

CARING FOR DISABLED HUSBANDS:

Wives' Perspectives

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ABSTRACT

There is presently an increasing trend towards deinstitutionalization of several different populations, including physically disabled adults. Although a variety of staffed resources provide for alternative care, 'home' and 'family' remain the primary resource in the community based care system.

Given that the family of the 1980's has a decreased capacity to care due to such factors as increased mobility and loss of extended family networks we must be concerned with the continued viability of this resource. And, given that 'family' is often a euphemism for 'nearest female relative' and that women's role in society has changed markedly in recent years the issue of women as caregivers is one of particularly urgent concern.

This study is based on extensive interviews with eight women caring for disabled husbands. The interview schedule and methodology facilitated descriptive data regarding caregiving tasks as well as a comprehensive exploration of what was problematic about the day to day reality of caregiving for these women.

The data analysis identified struggling with the 'role' of wife-caregiver, isolation and a changed marital dynamic as primary themes in the process of caregiving.

This study provides some insight into what is problematic about caregiving for these wives and some suggestions for improving social work practice and providing more effective services in relation to this population.

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CHAPTER 1

INTRODUCTION AND OBJECTIVES OF THE PRESENT STUDY

The Social Background of the Problem

Women have traditionally been the primary caregivers in our society (Brody, 1974; Shanas, 1979). Historically and presently this applies to unpaid caregiving in the home - care of children with or without special needs, care for aging parents, and care of unwell or disabled spouses - and to paid employment outside the home - nursing, homemaking services and childcare. While some research has examined the impact on family members of caregiving for the elderly or mentally infirm (Klein, 1967; Lezak, 1978; Sainsbury and Grad, 1970; Sanford, 1975), few studies have focussed on women caring for physically disabled spouses.

Studies have shown that women are the primary caregivers of those disabled persons living in the community in 80% - 90% of all cases (Schwartz, 1957; Goffman, 1963; Voysey, 1975). As a consequence of a husband's disability a wife will also be faced with changes in her psychological and social situation (Hilbourne, 1973). Lack of appropriate attention to the needs of such women is likely to result in negative consequences for the mental and physical health of both her and the disabled spouse.

The trend towards deinstitutionalization of several different populations, including physically disabled adults, continues in the 1980's. And, although a variety of staffed resources provide alternative care, 'home' and 'family' remain the primary resource in the community based care system. Given that the family of the 1980's has a decreased capacity to care due to such factors as increased mobility and loss of extended family networks we must be concerned with the continued viability of this resource. And, given that 'family' is essentially a euphemism for 'nearest female relative' and that women's role in society has changed markedly in recent years the issue of women as caregivers is one of particularly urgent concern.

Objectives of the Present Study

The primary objective of this thesis is to explore the day to day reality of caregiving for wives of disabled husbands and to examine what is problematic for this population about the caregiving process. The premise is that these subjects are the 'experts' in regards to caregiving and thus, can offer through the descriptions of their own experience the most reliable information about what that work entails, what is problematic and what would be of assistance.

The researcher holds some assumptions about the role that our British Columbia Home Care and Home Health services play in the caregiving experience - assumptions which are explicated in the Policy chapter - but the Analysis and Results will only focus on those aspects which are, in fact, emergent from the data.

Policies such as those expressed in the above service systems represent one part of our institutional structure which reflect the

greater cultural/economic/political context and, presumably, reflect societal attitudes towards women in the family. As Dorothy Smith (1974) states, "...the domestic world stands in a dependent relation to the other [governing systems] and its whole character is subordinate to it." (p.7) In elaborating on the experience of caregiving we are elaborating on an experience which is externally ordered and determined. "The everyday world, the world where people are located as they live and which organizes their experience is one which can be viewed as generated in its varieties by an organization of social relations which originates elsewhere." (Smith, 1977, p.20)

And so this study can be seen as a mode of discovering the governing societal structures from within; through the experience of a 'wife' caregiver. Kleinman (1980) also states support for such an approach as follows:

"External factors exert an enormous impact on medical systems...defining, for example, the way power relationships in (capitalist) societies simultaneously contribute to inequality in access to and allocation of limited health care resources. Whether or not one accepts this line of analysis, awareness of the enormous effect societal-wide forces exert on health care systems is essential if one is to avoid the mistake made by Illich (1975) among others, in attributing the failure of health care systems solely to the machinations of the medical profession, as if it were able to operate entirely independent of its social and political context. An ecological perspective on health care systems prevents this type of solecism."

Therefore this paper adopts an ecological perspective to the problem area. An ecological perspective involves approaching the present caregiving experience as a function of the individual's past and

present history and their interaction with a variety of formal and informal systems. It is hoped that this will usefully portray the very real emotional and physical difficulties confronted by women caring for disabled family members.

Better understanding of the caregiving reality should enable us in more accurately assessing the community impact of deinstitutionalization; such an assessment must take into account the often high economic and emotional costs to families. And we must be aware of how much of this cost is borne by the women in these families.

The research at hand focuses on non-static disability. Much of the discussion could be applied, not only to other types of physical disability, but to other populations. Common to all of them is the concern that families (read 'women') continue to be presumed to be a willing, able, largely unrecognized, and unpaid labour force.

The following is a case in point:

Steven Pickering suffered serious head injuries in a 1980 motor vehicle accident. In awarding damages to Pickering at the 1983 trial, Justice Albert Mackoff of the B.C. Supreme Court denied a portion of the claim in which Pickering sought the cost of hiring a live in housekeeper. "It is only if Steven were not married to Donna that the need for such a live in homemaker would arise," the judge said. "However, Donna states that she loves Steven and intends to stay with him. That being so, there is no basis for this claim."

On appeal, the slim prospects of the marriage surviving the tragedy were taken into account. In weighing two principal contingencies in the case - first the wife's death or sickness, and second, marriage breakdown - the court decided the wife would continue to perform her homemaking skills for her husband for 20 years.

Thus, based on a life expectancy of 39.45 years, the court decided Pickering was entitled to additional damages of \$168,116 to enable him to hire a live in homemaker for the last 19.45 years of his life. (see Appendix A)

This judgement illustrates a number of issues raised in the preceding pages including the issues of women's role in the family, the ways in which various institutional structures take this role to be a 'given', how funding and service delivery 'gatekeepers' reflect societal expectations that wives' capacity for and acceptance of the caregiving role will increase with need; death or divorce alone providing exemption. In the course of exploring the experience of caregiving for women whose spouses are physically disabled this thesis will attempt to determine the significance of the above issues.

The everyday reality of caregiving for these women and the process of 'becoming a caregiver' will be explored through comprehensive, qualitative interviews. The subjects chosen for this study are women caring for disabled husbands. Specifically, these are women caring for a spouse disabled by an illness with an uncertain rate and extent of deterioration or improvement. Therefore, these are women who must deal with the double stress of present disability and the prospect of uncertain and unpredictable processes of deterioration. Uncertainty of disease progression has been shown to pose particular difficulties for family members (Harrower and Herrman, 1953; Weinstein, 1970; Matson and Brooks, 1977) and to negatively impact on the well being of the spouse and marital satisfaction (Zahn, 1973). The significance of uncertainty for caregivers will be discussed in more depth in later chapters.

The following literature review will provide an historical overview of caregiving and discuss research findings relevant to our present study.

CHAPTER 2

REVIEW OF RELATED RESEARCH AND LITERATURE

In spite of the fact that a partner's disability is likely to result in changes in the sexual, parental, occupational, and educational aspects of a wife's life and that the wife may pay a high physical and emotional price for her husband's chronic illness, proportionately little attention is paid to the position of wives vis a vis caregiving situations. The bulk of the literature on the costs and consequences of chronic illness focusses on the disabled member of the family. In regards to adjustment to chronic illness there is, again, considerable literature on the 'patient' but less information regarding the caregiver's adjustment to the patient's illness. What research is available demonstrates that chronic illness impacts on the spouse's mental and physical health and that this impact has a significant effect on the patient's well being (Shambaugh, 1967; Abram, Moore, and Westerwelt) The review at hand, however, will be primarily concerned with wife-caregivers; with what we do know about how these women come to be caregivers and about the costs and consequences of caregiving for them.

Research indicates that single, childless, divorced and widowed people are more likely to be institutionalized than those who have family support. (Palmore, 1976; Townsend, 1965; Treas, 1977; Wawzonik, 1974) And where there is family but the wife is so disabled as to be unable to provide care for her elderly husband, the care needs of elderly parents most often fall to daughters. (Golodetz, 1969) Generally, family

contacts of older people most often are with the female members of the family, most frequently a daughter, who also provides most of the services needed. (Riley and Foner, 1968)

Fengler and Goodrich's 1979 study is another one which looked at the questions: 1) whether being single, widowed or divorced affects the likelihood of institutionalization among disabled men and 2) whether there is a price paid by the non-disabled caregiving wife. Their answer, congruent with other literature is that being married greatly decreases the likelihood of institutionalization for men and that isolation, loneliness, economic hardship and role overload were the most significant consequences for the caregiving wife.

The health care service needs of those caring for spouses with chronic conditions cannot be dismissed as the need of only a few isolated families. Glazier (1973) points out that the overwhelming problems of medical practice in industrial countries are with chronic illness and with the community health care system. It has been suggested that present lack of attention to this area is related to the fact that more knowledge and prestige is attached to those professionals and areas of work/research that are concerned with acute care. At any rate, the present situation is that although the deinstitutionalization movement became well established over a decade ago, the adequacy of community funding remains questionable and services focussing on supporting the family member caring for a disabled adult in the home has finished last when compared to other thrusts of deinstitutionalization.

One of the first studies on caregivers was conducted by Golodetz (1969) and it described the role of a person who takes care of a chronically ill relative at home. The family or caregiver is referred to as the 'responsor', a word designed to connote both response to the

patient and responsibility for the patient's needs. The investigation involved sixty housebound and elderly patients with chronic and terminal conditions, all of whom were receiving multi-disciplinary services of a home-care team from the Boston Dispensary and the Tufts Department of Preventive Medicine. Of the 60 respondents, 82% were wives and daughters of the patients; in 70% of the cases the responsor health was poor; significant illness of the caregivers was found in more than 50% of the cases, regardless of age.

Golodetz describes the position of these caregiving women in the following way: (this statement is made within the context of criticising the attitude of home health care team members towards the caregiver).

The most facile attitude of the (home care) team is to regard the responsor (caregiver) as their assistant on the scene. But she is not a member of the team. She lacks many of the characteristics of a team member. She is not trained for her job, a priori. She may have little or no choice about doing the job. She belongs to no union or guild, works no fixed maximum of hours. She lacks formal compensation, job advancement and even the possibility of being fired. She has no job mobility. In her work situation, she bears a heavy emotional load, but has no colleagues or education to help her handle this. Her own life and its needs compete constantly with her work requirements. She may be limited in her performance by her own ailments (there is usually no pre-employment physical) or even such an inherent characteristic as sex (e.g. a daughter taking care of a bed-ridden father). Although, the responsor's lack of preparedness for what she is asked to do may be formidable, her dissimilarity from the member of the home care team is striking.

On the other side of the coin, of course, are those special attributes of a responsor that may make her so much more valuable than even a first class therapist - extraordinary motivation, perhaps, and total emotional commitment and sympathy that can invaluablely complement professional detachment. (1969, p.390)

The theme of Golodetz' study is that we are a society which holds that meaningful life means home living and a society that, philosophical consideration aside, requires the home-site for the ever-expanding population of infirm and elderly. We must, for these reasons, explore and attend to the needs of the 'responzor'. One of those needs may be for work after their 'home-care story' comes to an end. And, in conclusion Golodetz states, "...the debt which society owes them could be paid, at least in some instances, by helping them to re-establish contact with the larger world. And, if work seems possible, then indeed it might be time to regard them as nurse's aids. After all, they have had an extraordinary kind of on-the-job training." (p.394) And, although it might be argued that 'paying the debt' in such a manner perpetuates societal presumptions regarding women's role, albeit in the paid workforce, it does at least suggest the appropriateness of tangible recognition of the skills inherent in caregiving.

Even when the differences in life expectancy of men and women are controlled for, elderly ill men are more likely to live with a spouse; with disabled and/or elderly men being relatively unlikely to live alone. It is, however, quite common for women in either of these categories to live alone. (Mindel, 1979; Shanas, 1979) Montgomery (1982) writes eloquently about how, for both the disabled and elderly populations, the general public underestimates what families do and exaggerates what government agencies do, and emphasizes the need to acknowledge the reality - that families do not, as a rule, abandon their elderly or disabled members. Montgomery does not specify the proportionate spending for the care of the disabled, per se, but does state that in the United States

families, kin and friends expend far more money on the care of the elderly than all public agencies combined.

The problem is twofold. 1) that women do fulfill this role as primary caregivers and 2) that this role and all of what that entails is so taken for granted that it often seems to be 'invisible.' The fact that women's work is largely taken for granted is true regardless of whether this work involves the care of a child, husband, neighbour or friend. But, as is pointed out by Shirley Cohen (1982), although we may take the care provided by new mothers for granted we also 'take for granted' their need for 'time out' from the "...rewarding, life-enriching experience....often tedious, exhausting, and stressful job of caring for an infant"(p.7) She points out that where there is a lack of informal support networks (i.e. extended family) or where there are extenuating circumstances (i.e. a developmental handicap or a physical disability) which impedes or prevents the utilization of support networks, the need not only remains but is compounded by the isolation resulting from withdrawal of family/friends from the 'difficulty' and by the increased physical, monetary, and emotional stresses of the caregiving situation. We might extrapolate from this to the woman caring for a spouse and see that her needs for respite and assistance are not only thus compounded but further exacerbated by a lack of acknowledgement and/or societal response to her situation.

Willingness to Care

The literature shows that most family members of chronically ill adults are very willing to have their patients come home to their care. Most families inexperienced with caregiving do not initiate a request for

assistance with patient care at the time of hospital discharge. (Eggert, Granger, Morris, and Pendleton, 1977) When a family member does request assistance, the response of the doctor, nurse, or social worker can all too often communicate that the family member does not really need assistance, and that they 'should' really provide the care by themselves. Because women in particular have been raised with a strong sense of family (and caregiving/nurturing) obligation, few challenge the 'professional' person's evaluation of their situation. Yet, as Benjamin Danis (1980) put it, "A family's willingness to care for an ill member says nothing about its actual ability to do so." Danis goes on to question the ability of the family to serve as the primary caretaking source, documenting that many studies have revealed the disequilibrium, including physical and emotional problems, which often affects those providing total care for a seriously ill or disabled family member. Other false assumptions often made concerning the capacity of the family to care for its chronically ill at home relates to such matters as living costs, the quality of care which can actually be provided by family caregivers for those spouses who are severely disabled, as well as the social and psychological burdens of caregiving.

Sussman (1979) makes the following statement about the discrepancy between a family's willingness to care and their capacity to care - given present services:

In our research and in a review of studies by other investigators, there is found a persistent willingness to look after one's own kin who are sick or disabled. In accepting this willingness and exploiting it, what is forgotten is that many families are sacrificing their own well being and enjoyment of some quality of life and they themselves may become dependent on community handouts. At a rapid rate they consume whatever psychological and economical resources they have, are in danger of family breakup, mental illness and an existence in poverty.

In fact it is often the love and the persistence of family members' determination to care for their loved ones that works against them. This very insistence, as Packwood (1980) states, "...has led to it (caregiving) being taken for granted. Ritual observations mention the pressures on families and how the welfare services would collapse if the family ceased to provide care, but the possibility is hardly ever taken seriously.."

Consequences of Caregiving

Studies which have considered the difficulties and strains of caregiving on relatives point out that one of the crucial problems faced by health and social service professionals is the effect that caring has on the people the patient lives with (Golodetz, 1969; Lopata 1973; Sanford, 1975; Schwatz, 1957). Although Sainsbury and Grad's study involved mental patients, they, too, found that the effect of chronic or long term illness on the family was significantly greater than when the patient's illness was acute.

Fengler and Goodrich (1979) called attention to three main components of the caregiving experience: **Role overload** - where the

cumulation of domestic and other responsibilities and demands exceeds the caregivers capacity for coping; **Loneliness** - where caregiving responsibilities limit contacts with other than spouse and especially where spouse was not the primary confidant or companion prior to disability; **Isolation** - the results of loneliness compounded by permanently disrupted patterns of socialization and friendships. Added to these factors is the **role ambiguity** experienced as the women shift from the role of wife in a traditional marriage to health care worker and nurse. While this study did not find a correlation between functional limitation and Life Satisfaction Scores (of wives) as did a study by Zahn (1973) it should be noted that in the study by Fengler and Godrich, functional limitation was defined on the basis of mobility whereas Zahn's conclusions were based on sexual impairment, inability to work and other functional limitation including mobility. Fengler and Goodrich did go on to say in this study that role overload decreases as the impairment increases to a point where the role of caregiver clearly supercedes the conventionally defined role of wife.

Fengler and Goodrich (1979) conclude that learning more about the problems and needs of such wives would help to develop policies which might improve the wife's morale and, as a consequence, the husband's as well. It also appears that others who might also require her caregiving would benefit as well.

Social Isolation

In Elinor Polanski's (1984) study of family caregivers 'wife-caregiver' were found to have the highest level of Physical; Psychological Stress and amongst the factors identified social isolation was found to be a primary contributor to this stress.

Golodetz's (1969) study enumerates the many consequences, for the wife, of their partner's illness; elaborating on how the disability effects changes in the psychological and social situation of both partners. It was noted that: "...the responders were not involved in a great many outside activities...The sense of isolation in the household units was palpable...the home-care households were small, isolated, and pre-occupied with the care of illness." (p. 388) Social supports taken for granted may not, in whole, survive the advent of disability and although the literature suggests support group as one mechanism which may compensate for the isolation wrought by the loss of 'natural' networks such support groups are largely accessed through self referral and are therefore dependent upon an acceptance, identification of self, and emotional willingness which cannot be assumed.

