feelings of burden.

On Factor 2, "Developmental Burden", which is the caregiver's feeling of being "off-time" with peers and "missing out" on their own stage of life, Joanne scored quite high with a 12 on the pre-test and 11 on the post-test. However, these results are still comparable to mean scores ($x=7.08$, $s.d.=5.89$) derived from the Novak and Guest (1989) study. The relatively high scores could result from Joanne's ambivalence with respect to caregiving at a time where her own family has just become more independent, and she could have been developing her own interests.

On Factor 3, "Physical Burden", the chronic fatigue and damage to their own health that caregivers experience, Joanne scored a 2.5 on the pre-test and 5 on the post-test,

Figure 4.4 CHANGES IN BURDEN BY SUB-SCALE
Client #2: Joanne



CAREGIVER BURDEN INVENTORY (CBI)

Factor 1 - Time Dependence
Factor 2 - Developmental Burden
Factor 3 - Physical Burden
Factor 4 - Social Burden
Factor 5 - Emotional Burden

indicative of an increase in this aspect of burden. However, Joanne's scores are still comparable to the mean score derived from Novak and Guest's (1989) study which was $x=4.37$, $s.d.=4.72$. The increase in physical burden may be related to her mother's increasing need for care as her health deteriorated, as well as Joanne's own aging process.

On Factor 4, "Social Burden" which relates to feelings of role conflict, Joanne scored 10 on the pre-test and 6 on the post-test, demonstrating a decrease in burden. These burden scores were slightly higher than the mean score derived from Novak and Guest's (1989) study which was $x=2.54$, $s.d.=3.54$. As Joanne was providing "Part-Time Full Care", she experienced a great deal of conflict between her work and family commitments. Joanne also had her own family still living with her which exacerbated this role conflict.

On Factor 5, "Emotional Burden", which relates to the caregiver's negative feelings toward the care recipient, Joanne's results were 6 on the pre-test and 2 on the post-test, indicating a decrease in burden. These results are comparable to the Novak and Guest (1989) study with a mean score of $x=2.02$, $s.d.=3.04$. The decrease in emotional burden may be related to the group intervention, as supported by Joanne's self-report, as she found the group helped her to deal with negative feelings toward her mother, such as guilt, anger and frustration.

Figure 4.5 (p.85) depicts changes in social network as

measured by the Lubben Social Network Scale (Lubben, 1988). Joanne scored 39 on the pre-test and 37 on the post-test, indicating a slight decrease. Joanne's result is higher than the mean score result reported through a large study (n=1,037) conducted by Lubben (1988) which was $x=25.1$, $s.d.=9.6$. Joanne, however, stated that she experienced an increase in social support through the contact with other group members.

Figure 4.6 (p.85) depicts changes in Self-Efficacy as measured by the Self-Efficacy Scale (Sherer et al., 1982). This scale has two sub-scales which examine social self-efficacy and general self-efficacy. On the pre-test, Joanne scored a 19 on the social sub-scale and 70 on the general scale, for a total of 89. Post-group results indicated a 22 on the social sub-scale and 71 on the general scale, for a total score of 93 which represented an increase in self-efficacy. These scores are comparable to those obtained in the study conducted by Sherer et al. (1982) whose results were $x=21.20$, $s.d.=3.63$ for the social sub-scale, and $x=64.31$, $s.d.=8.58$ for the general sub-scale. Joanne described feeling empowered and becoming more assertive as a result of the group which could account for the increase in her self-efficacy score.

CASE SUMMARY:

In summary, Joanne maintained her status as "Part-time Full Care" caregiver throughout the group, as she continued to

Figure 4.5 CHANGES IN SOCIAL NETWORK (Pre/Post Group)

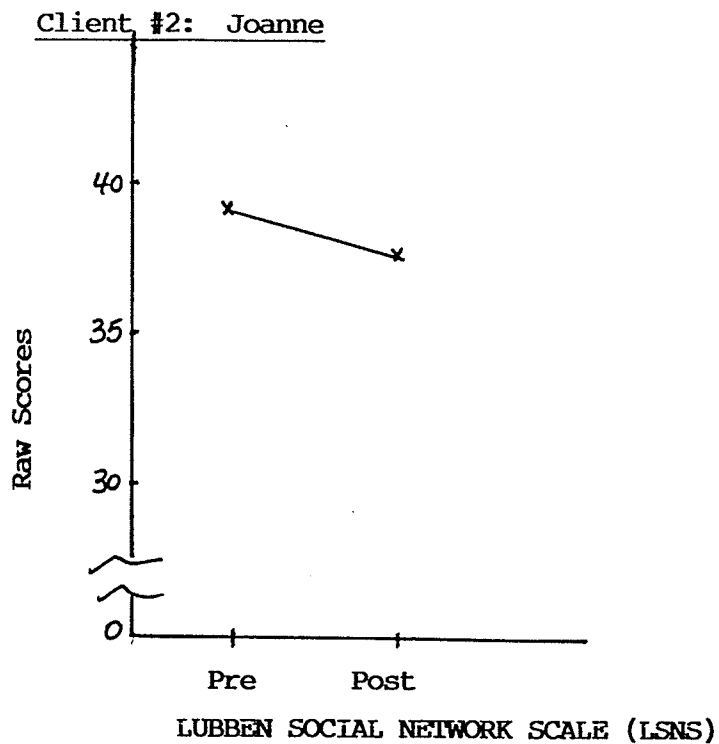
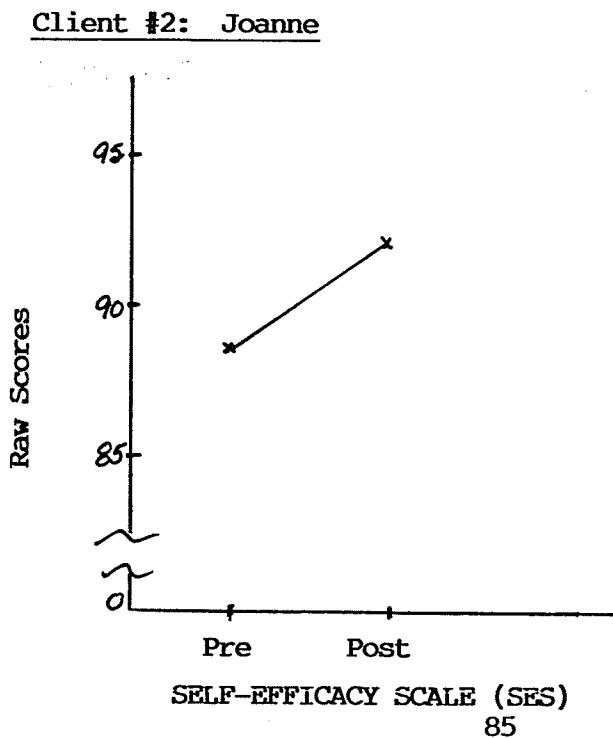


Figure 4.6 CHANGES IN SELF-EFFICACY (Pre/Post Group)



work outside the home, and provide care to her mother. Joanne indicated that her mother's condition remained fairly constant, although some care needs did increase slightly. As an example, her mother now required assistance with bathing. However, Joanne's perception of the care she provided changed markedly, which she attributed to the group assisting her to deal with feelings of guilt and anger. The result was a perceived decrease in the care demands, despite the needs remaining constant. Joanne also reported a positive change in her relationship with her mother when she herself was able to "let go" of some of the responsibility for her mother's well-being. The results of the Caregiver Burden Inventory (Novak and Guest, 1989) supported the qualitative data on every subscale, but Factor 3 (Physical Burden) upon which Joanne's burden increased slightly. Again, this may be a direct result of increasing physical care needs on the part of Joanne's mother.

With respect to social networks, Joanne did not report a significant change in her family/friendship networks over the course of the group, but did hope to build friendships with other group members over time. The Lubben Social Network Scale (Lubben, 1988), in fact, represented a slight decrease in Joanne's reported social networks.

Joanne reported some rather significant changes in self-efficacy in the qualitative data. She felt empowered by the group to cope with caregiving more effectively and to engage

in better self-care. She felt the group assisted her in building her confidence and increasing her assertion skills. The Self-Efficacy Scale (Sherer et al., 1982) results also supported the increase in self-efficacy from pre to post-group.

#3. A Case of Transition: "Helen"

Helen first classified herself as a "part-time full care" caregiver, which Lewis and Meredith (1988) define as the period where a great deal of personal care is required, but the caregiver continues to fulfil work and family commitments. Helen experienced a transition to "full care" during the period that the Group was running as she retired from her job, and the demands of care increased. As her father's health deteriorated, he could not be left alone without a substitute carer and required more assistance with personal care.

Contextual Information--

Helen is 55 years of age, and is single. She worked at a large grocery store for most of her working years, but took early retirement during the course of the Group. Helen has always lived in her parent's home, and cared for her mother until her death, prior to caring for her father, who is now 92 years of age.

Helen reported no significant changes in contextual information during the post-group interview.

Characteristics of Care--

Helen's father suffers from emphysema and visual impairment. He had a stroke about three years ago from which he recovered physically, but is still experiencing ongoing mental deterioration.

Helen provides assistance with meal preparation, all household chores, medication supervision, banking, transportation, assistance with walking, toileting, dressing. Although Helen at times feels angry and resentful, she wanted to "repay" the love and support that she had received from her parents. She denied feeling "burdened", but rather was sometimes "overwhelmed" by care responsibilities. Helen was always expected to be the caregiver given she had remained single. She described her relationship with her dad as very strong, but saw how their roles were changing as her father's health deteriorated.

In the post-group interview, Helen stated that her father's physical strength may have improved, but found he had declined cognitively. As she was at home full-time, Helen took on more caregiving duties herself. However, the group helped Helen to realize that she had to "back off" and not create dependence in her father. She also found the Group taught her to be more assertive in identifying her own needs and in asking for, and accepting outside help. The Group also reduced her sense of isolation by connecting her with other caregivers.

Helen perceived that amount of burden she experienced had remained unchanged, despite an increase in the amount of care she herself was providing. The group normalized feelings of guilt which Helen was struggling with. Despite the changes that did occur in their relationship, Helen reported that

both she and her father adapted.

Social Networks--

Helen came from a large family of ten children. She had two sisters living in the same town and other living either in Winnipeg or out-of-province. She saw her one sister from British Columbia as the most supportive emotionally and practically as she would come home and "take over" the caring once or twice a year. While other siblings came out to visit, they rarely gave Helen the break she needed. Helen relayed that she relied mostly on family to meet her social needs, not having close friends.

Although Helen's siblings were not really taking a greater role in caregiving, Helen herself indicated a greater willingness to ask for help if needed at the time of the post-group interview. She also expressed a desire to develop relationships from the Group into friendships.

Other Stressors--

Helen had to balance work with caring responsibilities and found it to be "a real juggle". Although her employer and co-workers were supportive, Helen was finding the competing demands very taxing and elected to take early retirement. She therefore moved from part-time full care to full care.

Post-group, Helen indicated that she had experienced a significant reduction of stress when she retired. She found more time for her "at-home" work and for relaxing. She was even finding some time every day just for herself.

Social Life--

Helen limited her social activities as she worried about leaving her father alone for any length of time.

Post-group, Helen indicated that her social life had improved over the course of the Group as her family were visiting and she was able to take a holiday during that period of time.

Expectations re. Caring--

Helen described women as "natural caregivers" and felt that society expected women to carry out that role. Helen "naturally" fell into a caregiving role herself.

Interestingly, however, she did not expect anyone to care for her in her old age.

In the post-group interview, Helen stated that her expectations about women's role as caregivers had changed as a result of the group in that she actually examined the issue whereas she always took it for granted previously. She did believe that women's caring labour should be formally recognized such as providing a tax deduction for elderly dependents. The Group helped her to change her attitude about women's roles as caregivers. Helen herself often felt that she had been taken for granted by most of her family as they expected her to take on a caregiving role. The Group helped Helen to recognize that she was "doing an important job".

Assistance Through Formal Care--

Helen's father received medication monitoring, morning

care five times a week, and assistance with bathing twice a week through Continuing Care Services. Helen related that they were satisfied with the services provided, but also agreed that the state should play a greater role in provision of care to the elderly.

Post-group, Helen remained satisfied with the services through Continuing Care. She also felt more entitled to formal services and became more assertive in asking for needed services, which she attributed to the influence of the Group.

Helen felt that the state should play a greater role in supporting the elderly through programmes which allow greater flexibility, specific to identified needs. The Group educated her regarding available resources and the names of contact people, which she also found helpful.

Self-Efficacy--

Helen felt that she could cope with the demands of caregiving, although she often found making decisions difficult. She would talk to her sister or brother about the situation to gain their advice and support. Helen found reading and deep breathing to be positive forms of relaxation.

In the post-group interview, Helen stated that retiring had reduced the pressure she experienced as a result of competing demands. In terms of new ways of coping, Helen learned to "back off": she no longer felt the need to provide all care to her father, but rather allowed others to care for him at times. Further, the group taught her to relax and

attend to her own self-care.

Helen attributes changes in assertiveness to the Group. She learned to ask for what she needed and to share her emotions with others rather than denying the stress. With respect to empowerment, Helen felt that the Group helped her to act upon her needs. She was aware of the needs previously, but did not exercise her right to make choices.

Outcomes--

Helen reported that she would become depressed when her father was ill, but overall, felt healthy and well most of the time.

Post-group, Helen related that she felt less anxious and more relaxed as a result of her learning in the group. She allowed others to care for her father without worrying and learned to "let go" of the need to control all aspects of his care. She also thought the relaxation tapes would be useful to her. Helen remarked that she felt more rested as she was increasingly sharing the caregiving responsibilities.

Quantitative Data:

Quantitative results from the Caregiver Burden Inventory, the Lubben Social Network Scale, and the Self-Efficacy Scale for Helen (Client #3) are presented in Figure 4.7, Figure 4.8, and Figure 4.9.

Figure 4.7 (p.95) depicts changes in burden on a pre/post basis by factors of the Caregiver Burden Inventory developed

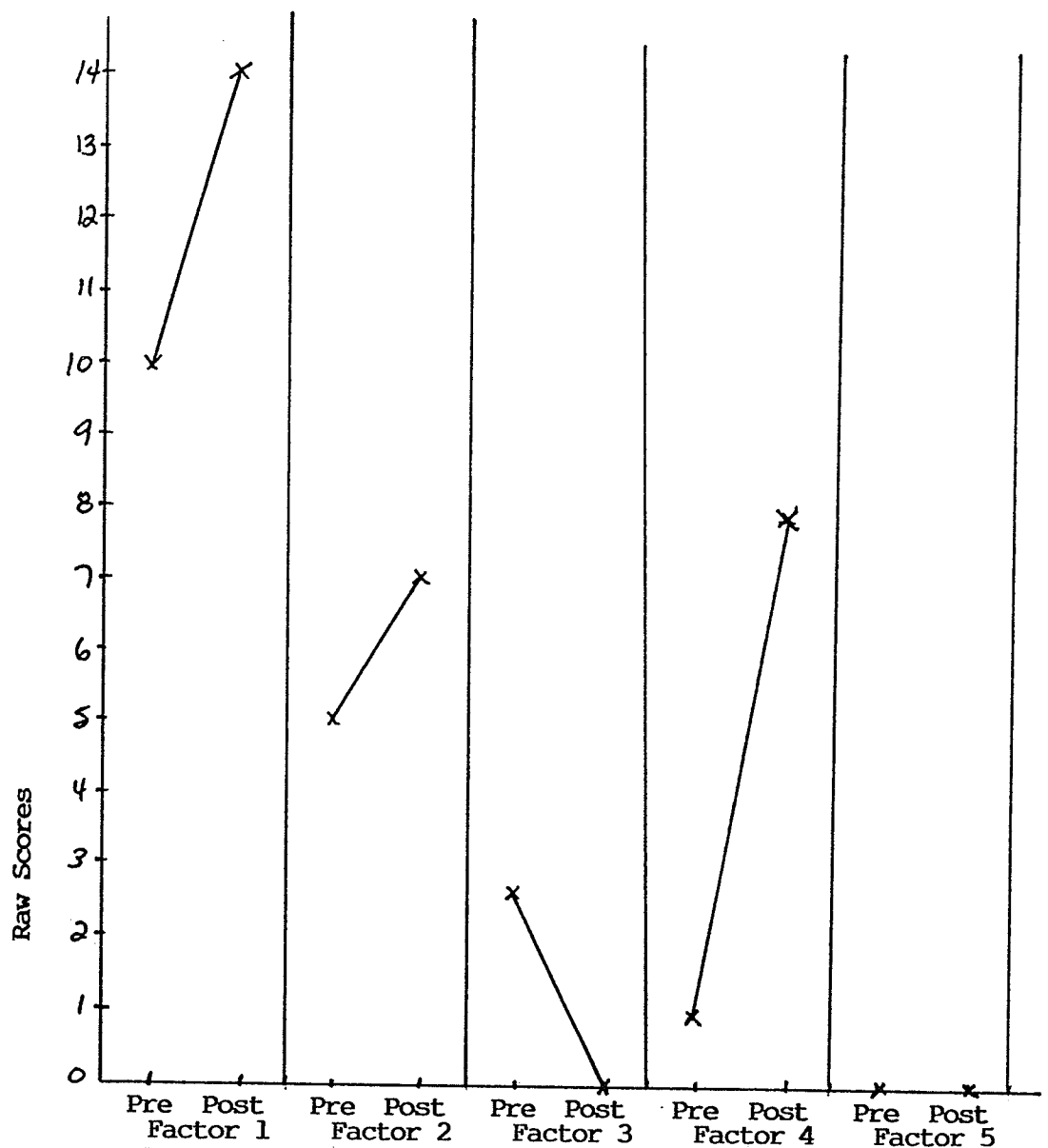
by Novak and Guest (1989). On Factor 1, which describes "Time Dependence" or the amount of burden resulting from demands upon the caregiver's time, Helen scored 10 on the pre-test and 14 on the post-test, indicating an increase in perceived burden. This result is slightly higher than the mean score ($x=6.98$, $s.d.=5.89$) derived from Novak and Guest's (1989) study of caregivers. Helen underwent a transition from "Part-Time Full Care" to "Full Care" which involves greater amounts of time spent caregiving and thus, would account for this change in burden.