III Health

One retrospective study of elderly widows found that 46% of the women interviewed had cared for their husbands at home before their deaths and 40% of them for more than a year. (Lopata, 1973) These women were identified as constituting a particularly high risk group of elders and were labelled the "hidden victims" six years later by Fengler

and Goodrich (1977). Fengler and Goodrich's study focussed on wives between 59 and 81 years of age caring for husbands aged 65 to 86. The husbands' disabilities ranged from cardiac disabilities (affecting mobility and/or use of limbs and, in about 20% of the cases, affecting communication) to M.S., hemaplegia, arthritis and cancer. In this group of caregiving wives it was found that these women had serious health problems of their own. All of the women had at least one chronic condition and some were themselves seriously disabled. This study is consistent with others, including Golodetz' 1969 study, which supports the contention that a wife's health has to clearly render her physically unable to provide care before she is (socially) exempted from caregiving responsibility. An aged woman is not only less likely to have a spouse to look after her but,

...even when the spouse is present the social role of the aged husband equips him less well to look after a sick woman and run the home than does that of a woman similarly placed...in addition, being younger than their spouses, older women are less likely than older men to suffer a condition that hinders them from providing major care for disabled spouses. These facts will often result in the wife assuming the role of caregiver in a couple where both spouses are disabled to a similar degree. (USDEHEW 1971, from Fengler & Goodrich, pp. 176)

Much clinical and epidemiological research has pointed to a relationship between prolonged exposure to a stressful life experience (such as chronic illness) and emotional dysfunction (Rabkin and Streuning, 1976). There is, in the literature, evidence that one of the consequences of the stress of simply living with the illness or disability of a family member is depression. (Holmes and Masuda, 1974) It has been

noted, in fact, that the two most frequent responses to stressful events are anxiety and depression (Paykel, 1978) and that living with chronic illness is, thus, debilitating not only for the patient, but for the other members of the family as well (Bruhn, 1977).

Role Overload

Another stressful aspect of caregiving in a society of increasing numbers of non or deinstitutionalized elderly and disabled is the caretaking responsibility for multiple patients that falls to some women. One of the women in Fengler and Goodrich's study saw caregiving as representing the continuity in her life, saying, "I was taking care of babies at 20. Now I'm taking care of my husband."

Another woman in Fengler and Goodrich's (1979) study,.....with a low life satisfaction score whose husband suffered from an advanced state of Multiple Sclerosis requiring a great deal of care also had to comfort a mother whose husband was dying. When he died, the mother's depression and demands on her daughter became excessive. "I get down when she talks about their being no point in living. Mother's expectations of me are getting unreasonable. I can't continue to cart her around because I can't leave my husband alone".

Relationship Between Degree of Disability and Stress

Two studies which will be reviewed in this section were conducted by Mishel (1981) and Zahn (1973). As the women being interviewed for the study at hand are confronting illness or disability with uncertain prognoses, this work is of particular relevance. Mishel's

work provides some evidence that severe disability may be less stressful than moderate or mild disability and that this is due to the fact that when the expectations and role definitions are ambiguous and uncertain, serious strain is placed on the family. Where the wife/husband assumes some or all responsibilities for caregiving, the stress resulting from the disease is compounded by the ambiguity in the role definition within the marriage. And in Zahn's (1973) study, it was hypothesized that those characteristics of impairment affecting relationships between impaired and non-impaired would include severity of impairment, the kind of functional limitations associated with the impairment and visibility of the impairment.

Mishel

Mishel's (1979) work deals with ambiguity as a factor of uncertainty; uncertainty as a condition having considerable bearing on many aspects of illness-related events. One purpose of Mishel's investigation was to explore the role of uncertainty as a significant variable influencing patients' experiences in illness. Mishel's study also addressed the absence of any conceptualization of uncertainty in illness and the lack of any instrument to measure the concept. This work is of interest due to the evidence it provides as to the extreme stress which ambiguity engenders in many aspects of illness - for patients and for family members.

Figure 1 shows Mishel's model of perceived uncertainty in illness.

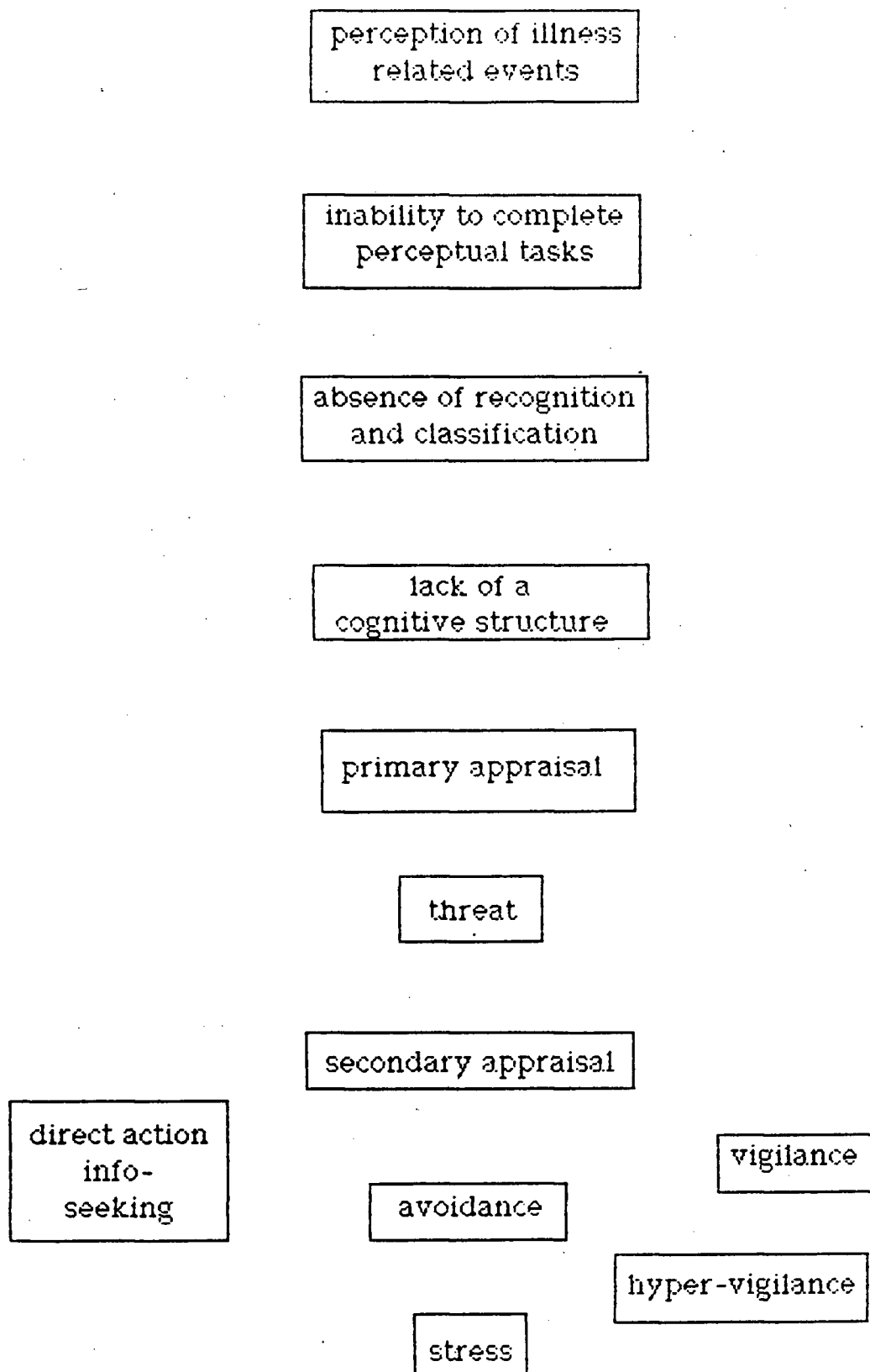


FIGURE 1: Model of Perceived Uncertainty in Illness

This model is based upon a cognitive appraisal model and utilizes the work of several theorists. As the model illustrates, uncertainty prevents or inhibits the formation of a cognitive structure, which in turn limits the person's ability to adequately appraise a situation. Appraisal begins by evaluating an event as a threat, as benign, or as a challenge. And when an event is uncertain it is evaluated as a threat because the individual is not able to obtain a clear cut conception of what is to occur. The suggestion is made that the ambiguity factor in uncertainty has the highest threat potential of all situational variables because it impedes coping.

This provides some clue as to why severe disability might be less stressful than moderate or mild disability. Expectations and role definitions which are ambiguous and uncertain place serious strain on the family. And being as uncertain and ambiguity as to the progression of the disease (which may be enhanced but not necessarily associated only with mild/moderate disability) makes it difficult to successfully deal with the major issue of resolving issues of dependence, independence, and interdependence it would follow that where progression of the disease is uncertain, as in Multiple Sclerosis, this stress would be inevitable. An event is judged uncertain when it contains one or more of the following (often overlapping) eight dimensions: 1) vagueness 2) lack of clarity 3) ambiguity 4) unpredictability 5) inconsistency 6) probability 7) multiple meanings 8) lack of information.

Where the wife/husband assumes some or all responsibilities for caregiving, the stress resulting from the uncertain progression of the disease is compounded by the ambiguity in the role definition within the marriage. As one husband was to put it, "It's difficult, sometimes, to

differentiate the role of wife vs. nurse. I know that sometimes this causes resentment, because I get confused whether I am a patient or a husband. In truth I am both." 'Sam'

Some studies reveal that physical impairment is disruptive of interactions between the impaired and his significant others (especially family members). It seems that impairment is disruptive in these contexts because the physical incapacity results in inability to fulfil the role requirements expected by these significant others (Mishel, 1981)

Zahn

In a study by Zahn (1973), 2,474 applicants for disability benefits were randomly selected and assessed for the impact of characteristics of impairment on family, friendship, and casual relationships of the physically disabled. The sample population suffered from a variety of impairments: 33% - circulatory impairments (primarily including heart disease); 22.5% - musculoskeletal disorders such as arthritis, low back disorders and amputation, or neurological disorders such as cerebral hemorrhage; 20.9% - disorders that could not be clearly classified into these four categories. The sample population suffered from a physical disability which was neither terminal or communicable, who were not receiving rehabilitative services and who were not institutionalized. However, the authors stated in their conclusions that, where disability benefits were being received by persons suffering from mild physical disability, some psychological disturbance was likely present and this psychiatric disorder may have affected the findings.

Severity of physical limitations and work capacity were based on panel evaluation incorporating findings of all members of the clinic

team. Severity was judged according to degree of work limitations imposed by the person's physical limitations. Type of impairment and degree of sexual impairment were judged by medical evaluation based on the medical history, physical examination and laboratory tests.

All data regarding the dependent variables, i.e. relationships with spouse, family, friends and others, were collected by trained social workers, through interviews with the physically impaired persons. The interviews consisted of: 1) semi-structured questions regarding the relationship of the person with his spouse, with his friends and with others; and 2) structured questions such as, "To what degree do you view the disability as a handicap in: 1) general family relations; 2) relations with friends, and 3) other relationships."

Findings, in general, supported the conclusion that characteristics of impairments that clearly indicate sickness or disability are associated with better interpersonal relations. This clarity, as indicated by severity of functional limitations, inability to work, and established sexual impairment legitimizes the sick or disabled role for incumbents and facilitates unimpaired functioning. When the health condition is in doubt, greater problems in interpersonal relations seem to arise.

Table 1 represents the finding that the more severely impaired are likely to have better interpersonal relations than are the less severely impaired. The 'none' category in Table 1 refers to those persons whose physical limitations were not great enough to appreciably limit work capacity and therefore (the authors surmised) those persons whose receipt of disability benefits was likely due to psychological difficulty rather than the minimal physical disorder.

TABLE 1:
RELATIONS WITH SPOUSE BY SEVERITY OF LIMITATION

SEVERITY LEVELS										
RELATIONS WITH SPOUSE	NONE		SLIGHT		MODERATE		SEVERE		TOTAL	
	N	%	N	%	N	%	N	%	N	%
POOR	13	48.2	75	32.3	170	29.1	203	26.6	40	20.4
AVERAGE	7	25.9	48	20.7	131	22.4	147	19.2	39	19.9
GOOD	7	25.9	109	47.0	288	48.5	414	54.2	117	59.7
TOTAL	27	100.0	232	100.0	584	100.0	764	100.0	196	100.0
=====										

$\chi^2 = 21.42$; d.f. = 8; $p < .01$

The study suggests a number of possible explanations for these data. On the one hand, it may be that those who apply for disability benefits but who are only slightly physically impaired are more likely to have a psychological disturbance; that this psychiatric disturbance accounts for the poorer interpersonal relations. On the other hand, perhaps as one demonstrates increasing physical limitations, ambiguity regarding one's status is removed and norms attendant the sick and/or disabled role become clearly applicable.

Summary

Knowing about some of the consequences of caregiving is important in understanding the experience of women caring for disabled husbands. The foregoing review has described some of the physical, social and emotional consequences for these wife-caregivers.

Knowledge about home and health care policy is also important in understanding the experience of caregiving. What services are offered to women caring for disabled husbands and what incentives or barriers to access exist are questions that will be explored in the following section.

CHAPTER 3

POLICY ISSUES

Home Care Policy in British Columbia.

This thesis is, in part, a beginning exploration of how the family (in itself an institutional structure) places women in a caregiving role and to what extent and in what ways this role is then encouraged and perpetuated - even enforced - by the administration and content of our (home) health care policies.

Knowledge of systems - families and service providers - is necessary as a first step towards developing more adaptive and responsive structures. Developing more responsive home health care systems is important as the ways in which these systems are encountered has a significant impact on the caregiving experience.

And there is evidence that even here in British Columbia where deinstitutionalization is strongly supported by government policy, that the home health care system fails to support in a substantial way for the chronically ill at home. It seems contradictory to have a prevailing philosophy of supporting (rather than supplanting) the family and a service delivery system whose wealth is evident in the treatment of acute episodic health problems (or for provision of rehabilitation work

within an institutional setting) but not in the treatment of long term health problems at home.

This imbalance between financial support for acute health care problems within institutions and financial support for home health care services might be interpreted as representing the government's position that money or services are not really needed by those chronically ill patients whose families are prepared to care for them at home. Perhaps this lack of proportionate funding for home care is due to an ignorance of the arduousness of home care or of the degree of need. Or, perhaps, it arises from a belief that, by ignoring the problem, women might continue bearing this 'traditional' role; either by sacrificing other aspects of their lives such as a career or by attempting to do both jobs.

The following is a brief assessment of the adaptiveness and responsiveness of one part of the health care delivery system, The Long Term Care Policy. It will be examined in regards to 'secondary beneficiaries' (secondary beneficiaries being those who, like women caring for a disabled family member, benefit or suffer depending upon the services offered to the patient). This examination will be based, in part, on Winnifred Bell's analytic framework (1969) which includes inclusiveness, access (distribution), adequacy, democratic involvement and administrative feasibility as evaluative concepts.

A primary consideration in the evaluation of service is **inclusiveness**, or the degree to which a program covers the population at risk. The fact that a physician's referral is necessary in order to access home nursing care and the fact that access to homemaker service is determined via a process which includes income testing are significant considerations in the assessment of program inclusiveness. The preceding literature review supports the notion that the 'population

at risk' must include the caregiver as well as the patient being that the simple presence of a spouse is no guarantee of optimal care and patient well-being and that, in fact, caregiver well-being and support is critical to viable home care. Therefore, in considering this concept of inclusiveness we must not only look at accessibility of services to the 'patient' but also at how accessible the program is to 'secondary consumers' of service. "...Home Care Services are available on referral from a doctor and there is no user charge for these services. However, the cost of materials such as dressing and equipment is the user's responsibility. Homemaker Services are income tested. (SPARC, 1982)

The first restriction, that the source of referral must be a physician and/or hospital, is very common. As stated in Home Care: A Comprehensive Overview: "While it is helpful to the home care program to receive referrals from physicians directly, and while such referrals may indicate that they have a greater interest in their patients' welfare, restricting access to physician's referrals excludes a majority of those in need of home care. The consequences of their exclusion may well be a more rapid deterioration or a breakdown in the family's ability to cope -- either of which is likely to increase the need for institutional care." (Home Care: A Comprehensive Overview, pp. 37)

In her book Home Health Care, Jane Emmert Stewart (1979) points out that all home health agencies require that a physician order their services before they can be provided, to make sure that the government will consider the services appropriate and reimburse the agencies for them. Many physicians are criticized for not making home care referrals often enough for their patients. Stewart claims that physicians and the other types of health care practitioners have a lack of knowledge concerning home health care services coupled with skepticism and

indifference about family members' difficulties with making such plans. Although this is an American reference, it is a criticism which has been made against the homenursing care program in British Columbia. Although the homenursing care program is not income tested as are homemaker services, it does utilize some eligibility criteria as the homemaker program such as severity of disability and family structure. The Homemaker services are, however, income tested. The only criticism of this which I will mention here is that, where recipients of home care services receive care and support from family members such as a spouse, it may be difficult to persuade the 'patient' that they should pay for outside services. This may place yet another pressure on the wife to maintain caregiving responsibilities. The problem in this regard is that such 'consumer discretion' is exercised by the patient and may involve rejection of service by the patient which the spouse or 'secondary consumer' considers essential; the spouse of the eligible person in this situation is not considered to be the consumer by the Continuing Care Division.....the person whose illness or disability determines eligibility is the consumer and their consent must be given prior to implementation of service. (except where they are declared mentally incompetent) This can cause problems where i.e. a patient is resistant to anyone other than their spouse providing domestic help or personal care.

Although only the 'client's' consent is required, family income is a determinant of homemaker service provision. (Homenursing care is based on physical need only but requires physician referral which again may be biased where a wife is deemed capable of providing the care) Where the husband has, in fact, borne the traditional role of primary income earner or primary decision maker regarding family spending, the wife may be doubly penalized. First she is penalized by simply being there and

receiving services intended only to augment her caregiving. Second, she is often further restricted by a husband who feels it more appropriate for her to provide the care and/or does not deem it worthwhile to pay X dollars for each hour of homemaker service. (Anyone with above subsistence income pays some portion of the service cost) A system which is premised upon women's traditional role therefore opens the door to this sort of internal familial pressure on women to bear the burden of care.

Another critical determinant of policy effectiveness is **access** and distribution of services. That Long Term Care services are distributed proportionate to race, age and sex is a positive feature of the Program. However, it must be noted that this non-prejudicial access to service applies to the patient. And, again, it is a problem that 'patient' need and 'patient' consent are prerequisites of service provision; that caregiver consent is not sufficient in the case of a spouse's refusal to allow non-kin to provide domestic service; that family and not patient income is a determinant; that the presence of a wife will likely be considered 'family structure' criteria minimizing need for services....all of these things not only clearly minimize a wife's freedom of access to services - the provision of which would positively impact on her own health as well as the patient's - but ususally results in her providing these desired services herself - unpaid, of course. In Home Care: A Comprehensive Overview, the following statement is made:

Access to health care is the most critical determinant in whether an individual receives and complies with the care needed and prescribed. Access means the initiation of care and its continuation. As a happening it 'involves the prospective provider and a range of socio-political, economic, psychological, cultural and organizational dimensions which affect the behaviours and attitudes of both'. In order to reach professional service, an individual needs to pass through a social or health services doorway. To do so requires a perception of need and some identification of the type of services that may be required and is provided by the medical establishment." (p. 125)

An interesting question to explore would be whether or not the barriers to access for the secondary consumer enumerated above are the result of an organization developed deliberately in order to meet institutional rather than consumer needs; even to meet institutional needs at the expense of the individual caregiver. Another question - one which will be addressed in the study at hand, is whether such barriers to access for the caregiver may be compounded by another barrier which is the attitude of the 'gatekeepers' to these services - health care personnel such as doctors, nurses, social workers, skilled health professionals, Long Term Care workers, and others.