On Factor 2 which describes "Developmental Burden", the feeling of being "off-time" with peers, Helen scored 5 on the pre-test and 7 on the post-test, again indicating an increase in perceived burden. These scores are, however, comparable to the mean score ($x=7.08$, $s.d.=5.89$) derived from the study by Novak and Guest (1989). Helen may have felt less "connected" with peers when she made the transition to full-time care, and thus, this would account for the increase in burden score.

On Factor 3 which describes "Physical Burden", Helen scored 2.5 (adjusted) on the pre-test and 0 (adjusted) on the post-test which indicates a decrease in physical burden. These scores are just slightly lower than mean score results ($x=4.37$, $s.d.=4.72$) derived from the Novak and Guest (1989) study.

On Factor 4, which measures "Social Burden" or burden resulting from role conflict, Helen scored 1 on the pre-test

Figure 4.7 CHANGES IN BURDEN BY SUB-SCALE
 Client #3: Helen



CAREGIVER BURDEN INVENTORY (CBI)

- Factor 1 - Time Dependence
- Factor 2 - Developmental Burden
- Factor 3 - Physical Burden
- Factor 4 - Social Burden
- Factor 5 - Emotional Burden

and 8 on the post-test, again indicating an increase in burden. The increasing demands for care with the transition to "Full Care" could have emphasized feelings of role conflict which would account for this increase in burden. These results are slightly higher than reported mean scores ($x=2.54$, $s.d.=3.54$) for this factor (Novak and Guest, 1989).

The last factor relates to emotional burden, which is the caregiver's negative feelings toward their care recipient. Helen scored 0 on both the pre and post-test. This result is lower than the reported values ($x=2.02$, $s.d.=3.04$) by Novak and Guest (1989). Helen had a difficult time admitting any negative feelings toward her father, despite feelings of burden, which may account for her low score.

Figure 4.8 (p.97) depicts changes in social network as measured by the Lubben Social Network Scale (Lubben, 1988). Helen scored 37 on the pre-test and dropped to 33 on the post-test. These results are slightly higher than mean scores ($x=25.1$, $s.d.=9.6$) obtained through Lubben's (1988) study. The decrease in social networks may be related to her transition into full-time caregiving, thus isolating her from her previous network at work.

Figure 4.9 (p.97) depicts changes in self-efficacy as measured by the Self-Efficacy Scale (Sherer et al., 1982). This scale is divided into two sub-scale measuring social and general self-efficacy. On the pre-test, Helen scored 21 on the social sub-scale, and 77 on the general scale, for a total

Figure 4.8 CHANGES IN SOCIAL NETWORK (Pre/Post Group)

Client #3: Helen

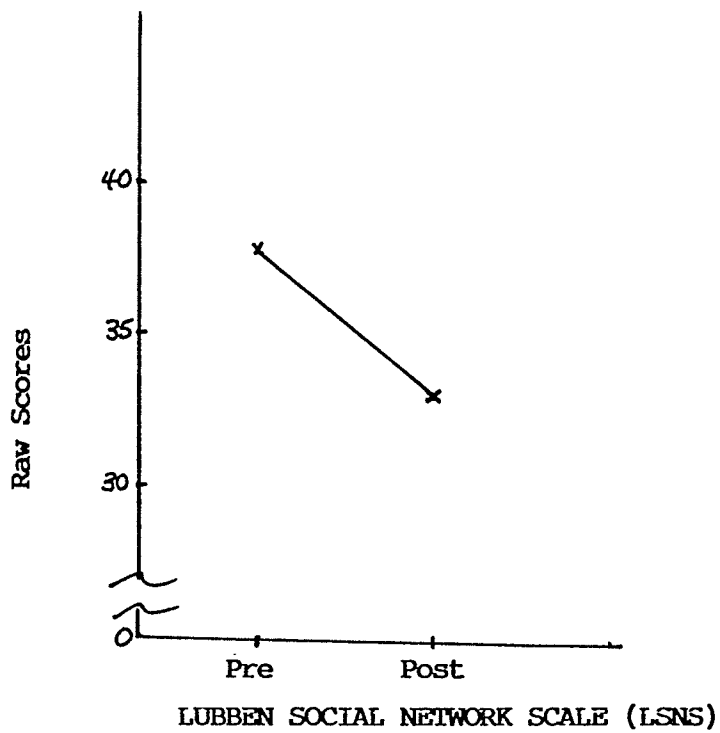
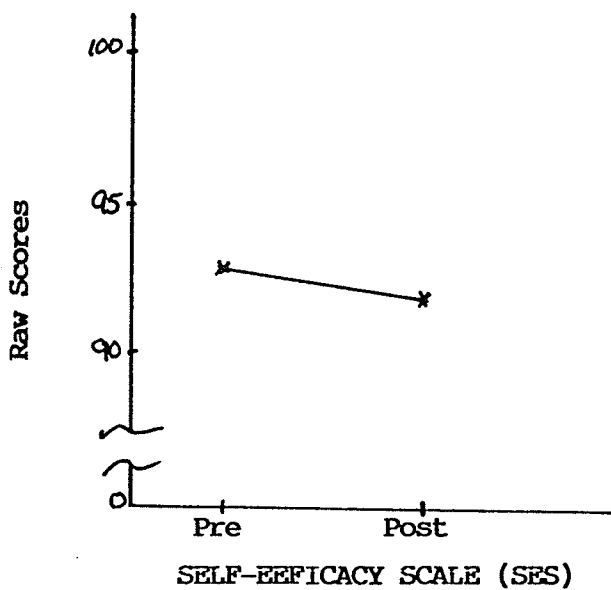


Figure 4.9 CHANGES IN SELF-EFFICACY (Pre/Post Group)

Client #3: Helen



score of 98. Comparatively, on the post-test, Helen scored 17 on the social scale and 80 on the general scale, for a total of 97. These results are slightly higher than the results obtained by a study of college students by Sherer et al. (1982) which indicated a mean of $x=21.20$, $s.d.=3.63$ for the social sub-scale, and $x=64.31$, $s.d.=8.58$ for the general sub-scale. Although these results show a slight decrease in self-efficacy, Helen herself reported increased feelings of assertiveness, self-confidence, and empowerment.

CASE SUMMARY:

In summary, Helen experienced a great deal of transition throughout the course of the group as she retired from her job and took on full-time caregiving, moving from "Part-Time Full Care" to "Full Care". Helen's father experienced some decline in cognitive status which resulted in greater dependency. As well, Helen was the sole caregiver as well as the primary caregiver, providing much more of the care on her own.

With respect to feelings of burden, Helen did not report any significant change despite the increasing amount of care she was providing. However, results on the Caregiver Burden Inventory (Novak and Guest, 1989) would indicate an increase in burden in all but two factors. This scale may have been more sensitive to actual changes in burden than self-report, but Helen also perceived changes in her ability to cope with burden. For instance, the group helped her to accept outside

assistance in caring for her father, and helped to normalize feelings of guilt and frustration.

With respect to social networks, Helen reported no significant changes other than the loss of work companions. This was borne out in the results of the Lubben Social Network Scale (Lubben, 1988) which indicated a decrease in social network size. However, Helen did state that she would be more willing to ask for help and utilize her network as a resource.

With respect to self-efficacy, Helen felt that retiring had reduced her level of stress considerably. She also learned assertiveness skills and self-care within the group setting, thus increasing her sense of empowerment. The scores on the Self-Efficacy Scale indicated a very slight decrease, but this is not supported by self-reported statements.

#4. A Case of Full Care: "Martha"

Martha classified herself as providing "full care" which Lewis and Meredith (1988) defined as the situation where the care recipient requires extensive assistance with personal care and could not be left alone without a substitute carer.

Contextual Information--

Martha was 65 years of age, divorced, and had two grown children. She lived with her mother, having moved back to Manitoba from Alberta nine years ago to care for her mother. Both Martha and her mother are of Ukrainian ethnic background.

Martha reported no significant change in her circumstances over the course of the Group in the post-group interview.

Characteristics of Care--

Martha provided almost total care to her mother, who at age 87 years, suffered from Alzheimer's Disease. She was severely cognitively impaired and required assistance with ambulation, toileting, feeding, dressing, as well as meal preparation, medication supervision, household chores, and management of finances.

Martha's mother calls out constantly at night, a behaviour not uncharacteristic of dementia patients, and disturbs Martha's sleep. And yet, Martha stated that she did not feel burdened by the care she must provide as her mother cannot be held responsible for her behaviour at this point.

Martha was expected to provide care by her family. She saw her mother's deterioration as sad, particularly as she is no longer able to communicate effectively.

In the post-group interview, Martha described her mother's health was progressively deteriorating due to a degenerative disease. Martha had secured her bed with siderails to prevent her mother from falling out. Martha stated that she did not view her role as caregiver differently than previously: she continued to see her role as providing total care to her mother despite the effects on her own health.

She felt that the burden she experienced had remained the same, despite deterioration in her mother's condition.

Martha found that the Group allowed her to hear other's experiences and to deal with feelings of guilt. She stated that she would now find it easier to place her mother in a personal care home, when she could no longer cope.

Social Networks--

Martha had three siblings, none of whom were particularly supportive. Her sister would care for their mother to give Martha a break, but often this was done reluctantly. Her siblings felt that their mother should be placed in a personal care home and this was their solution if Martha ever complained about the burden of caregiving.

Martha had a few friends, including a male friend who she went out with. She saw her friends on a weekly basis and

found them to be supportive of her situation.

Post-group, Martha related that the Group helped her to be more assertive with her sister: she told her that "it was up to her to visit Mother without prompting". Martha reported no changes in her friendship network and did not see Group members as developing into friends.

Other Stressors--

Martha did not work outside the home, so did not have to cope with balancing work demands with caregiving. Her own family lived in Alberta and in England. Martha would have liked to move to Alberta to be closer to her own family, but would not leave her mother.

Post-group, Martha indicated that her own family understood her decision to care, so did not make unrealistic demands upon her. Martha found that she often had to "let things go" around the house in order to care for her mother.

Social Life--

Martha went out every Saturday night with her male friend, and had two afternoons a week for shopping and meeting friends. During these periods, Continuing Care was providing respite.

Post-group, Martha continued to have respite three times a week and seemed satisfied with this amount of time away from home.

Expectations re. Caring--

Martha stated that she felt it was women's responsibility to "care for their own", but she also felt this responsibility should be shared as much as possible with siblings. She did not believe that anyone would care for herself in her old age.

In the post-group interview, Martha asserted that men should take a greater role in caring for their fathers. She also felt that siblings should share the burden of care rather than placing this responsibility onto one person. The Group helped her to express this changed view to her sister. Martha felt that "you cannot put a price on caring" in terms of recognizing women's caregiving contribution. She did express that the Group helped her feel more valued for caring.

Assistance Through Formal Care--

Martha received two afternoons and one evening respite through Continuing Care. Also, she was given another night's respite in order to attend the Caregiver Group. Martha was satisfied with the services and felt that the state was doing its part in caring for the elderly. She maintained that family should have primary responsibility in this arena.

Overall, Martha was satisfied with services from Continuing Care in the post-group interview. She would have appreciated assistance getting her mother to and from doctor's appointments, a service that is not provided by Continuing Care.

As a result of the group discussion, Martha expressed her opinion that the state should create programmes to involve young people in caring for the elderly. She also felt an Income Tax deduction would demonstrate recognition to caregivers.

Self-Efficacy--

Martha found it difficult to cope with the demands of caring, especially without the support of her family. She found crocheting, watching television and gardening to be positive forms of relaxation in coping with this stress.

Post-group, Martha could not identify any new coping skills which she learned through her involvement with the Group, but did indicate increased assertiveness in dealing with her sister.

Martha felt empowered to a certain degree through the group process, particularly with her increased ability to be assertive.

Outcomes--

Martha was depressed at times as she realized that her mother's condition was not going to improve. Martha often experienced anxiety as to whether her sister would come and replace her as planned. This anxiety was well-founded as her sister had backed out of this plan previously. Martha reported that she had never been a completely well person, but attempted to maintain a positive attitude and felt that this

contributed to wellness.

Post-group, Martha continued to feel depressed and anxious at times, but overall, she remained well most of the time.

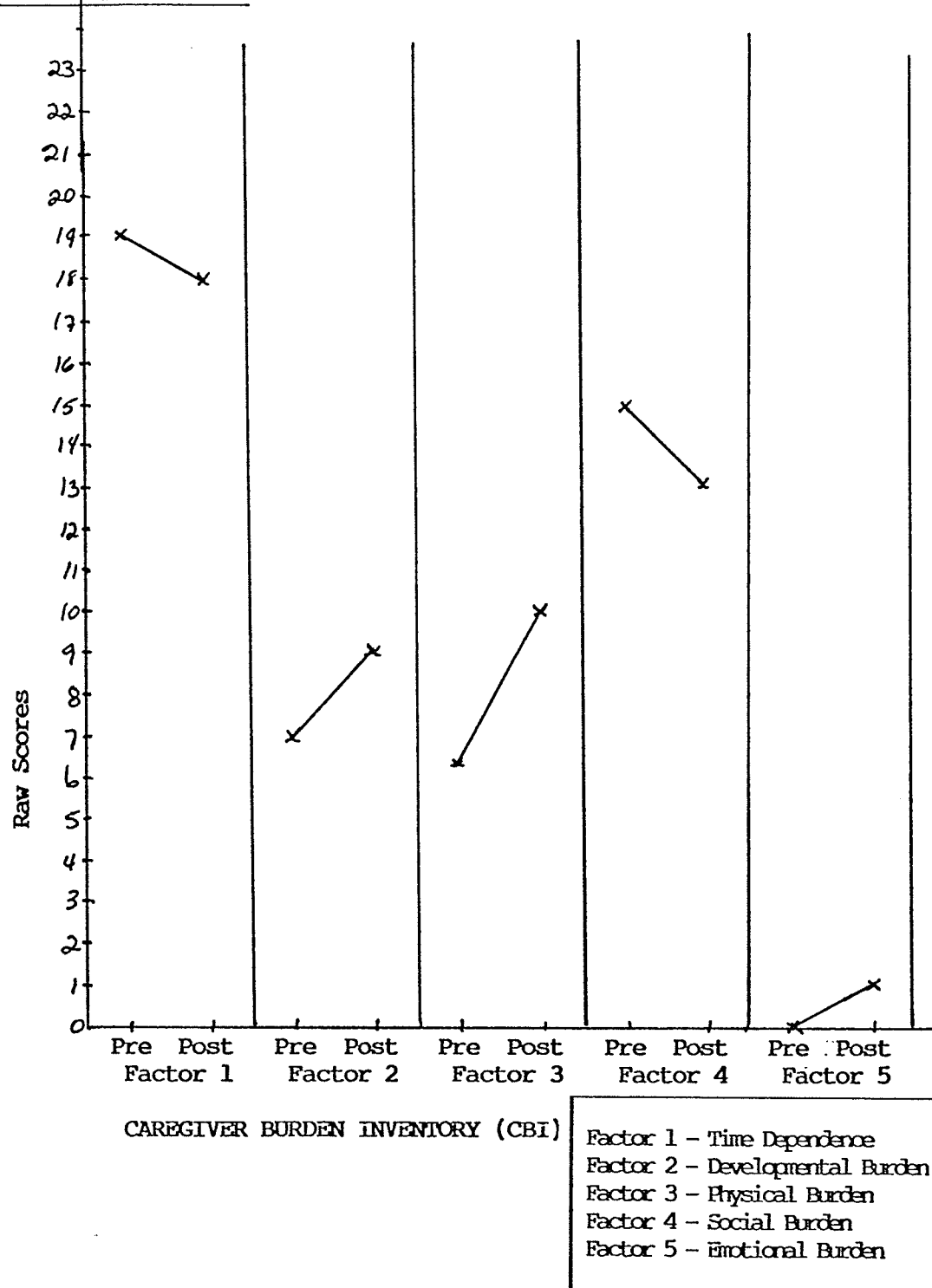
Quantitative Data:

Quantitative results from administration of the three scales for Martha (Client #4) is presented in Figures 4.10, 4.11, and 4.12 which follow.

Figure 4.10 (p.106) depicts changes in burden by factor analysis of the Caregiver Burden Inventory (Novak and Guest, 1989). On Factor 1, which relates to "Time Dependence", Martha scored 19 on the pre-test and 18 on the post-test, indicating a slight decrease in burden. These scores are higher than the mean score ($x=6.98$, $s.d.=5.89$) obtained through the Novak and Guest (1989) study of caregivers. Martha is the sole caregiver of an Alzheimer's victim in the latter stages which may account for the amount of time burden she feels.