Adequacy, or the degree to which programs accomplish their qualitative goals is another factor in assessing policy and service provision. The objectives of the British Columbia Long Term Care Program are:

- (a) make services available to persons who want to live at home but need help to do so.
- (b) to supply basic services and care with an emphasis on health need
- (c) to improve the quality of services and facilities.
- (d) to coordinate many of the previously separate services.

The adequacy rating of the program would certainly be higher if we took the evidence of the foregoing literature review and discussion into account and made caregiver concerns, consent and well-being integral to the eligibility, referral and delivery process - acknowledging the value of her role and the interconnectedness of patient and caregiver well-being.

Another evaluative concept to consider is **democratic involvement**, or "the degree to which service consumers, clients, patients, or target neighbourhoods are genuinely involved in program planning, implementation, improvement, or termination. This concept draws attention to alternative methods for "...increasing the relevance of the institutional structure in the lives of individuals and families." (Bell, pp.8)

It is the opinion of the author that one way to improve the relevance and responsiveness of the Long Term Care Program - and to enhance the involvement of the caregiving spouse might be to:

- offer night attendant services, providing some opportunities for a good night's sleep where the disability normally requires the wife rising to provide night care. This would, perhaps, give her the rest necessary for her to better perform her daytime caregiving and outside occupational tasks.
- to consider replacing the present system of allotting X hours of homemaker and X hours of homenuising, etc. It might, perhaps, be replaced with a more flexible system of allotting X dollars to be apportioned at the consumer's discretion between homemaker, homenuising, night-time, and other services. Such allocation to be determined via a process involving both patient and caregiver with professional consultation.

What is important is that home care services be offered in ways which are flexible rather than offering help in an 'either this way or not at all' manner. Enhancing flexibility in such a manner has value but does not substantively address the dilemma inherent in policies and services which approach home care delivery from the perspective of assisting women in better managing their task as primary caregivers. Much of the discussion so far suggests a need to question the validity of such an approach; to examine how policy allows essentially discriminatory practice (i.e. a differential application of 'family structure' criteria dependent on whether the 'patient' is male or female), and to candidly examine the ways in which present delivery of Home Care Services reinforce the status quo-further entrenching women's expected caregiving responsibilities. One way of increasing the relevance of the institutional structure would be to acknowledge the actualities of the economic and social processes being experienced by families today: acknowledging the social reality of family life for all family members. These should be the 'actualities for policy-makers and practitioners as well as for scholars' Unfortunately, it appears that the dual burden of work of all sorts - including caregiving - in the home and in the labour force faced by women has not resulted in significant change in the intra-family division of labour. Nor does it appear to have resulted in health care policies which do other than perpetuate the traditional intra-family division of labour.

The final evaluative concept we shall consider is **administrative feasibility** (effectiveness and efficiency) This concept is applicable to a consideration of the relationship between the public and private social welfare sector. A sense of how our public social welfare sector supports or doesn't support our 'natural caring networks' gives us an

increased awareness of the role of the informal sector in the social care of groups such as the elderly

Although this recognition of the contribution of the informal sector and the need for the formal sector to be more sensitive and responsive to informal caring systems, is long overdue and to be welcomed there has been some concern....that in the current economic and political climate the recent marked emphasis on the role of the family and other "natural" caring networks in the community may provide the rationale for further reductions in the level of provision of formal services..... adopting a more sceptical stance towards the motivations and outcomes of the current trend to expand the role of the informal care system would not be amiss.(Fitzgerald, 1983)

This British reference has obvious applicability to British Columbia's 'public vs. private sector' trend in that we face the danger that philosophical defense of 'the family' as the best caring network overrides any attention paid to the cost to families of providing this care and the necessity of increased personal and community supports. For the foregoing reasons it seems appropriate to take a different approach to Home Care; one which considers fundamental change; change which results in a reorganization of the Health Care System so as to eliminate the differential bias against women. The question is, how is this change to come about? From those persons within the Continuing Care Division? From the family? From women in the labour force? The conservative bias of our government is demonstrated in policies - such as that of the Long Term Care Program - which (even where they acknowledge the changes in family structure) treat changes as "ephemeral rather than comprehending them as central and fundamental"....escalating divorce rates have resulted in the emergence

of marriage as a more 'volitional union'. "This emergence of marriage as a voluntary union means that people's preformed expectations of marriage will have to change." (Eichler, 1983 p. 53)

And this means that our health system can not indefinitely continue with its present expectations of marriage. The critical question for professional social workers may also have to move away from the "what can we afford not to support?" question if asking that question continues to result in the exploitation and overburdening of women. Jessie Bernard (1973) demonstrated that, in general, marriage is good for men. Married men live longer and are happier and healthier than unmarried men. Married women, by contrast, are more likely to suffer from feelings of depression, to be unhappy, and generally be bothered by pains and ailments in various parts of the body than unmarried women. Bernard explains these findings by the objectively and subjectively different conditions of marriage for women and men. Margaret Eichler (1983) states that

With the increased labour force participation of women and the feminist movement, the value of housework has started to be appreciated. As housework is no longer performed on a full time basis by the majority of Canadian wives - in other words, as there is a partial withdrawal of previously automatically rendered services - their value is starting to be recognized." (pp.45-46)

If we are to look at the Continuing Care Division as a source of change we immediately come upon the response, "But, 'family structure' is not a prejudicial criteria - it can apply to a husband or a wife being at home."

It is difficult to argue with such a response. For although, as the foregoing sections illustrate, such a criteria as 'Family Structure'

reinforces the status quo, it does not in itself determine such a consequence. The two main determinants, in fact, are: 1) the attitudes and biases of Long Term Care Assessors, Physicians, Social Workers and other health care professionals which cause this criteria to be interpreted as meaning that where there is a wife (or other adult female) service need only supplement her work and 2) the fact that Home Care is determined, in part, on what domestic needs exist that were previously being met by the 'patient' (i.e. cooking, cleaning, laundry, etc.) Without such influences coming to bear upon the process, 'Family Structure' indeed becomes a quite benign criteria.

The British Columbia Long Term Care Program is one aspect of a Health Care Delivery System which presumes the status quo regarding women's availability as caregivers. Such a system impacts upon women's opportunities to participate in the outside labour market. Whether women respond to this expectation by opting out of the outside work force or by maintaining both their traditional domestic work and their outside occupation - the status quo is reinforced.

The subsequent issue of what programs and policies would better meet the needs of caregivers than those in existence is a substantive one which can only be adequately addressed through describing and exploring the needs and responses of wife caregivers in regards to their disability. For, as Patton (1980) states,

The raw data obtained through interviews can be used by program staff and administrative/decision makers understand how the program functions, why it functions as it does and the way in which the impact/consequences/outcomes of the program flow from program activities. Program staff can use such grounded evaluation theory to reality-test their own theories of programmatic action, program effects, and the relationship between action and effects. Such grounded evaluation theory can serve to take decision makers into the empirical world so that they can discover whether what they think about the nature of the empirical world is actually the case. (p.81)

For unless the researcher has laid the foundation of understanding the phenomenon/situation as a whole, the evaluator cannot understand the strengths and inadequacies of the program.

We have already discussed some issues in regards to existing programs and policies which may impact on the day to day experience of caregiving and will proceed in the next chapter to explicate the research process and the analysis of interviews with wife-caregivers with whom we will explore the significance of the following issues:

- whether requirements for a physician's referral for home nursing care is a barrier to access. If so, how?
- whether income as a determinant for home-care is problematic and how.
- in what ways spousal resistance to paying for outside services or simply to having someone other than spouse provide personal care is a significant barrier to access.
- whether present services are perceived as adequate (whether or not the caregiver accesses them) and if not, in what ways they could be improved.
- what barriers to access other than those considered are perceived as significant.
- how physical care demands and degree of disability exacerbate their stress.

The methodology detailed in the next chapter allows for the systematic description of the meaning, for wife-caregivers, of caregiving and works to develop theory that will be useful and relevant to consumers and concerned professionals. And, although it may be somewhat idealistic to believe that such an explication and subsequent understanding/acknowledgement of a problem necessarily leads to movement on the part of policy makers and planners towards remedy it can be argued that a methodology which provides findings understandable to consumers and professionals, which involves caregivers as experts and helps them to articulate their needs allows the researcher to engage with the consumer in a potentially more effective change effort.

The following section, therefore, will provide the rationale, from a feminist perspective, for using a Grounded Theory methodology to explore the above issues and questions.

CHAPTER 4

WHY GROUNDED THEORY: A FEMINIST PERSPECTIVE

As noted in the preceding chapter we are engaging in a research process which, hopefully, will give caregivers a voice, an opportunity to share the experience of caregiving in a meaningful, egalitarian and respectful way and an opportunity, in regards to programs and policies, to have a say about what constitutes 'improvement'.

Grounded Theory is the methodology chosen to explore the issues and questions outlined in the previous chapters and the procedural details of this research method are provided in Chapter 5. Grounded Theory is a qualitative, inductive methodology which allows a data base to be developed through a comprehensive interview-observation process. As answering the questions outlined earlier requires that we elicit as detailed an account of caregiving from the caregiver's perspective as possible, a method such as this is required. Grounded Theory is a particularly appropriate qualitative methodology as it imposes upon the accumulated data an insistence that presuppositions or sociological concepts stand, become rephrased or fall solely on the basis of what emerges, unmanipulated, from the data. It thus lends itself to the development of answers or new questions entirely unanticipated by the researcher.

Exploring the day to day reality of caregiving within such a

which complies with stated hypotheses or which fits into pre-established categories (a problem with using quantitative or experimental methodologies to explore such experiential issues as caregiving). However, Grounded Theory is not necessarily, in itself, a 'feminist' research method. It is a method which, depending on the researcher's approach, the construction of the interview schedule and process, and analytic sensitivity to what is emergent from the data, may still be vulnerable to the development of theory which conforms to convention and/or reinforces the status quo. It will be argued in this chapter that Grounded Theory, when coupled with a feminist approach and perspective, is best suited to the purposes of this study.

The most important objective of the study at hand is to explore the reality of caregiving for wives of disabled husbands; to 'get at' the meaning and to understand the phenomenon. Within the context of this methodology 'meaning' is synonymous with essential structure. To identify the meaning and its constituents is to define the essential structure of the phenomenon. And there is growing support for the idea that conventional methodologies fail to allow for an understanding of reality when that reality is owned by a woman and may be radically different from the reality of men engaged in the 'same' experience or set of circumstances.

For example, in looking at studies on family behaviour and satisfaction; studies which purported to describe the reality from within the family itself, Constantina Safillios-Rothschild (1969) asks of conventional research, "Was what they were getting with their best research techniques, family sociology or wives' family sociology?" She goes on to elaborate on the possibility that family sociology may not be valid as 'a' reality given that, for example, a husband's subjective reality

may be manifestly different from the wife's subjective reality. She goes on to suggest that,

interpreting the different replies of husbands and wives in terms of selective perception, projection of needs, attitudes, values and beliefs, or different definitions of the situation, by no means renders them trivial or incidental or justifies dismissing or ignoring them. They are, rather, fundamental for an understanding of the two marriages, his and hers, and we ignore them at the peril of serious misunderstanding of marriage, present as well as future. (from Bernard, 1982, pp. 8)

In regards to spousal caregiving systems the wives' understanding of the situation is the reality we are primarily interested in here. It is only through a careful analysis of her description of the taking on and maintaining of an expanded caregiving role that we can elicit the components of becoming a wife-caregiver and how these factors impact on the experience as a wife, as a woman, and as a participant in other family or outside activities. It is often suggested that, in developing or evaluating service for others, we 'stand in their shoes' and the methodology chosen for this study is intended to allow this; to approach the subject as a 'co-researcher' who will thus more easily enlighten us as to the experience of caring for a disabled spouse.

Therefore, the researcher may apply the Grounded Theory methodology but it is locating herself within the caregiving context and approaching the subject as a co-researcher that, in part, imposes a feminist attitude to the process.

Certainly the simple requirement of obtaining first hand descriptions and the importance of such information is not a new sociological concept in itself. That a first hand description of these

sorts of problems is essential to appropriate service provision was pointed out as early as 1907. In this year, members of the Women's Industrial Council wrote to Herbert Gladstone concerning the parliamentary inquiry into home work, stating that,

...Our experience of years of study of the question of home work...convinces us that in order to understand the elements of the subject we must have first hand knowledge of the work done and the surrounding in which it is done; thus again emphasizing the council's belief that 'without full investigation it was impossible either to legislate or to organize wisely. (Black, 1983, p. v)

It was found, for example, that the situation of women in the labour force could not be isolated from their situation in the family. Accordingly, one of their subsequent recommendations which was that the concept of policy-oriented research include the policy concerns of others than government. Their claim was that there is a need to know more about the contribution of domestic labour to the political economy and about the increasing proposition of domestic work to all work. (Meissner, 1975)

In regards to the importance of first hand descriptions we require a methodology that not only facilitates such description but maximizes substantive content. It would be possible to construct an interview schedule and utilize it in such a way that the 'experience' of caregiving was provided only in relation to such concrete factors as personal care tasks. Appropriating Grounded Theory to such use might not be methodologically incorrect but would be problematic in regards to this study in two significant ways. Firstly it would prevent or inhibit the elicitation of factors which may, in fact, be much more fundamental to

the caregiving experience than the degree of physical care required. And secondly, while technically allowing a natural emergence of categories from the data it effectively allows this only within the researcher's presupposition that it is physical care variants which determine the experience.

Therefore we desire a methodology which will provide description of such personal care tasks without unduly limiting analysis of other - perhaps more critical - factors such as societal pressure, internalized role expectations or the wives' sense of their changed marital relationship. For, "in order to capture participants in their own terms, one must learn their categories for rendering explicable and coherent the flux of raw reality. That, indeed, is the first principle of qualitative analysis" (Lofland, 1971)*

There is an argument that one of the reasons we remain largely ignorant about womens' experience in the domestic sphere is that most social analyses have remained dependent upon conventional methodology. Such methodologies are constituted by frameworks which are dependent on the scientific method and the consideration of the objective social world; dependent on an order which is sustained by the consensus of a society which - in spite of those who believe 'we've come a long way, baby!! - is still essentially a patriarchal one.

To be more specific; mainstream sociology, it has been argued, has served to reinforce traditional views of women, in part through the ways in which it takes for granted the division of labour within families. In applying a feminist approach to the use of grounded theory we are

*Although there is much to differentiate grounded theory from conventional qualitative methodology - arguments for qualitative analysis is often valid for grounded theory.

considering Safillios-Rothschild's concerns about Morgan's (1978) claim that we must 'raise the possibility that the family is not to be seen merely as a universal 'given'; or as a cultural necessity but as something that can be actively and critically evaluated, acted upon and changed or abolished." This is not to suggest an 'anti-family' agenda; but to accept that our objective - defining the experience of caregiving - is a theoretical one that involves conceptualizing the family as a 'system' in the process of change (where disability has instigated or contributed to that process) and involves the treatment of women as social actors within that system whose experience of being a nurturer/caregiver may be (in fact, most probably is) different from the general perception of that experience; for whom caregiving may involve tasks, sacrifices, costs, consequences, dilemmas and feelings that have not been acknowledged by our society and therefore not reflected in policies and programs.

Having an open enough inquiry to elicit data regarding this, the wives' sense of their changed marital relationship, is particularly relevant to this study. This is because, historically, family and marriage have been socially organized structures which presume the wife as nurturer/caregiver. Such a presumption not only impacts on family structure/marital relationships generally but must impact on the marital relationship post-illness as the presumed caregiving role expands and this, in turn, must impact on the caregiving experience as a whole.

It should be noted that we do not wish to discard data related to such factors as personal care tasks - they remain significant to whatever degree the data indicates and they also have usefulness in

determining whether the stress experienced by the wives interviewed is related to these factors as Zahn's work suggests.

There is considerable evidence that the historical intra familial division of labour and assignment of roles has impacted, amongst other things, upon wives' participation in the labour market. In spite of this,

...most empirical studies of women and the labour force treat as exogenous any states other than those of employment or unemployment. In so doing, these studies follow a well established tradition of compartmentalizing human (male) activity into different spheres and ignoring the connections behind spheres..females do not have the same freedom as males to compartmentalize their 'other' lives, nor do they get the same rewards from effectively doing so as males. (Smith, 1981, p.367)

The ways in which women/wives are prevented from separating intra and extra familial spheres is a complicated process which impacts on all aspects of a woman's life including caregiving. Smith states that, "the family is the key institution in women's oppression...family institutions create a determinate structure of sex roles and relations of dominance transforming biological differences into the social relations of oppression for women." (Smith, 1981, p. 369)

This suggests, again, that given that a wife maintaining a caregiving role is presumed (a presumption which she may be seen as having 'bought into'; simply by her location within the family context) it may be exceedingly difficult to perceive choice in the caregiving role post-illness being, as it is, a role which has in essence already been accepted.

Although it may be a serious oversimplification to treat the family as the sole basis of women's inequality, it is the social

organization of women's labour in the home and outside, and the relations between the two which is women's inequality. It is this social organization that allows intra family caregiving of any sort to fall naturally upon wives. Thus, the claim is made that caregiving is but one aspect of women's presumed household labour, work which stands, in the 1980's, as 'invisible', as taken for granted, and as essentially a female lot as ever.

That women's work is invisible is demonstrated again and again in cases such as the celebrated Murdoch case where even the dissenting opinion of Bora Laskin did not recognize the wife's contribution of labour to the overall enterprise as constituting a claim on the property. He dissented only on the grounds that her contribution had been exceptional. Women's labour as such, as the labour of a wife, had no claim. (Smith, 1981, p.17)

This statement, that the family is the key institution in women's oppression, may seem a truism to some but to others, including many wife-caregivers, it epitomizes radical feminism (which, almost by definition, is threatening). Therefore, in conducting the interviews, the researcher, while locating the data within this philosophical (feminist) framework must be sensitive to the complexity and emotional difficulty for some women of an inquiry which, too blatantly, questions the status quo. However benign the researcher's intent, she must be aware that the family is the key institution in our society and one cannot address it as a source of oppression strictly within the context of how we deliver certain health services.