On Factor 2, which relates to "Developmental Burden" or the sense of being "off-time" with peers, Martha's score increased slightly from 7 on the pre-test to 9 on the post-test. These scores, however, are comparable to the mean score ($x=7.08$, $s.d.=5.89$) reported by Novak and Guest (1989). As Martha's mother deteriorated and required additional care, she may have felt increasingly isolated and alienated from her friends.

Figure 4.10 CHANGES IN BURDEN BY SUB-SCALE
Client #4: Martha



On Factor 3, which describes "Physical Burden", Martha again experienced an increase in burden from 6.25 (adjusted) on the pre-test to 10 (adjusted) on the post-test. These results are slightly higher than the mean score ($x=4.37$, $s.d.=4.72$) from the Novak and Guest (1989) study. Martha's mother was deteriorating physically and cognitively, which may account for the increase in physical burden, as her care needs were steadily increasing.

On Factor 4, which describes "Social Burden" or the experience of role conflict, Martha scored 15 on the pre-test and 13 on the post-test. Again, these results are significantly higher than reported values ($x=2.54$, $s.d.=3.54$) from the Novak and Guest (1989) study. New learning from the group process in terms of coping with conflict may account for the decrease in burden on this factor.

On Factor 5, which relates to "Emotional Burden" or the caregiver's negative feelings toward the care recipient, Martha scored 0 on the pre-test and 1 on the post-test which was comparable to results from Novak and Guest (1989) which were $x=2.02$, $s.d.=3.04$. Martha had a difficult time admitting any negative feelings about her mother, and perhaps the increase on this factor is an indication that the group helped Martha to express her true feelings.

Figure 4.11 (p.108) depicts changes in social network as measured by the Lubben Social Network Scale (Lubben, 1988). Martha experienced a slight increase from 33 on the pre-test

Figure 4.11 CHANGES IN SOCIAL NETWORK (Pre/Post Group)

Client #4: Martha

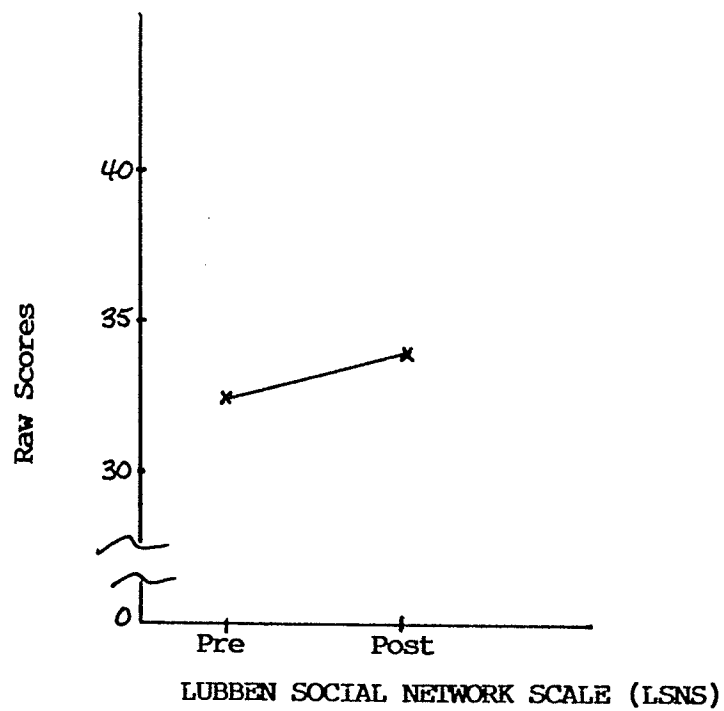
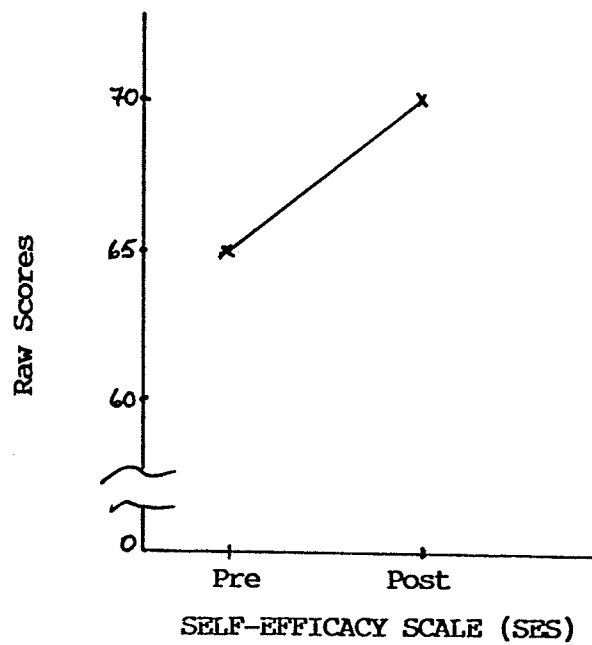


Figure 4.12 CHANGES IN SELF EFFICACY (Pre/Post Group)

Client #4: Martha



to 34 on the post-test. These results are comparable to the mean score ($x=25.1$, $s.d.=9.6$) derived from Lubben's (1988) study of Medicaid recipients. Martha had limited social contacts as she could only leave her mother occasionally, but the group interaction provided her with one night of socialization which may account for the slight increase. As well, Martha stated that the quality of her relationships, particularly with her sister, improved as she became more direct and assertive.

Figure 4.12 (p.108) depicts changes in self-efficacy as measured by the Self-Efficacy Scale (Sherer et al., 1982). This scale is divided into two sub-scales which specifically examine social and general self-efficacy. On the pre-test, Martha scored 9 on the social scale, and 56 on the general scale, for a total score of 65. On the post-test, Martha scored 11 and 59 respectively, for a total score of 70, thus, indicative of an increase in self-efficacy. These scores are comparable to results obtained through Sherer et al.'s (1982) study whose mean score was $x=21.20$, $s.d.=3.63$ for the social sub-scale and $x=64.31$, $s.d.=8.58$ for the general sub-scale. These scores are also supported by qualitative data which indicates that Martha became more assertive as a result of the group.

CASE SUMMARY:

In summary, Martha continued to provide "Full Care" to

her mother who suffered from Alzheimer's Disease. Martha was faced with increasing care needs due to her mother's physical and cognitive deterioration.

In spite of these increasing care needs, Martha maintained that her level of burden had not increased. However, this was not borne out by results on the Caregiver Burden Inventory (Novak and Guest, 1989) which showed an increase in burden on most of the factors. In this case, Martha may have been denying the actual amount of burden she felt, but the scale was more sensitive in quantifying the measure.

With respect to social networks, Martha reported little change in their composition, but did feel the group had helped her to draw upon her social network for more support, and that the quality of her relationships had improved. The Lubben Social Network Scale (Lubben, 1988) demonstrated a slight increase in social networks, which may be accounted for by the increase in social contacts through the group.

Martha reported some positive changes with respect to self-efficacy in that she had gained assertiveness skills which she utilized in interacting with her sister. The results of the Self-Efficacy Scale (Sherer et al., 1982) reflected a similar movement toward greater self-efficacy.

OVERALL SUMMARY:

Although the results demonstrated some common trends, it must also be borne in mind that individual differences account

for some of the change. It appears that the "stage" of caregiving has a significant effect upon changes in burden, social networks, and self-efficacy. The "Semi-Care" and "Part-Time Full Care" caregivers both experienced a decrease in burden, whereas the "Transition" and "Full Care" caregivers experienced an increase in burden, as measured by the Caregiver Burden Inventory (Novak and Guest, 1989). However, interestingly, all of the participants reported either a decrease or no change in their perceived burden. This difference may be accounted for by the sensitivity of the measure which can discriminate specific types of burden. The increase in burden in the latter two stages may relate to increasing care demands which overshadowed the positive effects of the group in terms of coping with burden.

With respect to social networks, all participants reported positive changes in the quality of relationships and the kind of support they received from their network. However, this result was not borne out by the Lubben Social Network Scale (Lubben, 1988) which demonstrated an increase for the "Full Care" caregiver, but a decrease for the remaining caregivers. The most dramatic change occurred with the "Transition" caregiver who experienced a substantial decrease in social networks when she retired from her full-time job to provide care on a full-time basis.

With respect to self-efficacy, a similar discrepancy was found between results from self-report and from the measure.

All participants decribed changes in their assertiveness, self-confidence, and feelings of empowerment, all of which are components of self-efficacy. However, the scores from the Self-Efficacy Scale (Sherer et al., 1982) did not consistently support these changes, which may be attributed to a lack of sensitivity or relevance of this measure to women caregivers.

CHAPTER V -- GROUP FINDINGS

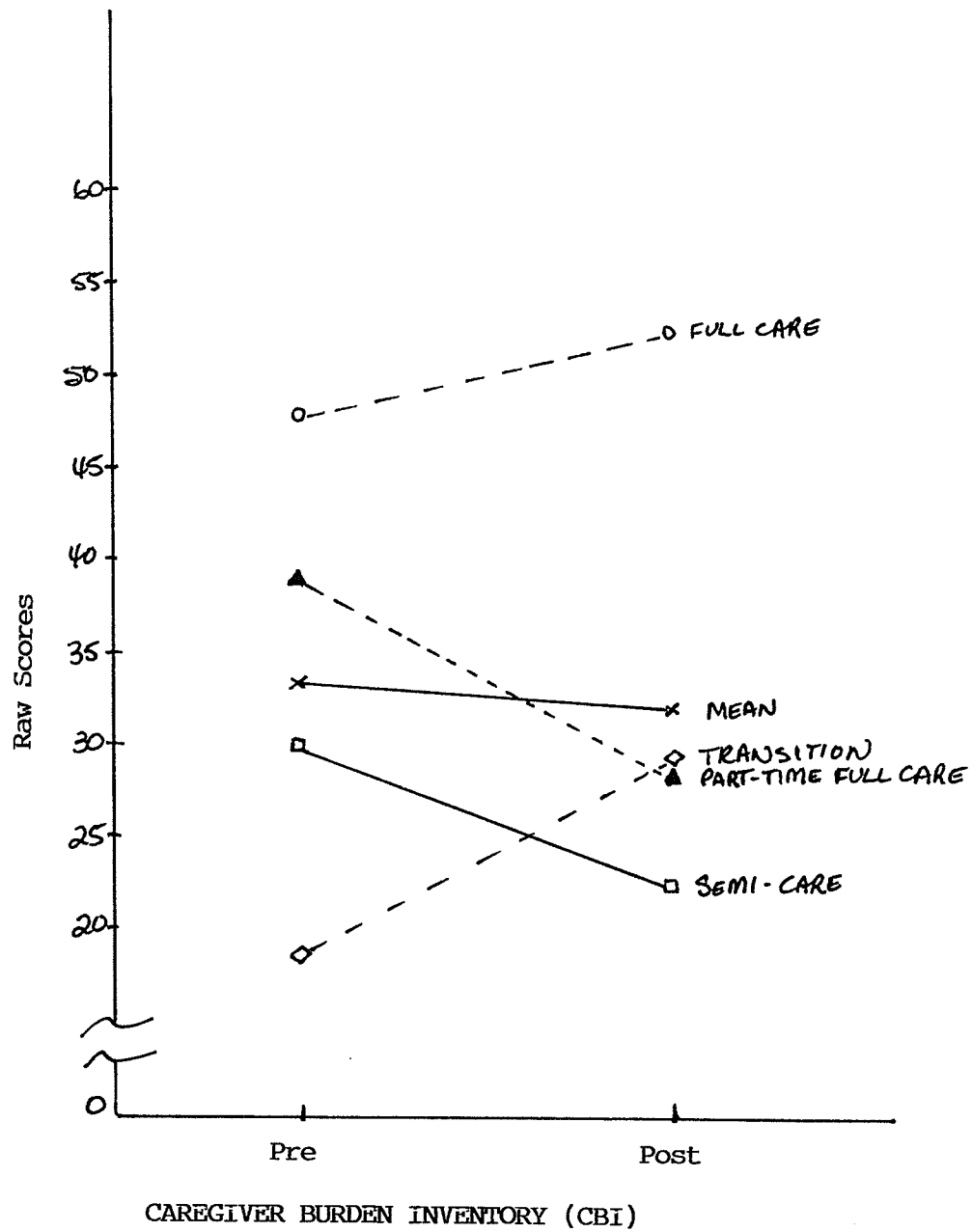
The focus of this chapter is an examination of significant and common issues for women caregivers which were addressed within the group context. As well, on a session-by-session basis, the author will present the topic for discussion, the participants' sharing about common issues, and an analysis of the group process. The group findings presented here will further support the individual qualitative data gathered from the pre and post interviews.

The Women Caregivers Support Group took place in Portage la Prairie, Manitoba, in May and June of 1992. Although six participants were initially recruited for pre-group interviews, two women were unable to continue and the group stabilized with four members. Interestingly, as alluded to in the individual case studies, the four women also represented four different phases of caregiving, adding to the variety of experience and richness of data derived from the group.

The graphs which follow depict the quantitative group findings, by comparative analysis of individual results utilizing the three scales: the Caregiver Burden Inventory, the Lubben Social Network Scale, and the Self-Efficacy Scale. As well, mean scores (\bar{x}) for each scale are presented on a pre/post basis. These results can be referenced in Figures 4.13, 4.14, and 4.15.

Figure 4.13 (p.114) demonstrates comparative changes in burden of the participants, as classified by their stage of

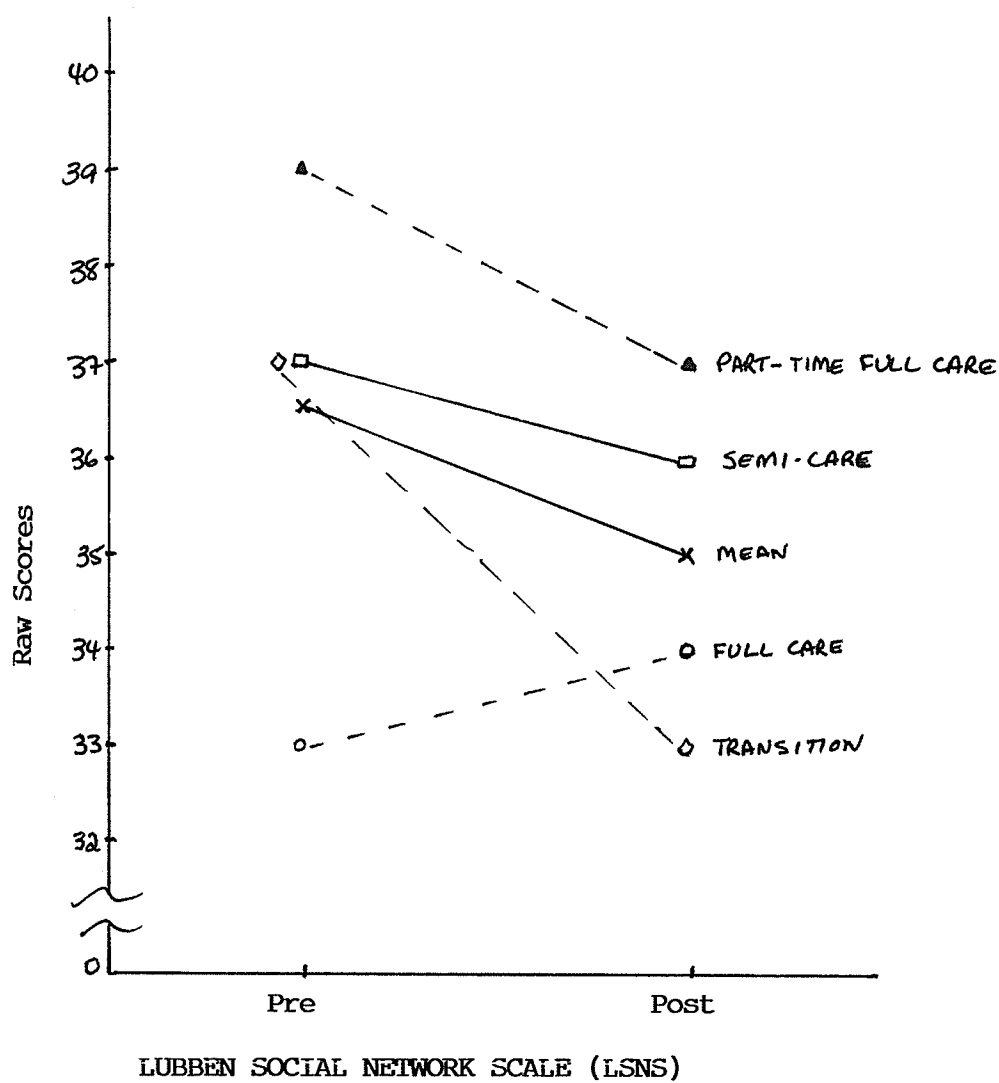
Figure 4.13 COMPARATIVE CHANGES IN BURDEN (Pre/Post)



caregiving. The highest level of burden is shown by the "Full Care" participant, with 47.25 pre-group and a slight increase to 51 post-group. The "Part-Time Full Care" participant had the next highest score, 38.5, which decreased post-group to 28. The "Semi-Care" participant experienced a decrease in burden from 29.75 to 22.25 post-group. The participant in transition from "Part-Time Full Care" to "Full Care" experienced an increase in burden from 18.5 to 29 post-group. The overall mean scores were $x=33.5$ (pre-group) and $x=32.57$ (post-group). One would expect the greatest amount of burden to be experienced by the "Full Care" participant as the care demands are greater. As well, the "Transition" caregiver experienced a significant increase in burden when she began full-time caregiving. The other two stages, "Semi-Care" and "Part-Time Full Care" demonstrated decreases in burden, as the care demands were relatively stable, and they perhaps were better able to apply stress management techniques in balancing their own lives and their caregiving lives.