This study requires a research method which doesn't insist that we put aside aspects of our experience, keeping in mind that "the traditional approach to research can give us trouble when we want the

ordinary experience of women in the everyday world at the heart and centre of our inquiry." (Smith, 1982, p. 320)

The grounded theory strategy is adopted in the interests of pursuing a consciously open-ended inquiry into the actual processes which are presently and historically at work in our society. Such an inquiry has theoretical and political importance in articulating the central issues. However, this inquiry holds as its mandate discovery of the experience from which the theoretical debate arises and in which it is originally expressed. Smith states that,

the concept of patriarchy, as it has been developed in the women's movement, locates and conceptualizes women's direct personal experience of inequality in directly personal and indeed sometimes most intimate relations with men. As intellectuals we begin ordinarily outside experienced actuality and in the discourse - the conversation-in-texts going forward among an intelligentsia. (1982, p. 128)

The context of this study is the domestic sphere in which the experience of caregiving arises and can be seen, in part or in whole, as a reflection of the larger social and historical process. A grounded theory methodology, in itself, does not necessarily amount to application of a feminist perspective. The methodological difficulty with which we are presented is that sociology (including grounded theory) - its methods, conceptual schemes and theories - has been based on and built up within a male social universe (even where women have been participants).

Applying a feminist perspective, enhances the usefulness of the grounded theory method as it means not only coming at the study with sociological constructs as opposed to inflexible hypotheses but also keeping the above considerations regarding the interconnectedness of

such things as cultural norms and family activities in mind when constructing interview schedules and analyzing data. We must be able to make more than a token gesture and avoid "working within the vocabularies and within the conceptual boundaries of what we have come to know as 'the sociological perspective'. (Smith, 1974, p.9))

Grounded theory doesn't adhere (as conventional sociology does) to the ethic of objectivity (in the conventional manner) and, subsequently, methods which seem to achieve separation of the knower from what he knows. However, one must still be cautioned against proceeding within existing interests, concerns and boundaries authorized by the discipline. An example of such an authorized interest might be to support the necessity of the nuclear family structure in our society. It might be argued that this interest is more relevant to data analysis than the methodology by which the data to be analyzed is gathered. But one's methodology, however open ended, will impact on outcome.

For example, in the study at hand, we are approaching the interviews with the general sociological construct that 'the experience of caregiving for women is affected by society's expectations of women'. If we take this construct with a mind to improving the lot of women as caregivers our trigger questions and beginning analysis will be different than if we take this construct and impose upon it a question as to the validity of the caregiving role itself. The latter will suggest 'trigger questions' and analyses which looks closely at how one becomes a caregiver and how a wife-caregiver's situation might be positively impacted through changes in existing social policies or service provision.

Smith points out that sociological inquiry cannot divorce itself from the (patriarchal) ideology simply by 'repatriating sociology or by developing a critical approach". A methodology consistent with locating

the 'sociological problematic' in the everyday world requires more than beginning the process with comprehensive interviews with (in this case) the wives themselves with some construct acknowledging the role of societal attitudes on experience and the expertise of the wives in defining this impact.

There is a methodological problem, as seen from a feminist perspective, of the relationship between the local actual everyday worlds of experience and the abstracted structure of concepts, generalizing statements and methods of warranting generalizing statements" inherent in contemporary sociological practice.

Attempting to address this problem via the simple strategy of interviewing wives as expert representatives of the population may serve to acknowledge the everyday world as the locus of the problematic but this is not as Smith points out, the same as making the everyday world an object of study in itself. She suggests that "the social organization and determination of the everyday world may be constituted in the process of inquiry...that, the purpose and direction of inquiry is, in part, the explication or codification of a problematic that is implicitly in the everyday world.

The fact that, as in grounded theory, the 'knower' is located in the world she experiences and is approached as an expert representative of the target population is consistent with a feminist perspective but only to the superficial point of avoiding the separation of knower from known. Smith's claim is that the analyst's responsibility is to place what the subject knows within the context of social phenomena organized prior to what is observed and related. The work of the analyst then becomes, in part, an explication of how the social phenomena (i.e. the family) impacts on her knowledge. This approach has, as a component, a strong sense of

the analyst's responsibility to women in the society as subjects; a responsibility to 'develop forms of thought and knowledge capable of expressing their experience, examining and being capable of making intelligible to them how the world as they know and suffer it is determined, providing them with the knowledge, information and means to think and act in relation to it.' (Smith, 1975, p. 367) However, it must be noted that the role of the 'analyst' is necessarily different in terms of availability to the 'co-researcher' than the role of 'counsellor' in this regard to a client. To elaborate, one tenet of feminist counselling is that an assessment of social/cultural restraints impinging internally and externally on the client is made and used to assist clients in cognitively restructuring their world within the contextual framework. To attempt to apply this counselling strategy from the much more limited position of researcher may be neither realistic, nor perhaps, responsible.

The desired outcome of our methodological and analytic approach is an illumination of 'the problematic of the everyday world in terms of actual organized practices (how it actually works). The experiential explications need not be formal; they are, rather, increasingly explications and descriptions of actual processes of social organization.

CHAPTER 5

RESEARCH DESIGN

Research Design and Methodology

The objective of this research is: 1) exploring the experience of caregiving in terms of what that looks like on a day to day basis 2) examining some of the processes involved in becoming a caregiver and maintaining this role 3) to formulate some hypotheses regarding how our present delivery of home/health care services impacts upon the processes of becoming a caregiver, the day to day experience of caregiving, and maintaining the caregiver role. The study, therefore, is an exploratory-formative one. While an experimental approach could yield valuable information regarding use and effectiveness of various services and the various tasks involved for the wife in her caregiving role, a phenomenological approach seems more appropriate where the focus is on the woman's perspective of the impact caregiving has had on the various aspects of her life. One of the particular advantages of qualitative research is development of more specific hypotheses which may then become the basis for quantitative study.

Method of Analysis: The Constant Comparative Method

Grounded Theory (Glaser and Strauss, 1969) utilizes a constant comparative method of analysis. This constant comparative method is a qualitative, inductive methodology. It involves coming to the research with general sociological concepts rather than specific hypotheses. If, as in this case, one of those general sociological concepts is that 'the experience of caregiving for women is, in part, determined by societal expectations of women' it is also necessary that the indicators and properties emerging from the various data sources support this assumption..or that the concept is modified or changed. As noted, the primary source of data for this study will be comprehensive, in-depth interviews with women who are caring for a disabled spouse. The steps of this process of analysis - in brief - are:

1/ A theme for theoretical development is chosen - in this case - 'societal expectations of women impact on the experience of caregiving for women caring for disabled husbands'.

2/ An interview schedule is constructed. A semi-structured interview format is utilized, including a series of 'trigger' questions whose use will be determined by what information has been covered spontaneously by the subject in response to the initial open-ended question. Such an interview schedule is intended to provide only a basic guide. With respect to the research question of how degree of disability impacts on stress and marital satisfaction, these trigger questions will also attempt to elicit indicators regarding marital satisfaction and degree of disability in order to determine through a comparison of responses whether the trend found by Zahn is confirmed.

3/ Subjects are interviewed; interviews being taped for accurate transcription. Strict adherence to Glaser and Strauss's principle of theoretical sampling requires that decisions regarding 'where to go next' for data be determined in the course of simultaneous analysis, coding and memoing of each interview. Constraints of time and available number of subjects make this impractical. Therefore, this concurrent analysis-coding-memoing process will be carried out but with the order of transcriptions used determined by the order in which the predetermined sample becomes available.

4/ Responses are selected which address the first category developed via the above process. These categories may be a mixture of 'labels in use' and constructed categories. Each response is compared with respect to similarities and dissimilarities in topics dealt with. After this process of comparison is complete, the numbers of topics under each category are reduced to a set of sub-categories by supplying them with labels.

5) Repeat for each category.

6) For the research report, a memo is prepared on each category and its subcategories, with cross references to illustrations on the completed interview schedules. These materials serve as a draft of the report.

7) Hypotheses suggested by the foregoing analyses are stated. Examples of content of these hypotheses, correlations between variables, conditions of the salience of the categories or subcategories are given.

8) The theory is restated in its most abstract possible form.

9) Implications for practice, policy change or modifications, etc. are stated and related to any of the above steps as appropriate.

The rationale presented in Chapter 4 argues that applying a feminist perspective to the grounded theory methodology provides the best means by which to conceptualize the particular problem areas at hand, to define the relevant variables and to arrive at conclusions useful to consumers and concerned professionals alike.

Interview Format and Instrument

Direct and specific questions common to standard survey or questionnaire instruments would allow one to draw, from a large number of subjects, interesting data on the hours required for such personal care tasks as bathing, dressing, etc., information on if and how caregiving has impacted on labour force participation, social, education and other pursuits of the wife. Such research methods might also even elicit comments about how caregiving has evolved from being a wife (woman). This latter would, by extrapolation, give us a beginning picture of how the wives perceive the wife/caregiver relationship. Limitations common to such standard quantitative methods that we wish to avoid in the study at hand may include:

(a) In a society where caregiving and nurturing is seen as an essential component of woman/wife-hood, eliciting the latter at all would be difficult. In our society one's identity as a successful wife may be closely tied to how one adapts to these changes or how one minimizes their impact. Conventional survey or questionnaire methods do not allow us to address the problem of response set bias (or eliciting socially desirable responses). The phenomenological approach addresses this problem with its open-ended questions and opportunity for rapport between subject and interviewer.

(b) where acknowledgement of the being a woman - becoming a caregiver dynamic is addressed by the respondent, the boundaries of direct question/answer techniques constrain the accounting. An in-depth exploration of societal pressure is necessary to provide adequate datum for a substantial analysis of the caregiving experience.

Therefore, we desire a methodology and an instrument which will allow description (of such things as personal care tasks) without unduly limiting analysis of factors which are perhaps more fundamental to the wives' changed role within the marital relationship. Thus, the interview schedule developed is intended to meet the above criteria. (see Appendix B for copy of Interview Schedule)

Sampling

The primary objective of this study is to gather descriptive data regarding the experience of caregiving for women whose husbands are disabled. Therefore, the sampling strategy was to access 'expert representatives' of this target population. Although the lack of a random sample lessens the generalizability of results, this limitation is hopefully offset by the depth of data which can be obtained through intensive qualitative interviews. The sample is to be composed of women, caring for disabled husbands, who were aware of this study and expressed an interest in participating. In order to facilitate such interest, Nurse-assessors from the Long Term Care - Home Care Program were familiarized with the study plan and passed the information on to clients whom they felt might be appropriate subjects. Thus, another limitation with this sample will be self-selection; self-selection by the

subjects and bias on the part of the Long Term Care Assessors. The names and phone numbers of interested clients were then given to the Investigator who then made telephone contact. At this time an interview date was set.

All subjects signed an identical letter of consent at the time of the interview. (see Appendix C for copy of Letter of Consent) The final N, which equalled 8, consisted of women whose husbands had been disabled for at least 3 years. The Long Term Care (Home Care) Team was chosen as a starting place as it seemed likely to be a location which would maximize the possibilities of obtaining subjects who were representative of those most knowledgeable in the problem area. An understanding, outlined in the preceding paragraphs, was reached with this team that they would inform, in person or by telephone, as many of their clients as possible about the nature of the study. If an interest was expressed in discussing participation further, they would be given the choice of taking this researcher's name and telephone number to contact at their convenience or of having their name and telephone number given to me. As it turned out, the first seven women contacted expressed considerable interest in participating in the study and all elected to have this researcher contact them. These seven women were then contacted by telephone and all reaffirmed their willingness to participate and, over a period of three weeks, dates and times for interviews were arranged.

Six of these interviews proceeded as planned; each being approximately 2 1/2 hours in duration. One interview did not proceed in the usual manner; I refer to this as Mrs. 'J'.

Mrs. 'J'

Mrs. J., like the other subjects, had agreed to meet with me at her home. The usual understanding had been arrived at that we would have privacy. However, upon arrival at her home, she greeted me in an extremely nervous manner and, quite agitated, introduced me to her husband who, upon introduction, expressed very strongly his anger that his wife had agreed to talk to me without him being present. It was mid-afternoon at the time of my call; Mr. 'J' was not yet dressed, continually barked orders at his wife during my half hour in their home and insisted that all I needed to know was that he provided as much care for her as she did for him. She acquiesced to all of his demands while agreeing with this claim. I provided my name and phone number and left, as requested by Mr. 'J', after about half an hour. Although I was subsequently contacted by telephone by Mrs. 'J' and a lengthy discussion ensued regarding her day to day experience of caregiving, I have not included any of this information in my results or conclusions as I was unable to obtain consents, etc.

Mrs. 'B' and Mrs. 'D'

Mrs. B and Mrs. D. are two women caring for husbands who are disabled. They contacted me as a result of hearing about the present study from friends. Both fit the profile of the other subjects and had, at one time, received services through the Long Term Care (Home Care)

Team. I included them in my sample and proceeded, once initial contact was made, as with the other subjects.

The final N, therefore, was 8. The women's ages ranged from 55 to 82. Their husband's ages ranged from 57 to 95. Two of the subjects enjoyed considerable investment income as well as owning substantial property. The remainder of the households varied from 'struggling to make ends meet' to 'adequate' by their own description. Four of the women worked a minimum of 35 hours a week. Two of these women were employed outside the home, one worked full time from her home and one worked approximately 40 hours a week providing domestic labour and/or child care to relatives. Only one of the four saw work as her 'escape'; for the others it was a financial necessity which increased their burden without providing any identifiable benefits other than basic financial requirements. Of the four women who did not work, one was retired from a professional career. The remaining three had never been employed outside the home.

Reliability and Validity

The problem of assessing the reliability and validity of the instrument - in this case, a series of open ended 'trigger questions' which will or will not be asked depending on the answer given in response to the introductory (overview) question- is quite different from the problem of assessing more conventional instruments. The consistency with which it measures the attributes of interest will depend entirely on such things as 'trustworthiness' of the subject and the quality of the researcher-subject interaction.

Aside from these aspects of reliability and validity there is the problem of response set bias. Protecting against the subject's inclination to give socially desirable responses can obviously not be as easily dealt with as is possible in some kinds of questionnaires. It requires, ideally, multiple interviews.

1st interview - to elicit initial description; spontaneous unstructured responses about the caregivers' perceptions of their daily lives, the evaluation of their role as caregivers and the impact, over time, of this role.

2nd interview - to provide clarification, expansion of descriptions, validation of dialogue up to that point.

3rd interview - to share essential structure of caregiving with co-researchers (i.e. the subjects) and determine again, whether it captured the individual's experience of caregiving for validation purpose.

The assumption is that, in the course of multiple interviews, greater rapport will be fostered between the researcher and co-researcher and this will encourage an atmosphere in which amendments may be made to earlier answers which more accurately reflect the caregiver's actual experience.

Certain constraints prevented completion of the 3 interview mode as outlined in Chapter 4. This researcher found that, following the initial description interview (approximately 1 1/2 hours for each subject), all of the subjects expressed a need to review some of the taped material, clarify certain points, and seek validation of their feelings and of their information. Therefore, to one degree or another the purposes of the 2nd and 3rd interviews were achieved at this initial interview.

The second interview did proceed as intended - but not 'in person' with all subjects. Five of the subjects expressed a preference to provide clarification and expansion via the telephone - giving as the primary reason the fact that they had found the initial recounting of their experiences a much more emotional experience than anticipated and, though interested in continuing participation, felt they would be able to remain more composed given the 'distancing' effect of a telephone conversation. For these five women, the 2nd interview did take place via the telephone - interestingly enough, the telephone strategy seemed to disinhibit more than 'distance' and tears were, if anything, more frequent than during the initial interviews with these same women. (this may also have been partly due to the rapport that had been established between the subjects and the researcher) One significant difference was that while tears or embarrassment had effected a change of topic during the initial interviews, this rarely happened over the telephone. Rather, subjects which elicited an emotional response were pursued. These telephone interviews - perhaps because of the disinhibition they facilitated - were lengthy - between 1 and 1 1/2 hours and were selectively process-recorded. For the three women who agreed to a second 'in person' interview the interviews were taped and transcribed verbatim. These interviews were approximately 1/2 hour in duration.

The five women whose 2nd interview had taken place over the phone requested the 3rd, follow up, interview take place in person while 2 of the 3 whose 2nd interview had taken place in person requested follow up by phone. Therefore, only one subject participated in all three interviews 'in person' and the researcher's relationship with this woman continued over a period of months.

Ethics

This research project has been approved by the University of British Columbia Ethics Review Committee. (see Appendix D) The research project was explained to the subjects as being in the interests of understanding the experience of caregiving for women with disabled spouses and in the interests of understanding what services, programs, etc. would be most useful. It was explained that it is unknown at this time what change, if any, will arise directly from the study.

In the consent form and in the introduction to the interview it will be explained that participation is voluntary, that they may refuse to answer any questions at any time, and that they may withdraw from the study at any time.

Only the student researcher and the faculty advisor will have access to the gathered data. Interviews have been tape recorded for transcription but there will be no identifying information on these tapes. Only the researcher and the faculty advisor have access to these tapes and transcripts have been number coded but no one other than the researcher has had access to the 'key'. There are no future plans for use of this data and all data will be shredded or burned after completion of analysis.

It was explained that what benefits might accrue to the caregiving population as a result of the study is unknown. It is anticipated that some benefit may accrue directly as a result of the opportunity to discuss these issues. It is anticipated that a better understanding of appropriate home care programs to benefit care-givers will be available to planners and practitioners as a result. There are no monetary benefits

to the subjects and the cost in time was approximately three to four hours.

It may be emotionally stressful to address some of these issues related to caring for a loved one. It was explained at the beginning of the interview that it is appreciated that discussing these issues may be stressful and that a 'debriefing' 'off the record' opportunity will be made available at the end of the interview. As explained earlier in this section, this debriefing took place concurrently with the entire interview process. No other risks are anticipated.

All subjects were competent to consent, had consent forms read to them and were given an opportunity to read them over themselves.

The Interviews

Tape Recording

Approximately 1 1/2 hours of each of the initial interviews were taped. Approximately 1/2 to 1 hour of five of the 2nd interviews were 'process recorded' as immediately following the interview as was possible. Approximately 1/2 hour of three of the 2nd interviews were taped. There were three main reasons for the use of process recording:

- 1) there were times when the subject(s) became very emotional, often breaking down in tears for periods of time, and requested the recorder be turned off until they had composed themselves and/or finished talking about these particularly sensitive areas. The areas of discussion which brought subjects to this point did not follow any particular pattern. For one it was discussing how she felt about the loss of sexual companionship since her husband's illness, for another the fact that her grandchildren had never known

'Poppa' as a well man. For one woman it was the fear she felt of her husband whenever she tried to "assert my independence", and for a number of the women, talking about the character change their husband's had undergone was very difficult.

2) an area perceived by the subjects to be too personal to be taped often brought a request to turn off the recorder. Sexual issues, again, were often the reason. Details about personal care tasks were frequently 'off tape'. In one case this was explained by the woman's embarrassment.....however, in all other cases, the reason given was respect for the husband's privacy.

3) interview time which took place via telephone

Although the researcher had spent some time, prior to commencement of the interviews, talking about the issue of recording, in retrospect it was not sufficient. More time and more attention would be paid, in any future research of a similar nature, to a) getting the subjects comfortable with being recorded b) being aware in advance of what topics might precipitate requests to 'turn it off' and expressing this awareness in conjunction with the reassurances about confidentiality etc. c) Using recording equipment with adequate range to allow placement out of immediate sight.

Another limitation, not so much around 'getting the information', but related to transcribing, was the subject's inclination to whisper their way through sensitive, personal or difficult information. Because transcription took place so soon after the interview(s), the researcher was able to use fairly minimal cues to 'fill in the gaps'. Again, this researcher feels that the above noted precautions would have lessened this problem.

Debriefing

A certain amount of time during the 1st and 2nd interviews spent with each subject was used for 'debriefing', 'small talk' and answering questions for the subjects. As mentioned earlier, all of the women requested some of this time be used to listen to parts of the tape, elaborate on some of their comments, and ask for validation and support. Subsequent telephone calls to the researcher at work or at home accomplished the same purpose. Comments made by the subjects during the main body of the interview along the lines of, "I have effectively been a widow, for x years", "it's like being a mother only things don't get better", "I feel like a maid...", "I feel more like a nurse than a wife" were, without exception, one of the main areas of these 'subject-initiated' discussions. This provided a natural lead-in to explore, with these women, how the 'ambiguity' of their husband's disability impacted on their overall stress and/or sense of marital satisfaction. Exploring this also involved exploring with them how questions about marital satisfaction made sense given the various ways they had described themselves as feeling (i.e. nurse rather than wife). This will be dealt with in detail further on in the Results chapter.

Analysing the Data

The initial decision, of how to proceed, was based on a general sociological concept. In this case, the general sociological concept was, 'the experience of caregiving for women is, in part, determined by societal expectations of women'.

From the beginning of the data collection process i.e. the first interview, previously unanticipated concepts emerged and, thus, the process of theoretical sampling and constant comparison of incidents began. This is not to say that expected concepts did not also instigate the theoretical sampling process. But it is one of the distinctions of the grounded theory process that the researcher be equally sensitive to those concepts or 'codes' that had not been anticipated.

The first three initial interviews took place in rapid succession. Verbatim transcripts of these interviews was completed. The initial unit by unit analysis was done keeping the 'theme' (societal expectations of women impact on the caregiving experience) in mind but, as much as possible, without preconceived notions of what 'codes' would emerge. The following excerpt from one interview illustrates the unit breakdown and the application of initial coding. These units will be referred to as 'meaning units' and represent a particular thought, feeling or expression of circumstance. In this excerpt the end of each meaning unit is indicated by a 'first run' code in brackets.

"At age 45 I was certainly not ready to give up an active sex life... this was certainly one very traumatic effect of the stroke [**loss-sexual**] Of course there were so many changes to cope with all at once not the least of which was putting on a strong front for my husband and my children and everyone [**internalized role expectations - to be strong**]. It was a monumental task to bury the fear and loss [**repressing feelings**] and I had to just, oh I don't know, make the maternal urge to be needed to dominate and overpower all those sexual, romantic feelings [**changing**

marital dynamic] but it worked, it worked for a long time...maybe even until right now...tears...oh, why am I doing this? The only way you can survive something like this is by locking up your feelings and not talking about them **[grief, isolation]**.

I don't know what the breaking point is - there must be a point where you can't fake it - if I break down - well, I just can't or what will happen to him **[fear, guilt]**. It's such a pressure to appear okay all the time **[internalized role expectations]** to make sure that everything is orchestrated - that noone, not even the children just drop by at difficult times - when he's in a bad mood or needs personal care **[pressure - to maintain appearances]**, he needs so much care now - bathing, shaving, he even needs help with eating and going to the toilet...it's really exhausting with him being such a big man and me being quite slight **[exhaustion - physical care demands]**. And everything has to be done just right or he gets so upset and of course meals have to be at exactly the same time **[resentment]**. So, anyway, I make sure that noone comes over except when he's been properly dressed and fed and I've got a smile on my face **[pressure- to maintain appearances]**. Not that I have to worry much about people dropping over - funny how people disappear when something like this happens...we used to have lots of friends but not anymore **[loss - social life]**. My women friends lasted longer - a few came around regularly for a year or so after the stroke and that helped me get through it but they've

drifted away now, too. **[loss-peer support]** And I can't really blame them - how do you maintain friendships when you can't get away or do anything or even have people over for meals - he won't have anyone see him needing help **[isolation, resentment]**.

I'm sure you're looking around and thinking I could afford any help I wanted and you're right - but it's my job **[internalized role expectations]** and when I start to think that's not right and suggest some help comes in he gets so upset, tells me how humiliating it would be for him to have a stranger bathing him or whatever **[external pressure - role expectations]**. He'll say I'm his wife and it's my duty but I don't feel like a wife - I feel like a nurse or a maid **[changed marital dynamic]**. Well, almost - it's feeling like both that's hard - I still get caught up in the memories of what we used to share and then I'll come crashing back into the reality of helping him on the toilet and him yelling at me because I haven't got him positioned just right **[loss - husband, changed marital dynamic]**. He used to be so strong and intelligent - now all the strength has to come from me **[loss - someone to lean on, husband as partner]**."

The whole interview transcript, from which this excerpt was taken, was then coded in the same way; giving of names to frequent expressions with a common flavour. Concurrent with the process of coding is the process of 'memoing' or elaboration of initial codes. Memoing, as another part of the process which may be repeated many

times, involves describing the units or offering an interpretation of their meaning. For example:

[loss - sexual]	coming to terms with what consequences arise from the disability
[internalized role expectations]	a sense that somehow all of the things that are happening have to be sorted out internally and alone
[changing marital dynamic]	feeling that she needed to keep 'negative feelings' to herself - redefine the marriage; using a known model - mothering - to rationalize unknown future - having a dependent husband

In order that this process maximize rather than prematurely limit the usefulness of the information, it is best to make several copies of each transcript, cutting out meaning units and memoing each unit in as many different ways as the emerging data requires. This process assists in the delineation of themes and becomes increasingly complex as the open coding and constant comparison of incidents enriches the analysis. This open-coding continues in such a way that 'units' labelled one way may be re-labelled over and over again. The following illustration uses the first two 'sectors' of 'meaning units' from the above transcript excerpt to show how the memoing noted above drives re-coding:

What is Happening in the Data?

-Loss - sexual

-Shock at diagnosis/implications of
disability

Meaning Unit

"At age 45 I was certainly not ready to
give up an active sex life...this was
certainly one very traumatic effect of -
the stroke ...

-Internalized role expectations -
to be strong

Overwhelmed/withdrawing

Of course there were so many changes to
cope with all at once not the least of
which was putting on a strong front for
my husband and my children and everyone
[internalized role expectations -
to be strong].

As comparable meaning units appear - previously labelled meaning units may be re-labelled/coded over and over again. At this point the degree of relevance or validity of labelling is not as consequential as the process itself which will force more relevance in the development if the data so suggests. What is important is being sensitive to the data as it is presented and continuing, with an open and receptive mind, the sampling and analytic process.

Every attempt is made to take this open-coding approach to subsequent transcripts. However, super-imposed upon subsequent analyses is the inevitably heightened sensitivity to categories emergent from the previous interviews. And, although the interview format remained the same for subsequent interviews more attention and

emphasis was put on exploring categories identified as significant by women interviewed earlier.

In analysing the data it was necessary to exercise a certain delimiting of issues in order to keep the researcher from going off in an unmanageable number of directions. This delimiting was, hopefully, not at the expense of an awareness and sensitivity as to how the data supports new questions and/or supports the questions differently from the ways in which the researcher had supposed. However, the Core Categories delineated are those drawn from the Data as most significant and are not intended to be viewed as exclusive or comprehensive.

For example, the issues of 'role of wife' and a 'changed marital dynamic' were core categories which emerged early on in the data analysis and the process of analysis continued with a focus on these categories. However, although the researcher had anticipated 'role of wife' would impact on caregiving, what was unexpected was the degree to which the pressure of role would come from the women themselves rather than from any present and or identifiable external source. Likewise, isolation was an anticipated consequence of caregiving but it was unexpected that the isolation would be both so self-imposed and so strongly rationalized on the basis of fulfilling this internalized sense of role as wives and women. Identifying how issues such as 'role of wife' and the 'changed marital dynamic' relate to the three stages of Becoming, Maintaining, and Jeopardy required that the researcher remain sensitive to what was happening in the data, as mentioned earlier - to delimit directions without forcing the data into pre-established assumptions.

It is particularly helpful, prior to the 'cut and paste' method of memoing, to review the transcript in its entirety, making notes in the margin based on a consistent form of asking what is happening in the

data. Whichever method is being applied, it is being consistent is asking, "What is this data a study of?", which assists in delimiting the directions the researcher took while reinforcing awareness and sensitivity as to how the data is supporting the question differently from the ways in which the researcher had supposed. Again, taking the first two 'sectors', we see how asking these questions helps in the ongoing coding process. The 'what is happening' column refers to (loosely) the following questions: 1) What conditions give rise to what is being expressed? 2) What are the relevant interactions? 3) What strategies is the subject using at this point and 4) What are the consequences of what is being expressed?

What is Happening in the Data?

Meaning Unit

-Disability of partner
-Lack of Information at point of diagnosis
-Premature acceptance of loss
-Initial equation of disability with
no marital sex

"At age 45 I was certainly not ready to
give up an active sex life...this was
certainly one very traumatic effect of -
the stroke [less-sexual]

-Disability/pre-disability family struc-
ture with mother as harmonizer
-Inflexible or perceived inflexible family
communication boundaries
-Pretending
-Withdrawal from potential family
support

Of course there were so many changes to
cope with all at once not the least of
which was putting on a strong front for
my husband and my children and everyone
[internalized role expectations -
to be strong].

See Appendix E for an illustration of the memoing process as it is applied to the entire transcript excerpt. Determining the core category or categories involves the above delineated means of remaining 'theoretically sensitive and transcending when analyzing, collecting and coding'. The most basic criteria for determining whether a category is core are that,

- (a) a core category must be central, that is related to as many indicators as possible and more than other candidates for the core category.
- (b) it must reoccur frequently in the data. By its frequent re-occurrence it comes to be seen as a stable pattern and becomes more and more related to other variables.

Other criteria apply to the identification of a core category and these will be detailed at a later point in the discussion. The core categories and their relationship to sub-codes and to the basic social and psychological processes are represented in the following pages. As described earlier, the eventual identification of Core Categories is facilitated through the coding/memoing/coding process illustrated in Appendix E..

Following is a list of indicators (sub-codes) which occurred frequently through all the interviews. The pattern and expression of these indicators defined the core categories and, subsequently, the differential relevance of these core categories to the Stages of Becoming, Maintaining and Jeopardy. At this point, the sub-codes are listed (and this is by no means an exhaustive list) without elaboration or illustrative quotes under tentative 'Core Category' headings:

Survival Strategies (severely exacerbating isolation, also expressed as 'Role' requirement)

'REPRESSION OF FEELINGS'

Repress feelings
Keeping up a good front

Problematic feelings (expressed as problematic due to inability to repress/bury/deny)

Fear
Guilt
Resentment
Exhaustion (physical)
Exhaustion (emotional)
Sexual frustration

This simultaneous process of coding, memoing and reviewing of indicator context and interconnectedness of indicators and tentative development of Core Categories facilitated the emergence of three primary Core Categories which are cursorily described as follows:

Role of Wife

- To be the caregiver - to whatever extent circumstances require and forever.
- To protect husband from loss of self-esteem, to not discuss openly within or without marriage the consequences of his dependence.
- To protect children and friends from changed image of father, friend.

Isolation

- Losses of peer support, sexual relationship with husband, social life, of spontaneous family relationships, of husband as partner, of financial status in some cases.
- Exacerbated, even created, by repression of feelings, own needs.
- Entrenched through sense of responsibility to 'act o.k.', to not share (interpreted as burdening) and to be self-sufficient.

Changed Marital Dynamic

- Repression of feelings block ongoing communication and/or entrenches previously dysfunctional communication within marriage
- Above plus loss of sexual relationship and husband's lessened capacity for previously shared activities changes previously held definition of husband as provider, partner, lover, friend
- Sense of self as nurse rather than wife in conflict with 'being a wife' necessitating ongoing caregiving role.

Prior to the confirmation of Core Categories and development of theory all memos are collated or sorted which leads to further memoing and the process thus continues until there is 'saturation'. As the analysis proceeded it became clear that these Core Categories of Role of Wife, Isolation and Changed Marital Dynamic varied significantly in substance and impact (as evidenced by the relative importance of indicators and the expressed context) depending on their 'location' in the caregiving experience. For example, 'loss of social life' was perceived and expressed as having a different impact and was experienced to a different degree immediately following diagnosis than at a later point. These variations in what was problematic about the caregiving experience defined a 'basic social psychological process' (a BSPP in Grounded Theory terminology) that was accounted for by the Stages of Caregiving. The BSPP of the caregiving experience is therefore 'discovered' and accounts for most of the variation in the behaviour about the problem. At the point of identification of a BSPP there is a clear shift in focus from studying units to studying process, and a substantive theory is generated through constant comparison of incidents, (ideally within different comparative groups in the same substantive class) in this case, within the experience of different women within the same sub-group of what may be a broader substantive class. The 'discovered' BSPP evolved into a definition of three stages of caregiving - 'Becoming', 'Maintaining' and 'Jeopardy'.

Therefore, the Results Chapter which follows is divided by sections with each section providing evidence of how the three primary themes of Woman's Role, Isolation and Changed Marital Dynamic differed in interpretation, impact and consequence at each of these three Stages.

This evidence is provided through illustrative quotes, sub-codes particularly relevant, and author's comments.

Each section begins with a general definition of the Stage and some prefacing comments regarding the transition into that particular part of the process.

CHAPTER 6

RESULTS

Becoming

Although Becoming, like the subsequent stages, may not have a clear beginning, it is characterized by the following factors:

- moving from the initial shock and denial to a sense that this illness/disability is not temporary
- a conscious realization of certain role changes within the marriage
- later in this stage there is a realization that some of these role/responsibility changes are radically upsetting the image she had held of her marriage

It is a time, for the women interviewed, when they are literally 'becoming a caregiver'; a time of struggling to integrate new information i.e. about the disability, changes in life style, and an altered marital relationship into a new reality with which they can cope.

Although adjusting to this new reality is a painful time it is a time of significant optimism and faith that this struggle towards a new reality will find them in a marriage which, though changed is viable, mutual and still reflective of the love upon which it was founded. The fact that there is a decision to be made (to become a caregiver or not)

may not be recognized by some women. For some who do see that there is a decision to be made there may be an inability or reluctance to articulate the choice. Although none of the women interviewed felt they had a choice in embarking upon this process of Becoming a Caregiver, the process clearly began, consciously or sub-consciously, with a decision that they would be the primary provider of care.

For all the wives interviewed this 'Becoming' was a painful process; a time of acknowledging, if not accepting, sometimes great losses and difficult changes in relationships and lifestyles. Moving into this stage may be more or less difficult depending on a number of factors. For some women, the fact that there had not been a clear beginning added to the difficulty:

"...He was sick when I married him....nowhere near this and, of course I had no idea how bad it would get or the character change that would come along with it, but I knew people would say..."You went in with your eyes open so you've got no choice..."

This woman found moving into the Becoming a Caregiver Stage very difficult because she felt that by having accepted illness she had no choice in the matter of accepting caregiving. This woman was not the only one interviewed for whom external pressure or perceived external pressure played a significant role in the assumption of caregiving duties. However, she was one of the two women interviewed who had an historical basis for the anticipated disapproval. In her case, divorcing her first husband during an illness had resulted in ostracism from church and family. Another woman's sense of failure in not 'seeing' the initial

symptoms made the transition into the 'Becoming' stage a time of great guilt:

"I should have seen the changes (mood swings, lessened coordination) for what they were...the beginnings, warnings...if I had been more aware, then, well I just felt responsible for how he is now...that taking care of him was the least I could do though I knew I'd never be able to make it up to him."

For another woman the transition into Becoming was made almost overwhelmingly traumatic by the sudden-ness with which she was thrust into the Caregiving role:

"During the months following the stroke I was strongly discouraged from having him come home for visits...something to do with funding for the bed or something...anyway, when he did come home it was all at once...and it was a shock for me to be suddenly on my own with so many needs to fulfil...."

This woman had never considered any option other than having her husband come home but was very nearly broken by the experience of that first uninformed, unprepared week. Another way in which transition into this stage was affected was by the attitudes of professionals at the initial point of contact. Although none of the women interviewed felt that professionals had coerced or pressured them in a deliberate way they did feel pressured by the 'positive assumptions' expressed. Positive

assumptions by attending professionals of the strength and solidity of the marital relationship and their perception of their love for each other, made at this point in the wives' experience, caused the women to feel they then had to live up to this image:

" the social worker said you're a couple who'll support each other, you'll make it.....what could I say, "that it's all just a front, I'm really terrified?"

"...the nurses said, "you're so devoted to each other - he's so lucky to have you to take care of him..."

This presumption by professionals of the wives' capacity to cope was not the only obstacle to expressing concerns or asking for information. A perceived disparity between the professionals' attitude and the wives' emotional state also discouraged asking for help.

"I was totally ignorant about strokes, about serious illness of any sort, I needed help and information and support....there I was with my life totally changed and the nurses and doctors treated it as such an everyday experience."

"I don't know anything about strokes and the doctors are so blase about everything. Your life's falling apart and they're blase."

Woman's Role

However individual the circumstances and experiences at the initiation of the Becoming Stage, the most significant factor determining that they would move forward in the Caregiving Process was the women's perception of 'woman's role'. How 'role of wife' impacted on Becoming was demonstrated by statements which were often presumptive and relatively simplistic compared to those explicating how 'role of wife' impacted on Maintaining. For example, Becoming statements such as,

"...of course I took care of him...because I was his wife.."