Figure 4.14 (p.116) depicts comparative changes in social network. In this instance, the "Part-Time Full Care" participant had the highest score with 39 pre-group and 37 post-group. The "Semi-Care" participant had 37 pre-group and 36 post-group. The "Transition" participant had 37 pre-group and decreased to 33 post-group. The "Full Care" participant increased from 33 to 34 post-group. The overall mean score was $x=36.5$ (pre-group) and $x=35$ (post-group). Although most

Figure 4.14 COMPARATIVE CHANGES IN SOCIAL NETWORK (Pre/Post)

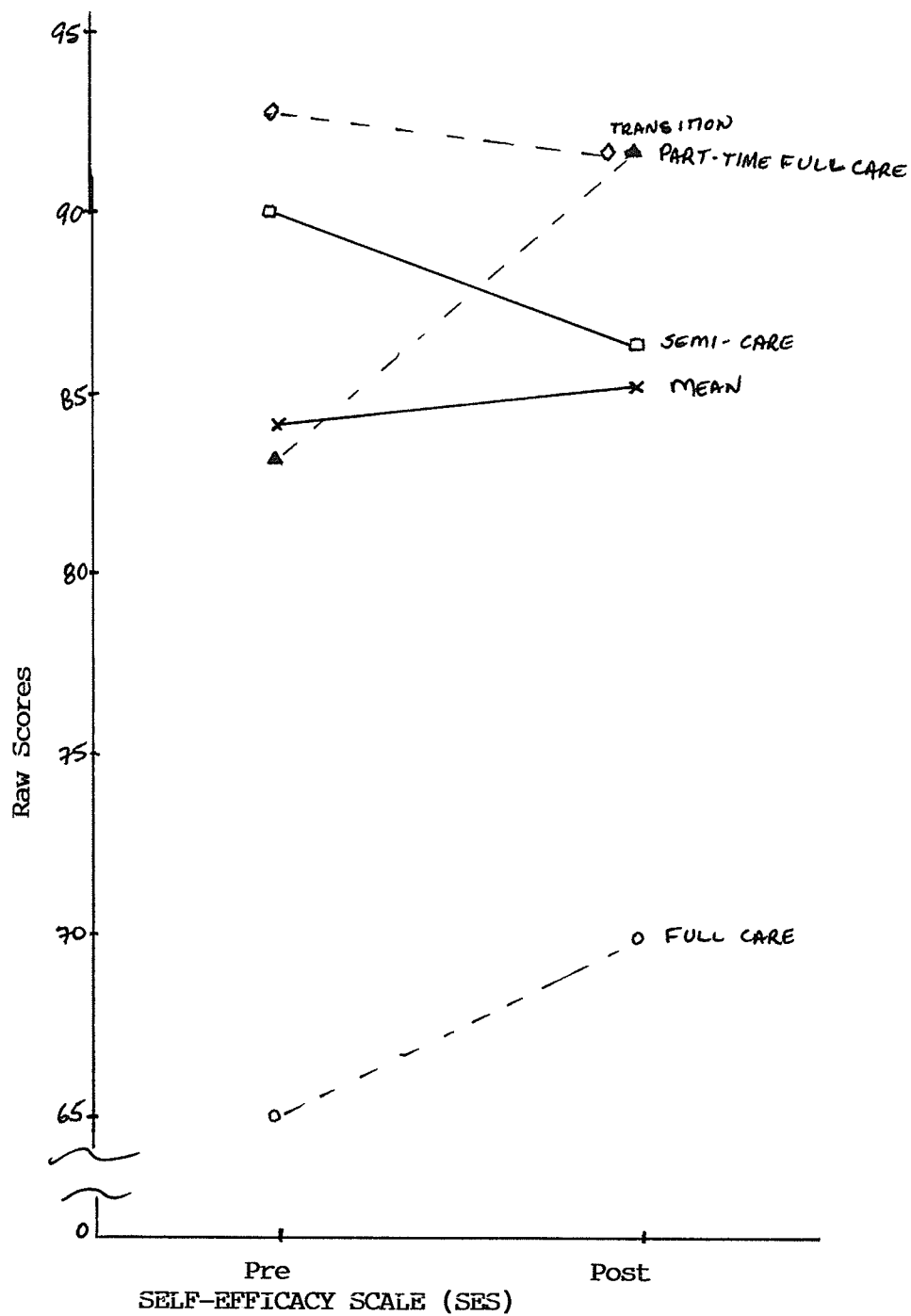


participants showed a decrease in score, the order of highest to lowest score was consistent with what would be expected. For instance, the "Part-Time Full Care" caregiver still has contacts at work, as often is the case with the "Semi-Care" caregiver. The "Full Care" caregiver tends to be more socially isolated, as she has less freedom to socialize outside her home due to caregiving demands. As well, the "Transition" caregiver showed a marked decrease with the loss of her social contacts at work, and a corresponding decrease in opportunities to socialize.

Figure 4.15 (p.118) shows changes in self-efficacy on a comparative basis. The "Transition" participant had the highest score with 98 pre-group and 97 post-group. "Semi-Care" quickly followed with 91 pre-group and a decrease to 86 post-group. The "Part-Time Full Care" participant scored 89 on the pre-test and increased to 93 on the post-test. The lowest score was the "Full Care" participant who increased from 65 to 70 pre/post-group. The overall mean scores were $\bar{x}=85.75$ pre-group and 86.75 post-group. Again, these scores do not correspond with self-reports, which indicated that all participants described positive changes in their level of self-efficacy. It is possible that the measure was not sensitive enough to the specific issues relevant to women caregivers.

Qualitative data from each group session was gathered through written progress notes and through the use of video

Figure 4.15 COMPARATIVE CHANGES IN SELF-EFFICACY (Pre/Post)



taping each session for analysis. For the purpose of presentation of results, the major findings will be reviewed, in terms of meeting the stated objectives of this practicum, as well as tracking the participants' own growth throughout the group process.

Session #1:

The main purpose of the first session was to facilitate group discussion and to contract around group purpose, goals, groundrules and topics for discussion, as well as to facilitate "sharing of their own stories" by group members. In attendance were four members, with one woman on holidays and joining the group in Session #3. The facilitator had developed the basic purpose, goals, and groundrules for the group and presented these to the members for their feedback. Although all members agreed to the original outline without revisions, members expressed their appreciation for being included in the process. The facilitator then outlined the topics for discussion in the other sessions which were also well received.

The facilitator then shared some information about herself and her interest in women caregivers, giving other members "permission" to begin sharing their experiences.

As the women described their individual circumstances, several significant issues emerged. For example, Helen raised the issue of increasing dependency of elderly parents and the difficulties presented to caregivers. Helen described her

father as being strong and determined throughout his life, but now is not certain "if he can make it off the couch", whereas his motto usually was "if I can't walk, I'll crawl".

Another issue described by both Helen and Joanne was the tendency of caregiving daughters to become overprotective of elderly parents. They could not relax and let substitute carers provide assistance.

It also became quite clear that there are differences between levels of care in terms of the amount of responsibility placed upon the caregiver. Ellen (Semi-Care) did not have the same level of responsibility as did caregivers in the other categories as her mother continued to live independently with support from family and the state. Ellen could maintain more "distance" than those whose care recipient shared living space with them.

Group Process:

The group quickly engaged and displayed cohesion around contracting for goals, topics and group groundrules. As the session progressed, interactions between members became more spontaneous, and led to the sharing of common experiences. Self-disclosure was encouraged by the facilitator, as was development of mutual support within and outside of the group setting.

Session #2:

This session was attended by only two members, as Sarah's mother had fallen, and Ellen had a conflicting commitment. The major issues raised by participants including the ability to "let go" of their need to take total responsibility for caregiving tasks. Joanne relayed that she had arranged for Meals on Wheels for her mother to lessen the burden of preparing meals to suit her mother's diet. Also raised was the fear that elderly parents have of becoming a "burden" to their daughters and the constant need for reassurance from caregiving daughters that they are not a burden. Both Joanne and Helen found themselves reassuring their parents, but feeling ambivalent at the same time.

The topic for this session was "The Aging Process and Stressors Associated with Caregiving". The facilitator focused upon describing normal aging (sensory changes, changes in body systems, etc.), as well as the diseases often associated with growing older. Cognitive changes, changes in personality, the need for socialization were also discussed. Members had questions regarding cognitive changes and confusion, withdrawal from social interaction due to sensory deficits. The contributing factors to caregiver stress were explained in detail, and feelings of anger, guilt and frustration were normalized by the facilitator. Joanne was relieved to be validated for having these feelings. In particular, guilt and feelings of inadequacy were difficult

emotions for the women to cope with.

The emotional strain of caregiving was particularly evident when caring for parents due to the additional attachment. Joanne described her mother as very needy, at times "sucking her dry" of emotional energy, and yet, she herself was not able to seek support from her mother. Helen felt that you could never "walk away" from your parent, as she was forever worrying about her father. Work provided a legitimate escape from caregiving, despite the added stress it entailed.

The importance of the caring labour provided by these women was reinforced and validated by the facilitator. The lack of response of society in recognizing women caregivers' contribution was discussed. Joanne expressed a desire to look at ways of advocating for more recognition. The whole issue of women caregivers was framed within a feminist perspective by the facilitator.

Group Process:

There was evidence of mutual sharing and increasing cohesion between group members, as the group began to take on a sense of "we-ness".

Session #3:

The fourth permanent member of the group, Martha joined after returning from a vacation. Martha was given some time at the beginning of the session to share her "story" and to begin integration into the group.

The topic for this session was "Stress Management and Self-Care". In her presentation, the facilitator focused upon the causes of stress, and how people react to stress, as well as coping methods, such as assertiveness-training, relaxation exercises. Also discussed was the importance of self-esteem, self-confidence, and empowerment as concepts related to coping with life's stressors.

Joanne and Helen reinforced the effectiveness of using relaxation exercises, but Martha was more sceptical. In her busy day as a caregiver, she felt she would have no time for "meditating"; if she had a free moment, she would watch television or crochet. The discussion on assertiveness-training challenged group members to look at their own patterns of coping and how they could use assertion skills to promote themselves as worthwhile, competent women. Joanne sometimes found herself being provoked and then "flying off the handle" as her "anger would take over". She also pointed to gender differences in how assertiveness and aggressiveness are viewed: what is seen as assertive for men is often viewed as aggressive for women. Ellen related a recent incident where she regretted her passivity and wished that she had responded more assertively.

The facilitator had photocopied material on self-care and relaxation exercises for participants to review and apply at home. Overall, the group members seemed to benefit from consciousness-raising around the importance of self-care.

Group Process:

In terms of process, the introduction of a new member into a "formed" group met with some resistance. There seemed to be an undercurrent that the group cohesiveness would be threatened by the addition of another member.

Session #4:

This session focused upon "Emotional Reactions to Caregiving" and all members shared the range of emotions they have experienced in the process of providing care. Martha first shared her anger, frustration about Alzheimer's Disease and how it "took away the mother she knew". Participants also discussed the issue of nursing home placement and how to decide when was appropriate. The differences between types of care again became evident in this discussion. Ellen's (Semi-Care) mother is waiting placement in a personal care home and seemed accepting of this move, but Ellen herself was feeling guilty for not providing more care, or having her mother move in her home. Martha (Full Care) wants to keep her mother at home for as long as possible, but realizes that she will not be able to meet the demands of her mother's care soon. Joanne questioned their motives for "keeping their parents at home". Is it for the care recipient or to alleviate the caregiver's sense of guilt and obligation?

In terms of self-care, the facilitator focused upon fitting caregiving tasks into the caregiver's schedule, in order to reduce the stress of juggling different demands. For

instance, Joanne relayed an incident where her mother scheduled a hairdresser appointment for a working day. Joanne did take time off work to transport her mother, but made it clear that she would only take her on weekends in the future.

Another topic for discussion was sibling relationships and the division of labour around caregiving. Interestingly, all members were basically sole providers of care, with siblings only assisting when asked. Helen found her sister from B. C. to be supportive, but she of course was limited by distance. Martha's siblings are critical of her efforts, and yet refuse to help. All members agreed that their siblings lacked understanding for their role as primary caregivers and did not have a realistic picture of their parents' capabilities.

Negative outcomes such as depression and anxiety were discussed with the women, and the use of cognitive restructuring was suggested as a method of reducing these negative outcomes. Joanne related that she held a distorted perception that it was her responsibility to ensure her mother and her daughter maintained a good relationship. When she learned to "let go" of their problems, she reduced her feelings of anxiety and depression.

Group Process:

This session saw a great deal of interpersonal communication and validation between group members, resulting in increasing cohesion and full integration of the new member.

The facilitator focused specifically on the new member at the beginning in order to establish that she was to be included.

Session #5:

In this session, participants were struggling once again with the issue of taking responsibility for other's behaviours or for ensuring their happiness. Ellen's uncle, to whom she also provided care, was admitted into a personal care home, but Ellen was finding it difficult to "let go" of her caring responsibilities and found herself dissatisfied with the care he was receiving. Joanne relayed that she had made progress in that she could see her mother from a different perspective by "stepping back" and not taking responsibility for her behaviour.

The topic this session was "Formal and Informal Care" and consisted mostly of describing existing services locally and across the province. Members were receptive to this information as they were all willing to look at alternatives to their present situations. We discussed the services provided by Continuing Care, and overall, the feedback was positive, with the exception that most found the system inflexible in meeting individual caregiver's needs.

The women maintained that primary responsibility for caregiving should rest with the family, but that the state should recognize this contribution to society. Joanne again raised the issue of paying caregivers a pension, or allowing an Income Tax deduction for dependent elderly. Helen

expressed the desire for physicians to make house calls to those elderly who could not get to the clinic.

Group Process:

The group members interacted in a comfortable manner, and have become increasingly aware of their boundaries in terms of not dominating group time. When this did occur, the facilitator would redirect the conversation.

Session #6:

This session was held on an informal basis due to environmental conditions at the building where the group was being held. Therefore, the facilitator chose to reverse the order of the topics of Session #6 and #7. The topic "New Ways of Coping and Achieving Increased Wellness" was discussed informally over coffee at a local restaurant. As the facilitator had been encouraging members to meet between group sessions and this had not yet occurred, this exercise was a good model. Helen's sister who was down for two months joined the group, and provided an interesting perspective from a sibling who was not primary caregiver. She, however, was very supportive and validating of the labour of these caregivers.

Ellen described a new stressor which was her mother's increasing demands for attention at night: she would call her in the middle of the night in a panic, but settle down when Ellen arrived. As well, her mother is now ambivalent about personal care home placement. A discussion followed about the pros and cons of personal care homes and how they fit into the

continuum of care.

These concerns raised were related to the topic in terms of group problem-solving around finding new ways to cope with stress in order to promote wellness for participants.

Group Process:

This informal session allowed members to learn about each other on a more personal level, and will hopefully translate into the development of friendships. The level of mutual support and cohesiveness was very high; overall, members felt very positive about the group and expressed a desire to reunite on a monthly basis next fall.

Session #7:

In this session, the topic for discussion was "Women as Caregivers" which the facilitator presented the feminist perspective on women's role as caregivers, the political implications of community care, the oppression of women within a gendered division of labour. We also discussed the financial implications of giving up work or taking early retirement or having to take time off without pay. Because women are the primary caregivers, there has not been a public outcry as this is seen as "natural", whereas if men were forced into the same position, community services would soon be developed. The attitudes of women caregivers, as expressed within the group, may also inhibit the sharing of caregiving labour: men were seen as incapable of providing care, or were viewed as "feminine" if they did. Socialization practices

have taught these women a gender-based division of labour. Joanne countered these views with "we can't even advocate in our own families, never mind in society at large".

Helen's sister felt it was important for primary caregivers to learn how to ask for help in order to increase the sharing of care responsibilities. The facilitator reframed this as the primary caregiver is helping other siblings by caring all the time, so it is permissible to ask for help when needed. There exists a circular reinforcement of the role of women caregivers: Helen stated that her family feels nobody can care as well, as much as her, and she has internalized this belief, so she will not ask for help, from family or from formal services. The facilitator reframed this issue as one of control and linked it to other common themes throughout the group: not letting go of the need to control the care, worrying about whether substitute carers can provide good care, and the overprotectiveness of caregivers.

A good discussion about sibling relationships ensued with Joanne stating that her sisters only came when it was convenient for them, and Helen's sister asking if that was true in their case. Martha feels comfortable when her sister comes to care for their mother and is able to relax, but this occurs very infrequently.

With respect to the formal care system, members expressed a need for services to be more flexible, to be tailored to individual circumstances, rather than fitting all caregivers

into a rigid system. Community Care needs to be better funded if adequate services are to be provided.

The group also discussed workplace support for caregivers and some of the innovative programmes in the United States such as in-house adult day programmes, flextime, flexplace (working at home), job-sharing, etc. Those members who were working found their employers quite understanding, although many formalized programmes were not in place.

Group Process:

The women seemed to connect as women around this common issue and the level of sharing was very high. The women were processing the information and attempting to apply it to their own situation which is consistent with feminist intervention.

Session #8:

This concluding session consisted of obtaining feedback, both written and oral, from group members on the effectiveness of the group intervention. As well, the group spent some time socializing as a "wind-up" to the eight weeks.

As a verbal evaluation, the facilitator began by reviewing the group goals initially set out to gain the members' perspective.

The first goal was to provide a safe environment in which women caregivers can share common experiences and feelings, as well as gain support and validation. The group members felt that this goal had been achieved, as they felt comfortable in sharing personal experiences, and found that their peers could

understand and empathize with their situations. Joanne commented that the group was a "safe place to complain" without fear of retribution, and where she would receive empathy, and understanding. The members also felt validated by other members in the group, as well as the facilitator.

The second goal was to provide education regarding self-care (stress management, assertiveness-training, problem-solving) and community resources. Ellen commented that the group was very informative. Joanne would have liked to have spent more time on stress management, but appreciated the hand-outs for reference at home. She would have liked a more practical application of some of the stress management techniques in the group session. Problem-solving occurred within the group, but was not formally discussed. Community resource material was well presented.

The third goal was to utilize cognitive restructuring techniques to assist in changing possible negative outcomes such as depression and anxiety. The group felt this goal was partially achieved, but more time could have been spent as it was incorporated into the session with stress management and self-care techniques. As a result of participant feedback, and the author's own observations, the number of group sessions should be increased to address this need more fully.

The fourth goal was to assist participants in making changes in their own networks and in the larger systems context to gain further support and recognition for their

caring labour. This goal referred to the translation of information into our own contexts. Joanne stated that she used the information in dealing with her daughter and mother, and wants to share some of the material with her sisters. Martha told her sister that it was her own responsibility to visit her mother, and that Martha would not make excuses for her, thus displaying increased assertiveness. Other participants stated that they had indeed been able to use the information to apply to their own situations, and all members proposed changes to the larger system context that could be implemented in the future.

The last goal was to form the basis for future advocacy and expansion of support services, both formal and informal. Joanne felt that the group had "planted the seeds", but more work needed to be done in this area, and agreed to reunite in the fall. Other members expressed an interest, but this was tempered by their limited time and energy. The group talked about meeting once a month next fall, and spinning off into a self-help group model with some continuing input from the facilitator.

In terms of written feedback, the Client Satisfaction Questionnaire (Attkisson et al., 1989) was administered to all participants on an anonymous basis. Table 5.1 (p.134) displays these results.

The responses to question #1 would indicate that the quality of the service received was high and that participants

were satisfied with the group.

Question #2 addresses the question of the appropriateness of the service, which again the participants were generally very satisfied. The group provided the participants with the kind of service they had expected.

Question #3 relates to the extent to which the group met the needs of the participants. Again, the responses were very positive, indicating that the group addressed needs identified by the women in the initial group session.

Question #4 inquires about the confidence that participants have in the programme with respect to referring friends. The group members felt very positive about their experience and commented that they felt the group could benefit other caregivers.

In question #5, the amount of help received is rated, and most of the participants were again positive, but one responded "quite dissatisfied", perhaps hoping she would have received more help than she did through the group.

Question #6 asked whether the services helped the respondent in coping more effectively with her problems, and again, the responses were positive. The participants felt that they had learned new ways of coping with their problems and issues.

Question #7 addresses the general satisfaction of the participant, and the responses were very positive, indicating that, overall, participants felt the group was a successful

intervention.

The last question asked if the participant would seek similar help from the programme in the future. The participants' responses were very positive, with three definite answers and one probable response.

Table 5.1: Results of the Client Satisfaction Questionnaire

QUESTION	RESPONSE		
	Excellent	Good	Poor
1.How would you rate the quality of service you have received?	* 2	2	0
2.Did you get the kind of service you wanted?	Yes, definitely 3	Yes, generally 1	No 0
3.To what extent has our program met your needs?	All needs met 3	Most met 1	None met 0
4.If a friend were in need of similar help, would you recommend our program to him or her?	Yes, definitely 3	Yes, I think so 1	No 0
5.How satisfied are you with the amount of help you have received?	Very satisfied 2	Mostly satis. 1	Quite dissat. 1
6.Have the services you received helped you to deal more effectively with your problems?	Yes, a great deal 2	helped some 2	Didn't help 0
7.In an overall, general sense, how satisfied are you with the service you have received?	Very satisfied 3	Mostly satis. 1	Dissat. 0
8.If you were to seek help again, would you come back to our program?	Yes, definitely 3	Yes, I think so 1	No 0

*the numerical values represent the number of responses in each category

Follow-Up Group Meeting:

As discussed in the last session of the group, the facilitator contacted all members and we met for an informal follow-up meeting on November 26, 1992. All members were able to attend and a number of changes had occurred in the women's situations.

Ellen's mother had recently moved to personal care home, and was settling in, although somewhat ambivalent. Ellen felt relieved, but still was at times plagued by guilt, often at the prompting of her sister, who remains unaccepting of their mother's deterioration.

Martha states that her situation has not changed dramatically, but her mother continues to decline mentally and physically. She maintains supports from Continuing Care, but receives limited family support.

Helen's father was quite ill over the summer, but has improved again this fall. However, he still requires a great deal of care. Helen has become increasingly assertive in accessing services through Continuing Care and in pursuing medical intervention; at present, she is coping effectively.

Joanne's mother underwent surgery for breast cancer and is recovering. Joanne now has sole responsibility for her daughter's children and therefore, must continue caregiving both the children and her mother.

The facilitator asked members if they found the group helpful, in retrospect, four months later. Joanne stated that

" Yes, I responded differently than I would have six months ago" (to her mother's surgery). She saw herself as more assertive with nursing staff regarding her mother's care, as well as with her sisters when it came to making decisions regarding their mother. She asked her sisters for "unconditional support", but to allow her, as primary caregiver, to make the decisions. Further, she expressed, "I don't know how I would have made it through the summer without the group."

Ellen felt the group had been very positive, particularly the support from other members. She now feels more freedom to pursue her own interests without guilt now that her mother is in the care home.

Martha continues to verbalize concerns around lack of support from her family, and was encouraged by other members to be more assertive with family and with the medical community.

Helen was very positive with respect to the assistance she received through the group. She stated that now, more than ever, she felt the lasting effects of the group in terms of support and helping her to increase her self-confidence, assert herself and practice self-care.

GROUP SUMMARY:

In summary, the group findings suggest that the goals were all met, at least to some degree, and that it was a

favourable experience for participants. As demonstrated in the individual results, the participants attributed much of their change to the group process. The interaction and sharing within a group setting provides the necessary support for caregivers to begin to change their styles of coping. Incorporation of a feminist perspective into the group intervention probed such issues as the gendered division of labour, the lack of recognition for women caregivers, and the resulting oppression, both economic and psychological, for women. The participants appreciated this different, more proactive approach to the issue of caregiving, and provided them with much learning to apply to their own circumstances.

CHAPTER VI -- DISCUSSION

The overall objective of this practicum study was to design, implement and evaluate the effectiveness of a short-term Caregiver Support Group for daughters and daughters-in-law caring for elderly parents in its ability to meet the needs of this population in terms of reducing feelings of burden, increasing support networks and increasing subjective feelings of self-efficacy as related to coping with the caregiving demands. A review of results, both quantitative and qualitative demonstrates that this objective has been achieved. This chapter will focus upon the important themes or common factors within this study, most of which are encompassed within the objective above. Included in the discussion are the following topics: 1) Women as Caregivers, 2) the Feminist Perspective, 3) Changes in Caregiver Burden, 4) Changes in Social Networks, 5) Changes in Self-Efficacy, 6) Use of a Group Format, and 7) the Author's Learning. By interpreting the results in greater detail, the author hopes to explore the research and practice value of this study within the field of social work.

I. Women As Caregivers:

All of the participants in this study were daughters caring for their elderly mother or father. These women often described their role as primary caregiver as "natural" or that they had been "appointed" by other family members for a number of reasons, including geographic proximity, being single,

being the oldest or youngest sibling. In some cases, the caregiving was previously shared between siblings, but other siblings were not prepared to take on the responsibility of primary caregiver.

The women in my study experienced many ambivalent feelings with respect to caregiving. Although most described their relationship with their parent as very close, this relationship had deteriorated with the constant and daily stress of caregiving. The most common feelings were anger, guilt, and frustration. These women welcomed the opportunity to share these feelings in an empathic, "safe" environment where they knew they would not be judged and could gain support from the other women.

In the literature review, several issues of particular concern to women caregivers were discussed. Some of these issues were also addressed within the scope of this study and the results will now be discussed in more detail.

With respect to relationships between caregivers and care recipients, most of the women in the group described their relationship with their parent as a good one. However, they also expressed feelings of role conflict, where they had to take on a parenting role with their own parents. As well, the parents had a difficult time accepting help from their daughters for fear that they became dependent and a burden. These results support findings by Qureshi and Walker (1989) and Aronson (1990) in their study of women caregivers.

The amount of care provided by the caregivers varied based upon need and "stage" of caregiving, but not upon employment status of the caregiver. As well, this study found that when conflicts arose between paid work and caregiving, that caregiving was the first priority: one women even took early retirement to care for her father. Again, these findings are similar to those of Lewis and Meredith (1988) and Brody and Schoover (1986) who described women changing work schedules, reducing their hours of work, quitting their jobs, or taking early retirement to allow them to continue caregiving.

Lewis and Meredith' (1988) definitions of care were very useful in classifying levels of care and the similarities and differences found among them. The author hypothesized that the differing levels or stages of caregiving would account for much of the differences in results in terms of amount of burden, social support networks, and self-efficacy. In reviewing the results, this hypothesis has been supported. Examples of such differences included that the "Full Care" participant reported significantly more burden than the "Semi-Care" caregiver both in terms of quantitative (Caregiver Burden Inventory) as well as qualitative data. As well, Helen, who underwent a transition from "Part-time Full Care" to "Full Care", demonstrated an increase in her burden score on the Caregiver Burden Inventory from pre to post-group. The greater time commitment required for "Full Care" appears to

contribute to greater feelings of burden.

Other differences were demonstrated in terms of social support whereby "Semi-Care" and "Part-time Full Care" caregivers reported larger, more supportive networks than the "Full Care" caregiver. Although a certain amount of these differences must be attributed to individual discrepancies, the author concluded that there was greater opportunity for women caregivers to connect with social networks if they were not caregiving on a full-time basis.

Self-efficacy scores were also higher for "Semi-Care" and "Part-time Full Care" participants which could be related to education, employment status. However, it also raises the question, "Does the "type" of woman who provides care on a full-time basis tend to be less assertive and more socially isolated, or is this the effect of providing care on a "full-time" basis?" Although this study raised this question, no direct conclusions can be drawn at this point, due to the small sample size. However, it does point to the need for more research in this area.

Despite the number of differences which were found between issues related to the "stage" of caregiving, the overall similarities of the caregiving situations allowed for empathy and support amongst participants, which is a strength of a groupwork approach.

Lewis and Meredith (1988) described a phenomenon where women became embedded in the caregiving role to the point that

it became a career and may involve caring for several people simultaneously or in succession. Two of the four women in this study had already cared for at least two people and indicated that they would care for others if necessary which again supports previous research.

Why do women care? Socialization, the desire to nurture, affection and obligation were amongst the factors listed in the Literature Review by Lewis and Meredith (1988) and Gilligan (1982). This study also asked the women about their decision to care and about the expectations around caregiving in their families. Most of the women "drifted" into caregiving as the need arose due to deterioration of their parents' health. All of the women had expectations placed upon them by themselves as well as their families to become primary caregiver. One woman even commented that it was a "natural" progression for her.

This study found that many of the caregivers' siblings provided limited support, sometimes due to distance, but also due to feelings of guilt. Many siblings would become critical of decisions made by the primary caregiver despite having limited involvement themselves. Often, siblings held unrealistic expectations of both the primary caregiver and their aged parent as to their capability to maintain independence. Throughout the group, the women discussed issues around dealing with siblings and were encouraged to respond in an assertive fashion. Although siblings did not

take a more active role in sharing the burden of care, most of the women reported an improvement in the quality of their relationship with siblings in the post-group interview.

II. The Feminist Perspective:

As stated in the Literature Review, the data derived from studies of family caregivers of the elderly is vast. However, the majority of these studies have not identified gender and relationship to the care recipient as important factors. This study focused specifically upon women caregivers who were daughters or daughters-in-law of the care recipients. Although a number of research and policy studies (Lewis and Meredith, 1988; Brody, 1990; Pascall, 1986; Finch and Groves, 1980) have been conducted, the bridging of policy and practice is not so apparent. The aim of this study was not only to analyze the issues for women caregivers from a Feminist perspective, but also to empower these women to make changes in their own lives out of an enlightened consciousness.

Throughout the group, the facilitator challenged static views about the responsibility of the state and the family (which in essence is women caregivers) in caring for the elderly. The policies around "public" and "private" spheres were discussed in terms of their perpetuation of women's oppression in society. The lack of recognition, both formal and informal, of their caregiving efforts was particularly poignant for these women. They felt like society as a whole,

the traditional family structure, and even their own self-expectations channelled them into this role as caregiver with little recognition or compensation for their labour of love.

"Community Care" equals as Finch and Groves (1980) described, "care by the family, and in practice care by the family equals care by women" (p.494). The women in my study saw the state as reneging on its responsibility to support women caregivers through increased community programmes such as Continuing Care, respite programmes, adult day care, as well as monetary compensation such as pensions, income tax deductions to off-set their tremendous personal cost. If the bulk of care was not provided by non-paid caregivers, the state would have enormous costs for residential and institutional care.

Within this study, the author set two objectives which relate to integrating the Feminist perspective into practice. The objectives read as follows: 1) the group began to raise the level of awareness of women participants about the oppressive nature of the gender division of labour sanctioned by the state, through a feminist analysis of the issues, and 2) the group explored alternatives for change in the private and public spheres based upon a vision of a more egalitarian division of caring responsibility. The review of results which follows will assist in evaluating the extent to which these objectives have been met.

When asked if their expectations regarding women's role

as caregivers had changed, all of the participants indicated some change in their attitude, most of which they attributed directly to the group intervention. Martha stated that men should be expected to look after their male relatives, and that sisters should share the burden of caregiving. Helen said that the group helped her to recognize the discrepancies in the division of labour between men and women.

All of the women felt that their caring labour was taken for granted by society and their own families. The only true recognition came from one another. They suggested a number of possible alternatives including an Income Tax deduction for dependent elderly, increasing public awareness regarding the inequities of the division of caregiving responsibility, and alternatives in the workplace to facilitate the work-caregiving balance.

In terms of the contribution of the formal care system to caring for the elderly, all of the participants felt that the system in place was too rigid, and did not accommodate individual circumstances, thus, not being very supportive of primary caregivers' efforts. Deficits in the Continuing Care Programme identified by the women included: no assistance to transport disabled elderly to doctor's appointments, the inconsistency of direct care workers became confusing for the elderly person, and caregivers must leave their home in order to obtain respite services. Ellen felt that the state should take responsibility to provide adequate housing options on a

continuum of care needs. Both Helen and Joanne felt that services should be directed more to meet the needs of the caregiver, supporting and validating the tremendous input of their time and energy.

Throughout the group process, the group members clearly demonstrated changes in their perception of women's role as caregivers, and attempted to operationalize their perceptual change into concrete changes in their own lives. The women talked about how they were "expected" to be caregivers, and began to question why men were not taking a more active role in the provision of care. As well, the women participants hypothesized that the issues faced by caregivers would have been "in the limelight" if the majority of primary caregivers were men. Given this scenario, there would be increased support and recognition of caring labour. The women then applied these insights into a re-evaluation of their own situation. In the post-group data, all of the participants indicated that they had made changes in their manner of relating to siblings regarding the division of caring labour, as they became increasingly assertive. Based upon these changes, the intervention objectives listed previously were met to the degree that the qualitative data supports a change in attitudes, beliefs, values, and presents alternatives for change. Because the data is descriptive (qualitative), it is difficult to measure or quantify the practical application of newly acquired knowledge or awareness, but it appears that the

women in this study have experienced a raising of their consciousness and have begun to look at alternatives to the status quo. More precise measurements of change would add to the validity of this study. As well, further research which replicates the findings described by this study will provide a greater body of knowledge in this field of study.

III. Changes in Caregiver Burden:

The intervention objective related to caregiver burden set out in this study was to "attempt to lessen the subjective perception of burden and stress experienced by women caregivers who are participating in this study, through mutual support, sharing of emotional experiences, and development of internal and external resources." Although there was some variation from participant to participant, these differences were accounted for by differing levels of care. At times, there were discrepancies between self-reported changes in burden and the results of the Caregiver Burden Inventory (Novak and Guest, 1989), but these differences are explained in the following section.

In referring to results from the Caregiver Burden Inventory (Novak and Guest, 1989), the "Full Care" participant, Martha, had the highest score, and experienced a slight increase in burden from 47.25 pre-test to 51 post-test. This increase can possibly be attributed to the deterioration of her mother who suffers from Alzheimer's Disease or possibly

to an increased reporting of burden due to better self-awareness. Martha reported little or no change in her feelings of burden by self-report, despite increasing care demands.

The "Part-Time Full Care" participant, Joanne, showed a decrease from 38.5 to 28 on her CBI score. This decrease was supported by qualitative data as Joanne described a change in her perception of burden, despite reporting a slight increase in the care needs of her mother. She attributed the decrease to the group helping her to put her negative feelings into perspective, and to release herself from total responsibility for her family's well-being.

Ellen, the "Semi-Care" participant, also showed a decrease in burden from 29.75 to 22.25 post-group. Qualitative data supported these results as Ellen described herself as feeling "less stressed" and that the group had helped her to deal with feelings of guilt.