"...who else but a wife should a man come home to?"

expressed an assumption of care that, notwithstanding the frustrations and problems noted in the preceding section, was made easier by ignorance of what caregiving would involve - a romanticizing as it were of caring, and a wealth of denial that at any rate, the state of affairs could be more than temporary. As 'a wife' the process of Becoming was also facilitated by the Love a wife has for a husband. Evidence of this was found in very straightforward statements as,

"...well, I loved him...that's all there was to it...he belonged with me.."

"...You marry...for better or for worse and when a little 'worse' comes along the love doesn't change one iota and you just show your love as best you can..."

The straightforwardness of the statements, when taken in context, reflects the straightforwardness of the Love itself at this stage of Becoming. None of these women - although their 'role as wives' as they saw it, pre-determined that they would take on the caregiving, doubted that they would take it on, and only two were significantly influenced by any stated or perceived pressure from family or professionals in making this choice. Throughout the interviews many references were made to a sense of being 'tested' - that this was a time of proving - to themselves and others that they were 'a good wife'. Referring to the professionals' assumption of her self-sufficiency one woman stated,

"...what little self-sufficiency I did feel I forced to the forefront of my mind; telling myself that it was a test - of love, of strength and if I gave in to the loneliness or fear I would have failed..."

This time of 'testing' was also a time for the women to articulate - for themselves - what being a 'good wife' meant; what was necessary to 'pass the test'. Some of the factors identified are expressed in the following comments:

"My children - my eldest daughter in particular, had always been my greatest joy and support and certainly... she [Jane] had been, in many ways, my closest friend but now - when I most needed that closeness I had to shut her out - because

it wouldn't have been sharing, it would have been burdening her - I couldn't burden the children with my problems...without failing somehow - as a parent and as a wife"

"...It was important to keep up a good front so that friends might be encouraged to keep coming to see him. No one wants to visit in an atmosphere of 'woe is me'."

"I had to shut down my sexual feelings and my needs for things he could no longer provide...so that I could better get on with the business at hand and not make him feel inadequate."

Therefore, one of the costs of 'passing the test' was isolation.

Isolation

Isolation, as a core category at this stage, emerged from a variety of indicators including restricted social activity, some degree of loss of social life per se, loss of marital companionship, change in or loss of marital sexual relationship, loss of mutuality aspects of the marriage, the beginning of 'distancing' in order to maintain an appearance that all was well. This latter 'distancing' also necessitated a fair repression of feelings, frustrations and own needs - precipitating a withdrawal into themselves.

And, as described earlier, many of the women spoke of the positive presumptions or indifference of professionals as contributing to this withdrawal into themselves. As one woman said,

"...after he had come home from the hospital I could have kicked myself...it seemed too late to go back and say 'you were wrong about me - I'm not strong enough, I don't know enough, I need help'...it was as if I'd set myself up with everyone - the hospital, my family, my husband - to be this totally self-sufficient person. But I didn't feel self-sufficient so much as just alone."

But, whatever role the attitude of professionals played in the precipitation of withdrawal, the self-imposed pressure to 'keep up a good front' quickly entrenched isolation as a way of life. The following quote relates to 'Role of Wife' but also very clearly articulates some of the pressures which established isolation:

"You have a role in life - as a woman - to keep up the harmony in the family...when something like this happens to you the only way to maintain harmony is to subjugate all your own feelings and be cheerful and positive...as our Doctor said to me when he first had his stroke - 'You are the captain of the ship now - you won't do him or the children any good by crying about it...'"

The Changed Marital Dynamic

As mentioned earlier, at the initiation of the Becoming stage, the denial that the disability was permanent, an ignorance of what caregiving would entail and/or a romanticizing of the task all combined to ensure that, although great changes had in actual fact occurred, the state of the 'emotional marriage' was not perceived as substantially changed at this point.

However, the concept of a changed marital dynamic is reflected in the Becoming as well as in the Maintaining stages and is particularly central to the stage of Jeopardy. Following is an explication of some of the ways in which this change is manifested as the Becoming stage becomes more established and how it impacts on this stage for the caregiver.

"..My first thought was, now I can return all that he did for me..this is my chance to pay him back..."

"At first, when he was first released from the hospital, of course, your first instinct, the maternal instinct comes out...you want to do everything for them."

"...there's some of that feeling, the same feeling that you have when you bring your babies home from the hospital..a very tender, I'll fix everything kind of feeling."

Again, there is a romanticizing of, among other things, the anticipated role reversal. The sense of balancing, of reciprocating in an important way, the positive love and support received from a spouse.....although, as will be detailed later, in some cases, the previously received love and support was somewhat illusory....magnifying the good was clearly necessary - for some of these women - in order to cope with their new burdens.

These sentiments, expressed by several women, reflect an almost rose-coloured glassed attitude...a romanticizing of what their role would be as a caregiver. And this romanticizing was significant in motivating them to take on the caregiving role in the beginning. These women elaborated that this romanticizing was strongly supported by what they see in retrospect as their denial that it could be anything but temporary.

"...but never in my wildest dreams did I ever think he wouldn't recover - ever."

This sentiment was frequently expressed by most of the women - some held out hope for a spontaneous recovery while others felt that if they were 'good enough' they would effect a recovery.

Maintaining

Role of Wife

Maintaining as a stage is differentiated from Becoming by the following characteristics:

- a struggle to reconcile the knowledge that this disability is permanent and, perhaps, becoming progressively worse with own sense of what constitutes an acceptable life
- a struggle to rationalize the caregiving role without the previous 'romanticizing', optimism, or expectations of previously defined marriage

The role of wife becomes an increasingly significant pressure as time progresses and/or the rigors of caregiving increases. Pressures experienced in the Becoming stage are now experienced quite differently. For example, keeping up appearances for the childrens'/husband's sake was previously tempered by surviving idealism about 'making him better', 'returning all the favours he's done for me', 'we love each other - he'd do as much for me'. Now 'keeping up appearances' means doing so in the face of increasing physical care, the hurtfulness of post illness/disability character change, and with dwindling peer/friendship support. All the women interviewed felt that this stage did not, in any way, temper their role or obligations - but that maintaining necessitated a further commitment to repressing their own needs or wants and coming to terms

with the fact that their relationship with their husband no longer bore much resemblance to 'marriage' as it had previously been understood.

Although the primary source of this pressure to maintain this role continues to be the woman herself the objectively evident and the perceived other sources of pressure become more numerous. Of these external sources of pressure, the pressure from the spouse is the most significant and the most problematic. Other most frequently identified sources of pressure include the wife's family, in-laws and adult children. Two of the women interviewed had a strong historical basis for an expectation that family would turn their backs on her if she were a less-than-perfect caregiver.

"My first husband had cancer when I left him....he's had a remission and is perfectly well after all these years, but at the time we had been unhappy in our marriage and then when he got sick, well I was working all day and coming home to so much work and bad temper and I finally just packed it in. Well, I paid dearly for it. I had expected some disapproval for leaving my husband but I had totally underestimated what a horrendous and unforgiveable sin it was to leave a husband when he was sick. I was totally ostracized from church and family. It's taken me many years to develop at least a little bit of warmth with my family and I'm not willing to lose it all again."

"My first husband died of cancer and my second husband committed suicide - not long after I had left him because I couldn't cope with all his mental problems. So this is my

third marriage and I'm taking care of someone else. And it seems to me that nobody ever gave me any credit for the many years of working and taking care of my first husband while raising the children but I've had a lot of grief from having it put on me that I was responsible for my second husband committing suicide - if I had stayed with him, taken better care of him he'd be alive."

One of the reasons these sources of pressure are as powerful in reinforcing the wives' sense of duty and role is that they feed, not only into the well established (and, as in the above cases, well founded) fear on the wife's part of negative judgement, but also feed into the guilt and self-blame mentioned earlier that prevent the wife from voicing her own needs to farm out some of the caregiving. As an example of guilt, the woman who had cared for many years for her first husband and has presently been caring for several years for her third stated that,

"I do feel it's unfair that women never get the credit for doing, just the blame for not doing, but I feel in my heart that I did fail as a wife, that his suicide is on my head."

Growing Isolation

Whether from guilt or fear or external pressure the perceived pressure to 'Maintain the role' not only facilitated Maintaining but played a very significant part in the 'Growing Isolation' of the caregiving experience. As evidenced by many of the Indicators, these women felt

very strongly that part of their role was to continue caring without sharing any of their struggle, their pain or their fears with family.

"It's important to not just do the job to be done but to do it with cheerfulness and enthusiasm. It's almost like a kind of test, to see how strong you can be, how well you can live up to 'the for better or for worse', how good a wife you really are."

Again we find reference to a 'test'.

The disinclination to share comes from evidenced or anticipated disapproval. But it also comes from a kind of credit these women give themselves for being able to differentiate themselves from women who couldn't cope. One of the ways in which they differentiate themselves is by their 'self-sufficiency.' This differentiation was often expressed in a quite judgemental manner,

"There's a woman in this building, I can't recall her name but her husband's been in a wheelchair for a long time. She smokes about 3 packs of cigarettes a day and her nerves are just shot and, well, she got someone in almost full time to help with housework and such but still couldn't handle it....she just lacked the determination or the faith or whatever....couldn't take it."

There was almost a sense that 'passing the test' - becoming a good wife - necessitated distinguishing themselves from others in a similar

situation. One of the consequences was an emotional inability to 'network' or access support groups. All of the women interviewed knew other women with critically ill or disabled husbands; all had been presented with opportunities for establishing further contact with these other women - but had felt that acting on these opportunities would have had negative consequences. Another interesting rationale for not aligning themselves with others in similar situations was a minimization of their own situation.

"I always wonder at the strength of people with kids who are sick or mentally handicapped. I have so much admiration for them. I'd just go out of my mind"

"When I had to take him to a respite bed when I had my operation I was so grateful to the staff there. If I had to face that work, that much caring every day all day I'd just go home and bag my head against the wall."

This last comment was made by a woman whose husband is totally dependent on her for all personal care tasks, who has limited speech, and is non-ambulatory. The irony is clear. But, for these women, such minimization was clearly an important part of their 'armour' without which they might be admitting and articulating a life which in the admission and articulation might be unbearable. And, in fact, when confronted with the opportunity to tell their story to a stranger, they all wept and were quite overwhelmed by the experience of recounting their social, economic and interpersonal losses and the pain of their struggle. What they clearly did believe, what they had internalized, was that they

would be failing as a wife, as a woman, if they shared this pain with any of those people who were most likely to be their greatest potential support.

It seemed that minimizing their own struggle was a part of their 'role' and therefore women who were 'out of the closet' on the magnitude of their struggle and especially those women who consequently opted out altogether were to be somewhat disdained. The disinclination to share with these other women comes not only from an urge to be 'better than them' and therefore a more successful wife but also from the strong sense that 'not burdening' is part of successfully fulfilling their role. And, at this state, 'not burdening' was seen as important in relation to the general public as well as family and friends. Being successful in 'not burdening' seemed to accomplish some important tasks.

One of these tasks is to protect their children, in their youth and in their adulthood, from a changed image of their father.

"It was bad enough that the grandchildren would never know him as a whole person but at least I could do a lot to protect his image with the children...the image they so wanted to hang onto of him as he was when they were young. So I make sure that I've done everything to put him in a good mood before they visit, make sure it's the right time of day and that the little ones, if they come along, are well entertained so he's not annoyed...and I make a special effort to be well dressed and cheerful. Spontaneous visiting has been subtly discouraged so this will all go smoothly. So they never see the demands for perfectionism, the orneriness, or see him in

situations where he needs any kind of personal care if at all possible."

Protecting them from a changed physical image was important, although much of the physical change may have been obvious, the exacerbations or deterioration and the resultant increases in caregiving were not and they were kept as much as possible from family. By manipulating social situations so that a minimum of personal care is required when company is around as mentioned above. The shielding of their children as much as possible from the character change or depression attending the illness or from the fact that the personality traits such as dogmatism, being overly demanding or critical, or perfectionism present prior to the illness were now, given the increased demands, was of even greater importance to these women. There seemed to be a deep sense of shame - of the demands placed on them, of their difficulty in either coming to terms with or changing the nature of the demands, of feeling responsible for not being able to make things the way they were.

This determination to protect everyone else from the realities of the caregiving role has been entrenched at this point and is a central feature of the Maintaining stage. It also significantly contributes to isolation and to the loss of pre-illness friendships or, at least, to the reduction of the depth/intimacy/kindredness of these relationships. And, it was not necessarily because of a lack of willingness of former women friends to remain involved. In fact, as evidenced in the comments, there was virtual unanimity that, while former male friends had all but vanished, the women had attempted to remain connected,

"You know, I realized after he had come home from the hospital that women, women really could conquer the world! Of all the couples we knew the men just vanished. I've often speculated and thought it was because of their having to face their own mortality when they saw him..whatever...but the women just kept coming, not as much but they'd come and be as natural as possible. I was so grateful to them...for making him feel included, like still part of the world."

But, for the women interviewed, their relationships, their friendships with these women had changed or fallen away completely because they felt they could not/should not share what had become the central fact and the predominant problem of their lives - caring for their husbands and the changed relationship.

Changed Marital Dynamic

At this stage the marital relationship has changed substantially and is perceived, by the wives, as having changed substantially.

"All of the things - almost all - that I had valued in our marriage - ended but these were also the things that made him a man - in his own eyes - being a good provider, sexually attractive, being a very suave and charming companion...how could I complain or express these losses out loud without being cruel to him or disloyal...loyalty to him, to his pride and dignity kept me quiet...and alone.."

For those women whose marriage had been one of happy companionship, sexual compatibility and fulfilled expectations the isolation within the marriage post-illness was particularly painful and the redefinition of their role as wife compounded by daily grieving over the losses in their relationship.

"He was my friend, my lover, my confidante - he was the centre of my life - well he's still the centre of my life but now it's like - well, like it's 'all work and no play' - here I am trapped in this house attending to him day and night and even while I'm carrying on with the bathing and feeding and housework I'm missing him...tears...I miss him so much."

For some women the Maintaining stage with its knowledge of permanence and evaluation of the meaning/definition of their marriage was a frustrating one of acknowledging some truths of what the pre-illness marriage had been.

"We never talked much before the illness...he's a very traditional man who feels that a wife is, well a wife and friends are another matter. You can't change that pattern just because there's been a stroke and you've lost your other social outlets."

"If we had talked about things before he got sick then maybe I could more easily broach some of these sensitive subjects now like getting some help.....but he just says, "Of course you'll not get anyone else to bathe me..and that's the end of the conversation because that's always been the way it's worked between us."

Jeopardy

Much of what appears to jeopardize the Caregiving Process is simply a problematic extension of the Woman's Role, Isolation and Changed Marital Dynamic experiences in the Maintaining Stage; Jeopardy being constituted by those aspects of 'Role', 'Isolation', and Changed Marital Dynamic which extend to a point of untenability or which change in certain critical ways so that Maintaining strategies no longer 'work'. Therefore, the events, perceptions and feelings which characterize the stage of Jeopardy are factors which potentiate a breakdown in the Caregiving Process.

It needs to be noted that all the subjects interviewed were still, at the time of the interviews, essentially, in the Maintaining Stage. The stage of Jeopardy is valid as an extant stage for these women to one degree or another. However, it is presented here primarily as a speculative, anticipated stage. As far as is known to this researcher, only one woman has actually separated from her husband since the interviews. (and, though no longer living with him, continues to take responsibility for a considerable amount of caregiving).

Role of Wife

One of the ways in which an acceptable redefinition of 'Role of Wife' has been sustained through the Becoming and Maintaining Stages was through perceiving credit or appreciation for efforts made. The following comments illustrate the failing of this strategy.

"Well, sometimes I'll take him his meal and there will be a look - I can't describe it but I know he's trying to say thank you....more and more often I see that as projection; my imagination rather than his appreciation.."

"Sometimes I need to hear I'm appreciated so I'll say to him after a meal or a walk, "Wasn't that nice...Did you like that? and if I keep at it he'll sometimes say, "You know I do....in the beginning that was good enough but now it doesn't feel so much like playful nagging as cajoling - like cajoling a child into saying thank you - and it's not good enough. I mean who am I kidding - he's so dependent I could badger him into saying anything - that doesn't make it real."

"There are things you just know - he was never much for actually saying these things so I can't expect it now...there's so much I don't know anymore but I need to at least pretend what I'm doing is appreciated - I'm afraid of what would happen if I couldn't even pretend anymore..."

This need, to interpret a look, a word as a sign of appreciation was very strong. This determination to defend the fact that they were appreciated in the face of little if any concrete evidence sometimes broke down in the course of the interview:

"As I was going out the other day he called after me and said how careful I must be in the traffic and how he'd worry

about me if I was late....and, as usual I started to say to myself, oh isn't it nice that he does care, that he doesn't take me for granted...but I realized that it was just fear on his part, fear of being without a nurse and a cook and all that."

It is this extension of being taken for granted or the feeling of being emotionally abused which placed the caregiving in jeopardy. Not physical demands. One of the women whose husband required the greatest amount of care made the following comments,

"He's been in the hospital for about a week now and although I should have been using this for some time off it's actually been more of a strain, going to the hospital to feed him and bathe him because he hates having anyone else doing it and all the travelling....but he was putting a lot of pressure on me last night to bring him home early and I wanted him to say that he missed having me there all the time or something but he said he wanted to come home, "because it's not right having these nurses feeding me breakfast and changing the sheets...that's your job." and it was just the way he said it...I nearly walked out to never return."

Notwithstanding the above comments all the wives interviewed expressed the following,

"Being taken for granted would be the final straw...if I felt he took all this for granted I would just quit.."

One of the ways the women felt taken for granted was through what they perceived as a 'double standard'.

"He should appreciate more what I do...If the situation were reversed I'd be in a hospital so quick...not because he doesn't care but because he can't boil an egg to save his life and could never take care of himself when he was well let alone someone else."

"His super-possessiveness really bothers me...it's not been easy going all these years without any sexual satisfaction or even any affection. But if I were in his position I'd want to go out of my way to allow the freedom....women aren't any different from men...you can't expect a life of celibacy just because one partner becomes disabled."

This sense that they would behave very differently from their husbands if the situation were reversed presented a real dilemma. And it represented a radical departure from sentiments of the Becoming stage where a reciprocity was assumed. These women all saw themselves behaving differently because they were 'nice' and 'kind' people yet felt compelled to defend their husbands' niceness and kindness even when confronted with reverse behaviour. The following quote amplifies this point which has been illustrated, to some extent, by the foregoing comments:

"..if I met him today what would I see? - a demanding, ornery, quite self-centred man - maybe that's who I married

but those aspects of his personality were, oh I don't know, not seen or seen but compensated for by so many things no longer a part of our lives - maybe he was never a very nice person but you have to justify to yourself why you ended up in this situation... 'he was such a wonderful husband until his stroke' works - saying, 'I'm here because I made a mistake' doesn't - this is difficult enough without feeling like a fool."

"I like to think I'd behave differently if the situation were reversed - maybe it's harder for a man, being used to a lot of control and being the 'boss' and all and then being suddenly weak and dependent - maybe there's just nowhere for the resentment and frustration to go except on to me - it's not that he's not a nice person - he's just a man."

The character change or depression which was attendant to the illness was problematic, in part, because the affected women felt so strongly they must shield others from it and because it contributed to their sense of being taken for granted and negatively impacted on their sense of 'role'. The ways in which this was manifested were several. How it jeopardized the capacity to continue caring is outlined below.

"When he talks with other people he tries to enunciate his words more clearly but with me he almost expects me to mind read him and I can't do it. And when I can't he gets so ornery...I mean, why can't he at least put out the effort he does with others?"

"...for one thing he's much much more possessive, even than he used to be."

"He used to be a flexible person...now it's breakfast at 8:30, lunch at 12 and dinner at 6 and if there's any variation there's hell to pay."

"Of course, in the beginning I was able to meet all his demands - the demands weren't so great as they are now, and I was younger and so on so there wasn't the conflict....now it's more difficult for me physically so I don't have the same tolerance when he's crabby about my not doing something just right...and it always has to be 'just right'."

This last comment speaks to an issue raised over and over again by the women and which has been illustrated previously; the sense that what was referred to as a 'character change' was not always a changed behaviour...that, rather, it was a long-standing behaviour or pattern of relating established long before the illness which, because of the illness, was now problematic. The reasons for the behaviours becoming problematic were described in many ways,

"We had a very traditional marriage...my husband took the lead and I followed - sometimes whether I wanted to or not...my expectations were traditional but also normal and

usual and the relationship is no longer normal or usual. Now I get all the demands without the payoffs."

"It's easier to accept a little possessiveness or bossiness from someone who's also a good provider and companion...but just because circumstances change and it no longer feels acceptable that doesn't mean you can change how you relate to each other."

In elaborating on this problem it became clear that not being able to change patterns of (non) communication in the face of increased demands and decreased rewards had a tremendously negative impact; greatly exacerbating the feeling of being trapped and alone in the caregiving role. Inevitably this problematic extension of their 'role' contributed greatly to the entire sense of their marriage changing in a way which created 'Jeopardy'.

Changed Marital Dynamic

The subject whose husband had been disabled for the longest period of time made the following comment about how she viewed her marriage in the present,

"I've been a widow in a way for 19 years. Oh, there wasn't that feeling initially - there's all those feelings of 'it will be temporary' and then you move on to some kind of adjustment to the changed state of affairs but you still have a sense of being husband and wife but eventually the memories or whatever burn themselves out and you feel,

well, widowed...After 19 years of living, really, without a husband...I'm amazed that he's still the force in the family that he is..and I've worked damn hard to maintain that role for him, as the 'patriarch'...but nobody knows that this has not been a marriage to me for a very long time."

Other comments made were,

"Maybe I'm not exactly a widow, but certainly, at least, more like a nurse than a wife."

"I miss the camaraderie, the close relationship. Now it's on a completely different level. Now if I put my arms around him and give him a hug it's not, there's sort of not the same feeling anymore. It's like hugging a patient or a friend."

This was a real dilemma as summarized in the following comment,

"...you know, sitting here talking, it occurs to me that it is only because I'm a wife that I'm here and yet, it's not feeling like a wife that makes it so hard to go on..."

This comment warrants elaboration as it relects a significant dilemma faced by these women; the dilemma of the 'wife's role as caregiver' being jeopardized by 'being widowed' or 'being a nurse'.

"...I wasn't ready to give up a sexual relationship but that's certainly been over since the illness...maybe if I had accepted things right at the beginning but I managed in the

beginning by thinking there would be this brief interlude of nursing and then we'd pick up our marriage...but of course it went on and by the time I realized he wasn't going to get better physically I'd forgotten how to think of him sexually or romantically and there was no way to get it back."

"We used to do quite simple things together, pleasurable little things like meals or walks or just talking...now even our little conversation is pre-occupied with the illness...it doesn't bother me any more to talk about laxatives over breakfast or whatever but that's because I don't see him as a lover anymore - more like a patient."

Losses such as the loss of a satisfactory sexual relationship are not simply the result of the illness per se but are often compounded by the demands of caregiving and the emotional conflict over what role dominates,

"It's not even that he's incapable [sexually], at least not all of the time. It's just that...well...how can you bathe someone and toilet them and then feel sexually aroused by them?"

This woman and others talked at length about how the 'distancing' necessary for effective 'nursing' ever decreased the gut level sense of wife-likeness which increased their sense of loss which increased the personal burden of providing care. And, although the increased emotional burden of care did jeopardize caregiving, whatever increased physical demands did not seem to have a significant impact.

When asked at what point the physical demands might bring them to put their husband in hospital, when they might not be able to cope, they all responded with comments almost identical to,

"If I get hit by a truck or something, when I'm dead and gone, I can't think of doing it otherwise - not for the physical work of it anyway."

CHAPTER 7

CONCLUSIONS

The primary objective of this thesis was to explore the day to day experience of caregiving for wives of disabled husbands. The objective and the initial data analysis was approached with one main sociological theme in mind - an assumption that 'societal expectations of women impact on the experience of caregiving'. And, while this assumption was not totally discarded the foregoing results provide some insight into why the validity of this concept became less relevant than 'women's perceptions of their role and internalized societal expectations impact on the caregiving experience'.

To elaborate, however determined a person's perception of their role might be by societal structures and cultural and socio-economic norms, theories about the experience of caregiving must begin with explication of what the knower perceives as positive or problematic in the present.

Analysing the data within the chosen methodological framework required that the question ' what societal structures or process defines the caregiving experience?' be considered relevant only to the extent that the data demonstrated these structures to be perceived and experienced as problematic. If, for example, non or under utilization of services had been primarily explained by the subjects on the basis of 'gatekeepers" (doctors, Long Term Care Assessors, social workers, etc.)

presumption of their caregiving role and bias against alleviating the burden then such a question would have remained at the centre of the inquiry. But, Instead, what we find in the data is a wealth of evidence that, although external pressure was seen as playing a role, for the most part such societal norms, traditions and expectations had long since been subsumed within the developmental process of self-identity - as a woman and as a wife. So that, regardless of the historical interplay between the societal context and the domestic sphere, the present experience of caregiving was more significantly impacted by thoroughly internalized and entrenched expectations of self. And the focus, therefore, of the data analysis and these conclusions is redirected to the question of how this internalization impacted on the caregiving experience. What was problematic for these wives caring for disabled husbands and what accounted for the variations in behaviour is the basic social psychological process of moving through the stages of caregiving, a process fraught with struggle and conflict between the objective of being a 'good wife'; successfully fulfilling the internalized definitions of that role and the consequences of isolation and a marital relationship privately acknowledged as not working. In focussing the analysis in this way we limit ourselves to that data which is grounded and, while acknowledging the interplay between societal and domestic spheres, we don't attempt an in depth analysis of the basic social structural processes (BSSP). Consideration of the psychological processes does, however, offer implications for modification of these structural processes so that they might be more responsive and more useful to a population which is obstructed in self referral or easy acquiescence to external referral. These implications are noted later in this section.

To summarize the above, what we find in the data is that the women have internalized traditional role expectations to the extent that it is their own definition of being 'a good wife' that impedes access to existing services. Not that this self-definition isn't reinforced overtly and/or covertly by institutional and family players with a vested interest in maintaining the status quo - but it is a reinforcement rendered almost unnecessary in the present due to the extent to which these women have historically 'bought into' and invested themselves in the status quo. How does this fact and other aspects of the data analysis relate to findings noted in the literature review?

One of the first impressions in exploring the situation of wife-caregivers in this study is that, as Golodetz (1969) suggests, the personal caregiving experience is markedly different from the caregiving experience of professionals or of professionals' perception of caregiving in the home. For example, institutional care or out patient care intervention is driven by the needs and priorities of the system; hours of operation, time allotted to care tasks, scheduling of activities including meals, etc. are all a function of pre-determined limitations and 'structural' priorities. In contrast, a wife-caregiver's workload and task assignment are determined by very different factors. Hours of work are determined by availability which is constant, task assignment is based on simple presence rather than capacity or knowledge, and scheduling and workload is determined by varying degrees of personal commitment and/or coercion and most clearly reflects the difference of home care in that it is patient, rather than system, driven. As with most domestic work, the time required inevitably expands to equal the time available.

The invisibility and devaluation of the work involved in home care is evidenced by the manner in which ever-increasing demands correlate

with greater isolation, lack of tangible demonstrations of appreciation and increasing disengagement of friends, family and professionals as the process moves from the acute/diagnostic stage to long term chronic care.

The willingness to care which arises from love, a presumption of duty, and an internalized definition of being 'a good wife' becomes an onerous responsibility as the consequences described by Fengler and Goodrich (1979) become manifest. These consequences - role overload, loneliness, isolation and role ambiguity - are confirmed by our data as significant components of the caregiving experience. And, although internalized role expectations and love may continue to predominate, allowing the caregiving to continue, they represent severe dysfunction and unhappiness in the fulfillment of this job.

As to degree of disability and stress the data was first analyzed to provide information on three main disability factors: mobility (confined to wheelchair, ambulatory with aids/assistance, ability to transfer), personal care requirements (bathing, dressing, personal hygiene, feeding) and communication (non-verbal, speech difficulty). The transcripts were then reviewed to provide information regarding the degree to which 'stress' factors (isolation, loneliness, role ambiguity, caregiving tasks and changed marital dynamic) correlated to these physical factors. For the women interviewed it appeared that mobility and personal care factors, though playing a role, were not as significantly correlated to the degree of expressed stress and were not sufficient in themselves to threaten continued caregiving. Communication, however, was clearly significant in the stressfulness of the caregiving experience. It was also clear that physical communication difficulties were intertwined with communication

patterns established prior to the illness/disability. For those women who described their pre-disability marital relationship as one where communication was positive, mutual and respectful and where conversation was a valued aspect of companionship there was an added dimension of loss and grieving but the result was portrayed more as sadness than stress per se even where the disability involved almost total loss of verbal ability. However, for those women who described their marriage as having been one where communication was functional and/or where aspects of the relationship (sexual, social, financial, division of domestic labour) were presumed or determined arbitrarily by the husband rather than arrived at through consensus and discussion, the physical impairment of communication contributed significantly to resentment, frustration and an overall stress which was personally problematic and which threatened continued caregiving to a greater degree. The conclusion drawn is that, while physical communication impairment correlates to degree of caregiver stress for all women interviewed to a greater extent than does mobility or personal care tasks, communication impairment is ameliorated as a stress factor to the degree to which pre-illness/disability communication was/is perceived to have been positive. The reason for this appears to be that a relationship which was premised on mutuality, where individual autonomy and decision making was expressed as a right, and which evolved from a basis of friendship provided a foundation facilitating a greater self esteem and capacity for fulfillment of own needs (i.e. 'time out') - even in the face of post-illness arbitrariness - than where this was not the case.

Notwithstanding the above comments, we return to the essential fact that all the wives were impeded in accessing services by

internalized role expectations and found these expectations to be problematic in the caregiving experience. The perception that shouldering the caregiving role and shouldering it, more or less, alone is problematic at all stages of the process. The process of moving through the BSPP from 'Becoming' to 'Maintaining' to 'Jeopardy', although presented sequentially, involves considerable ebb and flow between stages. And, regardless of whether the accounts of moving through the process were retrospective, present-based or future-speculative this accounting was given within a framework of success or failure as 'a good wife'. For example, although the advent of the Maintaining stage may have been characterized, in part, by equating 'good wife' with 'good nurse' or 'good housekeeper' and such an equation may have been tremendously costly in terms of repression of feelings, isolation etc. it was still consistent with being a 'good wife'. "Jeopardy", presented as it is, as a speculative or anticipatory stage potentiates not only breakdown of the caregiving role but was expressed as a stage constituted by absolute failure in being a 'good wife'. To allow more than brief forays into the prospect of not 'carrying on' was to threaten their entire sense of self which was largely defined by these internalized 'good wife' expectations.

It may add to our understanding of the struggle these women face to consider some of the ways in which male and female engagement with the developmental process differs. It has been stated, for example, that, "In any given society, feminine personality comes to define itself in relation and connection to other people more than masculine personality does..." (Chodorow, 1974, p.44). Chodorow expands on this theme by considering how women define themselves (and are defined) as successful at key developmental stages on the basis of 'attachment'

whereas men define success, to a much greater degree, on the basis of separation (read autonomy). By extending this developmental process into the realm of caregiving we must consider Carol Gilligan's (1977) description of women's resulting 'ethic of caring and responsibility' versus men's 'ethic of rights' as greatly exacerbating the dilemma faced by the wives interviewed in this study. For, if one's success and maturity has been measured, internally and externally, on the basis of attachment and success has subsequently been determined by the degree to which the ethic of caring has been integrated with sense of self it becomes extremely problematic to consider withdrawal from caregiving responsibilities without threatening self-identity.

Certainly, with the women interviewed in this study, it is clear that the risks and costs of their present caregiving role are considered more tenable than the consequences of abandoning the caregiving role. What is unfortunate is the manner in which the choice is defined - either one continues in a mode of self abrogation and isolation or one admits failure as 'a good wife'. Given the investment already made to the latter, such a choice is no choice at all. As stated earlier, it is this investment which makes the status quo so easy to reinforce and maintain in respect to these women. Therefore, meaningful change cannot come about simply by removing 'status quo reinforcers' but through change which expresses an active challenge to the status quo. The data suggests certain ways in which policy and practice can be changed and be made proactive in this manner in order to contribute to a third option; caregiving as a choice which involves both partners to a greater degree and is not based on self-denial. These are as follows:

Information

Professionals could make information available in ways which show sensitivity to the caregiver's personal history and stage of readiness to access such information. For example, information that can be taken away and reviewed at a less anxious time should be provided when contact is made at the initial acute stage i.e. following a stroke or during an exacerbation of M.S. which brings a caregiver in contact with health professionals. This written information should, even if only cursorily, validate normal fears and concerns as well as providing care information for the well being of the 'patient'. This information should also make reference to the possibilities of attendant character change, to the possibly radical alteration of lifestyle of patient and caregiver and to the possibility of established or 'illness-induced' communication patterns having a significant impact on the experience of coping with the illness or disability.

Information provided at this early stage might also include a synopsis of sources of further information and support around such issues as sexuality, financial management, dealing with children and other family members and accessing of community supports and services.

Personal Counselling

The women interviewed indicated that they had been given inadequate opportunities to share their fears and concerns. It might be helpful if professionals clearly gave permission, anticipating concerns

and fears. The fostering of and capitalizing on strengths that did seem to occur for these women is seen as important. However, validating the apprehensiveness, the fears of not being able to cope, the anger and trauma which can be expected in the face of a life-altering event is also important.

Professionals could provide opportunities for open discussion about such feelings and clearly establish a time when the opportunity will be repeated. This is necessary in order to not leave the caregiver feeling 'set up' by her own initial optimism or 'romanticism' or simple inability to know or articulate her needs so early on in the situation.

Counselling or 'information sessions' should be accessible at any point without the caregiver having to negotiate an entirely new system at a difficult time. One of the ways this could be most easily affected judging from the data, would be for social work/counselling to carry beyond initial or continuing hospital contact as an integral part of Home Care or Long Term Care Assessment contact.

Marital Counselling

The following were all factors identified, by the wives, as exacerbating the difficult of their situation.

- established patterns of not communicating effectively with spouse increasing the difficulty of communicating post illness
- inability to express their dilemmas regarding such issues as role overload and sexuality.
- conflict between spouses expectations and wife's sense of what was reasonable.

Marital counselling, like individual counselling, needs to be made available in such a way that it can be accessed in 'the normal course of events'. And, as with individual counselling, the results indicate this might be most effectively achieved by incorporating marital counselling into the Home Care or Long Term Care Assessment system. Particularly in the case of marital counselling or 'spousal information systems' the incorporation of this service might be most effective if done not just in the normal course of events but in as much of an 'as a matter of course' way as possible.

Limitations of Study

Time and data: There is a risk with a relatively small sample that core categories will be 'forced' too early on and that the researcher's time and data constraints will play an inappropriate role in the delineation of such categories and resulting explanations. Faithful adherence to the criteria for determining core categories ensures the integrity of the analysis and the validity of the results for this population. And this population, while, in general terms, representing wives caring for disabled husbands, specifically represents wives of a particular generation caring for husbands with particular disabilities - in effect, a sub-set of wives of disabled husbands. Therefore, one limitation is that the Results and Conclusions of this study cannot be presumed to be generalizable to all women with disabled husbands.

Keeping the limitation of data and time in mind contributes to the identification of suggestions for areas of further study - in relation to

this sub-set as well as in relation to the wider population of caregiving spouses.

Sample: A number of limitations may be extrapolated from the fact that these women were older and, with two exceptions, had been married eleven years or more prior to the onset of significant caregiving responsibilities. And the two exceptions were women for whom this was not a first marriage.

Being older may be significant in that these women were of a generation where traditional roles were the roles and consideration of any deviation from this role was more alien and threatening than might have been the case with a younger population. And for those women who had been previously married, the pressure to 'succeed' as a 'good wife' this time may have thus been particularly intense.

All of the subjects' husbands, with two exceptions, were unable - to one degree or another - to communicate verbally as well as they had prior to their illness or disability. It was clear, throughout the interviews, that this aspect of the disability was most problematic and contributed significantly to the ways in which the wives experienced caregiving. A broader sample would have allowed for a much more detailed analysis in relation to the role communication deficits play in the caregiving experience.

This suggestion that investigation of younger caregivers or female caregivers whose spouse's disability is different would lead to more general theory is speculative. The data collection process utilized in this study, by 'skipping' certain steps necessary in 'pure' grounded theory, did not result in the selection of this sub-set through an emergence of age or sex as being of theoretical relevance. The relevance to

[substantive] theory of investigating this sub-set was determined by the researcher's subjective evaluation and, if through 'data collection' only insofar as own life experiences and contact with people in various caregiving situations provides. Therefore, that a study of caregivers in different circumstances, as different sub-sets of the same substantive group, would allow for more general theory may be valid but to be technically legitimate, such further investigation would have to 'begin at the beginning', to determine what factors - age, kind of disability, income, etc. - emerged and through this process decide on what constituted sub-groups of the same substantive class.