Helen made a transition from "Part-Time Full Care" to "Full Care" with an accompanying increase in her CBI score from 18.5 to 29 post-group. This increase can be explained, however, by two factors: increasing demands resulting from providing "full-time" care whereas she had received additional formal and informal help previously, and an increased self-awareness which allowed Helen to honestly describe her feelings of burden. By observing Helen's manner of presentation, self-esteem, and insight into her own emotional

state, the author considers her initial score of 18.5 was an underrepresentation of her feelings of burden. Although Helen probably did not intentionally bias the score, she may not have been willing to admit negative feelings before she joined the group. However, the group helped her to acknowledge and accept her negative feelings, and thus, her post-group score is probably more accurate.

Overall, the Caregiver Burden Inventory (Novak and Guest, 1989) exhibited high reliability in this study, with the majority of the scores falling within established mean score ranges. As well, validity was also established as the scale actually measures what it is intended to measure. The scale was easy to administer and received no negative feedback from participants. One point of note, however, is the relatively low scores on Factor 5 (Emotional Burden). Participants found these questions difficult to related to as they described feelings of embarrassment and shame directed at the care recipient. This scale was designed for caregivers of Alzheimer patients whose inappropriate behaviours can provoke such negative reactions. However, caregivers of cognitively intact elderly persons may not find these questions relevant to their situation.

Although not all participants experienced a decrease in burden scores, there were reasonable explanations for these discrepancies, and overall, the Caregiver Burden Inventory (Novak and Guest, 1989) was a very useful tool in this study.

IV. Changes in Social Networks:

One of the practicum objectives was to increase social support through increased networks. With respect to results obtained through administration of the Lubben Social Network Scale (Lubben, 1988), the comparative scores show that the "Part-Time Full Care" caregiver has the highest score with a 39 on the pre-test, decreasing to 37 on the post-test. The "Semi-Care" caregiver followed with 37 on the pre-test and 36 on the post-test. The caregiver in transition, Helen, demonstrated a decrease from 37 on the pre-test to 33 on the post-test, whereas the "Full Care" caregiver showed a slight increase from 33 to 34 post-group. The Lubben Social Network Scale (Lubben, 1988) measured size and number of contacts (frequency) of social networks, but did not measure quality of the relationships and whether or not the relationship was perceived as a source of stress or support. Abel (1991) stated that "social networks are not converted automatically into social support" (p.149).

The Lubben Social Network Scale (Lubben, 1988), in retrospect, was probably not the best choice for measuring the changes in perceived social support as it was not sensitive enough to the "support" aspect of social networks. Therefore, due to the inappropriate choice of scale, the qualitative data for measuring changes in social network is probably more relevant than quantitative measures.

Therefore, a more sensitive instrument for measuring

quantitative change in social support is needed. In conducting further research, this author found two scales which may be appropriate. These are the Perceived Social Support for Caregiving scale and the Social Conflict scale, both developed by Goodman (1991). The PSSC focuses upon positive aspects of support, whereas the SC scale focuses upon the negative aspects of close relationships. These scales are only in the preliminary stages of development, but may prove useful in the future.

Despite the results from the LSNS which indicated a decrease in all but one case, self-reports from participants indicated that their networks had remained stable. It is important to note that forming new relationships usually takes more time than eight weeks. The mutual support between group members was well developed within the group setting, and it was the hope of the author that this support would be translated to form ongoing relationships. Three of the four members expressed a desire to connect with other group members, but more time would be necessary to evaluate the effectiveness of this networking further. As well, participants reported an improvement in the quality of relationships, particularly with siblings, as these women began to assert themselves more. Joanne also reported a significant improvement in the quality of her relationship with her mother. Changes in the quality of relationships could translate into a more supportive network. The kind of

support needed by caregivers is unique and very subjective, according to Abel (1991) who asserts that:

It is important to note that the situation of caregivers differs from many other in which people appear to need support . . . The women I interviewed wanted members of their social networks to affirm the value of their endeavour, not just help them deal with the problems it provoked. They were enraged when people belittled their attachment to their parents, trivialized their involvement in caregiving, and failed to acknowledge their parents' unique worth and humanity (p.151).

Most of the women in the group felt that the members of their social networks were beginning to further understand and support their efforts as caregivers.

V. Changes in Self-Efficacy:

The concept of self-efficacy or mastery was, in the author's mind, closely tied to that of empowerment. One of the intervention objectives of this practicum was to strive to empower women participants to cope more effectively and increase their sense of self-efficacy through problem-solving, assertiveness-training, and stress management techniques. The results from both qualitative and quantitative data would suggest that this objective has, in fact, been achieved.

The quantitative results from the Self-Efficacy Scale (Sherer et al., 1982) were somewhat inconsistent, with two participants demonstrating an increase in self-efficacy scores, while the other two showed decreases. The participants who showed decreases were the "Transition" caregiver and the "Semi-Care" caregiver, both of whom had some doubts as to whether they could cope effectively with greater

care demands. The "Transition" participant had a pre-group score of 93 and a post-group result of 92 whereas the "Semi-Care" participant scored 90 pre-group and 86 post-group. The "Part-Time Full Care" participant showed an increase from 83 to 92 post-group and the "Full Care" participant scored 65 pre-group and 70 post-group. It is the opinion of the author, however, that the Self-Efficacy Scale (Sherer et al., 1982) utilized in this study was not sensitive enough the concept of empowerment and increases in self-esteem as related specifically to caregivers. The participants themselves commented that this scale was cumbersome and some questions seemed irrelevant to them. For future studies of this type, the scale should be more sensitive scale to the issues of self-esteem and how caregivers relate their self-esteem and feelings of mastery to their caregiving lives.

The self-reported data, however, was more useful in describing changes in feelings of self-efficacy and mastery as each person seemed to manifest these changes in an individualized fashion. All participants verbalized their sense of empowerment as learning to be more assertive. Martha found herself better able to cope with her sister by putting the onus back on her to assist with caregiving. Joanne described a process of "letting go" of her need to control others in her family and taking responsibility for her family's behaviours. She also attributed a change in self-care behaviours to new learning in the group setting as she

now used relaxation tapes, took "time out" for herself, and exercised more assertive behaviours. Helen found that retirement reduced her level of stress, and allowed her to have more time to herself. Her greatest change was accepting help from others without feeling guilty or worrying that her father was not being properly cared for. She described feeling empowered as she could now act upon having her needs met, in an assertive fashion. Ellen described a change in her interactions with her siblings where she now felt more "in control" and less vulnerable to their criticisms as she could be assertive with them. She also described feeling empowered by the group interaction and the validation she received.

Overall, participants stated that they acquired some new skills, and learned some new behaviours, as well as gaining validation for their efforts as caregivers, all of which were positive contributors to self-efficacy.

VI. Use of a Group Format:

In the literature review, the author outlined several justifications for choosing a group format to carry out this intervention with women caregivers, including promoting mutual growth and support, sharing of common emotions, reducing alienation and isolation, educating participants regarding self-care, information on the aging process and common diseases, raising the consciousness of group members, empowerment of women participants, and enabling alternative changes to occur within the lives of participants. This group

met all of the above purposes, at least to some degree.

This author firmly believes from observation of the group process and comparing results to individual counselling in her own practice that the group modality of intervention is far more effective in meeting the goals listed above. Having worked with the elderly and their families for five years, the author's own clinical experience suggests that groups are more effective as they provide support and validation to caregivers not only from the therapist or counsellor, but from others having similar experiences. It is the genuine nature of the empathy that group members share that promotes the cohesiveness and self-disclosure one finds in caregiver groups.

Despite the differences between caregivers in differing levels of care, which have been discussed previously, the group members shared a number of common issues which were addressed within the group setting. Some of these issues include:

- Becoming overprotective of your parent and not allowing others to provide care.

- Feelings of guilt, frustration, and anger directed at the care recipient, siblings and at the caregiver herself.

- A need to learn about stress management and self-care.

- The decision of when to place your parent in a personal care home.

- Negotiating the sharing of caregiving responsibilities

with other siblings.

- Negative outcomes such as depression and anxiety.

- The need for information regarding resources, both formal and informal, and how to access them.

- The lack of recognition women experience as caregivers and how this role is an ascribed one for women.

The feedback from group members was very positive in terms of their evaluation as to whether the group goals were met and their responses to the Client Satisfaction Questionnaire (Attkisson et al, 1989). The questions in this self-anchored scale dealt with the quality of service received, whether the programme met the client's needs, whether the client would recommend the programme, and whether the services helped the client to deal more effectively with his/her problems. All of the responses were positive, rating the service as "excellent" or "good", and the overall satisfaction rate as "very satisfied" and "mostly satisfied".

The author would recommend a few changes to the group design based upon the experience gained from this group. First, the group could be expanded to a minimum of ten weeks to allow more time to deal with the "stress management" topic, cognitive restructuring in coping with depression, and more time, in general, for the participants to process the information. As much of the information, particularly the Feminist analysis of caregiving as a women's issue, was unfamiliar to the participants, they would have benefitted

from additional sessions to process this information and apply it to their own situations. As well, a greater amount of time between pre and post measures may have strengthened the quantitative data, particularly in measuring social networks, which take time to develop and change.

The author would suggest to maintain a closed group format if possible as it stimulates increased cohesiveness. The reality is, however, that caregivers have many other demands upon their time and are often dependent upon outside resources to allow them to attend groups. Therefore, although a closed group format is preferable, facilitators must be flexible and accommodating to the pressures the caregivers are facing, and not create additional stress by making strict rules regarding attendance. A small number of participants is optimal, at least for the first eight to ten weeks, to promote cohesiveness and allow enough time for mutual sharing between all participants. As well, it proved very effective to target a specific group of caregivers, as in this study which focused upon female adult children. Targeting caregivers in practice not only help to ensure commonalities amongst participants, but also raises awareness as to who actually does the bulk of caregiving. Other groups of this type could broaden the referral base, by not restricting participation in the group to those served by Continuing Care. Opening up the group to other caregivers would increase accessibility to needed services.

In conclusion, it is important, from a feminist perspective, to reduce the isolation women experience as caregivers and to promote other women as potential resources for support and validation. The bonding within a group such as this one at a grass-roots level is the basis of the larger Feminist movement to examine and change the institutions contributing to the oppression of women in our society.

VII. The Author's Learning:

The experience of developing a specific area of inquiry and practice within the scope of this practicum was very valuable for this author, both in terms of professional and personal development. My learning was not only in the field of practice where I developed my counselling and groupwork skills, but also in the area of research where I learned to interpret results and evaluate the effectiveness of the intervention in a standardized manner. Groupwork proved to be a challenging mode of intervention as a clinician, I had to deal with interactions on a content and process level. However, the group setting was also very rewarding as the participants had so much to offer one another, and in contributing to the learning that went on within the group.

At the beginning of this report, I outlined five learning objectives which I will now review to evaluate whether they have been met.

The first objective was to develop and implement a Women Caregivers' Support Group targeted at daughters and daughters-

in-law caring for elderly parents. The support group was successfully developed and implemented in May and June 1992 in Portage la Prairie, Manitoba. Four group participants, who were all daughters caring for their elderly parents, completed the eight sessions. Therefore, this objective was successfully met.

The second objective was to develop an understanding of female adult children as caregivers utilizing a Feminist Perspective to analyze both policy and practice issues. Specific issues of importance to women caregivers included the gendered division of labour, the lack of recognition for caring labour, and the lack of responsiveness on the part of the State to women caregivers' concerns. A Feminist analysis reviewed both the role of the State in maintaining the oppressive status quo in terms of male and female roles in society, as well as the effect of these policies on the lives of women caregivers. The women spoke from their own experience of carrying out prescribed roles and their ambivalence as a result on their increased consciousness. While these women could see how their labour was taken for granted and unappreciated, they also cared deeply for their parents. The group examined practical suggestions for change at both a personal and political level, and these discussions provided great learning as the women spoke from their own experience. I therefore consider that this objective was met.

The third objective was to develop skills and experience

in short-term group counselling techniques, utilizing a Feminist framework as a theoretical base. Although I have had some previous experience with group counselling, my skills were further developed and enhanced by this experience. I played the role of leader, broker, information-sharer, and educator. The Feminist Perspective provided a useful framework for presenting information in examining how the policies and practices of the State, and the expectations of society specifically inferenced the women in the group. Feminist counselling involves use of self in terms of self-disclosure, and in minimizing the hierarchy between the therapist and group members. I utilized facilitation skills such as empathizing, validation, summarizing, probing, reframing, questioning, and clarifying to interpret the group interactions. I was not only concerned with the content of the interaction, but the process and its effect upon group development. As the group developed, so did the cohesion amongst members and the strong sense of mutual support. However, this group took the support group one step further in action: the members discussed issues of concern to them within their own families, as well as in greater society, and strategized positive change. This social action component resulted in the empowerment of members to make changes in their lives and in the "system of care".

The process of live supervision by reviewing the tapes from each session with my field supervisor, Grant Dunfield,

assisted me in developing further my counselling skills through critical analysis of my role as facilitator. Therefore, I felt that I achieved this learning goal.

The fourth goal was to develop a thorough knowledge of the difficulties associated with provision of care to the elderly, and their effect on female adult children caregivers. The sharing of feelings and experiences by participants gave new meaning to the theories on caregiver burden. I had researched the topic thoroughly and identified what I felt were major issues, but the participants also raised issues of their own which provided new learning for myself as a social worker. As well, I learned that women caregivers may describe an issue in very different terminology than the practice literature. For instance, many of the women found it difficult to identify with "caregiver stress" or "burden", but rather described themselves as "tired" or feeling "torn" by competing demands.

I certainly gained a great deal of practical knowledge and experience from the members of the group, and felt that I now have a good understanding of women caregivers, I believe that this goal has been achieved.

The final goal was to develop knowledge in analysis of policy issues and their relationship to social work intervention. Much of my research of the literature focused upon the policy of "community care" and the state's response to caring for the elderly. The Feminist analysis of these

policies depicted quite clearly how oppressive they were for women and how they maintained a gendered division of labour. In terms of intervention, the challenge was to convey this information to women who were socialized to be caregivers, and associated their own identities with caring for others, in a manner which promoted a sense of empowerment, rather than negation. When one reviews the literature, one could focus upon the weakness of these women for "falling into society's trap" in their caregiving roles. This author chose to focus on the incredible strength demonstrated by these women in their caring labour, despite little support from the state or from informal networks such as family. The facilitator also had to be conscious of the belief systems and age cohort of participants, tailoring the analysis of policy to their level of understanding, thus, maintaining a client-centred focus. I felt I was successful in integrating both the policy and practice issues into the group format, and thus, achieved this goal.

In conclusion, I felt that this practicum provided me with the opportunity to research an issue to gain further understanding, develop practice skills, experience direct supervision, and develop skills at analysis to make connections between practice and research, between policy and practice.

OVERALL SUMMARY:

The purpose of this practicum was to design and implement a support group for women caregivers, using a Feminist Perspective as a theoretical framework. The goals of this intervention were to help reduce feelings of burden, increase social support networks, and increase feelings of self-efficacy.

As was described in this chapter, results from both quantitative and qualitative data demonstrated a reduction in feelings of subjective burden, as measured by the Caregiver Burden Inventory (Novak & Guest, 1989) as well as personal interviews. Although there did not appear to be a consistent increase in the composition of social networks, as measured by the Lubben Social Network Scale (Lubben, 1988), participants did report positive changes in the amount of social support they received and an improvement in the quality of their relationships with members of their social networks. It was therefore concluded that a different scale which measured change in social support may have been more appropriate.

With respect to self-efficacy, participants reported feeling empowered by the group, and increasingly assertive in their interactions with family, both characteristics of increased self-efficacy. However, the Self-Efficacy Scale (Sherer et al., 1982) did not consistently demonstrate increases in self-efficacy scores. In reviewing the data, this scale may not have been sensitive enough to the issues

facing women caregivers, and a measure of increased self-esteem may have been more appropriate.

Overall, however, the goals of this practicum were met and indeed the group proved to be an effective mode of intervention with women caregivers. It was a great learning experience for the author as she explored both policy and practice issues within the context of a groupwork intervention.

CHAPTER VII -- CONCLUSION

The purpose of this concluding chapter is to review major findings from the practicum, and to relate these findings to future practice in social work.

There has been a great deal of research and practical group interventions with caregivers in recent years, but most of these interventions did not target women caregivers specifically. As well, I found a relatively large body of literature on policy issues related to women as caregivers. However, this practicum is unique in that it addresses the policy issues in the context of a practical group intervention, targeted specifically at women caregivers. Utilizing a Feminist Perspective, the author discussed such policy issues as the gender division of labour, lack of recognition or value placed upon caring labour, and alternatives for change on an individual and societal basis.

This practicum's objective was to design, implement and evaluate the effectiveness of a short-term Caregiver Support Group for daughters and daughters-in-law caring for elderly parents in its ability to meet the needs of this population in terms of reducing feelings of burden, increasing support networks, and increasing subjective feelings of self-efficacy as related to coping with caregiving demands. In fact, this study has proven, supported by both quantitative and qualitative data, that this group intervention was effective in meeting the needs of this population. The data suggests

that participants experienced a reduction in feelings of burden, which was coupled with increased self-efficacy in coping with the demands of caregiving. All of the participants reported having gained assertiveness and stress management skills which they used to cope. In terms of increased social networks, the study demonstrated a change in the quality of relationships, but not necessarily the number of contacts, or composition of the social network. As a result of increased assertiveness, the participants described an improvement in the way that they related to their family, in particular, and in the amount of support they received from their network.