Notwithstanding the above limitations it needs to be re-emphasized that the focus of this study was the Basic Social Psychological Process - i.e. Becoming a Caregiver - in relation to this sub-set and/or the wider population. The specific disabilities or characteristics of the wives merely represent sets of varying conditions of such a process.

Summary

This study has provided a beginning portrait of the wife-caregiver as someone whose isolation and burden is exacerbated by the pressure of her own definition of being a 'good wife'. That this 'caregiving reality' represents a manifestation of a lifetime of internalized societal expectations and norms is fairly clear. Some of the ways in which we, as health care professionals, can use this awareness to the advantage of prospective caregivers we encounter in practice have been described.

There are two points regarding this study that need to be emphasized in these conclusions. The first is that questions regarding

societal expectations of women are not posited with any agenda of negating the validity of wives caring for their spouses and the analysis of the data is not undertaken with an objective of having women reject such a role when faced with the disability of a partner. The women interviewed perceive their 'choice' as being between subjugation of self in order to continue caring and concession to failure through abandoning the role. An agenda predicated on a notion that caregiving is not valid only serves to reinforce its devaluation. We need, instead, to value what these women value - caring as a function of love, commitment and as an extension of an ethic constituted by meaningful, responsible attachment to others. Our agenda needs to be one which values these things while countering the exploitiveness and isolation presently inherent in the role.

The second point is that the above might be seen as contradicting previously stated intentions of explicating for the women the socio-political context of their experience (which, of course, includes how society exploits and devalues their role) and not simply looking for ways to enable women to be better caregivers. Explication, however, need not be concurrence and, in this situation, responsible explication is, in fact, an opportunity to validate and value - not reinforce what is evidenced in the system. And the suggestions made in respect to practice are not motivated by a desire to create 'better' caregivers but to address what is problematic about caregiving and to encourage real choice where a decision to care is not synonymous with isolation and self-denial.

Court foresaw limit to wife's love

By LARRY STILU

Is a loving wife likely to stay with her brain-damaged husband for the rest of his days, dutifully seeing as a nurse, companion and homemaker?

Donna Pickering, whose husband, Steven, suffered serious head injuries in a 1990 motor vehicle accident, argued the B.C. Supreme Court she would.

But the B.C. Court of Appeal, adopting a less romantic view of the relationship, recently decided the Pickering marriage may not endure.

In doing so, the court demonstrated a high degree of judicial insight.

Because after the Supreme Court proceedings, and before the Appeal Court heard the case, the couple separated — a fact that was not disclosed to the higher court.

Referring to "the effect of the vicissitudes

of life on even the most powerful feelings of love," Appeal Court Justice J.D. Lambert allowed that the wife may not stay with the husband.

Consider the reaction of a woman in her 40s who finds herself married to someone whose capabilities, personality and behavior have changed as markedly as Steven's have been changed, the judge said.

In short, Justice Lambert, with Justice P. B. Anderson concurring, recognized that Pickering might not always have his wife around to care for him.

With marriage breakdown in mind, as well as a possibility the wife might die before his husband, the Appeal Court increased

by 10 per cent the future care portion of the damages Pickering was awarded.

Vancouver lawyer John Laxton, who acted for the Pickering, said Thursday the couple

separated before the appeal was heard, although the court was not advised of the split.

He said the Appeal Court wasn't told about the separation because he reasoned the judges might think it had been concocted to influence the court. And his clients did not want any further delay.

Laxton said the Appeal Court's decision is significant because it indirectly acknowledges the basic premise that a spouse does not have to look after a stricken partner on a gratuitous basis.

But Laxton agreed the decision only partially resolves the issue; repeatedly pressed for whether an injured party is entitled to the cost of in-home care.

Lawyers such as Laxton who act for accident victims usually argue that an injured party should remain at home, instead of

being put into an institution.

Lawyers for the Insurance Corporation of B.C., which has an interest in keeping damage awards down, tend to argue that the victim is better off receiving institutional care.

The dollar factor was underscored in the Pickering case by evidence that an in-home housekeeper would cost \$37,960 per year, whereas a drop-in caseworker would cost only \$12,000.

Pickering, 29 at the time, was a passenger in one of two cars which, travelling side-by-side at more than 120 kilometres per hour, sideswiped each other. Both drivers lost control and the vehicle in which Pickering was sitting collided head-on with another car.

Pickering suffered multiple skull fractures and injury to the left side of his brain. He was blinded in his left eye, and suffered

"Court" A

APPENDIX A

Court raises injury award

Continued from page 1

periods post-traumatic epileptic seizures. He is not capable of gainful employment.

In awarding damages to Pickering at the 1983 trial, Justice Albert Macdonald of the P.C. Supreme Court denied a portion of the claim in which Pickering sought the cost of hiring a live-in housekeeper.

But Justice Macdonald was concerned to ensure that the trial judge, Justice Binnie, had not intended that the live-in housekeeper would be a woman who would be a companion for Mr. Pickering, and that she would be a woman who would be a companion for Mr. Pickering.

The result of the trial judge's decision reflecting the need for live-in help was to reduce Pickering's \$15.7 million claim by more than 50 per cent. Considered 25 per cent responsible for his injuries, he received damages totaling \$389,148.

As well as increasing the future care portion of the damages, the appeal judges also increased his award for loss of future earnings to \$350,000 from \$282,360. His total award now is \$787,575, which with interest is about \$1 million.

Laxton argued on appeal that Donna Pickering shouldn't be expected to care for her husband on a gratuitous basis just because she loves him. He told the appeal judges that "even with assistance and despite Mrs. Pickering's good will and intentions, the odds by any objective standards are very poor that the marriage will last for very long."

Agreeing, Justice Lambert noted that a psychologist who had extensive experience with rehabilitation cases testified at the trial that "the statistical chance of the marriage surviving was very slight."

"I think the trial judge must have concluded that the kind of care that would be required should be categorized as coming within the bounds of help and companionship expected in the relationship of marriage," Justice Lambert said.

But having said the award was proper if the wife stayed with Pickering, the Appeal Court said allowance should have been made for the possibility the wife might not stay with her husband, or might die before him.

"We live in a time when there is a very high incidence of marriage breakdown, even in couples where no tragic accident occurs to one of them," Justice Lambert said.

In weighing the two principal contingencies in the case — first, the wife's death or sickness, and, second, marriage breakdown — the court decided the wife would continue to perform her homemaking skills for her husband for 20 years.

Thus, based on a life expectancy of 39.45 years, the court decided Pickering was entitled to additional damages of \$168,116 to enable him to hire a live-in homemaker for the last 19.45 years of his life.

The fact the court was 20 years out in assessing the cost of the homemaker was "a further mitigation," Laxton said. Pickering is satisfied with the award and there won't be a further appeal.

APPENDIX B

INTERVIEW SCHEDULE

How the 'trigger questions' are utilized will depend on what has been or not been said in response to the Introduction and Open Ended Beginning Question which are as follows:

This 'Caring for the Carers' study is being conducted in an effort to understand what it's like for you to be providing the care your husband needs due to his being disabled. The hope is that a better understanding will be helpful in the planning and developing of services for people in situations such as yours. You are the expert on this subject and your participation is very much appreciated, especially as we realize that these are sometimes sensitive issues to talk about. Of course, you are still quite free to refuse to answer any question or discontinue participation at any time. There will be space after the interview for any 'off the record' issues you might want to discuss. I'll turn the tape recorder on now and we can begin. (request for reaffirmation)

"Could you think back to when your husband first became ill or was first diagnosed? Can you remember when and how your life was first affected by this diagnosis? What sort of help or assistance did you receive at that time and what was or wasn't helpful. What about in the time since...I'd just like you to give me a general overview - saying whatever comes to mind - of what this change in circumstance and taking care of your husband has been like for you."

Possible trigger questions:

What sort of things does your husband require help with? Normally? During exacerbations?

What sort of response have you had in your requests for help?

What is the attitude of other family or friends.

Who else helps you out when you need help?

Are you able to share with your husband when you feel tired?

Has a social worker or anyone offered you more help?

Do you or your husband discuss things that make life easier for you or for both of you?

How has your life been changed? career? independent social? health? education?

How do you feel your marriage has been affected? your social life? sexually? economically?

How would you describe your relationship with your husband now; your satisfaction with the marriage?

How would you describe your marriage prior to the onset of the illness?

What are the signs for you that you're feeling stressed; What precipitates particularly strong feelings of being stressed?

Do you feel there was much stress in your life prior to your husband's illness?

APPENDIX C

Consent Form

Title of Study: 'Caring for the Carers: Women Caring for Disabled Husbands.'

Principle Investigator: Anne Harbord

I hereby agree to participate in the 'Caring for the Carers' study being conducted by Anne Kelleher, Principle Investigator, under the auspices of the University of British Columbia School of Social Work.

I understand the purpose of the study to be twofold:

- 1) to explore the experience of caregiving for women whose husbands are disabled.
- 2) to make recommendations as to what policies and/or programs might better meet their needs than those presently in existence.

Specifically:

- 1) I understand that all information obtained during interviews will be held in absolute confidence and that the names of participants in the study will never appear in any form or report and will be known only to the principle investigator and her faculty advisor in code form.
- 2) I understand that in agreeing to participate I remain free to refuse to answer any question or to discontinue participation at any time.
- 3) I understand that I will not receive any monetary compensation for my participation.
- 4) Although it is hoped that information obtained during this study will, in some way, benefit people who are in the same situation as myself - I understand that it is not known what benefits or changes will accrue as a result of this study.
- 5) All inquiries concerning the study have been answered and are understood. I understand that any questions I may have in the future will also be freely answered.

Signature of Subject Participant

date

Signature of Investigator

date

12 Summary of methodology and procedures.

Grounded theory (Glaser and Strauss 1967) is the methodology to be used. This is a qualitative, inductive methodology. It involves coming to the research with general sociological concepts rather than specific hypotheses. If, as in this case, one of those general sociological concepts is 'the experience of care-giving for women is, in part, determined by societal expectations of women' it is also necessary that the indicators and properties emerging from various data sources support this assumption...or that the concept is modified or changed. The primary source of data for this study will be comprehensive, in-depth interviews with women who are caring for a disabled spouse. The steps of this process - in brief - are:

- 1) select a theme for theoretical development, i.e. women caring for disabled spouses.
- 2) select the interview questions that are relevant.
- 3) taking the completed interview schedules; analyse with respect to the main categories of the problems that are addressed, decisions about where to go next, coding of information, memoing are carried out simultaneously. These categories may be a mixture of 'labels in use' and 'constructed categories'. List these categories and write them on cards.
- 4) select the responses that address the first category. Compare each with respect to similarities and dissimilarities in topics dealt with and position on continua. After this process of comparison is completed, reduce the topics under each category to a set of subcategories by supplying them with labels.
- 5) repeat for each category.
- 6) for the research report, prepare a memo on each category and its subcategories, with cross references to illustrations on the completed interview schedules. These materials serve as a draft of the report.
- 7) state hypotheses suggested by the foregoing analyses. Examples of content of these hypotheses correlations between variables, conditions, of salience of the categories or subcategories.
- 8) restate the theory in its most abstract possible form.
- 9) suggest implications for practice, policy change or modifications, etc.. and relate to any of the above steps as appropriate.

DESCRIPTION OF POPULATION

3 How many subjects will be used?

How many in the control group? A maximum of 15 subjects.
N/A

4 Who is being recruited and what are the criteria for their selection?

Women caring for a spouse with a non-static disability.

15 What subjects will be excluded from participation?

Criteria for selection include: 1) married and living with spouse. 2) female
3) at least three years since onset of disability (defined as when first
needing assistance with such personal care/daily living tasks as toileting,
feeding, dressing, transfers, etc.

16 How are the subjects being recruited? (If initial contact is by letter or if a recruitment notice is
to be posted, attach a copy.) NOTE that USC policy absolutely prohibits initial contact by telephone.

Through Long Term Care. Those consenting will be contacted by phone by
researcher.

17 If a control group is involved, and if their selection and/or recruitment differs from the above,
provide details.

N/A

PROJECT DETAILS

18 Where will the project be conducted? (room or area)

Interviews will be conducted in the subjects' own home.

19 Who will actually conduct the study?

The student-researcher will conduct all interviews and transcribe all tapes and
notes.

20 Will the group of subjects have any problems giving informed consent on their own behalf? Consider
physical or mental condition, age, language, or other barriers.

No.

21 If the subjects are not competent to give fully informed consent, who will consent on their behalf?

N/A

22 What is known about the risks and benefits of the proposed research? Do you have additional opinions
on this issue?

It will be explained that what benefits might accrue to the caregiving population
as a result of the study is unknown. It is anticipated that some benefit may
accrue directly as a result of the opportunity to discuss these issues.

23 What discomfort or incapacity are the subjects likely to endure as a result of the experimental procedures?

It may be emotionally stressful to address some of these issues related to caring for a loved one. No physical or other risks are anticipated.

24 If monetary compensation is to be offered the subjects, provide details of amounts and payment schedules.

N/A

25 How much time will a subject have to dedicate to the project?

Approximately 3/4 to 1 1/2 hours of their time.

26 How much time will a member of the control group (if any) have to dedicate to the project?

N/A

ATA

27 Who will have access to the data?

The student researcher and the faculty advisor.

28 How will confidentiality of the data be maintained?

All data will be shredded or burned after completion of the analysis.

29 What are the plans for future use of the data (beyond that described in this protocol)? How and when will the data be destroyed?

None.

30 Will any data which identifies individuals be available to persons or agencies outside the university?

No.

APPENDIX E

Following is an illustration of how the memoing process is applied to the transcript excerpt initially coded in the 'Data Analysis' section of Chapter 5. The left hand column contains notes on 'what is happening' in the 'meaning units' in the right hand column. This is an illustration of one 'round' and one method of memoing only.

What is Happening in the Data?

- Disability of partner
- Lack of information at point of diagnosis
- Premature acceptance of loss
- Initial equation of disability with no marital sex

Meaning Unit

"At age 45 I was certainly not ready to give up an active sex life...this was certainly one very traumatic effect of the stroke [**loss-sexual**]

-
- Disability/pre-disability family structure with mother as harmonizer
 - Inflexible or perceived inflexible family communication boundaries
 - Pretending
 - Withdrawal from potential family support

Of course there were so many changes to cope with all at once not the least of which was -- putting on a strong front for my husband and my children and everyone [**internalized role expectations - to be strong**].

-
- Disability of spouse with no helpful referents in life experience
 - Ineffective family communication systems/ lack of appropriate intervention
 - Use of maternal role (known referent) to cope with spousal caregiving role
 - Premature/dysfunctional re-definition of marital relationship as asexual
-

It was a monumental task to bury the fear and loss [**repressing feelings**] and I had to just, oh I don't know, make the maternal urge to be needed to dominate and overpower all those sexual, romantic feelings [**changing marital dynamic**]

- 'Successful' caregiving based on repression
- Communication opportunity at this point threatening
- Questioning consequences of 'opening up'
- Dysfunctional choice between self and continued caregiving

but it worked, it worked for a long time...maybe even until right now...tears...oh, why am I doing this? The only way you can survive something like this is by locking up your feelings and not talking about them [**grief, isolation**]

- Opportunity to question
- Researcher presenting opportunity to discuss long-term effects
- Refusal to entertain thoughts of limits/ equated with failure
- Fear of possibility/guilt about entertaining discussion

I don't know what the breaking point is - there must be a point where you can't fake it - if I break down - well, I just can't or - what will happen to him [**fear, guilt**].

- Inadequate family communication systems; continued lack of appropriate intervention/ entrenchment of dysfunctional repression of feelings
- Unresponsive or unaware family, professionals
- Perfection of 'acting o.k.'
- Further withdrawal, denial of self/ isolation from social milieu

It's such a pressure to appear okay all the time [**internalized role expectations**] to make sure that everything is orchestrated - that noone, not even the children just drop by at difficult times - when he's in a -- bad mood or needs personal care [**pressure - to maintain appearances**]

- A disability involving physical dependence/ pre-disability dysfunctional norms
- Marital relationship not dynamic or open - husband entrenched in 'control' role
- Acquiescing overtly to expectations - internal and external
- Resentment/exhaustion/sense of martyrdom?

he needs so much care now - bathing, shaving, he even needs help with eating and - going to the toilet...it's really exhausting with him being such a big man and me being quite slight [**exhaustion - physical care demands**]. And everything has to be done just right or he gets so upset and of course meals have to be at exactly the same time [**resentment**]

- Continued dysfunctional definition of successful caregiving
- Lack of family/friends/professionals responsiveness/interventions
- Silent suffering
- Exacerbated isolation, further contribution to vicious cycle of repression of feelings, protecting others from reality creating further social isolation and loss of peer support

So, anyway, I make sure that noone comes over except when he's been properly dressed and fed and I've got a smile on my face [**pressure- to maintain appearances**]. Not that I have to worry much about people dropping over - funny how people disappear when something like this happens...we used to have lots of friends but not anymore [**loss - social life**]

- Equation of friendships with lifestyle
- Lack of 'corrective' reframing intervention
- Premature/innappropriate acquiescence
- Resentful acceptance

My women friends lasted longer - a few came around regularly for a year or so after the stroke and that helped me get through it but they've drifted away now, too. **[loss-peer support]** And I can't really blame them - how do you maintain friendships when you can't get away or do anything or even have people over for meals - he won't have anyone see him needing help **[isolation, resentment]**

- Historical and present societal context identifying wife as caregiver/traditional marriage defined by this status quo
- Husband reinforcing continuation and expansion of this role as his 'right'/wife partly through self definition and partly through acquiescence to pressure to uphold marriage vows submits to status quo
- Wife copes through struggling to rationalize this acquiescence within context of re-definition of role and marriage
- The maintenance of the family with wife as caregiver through internally required repression/external demands to fulfil role/and non-intervention by other systems due to maintenance of status quo

I'm sure you're looking around and thinking I could afford any help I wanted and you're right - but it's my job **[internalized role expectations]** and when I start to think that's not right and suggest some help comes in he gets so upset, tells me how humiliating it would be for him to have a stranger bathing him or whatever **[external pressure - role expectations]**. He'll say I'm his wife and it's my duty but I don't feel like a wife - I feel like a nurse or a maid **[changed marital dynamic]**. Well, almost - it's feeling like both that's hard - I still get caught up in the memories of what we used to share

- Entrenched dysfunctional marital relationship reinforced by increasing isolation
- Continued lack of responsiveness of natural support and non-intervention by formal systems
- Coping
- Grief, damaged marriage/self-esteem

and then I'll come crashing back into the reality of helping him on the toilet and him yelling at me because I haven't got him positioned just right **[loss - husband, changed marital dynamic]**. He used to be so strong and intelligent - now all the strength has to come from me **[loss - someone to lean on, husband as partner]**."

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