The author also successfully met her learning objectives, developing greater knowledge and awareness of the issues facing women caregivers, developing counselling skills utilized in a group setting, and developing a thorough understanding of the Feminist Perspective as related to women caregivers. The women in the group had much to offer each other and the author with their personal experiences. I see the sharing of similar experiences, the mutuality and cohesiveness as being the strengths of the group modality. In reducing the isolation of women, and striving to empower women through consciousness-raising and support, this group certainly embodies the very essence of the Feminist Perspective.

This study has answered some questions, but raised others

and certainly further study in this area is necessary. The section which follows will explore some major implications from the findings of this study.

Implications for Social Work Practice:

In terms of recommendations for future social work practice, I would like to begin by outlining some practical changes which I would implement for future groups of this type. My first recommendation would be to expand to length of sessions from eight to a minimum of ten weeks in order to cover basic topics. The group sessions dealt with too much information at once, making it difficult for participants to absorb. In particular, the session on "stress management" should have allowed time for practical exercises. As well, the pre/post measures were quite close together which perhaps influenced the accuracy of the data in some cases. For instance, social networks may not change dramatically over such a short term which may reflect in the data obtained.

I found some difficulties with the selected scales in this study, particularly with the measures of self-efficacy and social networks. The Self-Efficacy Scale (Sherer et al., 1982) was somewhat cumbersome to administer, and participants could not relate to the questions on the scale. I feel this scale was not sensitive enough to the issues facing this cohort of women, and the generic nature of the questions were not always applicable. In retrospect, perhaps a self-esteem index would have provided a more accurate account of changes

in personal assertiveness and empowerment. As well, the Lubben Social Network Scale (Lubben, 1988) is a good measure of changes in composition of social networks, but this study actually found little change in composition, but rather in quality of social support. I later found another scale which may be a more appropriate measure: the Perceived Social Support for Caregiving scale developed by Goodman (1991).

The participants in this study made a number of suggestions for societal changes in response to their identified need. For instance, all participants agreed that some form of formal recognition of their contribution as caregivers was important. They discussed lobbying women's groups and government for an Income Tax deduction for dependent elderly. As well, participants felt that their employers needed to be increasingly flexible to allow such arrangements as job-shares, flextime, flexplace, and on-site adult day care centres.

Although the participants were generally satisfied with the formal care system (Continuing Care Services), they suggested that the system should be more responsive to individual caregiver needs if it was to support their efforts. For instance, assistance with transportation to and from doctor's appointments for severely disabled patients, or having physicians make home visits, allowing caregivers to remain at home while respite service is in place, and minimizing the fluctuation of direct care workers were the

major recommendations for improving that service.

As this practicum explores a relatively new area of research, further study is certainly warranted. In particular, as this study demonstrates, the issues differ for different caregivers, whether they be male or female, spousal or adult child. As a comparative study, it would be interesting to determine if female spousal caregivers share similar concerns to the women in this study. This author is of the opinion that future research should focus upon clearly delineating *who* are the caregivers and *what* are their needs so that they can be supported and valued in their labour. The policy of "community care" relegates the responsibility of care to families, and to women caregivers. Further studies need to explore the roles of state and family in the provision of care to the elderly.

In conclusion, women are faced with a dilemma: they have been ascribed and have taken on a role which is both a form of oppression and of personal reward, that of being a caregiver. The intention of this practicum was to provide support and validation for their caring labour, while raising their consciousness to the exploitive nature of this role, and exploring alternative ways of sharing the caring responsibility. This intervention is a success as the "experts", the women who participated, felt both supported and supported by the group to make changes in their personal and political lives.

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APPENDICES

APPENDIX I

ANNOUNCEMENT NOTICE

LETTER TO PROSPECTIVE PARTICIPANTS

PARTICIPANTS' CONSENT FORM

WOMEN CAREGIVER'S GROUP IN PORTAGE LA PRAIRIE

As part of my studies for my Masters' Degree in Social Work, I will be running a support group for female adult children (daughters, daughters-in-law) caring for elderly parents. The group will provide an opportunity to gain support, improve coping skills and gain information about resources. The group will run in May and June and will be in Portage la Prairie. One criteria for participation is that the care recipient must be receiving Home Care services. If you are from the Portage area and are interested, please call MERILEE McCLELLAND at
for more information.

Manitoba



Health
Family Services

Central Region

25 Tupper Street, N.
Portage la Prairie, Manitoba,
CANADA
R1N 3K1

March 23, 1992

Dear

I am writing this letter to explain further my plan to start a Women's Caregiver Support Group in Portage la Prairie, and also to thank you for providing your name to the Continuing Care worker when you were contacted.

Just to let you know a little about my background, I am a Social Worker working with the Psychogeriatric Assessment Team under Mental Health Services in Portage la Prairie. I currently hold my Bachelor's Degree in Social Work and am working towards my Master's Degree, of which this group is part of my studies.

The Caregiver Support Group that I intend to start, while it serves a need that I have identified through my work in this community, also serves as a component of my field studies for my Master's Degree. In addition to planning, implementing, and evaluating the group, I am expected to write a written report about the group process and the progress of the group participants. For participants, this would involve interviewing each group member before and after the group to gain some background information, family history, etc. and to evaluate the effectiveness of the group upon its completion. It is important to note that all information is kept confidential.

The group itself is targeted at women caring for elderly parents (daughters and daughter-in-law) and will run once a week in the months of May and June 1992. I hope to gather six to eight participants for the group which will meet in the Provincial Building in Portage la Prairie. In terms of the time, this will depend on what is most convenient for participants upon surveying them in the initial interview. The group is designed to provide emotional support, encourage sharing of experiences common to women caregivers, as well as providing practical information around services available and how they might be improved.

I will be contacting you by telephone within the next two to three weeks to set up a time for a pre-group interview. I hope that you choose to become a part of the group as I believe that it will be both a learning and growth experience for all those involved.

Thank you for your time and attention.

Yours sincerely,

Merilee McClelland, B.S.W., R.S.W.

WOMEN CAREGIVER STUDY--PARTICIPANTS' CONSENT FORM

As a participant in this practicum study conducted by Merilee McClelland as part of her requirement for her Masters of Social Work Degree from the University of Manitoba, I _____
_____ hereby agree to the following:

- 1) That I understand the purpose of the study and my involvement and that I am free to withdraw from the study at any time. However, should I be unable to continue as a participant in the study, I agree to advise Ms. McClelland (group leader).
- 2) That the information gained from personal interviews, and the group process may be used in the written report (thesis) and oral presentation that accompanies this study. (All personal information is disguised to protect the confidentiality and anonymity of the client).
- 3) That the group leader has my permission to make audio and video tapes of personal interviews and group sessions and that these tapes will be reviewed for the purpose of learning, supervision and consultation with my field supervisor, Mr. Grant Dunfield, and my advising professors from the Faculty of Social Work. These tapes will remain the property of the group leader, Merilee McClelland.
- 4) As a participant in this study, I agree to answering interview questions and filling out questionnaires which are a part of the study.
- 5) That the group leader will provide oral feedback to participants pertaining to the results of the study once the data has been analyzed.

***ALL INFORMATION IS TO REMAIN CONFIDENTIAL AND THIS IS THE RESPONSIBILITY OF BOTH THE GROUP LEADER AND PARTICIPANTS. THE GROUP LEADER ADHERES TO THE CONFIDENTIALITY GUIDELINES SET OUT IN THE CODE OF ETHICS OF THE CANADIAN ASSOCIATION OF SOCIAL WORKERS.

Having read and understood the above, I agree to participate in the Women Caregivers Study.

Participant's signature

Date

Witness' signature

Date

APPENDIX II

EVALUATION TOOLS

THE CAREGIVER BURDEN INVENTORY

NOW WE'D LIKE TO KNOW HOW YOU SEE YOUR EXPERIENCE AS A CAREGIVER AND WHAT YOUR FEELINGS ARE ABOUT GIVING CARE.

THINK OF YOUR EXPERIENCES AS A FAMILY CAREGIVER. HOW WELL DOES EACH OF THE FOLLOWING STATEMENTS DESCRIBE YOUR EXPERIENCE IN CARING FOR YOUR CARERECEIVER IN THE PAST MONTH?

0	1	2	3	4
NOT AT ALL	SLIGHTLY	MODERATELY	QUITE	VERY
DESCRIPTIVE		DESCRIPTIVE		DESCRIPTIVE

- _____ 1. My carereceiver needs my help to perform many daily tasks.
- _____ 2. My carereceiver is dependent on me.
- _____ 3. I have to watch my carereceiver constantly.
- _____ 4. I have to help my carereceiver with many basic functions.
- _____ 5. I don't have a minute's break from my caregiving chores.
- _____ [FACTOR 1 BURDEN SCORE (TOTAL OF ALL FACTOR 1 ITEM SCORES.)]
- _____ 6. I feel that I am missing out on life.
- _____ 7. I wish I could escape from this situation.
- _____ 8. My social life has suffered.
- _____ 9. I feel emotionally drained due to caring for my carereceiver.
- _____ 10. I expected that things would be different at this point in my life.
- _____ [FACTOR 2 BURDEN SCORE (TOTAL OF ALL FACTOR 2 ITEM SCORES.)]
- _____ 11. I'm not getting enough sleep.
- _____ 12. My health has suffered.
- _____ 13. Caregiving has made me physically sick.
- _____ 14. I'm physically tired.
- _____ [FACTOR 3 BURDEN SCORE (TOTAL OF ALL FACTOR 3 ITEM SCORES.)]

0	1	2	3	4
NOT AT ALL	SLIGHTLY	MODERATELY	QUITE	VERY
DESCRIPTIVE		DESCRIPTIVE		DESCRIPTIVE

_____ 15. I don't get along with other family members as well as I used to.

_____ 16. My caregiving effort aren't appreciated by others in my family.

_____ 17. I've had problems with my marriage.

_____ 18. I don't do as good a job at work as I used to. (CODE 7 = NOT APPLICABLE FOR OTHER THAN PAID EMPLOYEE.)

_____ 19. I feel resentful of other relatives who could but do not help.

_____ [FACTOR 4 BURDEN SCORE (TOTAL OF ALL FACTOR 4 ITEM SCORES.)]

_____ 20. I feel embarrassed over my carereceiver's behavior.

_____ 21. I feel ashamed of my carereceiver.

_____ 22. I resent my carereceiver.

_____ 23. I feel uncomfortable when I have friends over.

_____ 24. I feel angry about my interactions with my carereceiver.

_____ [FACTOR 5 BURDEN SCORE (TOTAL OF ALL FACTOR 5 ITEM SCORES.)]

_____ [TOTAL BURDEN SCORE (SUM OF ALL INDIVIDUAL ITEMS.)]

SES

This questionnaire is a series of statements about your personal attitudes and traits. Each statement represents a commonly held belief. Read each statement and decide to what extent it describes you. There are no right or wrong answers. You will probably agree with some of the statements and disagree with others. Please indicate your own personal feelings about each statement below by marking the letter that best describes your attitude or feeling. Please be very truthful and describe yourself as you really are, not as you would like to be.

- A = Disagree strongly
- B = Disagree moderately
- C = Neither agree nor disagree
- D = Agree moderately
- E = Agree strongly

- ___ 1. I like to grow house plants.
- ___ 2. When I make plans, I am certain I can make them work.
- ___ 3. One of my problems is that I cannot get down to work when I should.
- ___ 4. If I can't do a job the first time, I keep trying until I can.
- ___ 5. Heredity plays the major role in determining one's personality.
- ___ 6. It is difficult for me to make new friends.
- ___ 7. When I set important goals for myself, I rarely achieve them.
- ___ 8. I give up on things before completing them.
- ___ 9. I like to cook.
- ___ 10. If I see someone I would like to meet, I go to that person instead of waiting for him or her to come to me.
- ___ 11. I avoid facing difficulties.
- ___ 12. If something looks too complicated, I will not even bother to try it.
- ___ 13. There is some good in everybody.
- ___ 14. If I meet someone interesting who is very hard to make friends with, I'll soon stop trying to make friends with that person.
- ___ 15. When I have something unpleasant to do, I stick to it until I finish it.
- ___ 16. When I decide to do something, I go right to work on it.
- ___ 17. I like science.
- ___ 18. When trying to learn something new, I soon give up if I am not initially successful.
- ___ 19. When I'm trying to become friends with someone who seems uninterested at first, I don't give up very easily.
- ___ 20. When unexpected problems occur, I don't handle them well.
- ___ 21. If I were an artist, I would like to draw children.
- ___ 22. I avoid trying to learn new things when they look too difficult for me.
- ___ 23. Failure just makes me try harder.
- ___ 24. I do not handle myself well in social gatherings.
- ___ 25. I very much like to ride horses.
- ___ 26. I feel insecure about my ability to do things.
- ___ 27. I am a self-reliant person.
- ___ 28. I have acquired my friends through my personal abilities at making friends.
- ___ 29. I give up easily.
- ___ 30. I do not seem capable of dealing with most problems that come up in my life.

Lubben Social Network Scale

Family networks

Q1. How many relatives do you see or hear from at least once a month?
(NOTE: Include in-laws with relatives.)

Q1 _____

0 - zero

3 - three or four

1 - one

4 - five to eight

2 - two

5 - nine or more

Q2. Tell me about the relative with whom you have the most contact. How often do you see or hear from that person?

Q2 _____

0 - < monthly

3 - weekly

1 - monthly

4 - a few times a week

2 - a few times a month

5 - daily

Q3. How many relatives do you feel close to? That is, how many of them do you feel at ease with, can talk to about private matters, or can call on for help?

Q3 _____

0 - zero

3 - three or four

1 - one

4 - five to eight

2 - two

5 - nine or more

Friends networks

Q4. Do you have any close friends? That is, do you have any friends with whom you feel at ease, can talk to about private matters, or can call on for help? If so, how many?

Q4 _____

0 - zero

3 - three or four

1 - one

4 - five to eight

2 - two

5 - nine or more

Q5. How many of these friends do you see or hear from at least once a month?

Q5 _____

0 - zero

3 - three or four

1 - one

4 - five to eight

2 - two

5 - nine or more

Q6. Tell me about the friend with whom you have the most contact. How often do you see or hear from that person?

Q6 _____

0 - < monthly

3 - weekly

1 - monthly

4 - a few times a week

2 - a few times a month

5 - daily

Confidant relationships

Q7. When you have an important decision to make, do you have someone you can talk to about it? Q7 _____

	Very				
Always	Often	Often	Sometimes	Seldom	Never
5	4	3	2	1	0

Q8. When other people you know have an important decision to make, do they talk to you about it? Q8 _____

	Very				
Always	Often	Often	Sometimes	Seldom	Never
5	4	3	2	1	0

Helping others

Q9a. Does anybody rely on you to do something for them each day? For example: shopping, cooking dinner, doing repairs, cleaning house, providing child care, etc.

NO—If no, go on to Q9b. YES—if yes, Q9 is scored "5" and skip to Q10

Q9b. Do you help anybody with things like shopping, filling out forms, doing repairs, providing child care, etc.? Q9 _____

Very				
Often	Often	Sometimes	Seldom	Never
4	3	2	1	0

Living arrangements

Q10. Do you live alone or with other people? (NOTE: Include in-laws with relatives.) Q10 _____

5 Live with spouse

4 Live with other relatives or friends

1 Live with other unrelated individuals (e.g., paid help)

0 live alone

TOTAL LSNS SCORE: _____

SCORING:

The total LSNS score is obtained by adding up scores from each of the ten individual items. Thus, total LSNS scores can range from 0 to 50. Scores on each item were anchored between 0 and 5 in order to permit equal weighting of the ten items.

CSQ-8
CLIENT SATISFACTION QUESTIONNAIRE

Please help us improve our program by answering some questions about the services you have received. We are interested in your honest opinions, whether they are positive or negative. *Please answer all of the questions.* We also welcome your comments and suggestions. Thank you very much, we really appreciate your help.

CIRCLE YOUR ANSWERS

1. How would you rate the quality of service you have received?

4	3	2	1
<i>Excellent</i>	<i>Good</i>	<i>Fair</i>	<i>Poor</i>
2. Did you get the kind of service you wanted?

1	2	3	4
<i>No, definitely not</i>	<i>No, not really</i>	<i>Yes, generally</i>	<i>Yes, definitely</i>
3. To what extent has our program met your needs?

4	3	2	1
<i>Almost all of my needs have been met</i>	<i>Most of my needs have been met</i>	<i>Only a few of my needs have been met</i>	<i>None of my needs have been met</i>
4. If a friend were in need of similar help, would you recommend our program to him or her?

1	2	3	4
<i>No, definitely not</i>	<i>No, I don't think so</i>	<i>Yes, I think so</i>	<i>Yes, definitely</i>
5. How satisfied are you with the amount of help you have received?

1	2	3	4
<i>Quite dissatisfied</i>	<i>Indifferent or mildly dissatisfied</i>	<i>Mostly satisfied</i>	<i>Very satisfied</i>
6. Have the services you received helped you to deal more effectively with your problems?

4	3	2	1
<i>Yes, they helped a great deal</i>	<i>Yes, they helped somewhat</i>	<i>No, they really didn't help</i>	<i>No, they seemed to make things worse</i>
7. In an overall, general sense, how satisfied are you with the service you have received?

4	3	2	1
<i>Very satisfied</i>	<i>Mostly satisfied</i>	<i>Indifferent or mildly dissatisfied</i>	<i>Quite dissatisfied</i>
8. If you were to seek help again, would you come back to our program?

1	2	3	4
<i>No, definitely not</i>	<i>No, I don't think so</i>	<i>Yes, I think so</i>	<i>Yes, definitely</i>

The Client Satisfaction Questionnaire (CSQ) was developed at the University of California, San Francisco (UCSF) by Drs. Clifford Attkisson and Daniel Larsen in collaboration with Drs. William A. Hargreaves, Maurice LeVois, Tuan Nguyen, Bob Roberts and Bruce Stegner. Every effort has been made to publish information and research on the CSQ for widest possible public use and evaluation. All proceeds from the publication of the CSQ will be used to support postdoctoral training in clinical services research.

UCSF

University of California, San Francisco

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APPENDIX III

LETTERS OF PERMISSION

Manitoba



Health
Family Services

Central Region

25 Tupper Street, N.
Portage la Prairie, Manitoba,
CANADA
R1N 3K1

March 1, 1992

Dr. Mark Novak
Continuing Education Division
The University of Manitoba
Winnipeg, Manitoba
R3T 2N2

Dear Dr. Novak.

I am writing to express my interest in your Caregiver Burden Inventory and to request your permission to utilize this scale in my practicum for completion of my Masters Degree in Social Work.

I have chosen to study female adult children as caregivers to the elderly in my practicum, and will be facilitating a support group as my intervention. One of the variables which I hope to measure is whether the group intervention affects subjective feelings of burden on the part of caregivers. I have reviewed several burden inventories, but find yours particularly useful in that it distinguishes between the various types of burden and therefore, can provide more detailed information.

Should you have any suggestions for references on the use of the CBI, it would be appreciated. I plan to begin my practicum by mid-April, so would ask for a reply to the above address as soon as is possible. Thank you for your anticipated assistance.

Yours truly.

Merilee McClelland, B.S.W., R.S.W.



THE UNIVERSITY OF MANITOBA

CONTINUING EDUCATION DIVISION

Winnipeg, Manitoba
Canada R3T 2N2

Tel: (204) 474-9921
FAX: (204) 275-5465

March 25, 1992

Merilee McClelland
Manitoba Health
Family Services
25 Tupper Street, N.
Portage la Prairie, MB
R1N 3K1

Dear Ms. McClelland:

Yes, you may use the CBI which was sent to you on March 9, 1992.

Thank you for your interest.

Sincerely

Mark Novak, Ph.D.
Associate Dean (Academic)

MN/pp

Manitoba



Health
Family Services

Central Region

25 Tupper Street, N.
Portage la Prairie, Manitoba,
CANADA
R1N 3K1

March 1, 1992

Dr. Mark Sherer

Dear Dr. Sherer,

I am writing to express my interest in the Self-Efficacy Scale which you and your colleagues developed, for use in my work. I am currently completing my Masters Degree in Social Work at the University of Manitoba, Winnipeg, Manitoba, Canada.

I have chosen to study female adult children as caregivers to the elderly in my practicum, and will be facilitating a support group as my intervention. One of the variables which I hope to measure is whether the group intervention affects the participants' feelings of mastery and self-efficacy in coping with the demands of the caregiving situation. In reviewing the Self-Efficacy Scale, I feel it is appropriate for my measurement needs, and would therefore request your permission to use the SES in my study.

I have had some difficulty finding references or studies in which the scale has been used previously. I did locate the journal article on the construction of the scale, but would appreciate any further information you could provide with respect to additional articles or references.

I plan to begin my practicum by mid-April, so would appreciate a response as soon as is possible. Thank you for your time and attention to this matter. I may be reached at the above address for your reply.

Yours truly

Merilee McClelland, B.S.W., R.S.W.



March 17, 1992

MANITOBA HEALTH
PORTAGE LA PRAIRIE

Merilee McClelland, B.S.W., R.S.W.
Manitoba Family Services
25 Tupper Street, N.
Portage la Prairie, Manitoba
Canada
R1N 3K1

Dear Ms. McClelland:

I am writing to give you formal permission to use the Self-efficacy Scale in your study. Also, as you requested, enclosed please find a list of references in which the scale has been used.

I hope this material is useful to you in your research.

Sincerely,

Mark Sherer, Ph.D.
Director of Neuropsychology

MS/lla
Enclosure

1333 Moursund
Houston, Texas 77030-3485
In the Texas Medical Center
Telephone: (713) 799-5008
Toll-Free: (800) 444-REHAB

Manitoba



Health
Family Services

Central Region

25 Tupper Street, N.
Portage la Prairie, Manitoba,
CANADA
R1N 3K1

October 24, 1990

Dr. James Lubben
Associate Professor
School of Social Welfare
247 Dodd Hall
U.C.L.A.
Los Angeles, California
90024 - 1452

Dear Dr. Lubben,

I am a Social Worker working as part of a Psychogeriatric Assessment Team in Portage la Prairie, Manitoba, Canada. Our mandate falls under the Mental Health Branch of the Health Department in Manitoba and the aim of our newly formed programme is to service the needs of the elderly with psychiatric or emotional difficulties in the community. This includes a formal, comprehensive assessment and short-term follow-up to determine what changes or supports could be put into place to assist these elderly people in maintaining themselves in the community for as long as possible.

I was speaking with Professor Don Fuchs, Faculty of Social Work, University of Manitoba, who you recently met when you were at the University for your lecture. He was indicating that you have some excellent assessment tools with respect to the social networks of the elderly. Unfortunately, I was unable to attend your lecture, but I understand that you have developed a Social Network Scale and I am writing to request your permission to obtain a copy.

I am looking for a rather concise assessment tool to guide my overall assessment of the elderly's social interactions and support or, on the contrary, lack of support, that they receive from significant others.

I have enclosed a copy of our programme description for your reference. If it is possible for our Team to utilize the Social Network Scale, it would certainly be most appreciated. Also, if feasible, could you forward a copy of the actual scale to the enclosed address?

Thank you for your anticipated cooperation.

Phone. #

Merilee McClelland, B.S.W.

MMcC/lh

SCHOOL OF SOCIAL WELFARE
LOS ANGELES, CALIFORNIA 90024-1452

January 19, 1991

Merilee McClelland
Manitoba Central Region Health Department
25 Tupper Street N.
Portage la Prairie,
Manitoba R1N 3K1

Dear Ms. McClelland:

I appreciate your interest in the Lubben Social Network Scale (LSNS). You certainly have my permission to use the LSNS in any research project and please feel free to call me should you need any clarification on use or scoring of the LSNS. Enclosed are some recent articles which describe the Lubben Social Network Scale (LSNS). These articles illustrate analyses which used individual items from the LSNS as well as those which used the composite score. More recent work has demonstrated the validity and reliability of the LSNS among diverse elderly populations. For example, a recent paper at the APHA meeting reported analyses using the LSNS in a large HMO study in Los Angeles. Dr. Iris Chi and I are also working on an article where we successfully used the LSNS in a study of Hong Kong elderly. I am also working an article which describes the LSNS factor structure which has remained stable among these diverse study populations.

Should you publish the results of your study, I would appreciate your providing me with appropriate citations or reprints of your articles. Because I am collecting data on the generalizability of the LSNS, I would especially appreciate your sharing with me selected statistics of the LSNS that you may calculate using your data (e.g., means, standard deviations, Cronbach Alphas, etc.). Accordingly, I will periodically provide you with similar data from other studies. By forming this informal network of researchers using the LSNS, I can inform each of similar applications of the LSNS as well as any further refinements in the scale. Thank you again for your interest in the LSNS and I look forward to hearing about your results.

Sincerely,

James E. Lubben, MPH, DSW
Associate Professor
(213) 825-6219

JEL/lsc

April 27, 1992

Dr. C. Clifford Attkisson
Professor of Medical Psychology
Department of Psychiatry
Box 33-C
University of California
San Francisco, CA
94143

Dear Dr. Attkisson,

I am writing to express my interest in the Client Satisfaction Questionnaire (CSQ-8) which was developed by yourself and your colleagues, for use in my work. I am currently completing my Masters Degree in Social Work at the University of Manitoba, Winnipeg, Manitoba, Canada.

I have chosen to study female adult children as caregivers to the elderly in my practicum, and will be facilitating a support group as my intervention. The CSQ would be very useful in gaining participant feedback and evaluation of the group process, and thus, I am requesting your permission to use this scale in my study.

As I am conducting my group in May and June 1992, I would appreciate your prompt reply. Thank you for your time and attention to this matter. Your reply may be forwarded to the above address.

Yours truly,

Merilee McClelland, B.S.W., R.S.W.

May 5, 1992

To: Merrill McClelland

From:

CLIFFORD ATTKISSON, Ph.D.
Professor of Medical Psychology
Department of Psychiatry

Box 33C, 401 Parnassus Avenue
UNIVERSITY OF CALIFORNIA
San Francisco, California 94143-0984

Area Code 415
476-7374 (Office)
476-7713 (Messages)

The attached reprints are enclosed with my compliments. Thank you for your interest in my research. You have my permission to use the CSQ for non-profit research and evaluation purposes as long as your copies include a clear copyright notice and explicitly name credit to us as scale developers. Please state you are using the scale with permission. The following notice should be placed on each copy of the scale(s) used:

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Clifford Attkisson, Ph.D.
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APPENDIX IV

PRE AND POST-GROUP INTERVIEW QUESTIONS

PRE-GROUP INTERVIEW QUESTIONS

PARTICIPANT NAME:
INTERVIEWER:

DATE:

PURPOSE OF STUDY AND THE GROUP:

The study I am conducting on women caregivers of the elderly is part of my programme for my Masters of Social Work Degree which has included taking courses and practical field experience. The group will provide me with the practical experience component of the programme. In addition to providing a needed service to participants in terms of support and counselling, the group will be used to gain certain information about women as caregivers, which is, in part, the purpose of this interview. Before I begin with my questions, I will need you to read and sign the consent form. (Explain contents of consent form and have participant sign).

BACKGROUND/CONTEXTUAL INFORMATION:

1. Care recipient's information

- a)Name: b)D.O.B.:
- c)Relationship to participant:
- d)Marital status:
- e)Level of education:
- f)Ethnic background:
- g)Socioeconomic Status: Lower/ Middle/ Upper Class?

2. Participant's information

- a)Marital Status: (if married, spouse's name and date of marriage)
- b)Occupation:
- c)Do you have children: (If so, provide names, ages, etc.)

- d)Living arrangements/Housing: Are you currently living with the care recipient? In whose home?

i) If not, are you living nearby and does the care recipient ever stay overnight?

3. CHARACTERISTICS OF CARE:

a) Tell me about the care recipient's (mother or father) health problems? (probe for disease, physical/cognitive deterioration, behaviour problems)

b) What kinds of care activities do you provide? How often? How long have you been providing care?

c) Do you remember how you started to act as a caregiver?

d) What do you find rewarding about caregiving?

e) What do you find difficult?

f) Do you feel burdened by the care demands you face? If so, in what way?

g) Definitions of care--read definitions and have participant categorize herself into most appropriate.

h)Were you expected to provide care? By whom?

i)How do you feel about your care recipient's aging?
increasing dependency?

j)How would you describe the quality of your relationship with
the care recipient? Has this changed over time?

4. SOCIAL NETWORKS OF PARTICIPANTS:

Family--

a)Do you have siblings? (if so, provide names, ages, where
they live)

b)Do you see your siblings as supportive? (if so, indicate
why or why not) Probe for sharing of duties and
responsibilities.

Friends--

c)Do you have close friends?

d)How often do you see them?

e)Do you find your friends supportive of your caregiving
activities?
(probe for kind of support received--practical, emotional)

f)Has your relationship with your friends changed since you began caregiving? If so, in what ways?

FILL IN LUBBEN SOCIAL NETWORK SCALE AND CAREGIVER BURDEN INVENTORY

5. OTHER STRESSORS:

Family

a)How does caregiving impact on your own family? (probe for marital relationship, relationship with children, conflict)

b)Do you feel you have enough time for your family? (probe for feelings of guilt, competing responsibilities)

Work

c)Are you currently working outside of the home? If so, are you working full-time/part-time?

d)How do you find "juggling" caring responsibilities with work?

e)Do you find your supervisor/colleagues at work supportive? (probe for time off for caregiving duties, emotional support)

f)Have you ever or would you consider giving up work for caregiving?

Social life

g)Do you feel you have enough free time? (probe for opportunities to get away, outings, feelings of guilt/worry)

h)Do you ever find social commitments to be unwelcome (too tired, overwhelmed)?

6. EXPECTATIONS RE. CARING:

a)Do you think society expects women to be caregivers? In what ways?

b)What are the expectations regarding women's role as a caregiver in your family?

c)What are you own expectations about caregiving? Do you expect to care for someone else within your lifetime? Do you expect someone to care for you when you are older?

7. ASSISTANCE:

a)What kind of help do you receive from Home Care?

b)Are you satisfied with the assistance?

c)Do you feel the state (government) should take a greater responsibility for providing care to the elderly?

7. SELF-EFFICACY:

a) Do you find yourself feeling able or unable to manage all the competing demands placed on your time?

b) Do you believe that you can cope with the demands of caring?

c) What are some of the methods you find useful in coping with stress?

COMPLETE SELF-EFFICACY SCALE

8. OUTCOMES:

a) Do you ever feel anxious or depressed? Under what circumstances would these feelings occur?

b) Have you sought counselling to deal with anxiety, depression or other stressors?

c) Overall, do you feel your sense of well-being has changed in any way as a result of caregiving?

d) Do you feel healthy and well most of the time?

9. PERSONAL DATA:

a) DOB:

b) Level of education:

c) Ethnic background:

e) Socioeconomic Status: Lower/ Middle/ Upper Class?

WOMEN CAREGIVERS SUPPORT GROUP

POST-GROUP INTERVIEW QUESTIONS

PARTICIPANT NAME:

DATE:

INTERVIEWER:

INTRODUCTION:

As part of completing my study on women caregivers, I would like to ask you a few questions regarding changes you have experienced in your life since our first interview and the effectiveness of the caregiver group.

1. BACKGROUND/CONTEXTUAL INFORMATION:

a. Has anything changed in you living arrangements or that of your care recipient since our first interview?

b. Has anything changed with respect to marital status or other personal information for either yourself or your care recipient?

2. CHARACTERISTICS OF CARE:

a. Have there been any major changes in your care recipient's health or behaviours since our first interview? If so, what do you attribute the change to?

b. Has the amount and type of care you provide changed? How?

c. How do you view your role as a caregiver? Has your perception of that role changed since our first interview? Describe the changes. What would you attribute the change to?

e. Has the amount of burden you experience changed (increased/decreased) or stayed about the same? What do you attribute the change to?

f. Did you find the caregiver group helpful in dealing with feelings of burden/guilt/emotional reactions to caregiving?

g. Has the quality of your relationship with your care recipient changed? If so, in what ways? What do you attribute the change to?

FILL IN CAREGIVER BURDEN INVENTORY

3. SOCIAL NETWORKS OF PARTICIPANTS:

FAMILY

a. Have you experienced any changes in your relationships with siblings regarding provision of care for your parent? If so, please describe. What do you attribute the change to?

FRIENDS

a. Have you experienced any changes in your relationships with friends? Do you see them more/less often?

- b. Did the Caregiver Group help you to expand your social network (family/friends)? In what way?

FILL IN LUBBEN SOCIAL NETWORK SCALE

4. OTHER STRESSORS:

FAMILY

- a. Has your ability to balance the demands of caregiving with your own family changed? If so, in what way? What do you attribute the change to?

WORK

- a. Has your work situation changed?
- b. Do you deal with the competing demands of work and caregiving any differently now? If so, in what way? What do you attribute the change to?
- c. How do you manage "at-home work" and caregiving? Has this changed since our first interview? What do you attribute the change to?

SOCIAL LIFE

- a. Are you able to get away from the caregiving at times? Has this improved, stayed the same, or become worse since our first interview? Do you feel socially involved enough to meet your needs?

5. EXPECTATIONS RE. CARING

a. Have your expectations about women's role as caregivers changed in any way? If so, how? (probe for sharing of responsibility between men and women, siblings) What do you attribute the change to?

b. Do you feel women are recognized for the care they provide? If not, how would you like to be recognized?

c. Did the Caregiver Group help you feel more valued and recognized for your caregiving? If so, in what way?

6. FORMAL CARE:

a. Are you satisfied with the services you receive from Home Care? How might they be improved? Please describe.

b. If you are not currently receiving Home Care, do you feel that you need the services offered?

c. What role do you feel the state should play in caring for the elderly? Should the support be directed at the caregivers? Has your opinion changed in this regard since our first interview? If so, what do you attribute the change to?

7. SELF-EFFICACY:

a. Has your ability to manage the strain of caregiving demands on your time changed? How? What do you attribute the change to?

b. Have you developed any new ways of coping with stress and caring for yourself?

c. Did the Caregiver Group help in developing your self-confidence and in increasing your self-esteem to any degree? If so, please explain.

d. Definition of Empowerment: the process of realizing one's personal power to make choices, and to respond to situations based upon a sense of our needs, values, and goals. Did the Caregiver Support Group assist you in developing a sense of empowerment?

COMPLETE SELF-EFFICACY SCALE

5. OUTCOMES

a. Do you feel anxious or depressed? Under what circumstances and has this changed since our first interview?

b. How do you deal with feelings of anxiety or depression? Did the group help you to improve your coping?

c. Do you feel healthy and well most of the time? Has this changed and if so, what do you attribute the change to?

GENERAL COMMENTS: