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Adaptation to Disability By the Wives of Spinal Cord Injured Males

by

Ⓒ Frances A. Vargo

A THESIS
SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH
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ABSTRACT

This study was conducted in order to expand our knowledge of the process of adaptation to physical disability by the spouses of the disabled. Ten women, whose husbands had become spinal cord injured after their marriage, were interviewed using an open-ended questionnaire format. Sixteen major themes emerged from the content analysis of the interviews, which was performed using the phenomenological methods of Giorgi (1975) and Collier and Kuiken (1977). Among the major themes were fear of death, control of her emotions, assumption of protector role, denial of her needs, importance of support systems, stability and control achieved through routines, commitment to the relationship, burden of responsibility, sexual adjustment, and personal growth. These were examined and discussed in the light of stage theories of adjustment, Maslow's needs hierarchy, and role theory, with a view to illuminating the need for services for the non-injured family members.

Implications of the study for medical rehabilitation and rehabilitation psychology were discussed and suggestions made for future research endeavors.

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The conduct of this research has been immensely pleasurable and rewarding for me, neither condition being greatly reduced by the frustrations and insecurities which have occasionally reared their heads. If, in the process, I have managed to generate knowledge or understanding, much of the credit is due the women who gave generously of their time and themselves in order that I might accurately represent their experience.

Heartfelt thanks go to my husband and confidant, Jim, and to my good friend, Dr. M. Westwood for the hours of "consultation" and confidence building. I hope that I have repaid that debt, at least in part, with a work well done.

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Introduction

Physical disability is a fact of life for a significant minority of North Americans. Without specifically delimiting the term "disabled", estimates nevertheless range as high as 10% of the North American population (Cook, 1976). According to Paquette (1976), the Canadian Rehabilitation Council for the Disabled estimated that one in seven Canadians is severely disabled. One group of severely disabled persons, those with spinal cord injuries, are estimated to be increasing in the U.S. at the rate of 10,000 new cases each year (Bray, 1978), of which almost four out of five are males (Trieschmann, 1980). Proportionately similar figures are assumed for Canada but no accurate records exist.

Although the number of severely disabled individuals has risen substantially in the last 20 to 30 years (Cook, 1976), little public attention was focussed on this group until the 1970's. At that time, increasing numbers of young disabled veterans of the Viet Nam war began demanding a better deal. Society, and especially governing bodies were beseiged with requests to guarantee quality education, adequate housing, and jobs for the disabled - in essence, the right to those things which most people take for granted. Public laws were subsequently passed guaranteeing access to public education for handicapped children

(Education For All Handicapped Children Act, U.S. Dept. Of Health, Education and Welfare, 1973) as well as basic civil rights for all disabled persons.

With increased awareness of the physical needs of the disabled, there has also been a renewed interest in the psychological well-being of persons with disabilities (Boone, et al., 1978; Dembo, et al., 1956; Morgan & Leung, 1980; Weinberg, 1978; Wright, 1980). Considerable effort has been expended towards identifying the correlates of "successful adjustment" to disability and suggesting effective intervention strategies (see, for example, Bray, 1978). Trieschmann (1980) has done a thorough job of summarizing and critiquing the literature pertaining to psychological adaptation to spinal cord injury by the disabled individual, including discussion of methodological problems. Concomitant with the study of the disabled individual and problems of physical and psychological adaptation, has been some recognition of the role that societal attitudes and values play in assisting or thwarting successful adaptation (Sussman, 1969; Weinberg, 1976; Wright, 1960).

Much of what has been written about adaptation by the individual is still controversial, in need of refinement and more carefully controlled study. There is, however, one major failing in this particular body of literature: the virtual absence of consideration for the effect of severe disability upon other family members, especially the spouse.

Purpose of the Study

The primary concern of this study was the effect upon spouses of sudden, severe injury resulting in permanent disability of their mates. The form of disability in question was paralysis (either paraplegia or quadriplegia) resulting from traumatic spinal cord injury. It has been pointed out that this type of injury occurs primarily in males (Trieschmann, 1980) in the 15-30 year age range (Cook, 1976). Those in the upper two thirds of this range are certainly of "marriageable" age and one might surmise that the effects of such a disability would have far reaching effects on one's ability (perceived or actual) to function as husband, father, breadwinner, etc. For those who are already married at the time of injury, the problem is not only their's but must be dealt with by their wives as well. Therefore, the purpose of this study was to examine and describe the process of adaptation to disability by the wives of spinal cord injured (SCI) males, in situations where the injury occurred <u>after</u> marriage and resulted in serious, permanent disability requiring the use of a wheelchair. This group was chosen because they were expected to be mainly young adults, essentially in the prime of their adult life. Their husbands were, by and large, healthy and active within the limits of their disability, without brain damage and without concern for recurrence of the traumatizing incident as might occur with stroke or heart attack victims.

In addition to describing the process of adaptation to disability, an effort was made to identify the salient factors which influenced the ways in which these women responded to the situation and how they felt within themselves. Of necessity, the study was descriptive, since, as the literature review will reveal, virtually nothing was written about the area.

Importance of the Study

The general practice of psychological counselling has recently leaned toward a systems approach, operating under the premise that one can better understand and deal with one's problems in the context in which they occur (Haley, 1978). This has resulted in the inclusion of various family members in the counselling sessions in order that the psychologist (or other helping professional) may understand the interpersonal dynamics of the problem or situation, thereby aiding intervention.

Why, then, does this approach not seem to have included work with SCI males and their wives? Buscaglia (1975) discussed the importance of helping parents to cope with disability in one of their children, and Vargo (1979) stressed the importance of family involvement in the rehabilitation of disabled wives/mothers. Yet, typical attempts to involve family members in the rehabilitation process have focussed mainly on information giving, coming at or near the end of the patient's hospital stay(Rohrer, et al., 1980). A notable exception described by Bray(1978) involved pre-discharge observation and assessment of families during a two day residency in hospital-owned cottages. The three facets of assessment included knowledge and information; practices or behaviors; and family attitudes. One is left with the impression, however, that such an approach was localized to the particular institution.

In Canada, the absence of personnel trained specifically in rehabilitation psychology means that considerable on-the-job training and experience would be necessary before the psychologist developed a "feel" for the problems. Lack of an appropriate model, shortage of psychologists in rehabilitation units, and de-emphasis on the psychological aspects of disability by the medical model of patient care mean that inadequate service is available to the disabled individual, as well as to his spouse or other family members. To put the problem in context, let us look at the largest spinal cord rehabilitation centre in Canada, Lyndhurst Hospital in Toronto. In 1981, there was one psychologist for 75 patients (Sterling, 1981). This meant that only the most worrisome individuals, those identified as "problem patients", were attended to and that post discharge follow-up and family involvement were impossible. The ratio of psychologists to patients may vary from one institution to another but the problems of inadequate training and shortage of personnel are likely universal in Canadian institutions.

Graduate training programs in rehabilitation psychology are currently being developed by at least three universities in Canada (McGill, University of British Columbia, and University of Alberta). While the main thrust of these programs may be at understanding the effects of disability on the individual, it is hoped that an understanding of the effects on other family members will be gleaned from studies such as this one, encouraging a more integrated approach in the future.

The importance of the present study is twofold. First, it provided some insight into the process of adaptation from the perspective of the wives of SCI males, both in the early stages and the post-discharge phase, where it was anticipated the bulk of the problems would occur. As a subset of this problem, it also highlighted the need for early and continued inclusion of the spouse to assist the couple in their mutual adaptation to the new situation. Second, the study suggested specific problems or areas for future research, problems which can be studied under more controlled conditions in the hypothesis testing tradition (Campbell & Stanley, 1967).

A study of this nature, gathering subjective data through means of semi-structured interviews, would ideally include a large number and variety of subjects who meet certain minimal criteria. These requisites were adhered to as much as possible within the constraints of availability of subjects, as discussed in the Methodology chapter.

The literature review demonstrated that no theoretical context had previously been developed within which to formulate hypotheses. Suggested areas of importance in the process of adaptation to disability were extrapolated from related literature, leaving an incomplete picture of potential problem areas. As there seemed no viable way to study this group of women adequately using questionnaires or rating scales, the semi-structured interview method was chosen as a data gathering technique, the data subsequently being treated according to the prescribed phenomenological method of Giorgi (1975) and Collier and Kuiken (1977).

Chapter 2

Literature Review

The literature on adaptation to disability can be classified into roughly three categories: emotional reactions, needs satisfaction, and roles. The emphasis of most authors in this area is solely on the disabled individual; little attention is paid to the potentially devastating effect that severe disability can have on the family and especially the spouse. Of necessity, then, insight into the problem must be gleaned from a variety of sources, some of which are only indirectly related to the question of adaptation to disability by the spouse. The three categories mentioned have been identified in the past as those most salient to the problem, and are, therefore, the most widely discussed.

Emotional Reactions to Disability

Wright(1960), Fink(1967) and Bray(1978) have postulated that the disabled individual passes through a number of stages or psychological phases from the onset of disability until some point at which the person would be judged "adjusted". These stages correspond roughly to those of Kubler-Ross(1975) on death and dying, and are indicated in Table 1.

Differences in terminology aside, these three proposals are essentially the same in that they suggest a transition

Table 1

Stages of Adaptation to Physical Disability

Wright(1960)		Bray(1978)		Fink(1967)	
Stage	Phase	Stage	Phase	Stage	Phase
I.Denial		I.Anxiety		I.Shock	
			A.Fear		A.Panic
			B.Denial		B.Anxiety
			C.Bargaining		C.Helplessness
			D.Depression		
II.Mourning		II.Accommodation		II.Defensive Retreat	
	A.Hostility		A.Mourning		A.Indifference/ euphoria
	B.Depression		B.Resignation		B.Low anxiety
			C.Compromise		
III.Adjustment (acceptance)		III.Assimilation		III.Acknowledgement	
	A.Enlarging the scope of values		A.Reconstruction		A.Depression
	B.Subordination of physique		B.Integration		B.Mourning
	C.Containment of disability effects		C.Acceptance		C.High anxiety
	D.Transformation of values				
		IV.Reflux -return to any former stage		IV.Adaptation	
					A.Reorganization
					B.Restructuring Values

or progression from early reactions of denial ("This can't be happening to me.") to mourning ("Why me?") and finally to some measure of acceptance of oneself as a person with a disability. Each acknowledges the variability of time spent at each stage but postulates that successful "adjustment" requires passage through all stages.

As with most stage theories, there is controversy surrounding the three positions, especially those of Bray and Wright. Cook(1976) has presented evidence suggesting that neither mourning nor depression may be necessary steps in the process of adjustment; that, in fact, spinal cord injured (SCI) patients may only learn from staff attitudes and reactions that mourning and depression are expected. In support of this view, Trieschmann(1978) stated the following: "there is no research which demonstrates that these stages of adjustment do occur, and, in fact,the research suggests that depression may be associated with a less successful adjustment to spinal injury" (p.70). In her review and critique of "stage" theories of adjustment, Trieschmann(1980) aptly pointed out that empirical evidence for such theories is either questionable, due to methodological problems; controversial, as a result of vague definitions of terms; or non-existent.

Controversy notwithstanding, Bray(1977,1978) also proposed that the families of SCI patients followed a similar pattern of adaptation to disability as that of their injured member. Some differences did occur as shown in

Table 2

Stages Following Spinal Cord Injury (Bray, 1978)

Patient Adaptation		Time	Family Adjustment	
Stage	Phase		Stage	Phase
I.Anxiety	A.Fear	0-9 mos.	I.Anxiety	A.Fear
	B.Denial			[illegible]Denial
	C.Bargaining			C.Depression
	D.Depression			D.Mourning
II.Accommodation	A.Mourning	10-24 mos.	II.Accommodation	A.Compromise
	B.Resignation			B.Reconstruction
	C.Compromise			
III.Assimilation	A.Reconstruction	25 mos. to life	III.Assimilation	A.Reintegration
	B.Integration			B.Acceptance
	C.Acceptance			

Table 2. The basis for his proposal stemmed from observations of families at the Georgia Warm Springs Hospital and Georgia Rehabilitation Center (Bray, 1977). About the families of SCI patients, Bray said,

> The family of the severely disabled individual experiences many of the same emotions, concerns, and conflicts as the client. They progress through developmental stages that parallel the adjustment process of the client. These stages are not envisioned as mutually exclusive with separate and easily identified boundaries. Interfaces may occur between aspects of any or all stages; however, a natural and logical progression has been observed in 180 families studied (p.237).

There is some evidence that, left to their own devices, some families do not follow a "natural and logical progression" towards successful adaptation (Berezowsky, 1979; D'Afflitti & Swanson, 1975; Shambaugh & Kanter, 1969; Peterson, 1979). Instead, the emotional reactions which spouses experience may be overwhelming and prohibitive of any progression without intervention by outsiders such as a psychiatrist, psychologist, or other professional trained to deal with these reactions.

Upon learning that one's spouse has been seriously injured, the immediate reaction is fear of death (Berezowsky, 1979; Bray, 1977). Once it has been determined that the client will not die, concern is shifted to the care given by hospital staff (Bray,1977) and the modifications in daily living necessary to accommodate hospital visits and an altered life style (Berezowsky, 1979). For some, this may mean a shift in decision making, control of finances, residence, or a host of other changes. In any case, a new pattern of living will develop for both client and spouse, one which may or may not give each maximum satisfaction.

Hart(1981) recently studied the significant others of seven SCI clients, two females and five males, in an effort to identify areas of common need. The study focussed on the very early days of hospitalization (five to 40 days after injury), pinpointing early reactions of persons closest to the clients. Essentially these people wanted to feel involved and helpful to the client but did not deny the need for venting of their own fears and anxieties, and, therefore, the need for someone other than the client to whom they could talk. Needs for information, hope, and emotional support were paramount.

Virtually nothing has been written about the role of spouse or family members in the process of physical rehabilitation. Their participation (or lack thereof) in the learning of new techniques for dressing, transfer, wheelchair mobility, etc. likely depends on a number of factors including the willingness and availability of staff assistance, acceptance of family participation by the client, and their own recognition of the need for such training. Bray(1977) emphasized that while the family displays denial of the reality of permanent physical disability, they may "refuse to deal with staff members' who confront them with the realities of paralysis"(p.237). This was not evident in Hart's(1981) sample, however. Most felt anxious about inadvertently harming the client and expressed a desire for instruction and information.

The length of time that an SCI client is initially hospitalized varies considerably but may range from about three months to nearly a year or more. Whether the client goes home or to some other institutional setting when physical rehabilitation is more or less complete is sometimes an awkward decision. Initially, the expectation would be that the client return home if at all possible. Assuming that life for both client and spouse has settled into some acceptable routine during hospitalization, the shift required in having the client at home may be very unsettling. Faced with responsibility for all aspects of assistance to the disabled individual previously provided by hospital staff, a variety of reactions might be observed in the spouse. Some insights are provided by studies involving persons on home dialysis.

Individuals suffering from kidney failure must undergo regular dialysis to cleanse impurities from the blood, usually in the order of three times per week. It is a time consuming procedure but one which can be done at home, assuming the availability of equipment and someone trained in its application. This responsibility usually falls to the spouse and the situation may, in some ways, parallel that of the SCI client returning home, requiring health care from the spouse.

According to Shambaugh and Kanter(1969), the initial reaction of spouses in their study was one of panic and denial associated with evidence of the seriousness of the client's condition, accompanied by fear that improper handling of the dialysis equipment would result in death (also Streltzer, 1976). Stress manifested itself in several ways. Wives of home hemodialysis patients were described as exhibiting depression; anger and hostility toward their spouses, about which they often felt guilty; feelings of helplessness, frustration, and disappointment; the sense of having a full time burden; and a sense of loss of "life as it used to be"(D'Afflitti & Swanson, 1975; Santopietro, 1975). Brackney (1975) asserted that the level of adaptation of the couple to hemodialysis was determined mainly by the physical and psychological well-being of the wife (where the husband was the one requiring dialysis), reinforcing the notion that it is unhealthy for spouses to become too closely bound to the emotional state of the patient(Shambaugh & Kanter, 1969).

Persons who have suffered brain damage present some additional problems, as when aphasia is evident or when cognitive and psychological functioning are impaired (Collette, 1970), but the reactions of spouses may be similar to those of SCI clients. Overprotection and unrealistic attitudes (such as belief in miracles or absolute will power) were observed by Kinsella and Duffy (1980) in the spouses of stroke victims. Where aphasia was present, families expressed many concerns including irritability, inability to express their frustrations, guilt that they were not doing enough for the aphasic, alternating oversolicitousness and rejection, financial problems, health problems resulting from disturbed sleep and worry, and social isolation (Malone, 1969). Berezowsky(1979) found similar problems in one of her families where aphasia was not present. Finally, in reference to families of characterologically brain injured patients, Lezak (1978) noted the following problems:

1. Feeling trapped by the situation
2. Social and emotional isolation
3. Abandonment by the extended family
4. Criticism of the caretaker by outside relatives
5. Caretaker becomes the focus of the patient's bitterness
6. Spouse cannot divorce with dignity or in good conscience
7. Sexual and affectional needs are frustrated.

From the data collected in the present study it should be possible to identify which, if any, of the observed difficulties noted are applicable to the wives of SCI males, and to pinpoint those which may be unique.

Needs Satisfaction

A second area of concern suggested by the literature is that of satisfaction of basic needs and the role this plays in adaptation to disability. Maslow(1970) theorized that basic human needs could be classified hierarchically on five levels: physiological, safety, love and belongingness, esteem, and self actualization.

These needs were ordered hierarchically because Maslow believed that each need category, starting with physiological, was prepotent over the higher needs, that they existed on a continuum with higher needs emerging only as lower needs were gratified.

A. Physiological needs

Included in this category are needs for food, water, sleep, etc., those elements which help maintain the body in a state of biological homeostasis. Under normal circumstances, these needs do not dominate the organism, but severe deprivation of any one may result in the person being "driven" to find food, water, etc.

B. Safety needs

These include needs for security; stability; dependency; freedom from fear, anxiety, and chaos; need for structure, order, and law; etc. When the world is viewed as a safe place and there exists someone who is seen as a powerful protector, unexpected or unmanageable situations are more easily taken in stride. These needs are most noticeable in children but manifest themselves in adults as well. One might hypothesize that these needs would be prepotent in situations involving great change, where order and stability are most disrupted.

C. Needs for belongingness and love

These needs involve both giving and receiving, and include the need for friends, acceptance, roots, contact, intimacy, and affectionate relations in general. They emerge only when safety and physiological needs have been adequately met.

D. Need for esteem

This was described as "a need or desire for a stable, firmly based, usually high evaluation of themselves, for self-respect, or self-esteem and for the esteem of others" (Maslow, 1970, p.45). The description divides esteem into self-esteem or a need for competence and independence, and the esteem of others or prestige and reputation. Satisfaction of these needs leads to feelings of worth while thwarting leads to feelings of inferiority and helplessness.

E. Self-actualization

Maslow(1970) described this as man's need to be "true to his own nature" (p.46), or a desire for self fulfillment. This is probably the most elusive of the needs and the one least well understood. It is perhaps only in modern society, with our relative abundance of leisure time and our freedom to make choices, that self fulfillment has emerged as something to be strived for by more than a select few.

From these descriptions, one can see that these needs do indeed form a sort of hierarchy of prepotency. Except in unusual cases, one is unlikely to be directed toward seeking esteem or self fulfillment when one is starving. Maslow has stressed, however, that the order of needs is not fixed absolutely, that variations do occur, and that any act may contain aspects of all the needs even though it is primarily motivated by one.

Finally, Maslow(1970) also believed that one could think of satisfied needs as forming a hierarchy of psychological health with the healthiest individuals being those with the highest needs satisfied. "a man who is safe and belongs and is loved will be healthier than a man who is safe and belongs, but who is rejected and unloved" (p.67). The person who has achieved satisfaction of the higher needs will be more independent and individualistic but at the same time more loving and less selfish than one whose higher needs have not been gratified. The most important implication of Maslow's theory for psychologists is the realization that psychotherapy can be most effective at the higher need levels, but only if the lower needs have been met.

While one might argue that no single individual can satisfy all of these needs in another person, there may be some expectation that spouses ought reciprocally to meet these needs within the marriage relationship. Hemodialysis patients and their spouses identified six major needs experienced by them and their wives: needs for identity, grieving, safety, communication, love, and optimum well-being (Santopietro, 1975). These very closely approximate those needs identified by Maslow.

The next section will discuss the place of needs satisfaction for the disabled client and his spouse in adaptation ~~to~~ disability. Most of the discussion is speculative in nature. Based on the author's knowledge of spinal cord injury and accepting the premise that such an injury does not alter one's personality (Trieschmann, 1980), there will simply be an effort made to apply Maslow's needs hierarchy to the specific circumstances.

Client (Husband) needs

With the advent of serious illness or injury, lower level needs may exert their prepotency over higher needs, at least for a time. While in hospital, physiological and safety needs are attended to primarily by hospital staff. In cases where movement is severely restricted, as by extensive paralysis, these needs undoubtedly become of prime importance both for client and staff, yet once the crisis aspect of the illness has passed, these needs will diminish in the eyes of the staff. However, for the person who cannot move his legs, who may not be able to balance in a sitting position, the need for safety may be prepotent for a considerable time as he learns to turn in bed, transfer to a wheelchair, and maintain the sitting position without the benefit of intact muscular control. As these needs gradually diminish with the acquisition of new skills, the needs for love and belongingness as well as for esteem may re-emerge (assuming they were present in the pre-injury individual) and be satisfied in varying degrees by staff, other patients, and by family members. The extent to which these needs are met undoubtedly influences the adaptation process but the nature and amount of impact has not been discussed in the literature.

When the SCI male returns home, there is a shift in responsibility for the basic needs of safety and physiological well-being. For the most part, this now rests with the spouse, although other family members and outside agents (such as those provided by home care services) may give assistance. Depending on the degree of physical impairment and the level of independence attained, these safety needs may recede into the background or, at the opposite extreme, predominate to the exclusion of other needs. While the growth needs (for love and belongingness and esteem) may have been more or less met by a variety of others in the hospital, the initial return home sees an end to this, with the spouse and family expected to be solely responsible for these needs as well. The degree to which meeting these needs is accomplished successfully might depend on several factors: pre-injury relationship (i.e., were need for love and esteem being met by the spouse and family before injury?), predominance of physical or safety needs, acceptance by the spouse of the client as a <u>person</u>

with a disability, and acceptance by the client of himself. To the extent that the client is willing and able to spend time outside the home in the company of others, the satisfaction of those higher needs will be shared by others, unless the client encounters the unhappy circumstance of experiencing mainly negative reactions by old friends, employers, and others.

Spouse (Wife) needs

One can speculate that the higher needs of the spouse would be set aside in the early post-injury phase while concern for the client's life is greatest. When the danger of death has diminished, and a new pattern of daily living has taken shape, the spouse may find that her needs for love and esteem resurface, needs that were formerly met by the now injured client. Unfortunately, he may not yet be in a state where he is sensitive to her needs. Inasmuch as her needs are met by others, few problems may arise unless there is an expectation by the spouse that the client will continue to function as before, when he is physically and/or psychologically unable or unwilling to do so.

Not only may the client's own needs be his central concern to the exclusion of consideration for his wife's needs, but she may ignore her own needs in her efforts to meet his needs. The demands of accommodating to a new and different life style may be so great that no time or energy are left for the nondisabled partner. "In so far as (the family) have to take on additional burdens, tasks and responsibilities, in addition to those they would normally be expected to assume, this limits the flexibility they have in playing other roles, and may mean foregoing activities and roles which would otherwise be available to them" (Hilbourne, 1973, p.502).

Only one study has attempted to look systematically at the problem of needs satisfaction where one spouse is physically disabled. Skipper, Fink, and Hallenbeck (1968) studied 36 couples in which the <u>wife</u> was disabled after marriage. Their sample was heterogeneous with respect to type and degree of disability, ranging from ambulatory with arthritic restrictions to complete immobility as a result of polio, yet their findings may have applicability to the current problem. These researchers looked at two major variables, those of needs satisfaction and marriage satisfaction, and found that, in general these were uncorrelated with the degree of the wife's disability (as measured by a mobility loss scale). This is an important finding because it suggests that the most obvious feature of severe physical disability, i.e. loss of mobility, by itself may have little influence on basic levels of satisfaction. Whether this would hold for the opposite case, in which the male partner is disabled, is currently unknown. Although mobility was discovered to be unimportant in this study, the authors did report high correlations for both husbands and wives between needs satisfaction and overall marriage satisfaction, but generally low correlations between husbands and wives on need satisfaction and marriage satisfaction. These authors stressed that all five need levels were likely to be present at once, and pointed out the error of focussing on only one set of needs at any time. They were, however, studying the later stages following injury, when the disabled person had returned home.

The question which comes to mind now is this: what relationship, if any, exists between the satisfaction of physical and emotional needs and the process of adaptation to physical disability? If the spouse's energies are directed toward satisfaction of the client's needs, and she perceives little or no reciprocation and hence low satisfaction of her own needs, does this then lead to depression, anger, hostility, and some of the other emotional reactions previously reported?

Roles

The final topic for discussion is that of roles, and their place in the process of adaptation to disability. Biddle and Thomas (1966) have likened us to actors upon the stage in that we take on different parts or "roles" when in the presence of others, and although different actors may take on the same role, it is never exactly the same for each actor. Nevertheless, enough similarities exist for the character to be recognized regardless of who takes on the role.

In a lifetime an individual may take on several roles, some of which we grow into or out of (e.g. child, student), and others which we do not (e.g. son, daughter); some of which we choose (e.g. mother, breadwinner), and others which we do not (e.g. male, female). The argument about sex role stereotyping is very familiar now, i.e., that males and females are socialized from infancy to perform their roles as male or female in stereotypic ways. With our broadening views of what is acceptable behavior for males and females there is slowly emerging permission from society for each of the sexes to establish roles previously thought to be the sole domain of the other. Among the most notable of these "switches" is the breadwinner/wife - homemaker/husband dyad. Typically, the role of breadwinner falls to the husband and that of homemaker to the wife, even in families where she also works outside the home (Nye,1976). For many this is a satisfactory arrangement while for some it is not. What results when individuals are forced, by circumstance, to take on unwanted roles?

In his review of the literature on role structure and the family, Nye(1976) identified eight roles in the positions of spouse, parent or both: 1)provider, 2)housekeeper, 3)child care, 4)child socialization, 5)sexual, 6)recreational, 7)therapeutic, and 8)kinship. Traditionally the roles of housekeeper (which differs from "housewife") and child care have been assigned to the wife and that of provider to the husband. Current trends are moving away from the strict delineation of duties which were acceptable 30 years ago, but Nye(1976) presented evidence to suggest that the change has been primarily in the lessening of negative sanctions for perceived failure to do one's duty to one's spouse, rather than in a changed attitude about which duties are the responsibility of each spouse. The principle problem for the couple may be that of expectations which are not shared by all parties. The successful performance of a role includes both a willingness to enact the role and competence in the performance of that role.

When one spouse becomes seriously ill or injured such that some duties cannot be performed as expected, some shifting of roles to other family members may be necessary. The success with which this is done has been pinpointed by some as one of the most important factors in the continued successful functioning of the family as a unit (Berezowsky, 1979; De-Nour, et al., 1974; Deutsch & Goldston, 1960; Power, 1979; Streltzer, 1976).

With specific reference to couples where one partner is disabled, Deutsch and Goldston(1960) and Wawzonek(1974) have pointed out that there may be a considerable discrepancy between role expectations for the disabled spouse on the part of each partner. Wives of aphasics described their husbands as "convalescent children" or regarded them "not as a husband, but as a boarder" (Malone, 1969). Berezowsky (1979) also observed a tendency for one of her families to treat the disabled father like an irresponsible child. Discrepancy can also occur between cultural role prescriptions and ability to assume the role. When this occurs, and the husband must abandon his role of breadwinner, for example, it sometimes happens that he is also stripped of related tasks such as money management or participation in decision making (Berezowsky, 1979; Carpenter, 1974).

Role flexibility and role ambiguity have surfaced as variables of key importance. Obviously where role intactness occurs there is unlikely to be much problem as each spouse is able to carry on in the pre-injury fashion. However, where this is not possible, two situations have been described. In the first, the nature and severity of the disability preclude performance of certain functions where mobility is the dominant factor. In such cases role flexibility plays an important part in the satisfactory adjustment of the couple to new demands and responsibilities (Livsey, 1972; Ludwig & Collette, 1969; Power, 1979). For example, there are many functions which a disabled woman can continue to perform in the kinship, therapeutic, and child socialization roles, even though she may be unable to perform those of laundress or shopper in the housekeeper role. In the second situation, the disabled spouse may be less disabled to the point where the duties that can or cannot be performed are unclear. The resultant role ambiguity may result in considerable marital discord

(Skipper, et al., 1968; Peterson, 1979).

Wawzonek (1974) asserted that two people relate well when roles are clearly defined. However, as we have seen, clear definition of roles in the post-injury phase requires a cooperative effort. An obvious factor which needs consideration is that of pre-injury roles. Able spouses react differently to shifts in responsibility (Malone, 1969) depending upon whether the pre-injury relationship with the disabled spouse was dominant-active or dependent-passive (De-Nour, et al., 1974; Streltzer, 1976) and on whether that role was forced or self-selected (De-Nour, et al., 1974). Women who have previously taken their roles reluctantly may seize the opportunity to take on more and different responsibilities when their husbands become disabled (Berezowsky, 1979), while others may feel helpless and frightened at the prospect (Malone, 1969).

There is consensus in the literature on a number of points in the discussion of roles where one spouse is disabled.

1. Role disruption and strained interpersonal relationships result from the presence of a disabled family member (Berezowsky, 1979; Carpenter, 1974; Deutsch & Goldston, 1960; Hilbourne, 1973; Malone, 1969; Peterson, 1979; Skipper, et al., 1968; Wawzonek, 1974).
2. "The return home of the severely disabled husband and father seems to present the maximum change and disorganization in family life" (Deutsch & Goldston,

1960, p.313).

3. To the extent that the disabled spouse had an instrumental role which can be maintained after disability, the problems of role ambiguity and discrepancy of performance may be less seriously disruptive (Deutsch & Goldston, 1960; Skipper, et al., 1968).

Clearly this an important area for consideration in any study of adaptation to disability.

Summary

The literature pertaining to previously identified areas of importance in the process of adaptation to disability has been reviewed with emphasis on the influence of these areas upon the spouses of the disabled. The picture which emerged is by no means clear or complete. A variety of emotional reactions in the non-disabled spouse may be anticipated, from fear and denial to anger and isolation. The suggestion that spouses and clients pass through defined "stages" in the adaptation process has been questioned but not empirically tested. Clearly there is a great deal of emotional upheaval and disruption of life in general during the acute post-injury phase, but is it resolved in a positive direction through predictable processes, and if so, by what means? Little attention has been paid to the post-discharge period, when the disabled client and his spouse must begin to cope with the day-to-day realities of disability, yet studies of couples where the husband has had a stroke or kidney failure suggest that this is a time of serious emotional turmoil.

Satisfaction of basic emotional needs as described by Maslow(1970) has been related to marriage satisfaction but to what extent is unknown, particularly in the situation where the male partner is disabled. Do some women merely accept a "martyr's role", denying their own needs; do they seek satisfaction of needs outside the marriage; or does the couple find mutual satisfaction in a closer relationship?

Finally, the importance of mutually agreeable role-taking has been emphasized, stressing particularly the influence of role flexibility and role ambiguity in the maintenance of a satisfactory marital relationship. Mobility of the disabled client and nature of the pre-injury relationship have been pinpointed as important factors in the amicable resolution of discordant role expectations, but once again the process of adaptation is unclear.

Since the ultimate aim in understanding the problems encountered by the wives of SCI males is to provide guidance to those professionals in the rehabilitation area, it is important to develop a clearer picture of the problems as these women see them, when they occur, and, lastly, how best to aid in their resolution.

At this point, it seems reasonable to let these women speak for themselves in an effort to answer the research questions posed in the following section.

Research Questions

This study, through its design and use of a qualitative methodology, attempted to examine and describe the subjective experience(s) of women whose husbands have become severely disabled after marriage. While wishing to remain open and receptive to the essence of what was said by these women, the researcher, nevertheless, recognized the need for some semblance of structure or direction by which to guide the gathering and analysis of data. Therefore, the interview was formulated to address the following questions, but not to the exclusion of other topics which might emerge as valuable to the understanding of the process of adaptation to disability by the wives of SCI males.

Question 1

What are the predominant features or constituents of the adaptation process for these women?

Question 2

Is there evidence of a sequential "stage" process of adaptation as outlined by Bray (1978)?

Question 3

What factors have been identified by the women as influencing the ways in which they react(ed) towards and/or how they feel(felt) about their new situation?

Question 4

As a result of the injury to their husbands, what changes have the wives identified in themselves and what meaning do these changes have for the ways in which they view themselves and their marital relationship?

Chapter 3

Methodology

The preceding literature review demonstrated that no coherent picture has been formed of the process of adaptation to disability by the spouses of the disabled. This presents some difficulty in formulating testable hypotheses, and this difficulty is compounded by the fact that the experimentally accessible population is quite limited given the constraints of various factors affecting experimental validity(Campbell & Stanley, 1967). Using quantitative methods, considerable time and trouble might have been expended testing various hypotheses on relatively small samples before any definitive information was obtained. Instead, it was proposed that the present study be carried out on an exploratory, rather than explanatory, basis, using a qualitative methodology.

Qualitative Methodology

Qualitative methodologies are most frequently described and utilized in the fields of sociology, anthropology, and history. Their increased use is also recently noted in education and psychology. There is general agreement that one of the purposes of qualitative research is not the testing of hypotheses but rather the generation of hypotheses and theoretical foundations (Cole, 1976; Collier & Kuiken, 1977; Giorgi, 1970; Glaser & Strauss, 1967;

Lofland, 1971; Macleod, 1947). As Macleod(1947) said, there is "first an attempt at an unbiased discription of phenomena, then systematic experimentation designed to reveal the essential determinants of these phenomena, and finally revision of existing theory in the light of the new principles discovered" (p.156). The intention of this study has, therefore, been to give an unbiased description of the phenomenon of spousal adaptation to disability, taking the wife's perspective when her husband is disabled.

The methods by which qualitative data are gathered may vary somewhat but generally involve procedures like participant observation, in-depth interviewing, written reports and examination of records, documents, and the like. Properly conducted, these methods can reveal a richness of experience and unexpected features of the phenomenon which might be missed by more restrictive methods (Collier & Kuiken, 1977).

The method of choice for this study might best be described as "phenomenological" or involving study of the total phenomenon of adapting to life with a disabled spouse, through the use of in-depth interviews. It is chosen because "there is a gap between psychological facts and everyday-living problems because psychology is not sufficiently receptive to those problems precisely as they exist in everyday life" (Giorgi,1970,p.86). The strength of the method lies in its willingness to temporarily suspend judgement and put aside theoretical constraints, asking not "why?" but "what?".

In practice, the interviews did not adhere strictly to the phenomenological style even though this had been the intent of the interviewer. It was found that with untrained subjects, particularly as they did not seem to be naturally introspective, it was necessary to be somewhat more directive or leading in the questions posed.

Determining the Sample

There are many factors which might influence the process of adaptation to disability by nondisabled spouses, of which some would be personal and others situational. By attempting to control for some of these through sample selection, it was hoped that a clearer picture would emerge for the group studied. Consequently, the criteria for inclusion in the sample were those listed below.

1. All subjects were females either married to, or cohabiting on a long-term basis with, a disabled male.
2. Subjects had been married to or living together with this man prior to his becoming disabled.
3. The disability resulted from a sudden traumatic injury to the spinal cord to the extent that permanent paralysis exists, necessitating the use of a wheelchair for locomotion.

Since four fifths of all traumatic spinal cord injuries occur to males, it was deemed likely that female spouses of disabled males would be more readily available for study than male spouses of disabled females. The criterion of marriage before injury was important to distinguish between those women who chose to marry disabled men and those who found themselves in a situation not of their own choosing. There could be vast qualitative differences in the ways in which each of these groups of women perceive their husbands and their marriages. Finally, the qualification that the injury be of a sudden-onset, nonprogressive type, with no concomitant brain injury, would alleviate the possibly confounding effects of progressive deterioration and/or characterological changes.

Beyond these considerations, the subjects were allowed to vary on several factors: age, length of marriage, time since onset of injury, number and ages of children, etc. By drawing on the subjective experience of a variety of women who met certain minimal criteria, it was believed that our knowledge of the process of adaptation to disability might be greatly expanded, and specific problems identified for further study.

The subjects of this study comprise a unique group of women in that they are all married to men who have sustained a traumatic spinal cord injury after they were married. Because no club or organization exists which caters to the needs of these women, finding out who they are can be a difficult task. Good statistical records of the spinal cord injured are virtually non-existent. Organizations such as the Canadian Paraplegic Association, which exist for the

SCI, are reluctant to give out information about members, and do not collect data about spouses in any case.

The source deemed to be the most reliable was the University of Alberta Hospital, which houses the spinal cord injury rehabilitation centre for northern Alberta and the Territories. Ultimately, 10 women were interviewed for this study whose husbands had been treated in this unit. The manner in which they were reached was somewhat complex. The Medical Records Librarian was requested to search the hospital files back to January 1978 for individuals who were male, traumatic SCI, and married at the time of injury. Patient names, addresses, and telephone numbers were requested, as well as spouse names. A total of 47 couples were recorded as meeting the stated criteria.

As a crosscheck on the list provided by Medical Records, the SCI unit in the hospital was contacted and their records were also reviewed. An additional 22 couples were added to the list, for a total of 69 potential subjects. Through the cooperative efforts of some of the nurses and the psychologist on the SCI unit, the entire list was reviewed for verification that each spouse was indeed a potential subject in the study, i.e. that the minimal criteria had been met.

The final result of the verification procedure left 26 potential subjects on the list. The 43 who were eliminated were done so for the following reasons:

2 - Native Indians (have a culturally different view

of illness and disability)

3 - English language proficiency was seriously questioned (English is a second language)

4 - deceased

4 - known to be divorced at time of discharge

11 - diagnosis other than SCI (polio, tumor, multiple sclerosis)

19 - unknown to the rehabilitation unit

The last group of 19 came entirely from the list provided by Medical Records. It was surmised that some of these would be persons who had become SCI many years previously but had been admitted elsewhere in the hospital for some medical problem in the time period encompassed by the search. Further checking on this group revealed that for some this was the case and that, while they were now married, they had not been at the time of injury. Some could not be traced.

Of the 26 women who were verified as meeting the criteria for inclusion in the study, 10 were ultimately interviewed and comprise the data for this study. Two more were no longer at the addresses provided and could not be traced. Three others initially agreed to participate but withdrew at a later date. Finally, 11 were never contacted because they lived great distances from the city, mostly in remote farming communities in northern Alberta and the Northwest Territories.

Pilot Study

In order for the investigator to develop a "feel" for the interview situation, a brief pilot study was conducted with two women. The first was married to a quadriplegic (due to spinal cord injury) who had been disabled for 11 of 21 years of their marriage. She was somewhat uneasy and asked that the interview not be tape recorded. The second was married to a paraplegic (due to multiple sclerosis) who had been disabled for 17 years. Although she did not meet the criterion of disability due to traumatic SCI, her husband's disease process had been that of sudden onset paraplegia with virtually no advancement in 17 years and therefore closely mimicked that of SCI. She was most anxious to participate and it was primarily her feedback which brought the interview questionnaire into its final form.

Each of these women highlighted potential difficulties with the interview content as well as the process, and while they were not included in the main study, their contributions were valuable in three areas: 1) refinement of the interview questionnaire, 2) refinement of the interview process, and 3) insight into the nature and quantity of data which might be expected from subsequent interviews.

Collection of Data

Subjects were contacted by telephone and the nature and purpose of the study explained. If the subject agreed to participate, a time was arranged, allowing at least two hours of uninterrupted time for the interview. Permission was also requested to allow taping of the interview session. Eight subjects were interviewed in their own homes, two at their places of work.

Prior to the start of the interview, the subject again received an explanation of the purpose of the study, confidentiality of the interview was stressed, and the subject was asked to sign a Consent to Participate form (see Appendix B). Data were collected by means of semi-structured interviews except demographic data which were collected systematically at the outset of each interview (see Appendix A). An outline of the general format of the interview is in Appendix C. This was developed and refined on the basis of the pilot interviews but was intended to serve mainly as a guide to the interviewer. As much as possible, subjects were encouraged to talk about their own life-world with minimal imposition of the interviewer's perspective. Questions focussed on "what", not "why", and avoided suggesting topics for discussion as much as possible.

Interviews varied in length from 25 minutes to two hours. All were taped and then transcribed except one, for which the subject wrote lengthy answers using the interview form in Appendix C as a guide. Follow-up telephone conversation clarified and expanded some of the material. This process was necessary if she was to participate at all, because she preferred not to be interviewed in her husband's presence and no suitable alternative could be found.

As much as possible, interviews were arranged so that interruptions would be minimal. This was not always achieved to the interviewer's satistaction but additional insights into the lives of these women were often gained by seeing them in their own homes, in a familiar and comfortable environment, rather than in an office or interview cubicle. Husbands were not present at the interview and in no instance was the physical environment seen to seriously hamper the freedom of the subject to speak openly and honestly. One final point should be made. Because the size of the experimentally accessible population was small, random selection of subjects was not a viable method. Nevertheless, some effort was made to fit available subjects into a loose developmental structure based on the length of time since the injury. This mainly involved making two types of choices: when to interview each subject, and which subjects to approach from among those who lived in distant places when not all could be included (because of travel constraints). In light of the stage theories discussed in Chapter 2, it seemed important to be able to sort subjects according to some time frame in order that the applicability of a stage theory of adjustment could be examined. For the size of the sample, the result seems quite satisfactory: three interviews took place at two, six, and eight months after injury, but before the men were discharged; the remaining seven interviews took place at 10 months, 13 months, 18 months, 30 months, 36 months, six years and 10 years after injury. This structure places the majority of subjects in the two year post-injury period where most changes are likely to be occurring. Beyond the two year mark, stage theorists suggest that the situation has pretty well stabilized.

The Subjects - Demographic Data

The nature of this study is such that the subjects are important individually as well as collectively. They have provided a wealth of information not only about the common themes associated with adaptation to disability, but about the individual differences as well. It is important, then, that their individual stories be told, however briefly. Appendix D gives somewhat abbreviated case descriptions of these 10 women and their efforts to adapt to life with a disabled husband.

Demographically speaking, the 10 women who participated in the study represent a varied group of persons. They ranged in age from 24 to 63 years at the time of interview, from 22 to 56 years at the time of their husband's injury. One woman had shared a common-law relationship with her husband for one year, beginning only two months prior to his injury. The others had been married from four to 40 years at the time of interview, from two to 35 years prior to injury. All had at least one child, although for one couple, the children were no longer living at home when the injury occurred. Three couples were farming at the time of the injury, one lived on an acreage, four in small towns, and two couples lived in the city. At the time of interview only two had relocated, moving from small towns to the city so they would have greater access to housing and other services which they needed. Seven of the women were married to quadriplegics and three to paraplegics.

(The terms "quadriplegic" and "paraplegic" generally indicate the approximate level of motor function remaining following SCI. There is great variability in the amount of function which remains for persons in each category, but "paraplegic" implies that the function in the shoulders, arms and hands is intact, while that in the legs is impaired, and "quadriplegic" suggests that some or all of the upper limb function is impaired as well as that of the lower limbs. The greater level of impairment usually means more reliance on mechanical aids and on other persons to assist with many of the tasks involved in living each day.)

Presently, only four of the women are employed outside the home, two on a full time basis and two on a part time basis. At the time of injury, five were employed outside the home. All of the husbands received some form of disability benefits following injury, except one. He derives income from their farming operation, as do two other husbands. One man had kept active in the running of his own business even during his hospitalization but the remaining six receive no income from employment. Only one subject indicated serious financial problems since the injury although four others suggested that finances had become somewhat strained with the loss of the husband's income. None of the husbands and only one of the wives had worked at other than blue collar or clerical jobs. This one factor represents a bias in the sample. Spinal cord injuries do occur in professionals but not at the same rate as in other groups.

Finally, when questioned about the use of outside assistance such as orderly services or home care, five indicated that they did make use of such services. Of the remaining five, three indicated they would not know if they needed these services until their husbands were discharged from the rehabilitation unit. These data are represented in Tables 3 and 4.

Analysis of Data

Unlike quantitative data analysis, one cannot select the specific "test" which best suits the data and the design employed. However, there has been an effort by those using the phenomenological method to outline and exemplify a step by step analysis of phenomenological data (Bruyn, 1966; Collier & Kuiken, 1977; Giorgi, 1975; Van Kaam, 1959). Although differing slightly in method, all agree that "the aim of the analysis is to find the necessary and sufficient

Table 3

Demographic Data - Personal

Ss	Age	Length of Marriage (yrs)	No. of Children	Employment
F.S.	37 (37)*	19	3	P.T. (P.T.)*
J.H.	37 (37)	18	2	F.T. (F.T.)
B.G.	24 (24)	5	1	P.T. (P.T.)
C.C.	39 (38)	1 (2 mo.)*	5	No (P.T.)
O.S.	57 (56)	36	3	No (Retired)
V.P.	35 (33)	16	2	No (P.T.)
C.P.	24 (22)	4	1	No (No)
J.A.H.	24 (21)	4	5 (4)*	No (No)
J.B.	40 (34)	20	3	F.T. (No)
J.R.	63 (53)	40	7	No (No)

* ( ) denotes condition at time of injury

Table 4

Demographic Data - Related to Injury

Ss	Injury Level	Elapsed Time*	Disability Income	Home Care	Location
F.S.	Quad	6 mo.	No	No	Farm
J.H.	Para	2 1/2 mo.	Yes	No	Urban
B.G.	Quad	8 mo.	Yes	No	Farm
C.C.	Para	10 mo.	Yes	Yes	Urban(Sm.Town)†
O.S.	Quad	13 mo.	Yes	Yes	Urban
V.P.	Quad	18 mo.	Yes	No	Rural
C.P.	Quad	30 mo.	Yes	No	Urban(Sm.Town)
J.A.H.	Quad	36 mo.	Yes	Yes	Small Town
J.B.	Quad	6 yr.	Yes	Yes	Farm
J.R.	Para	10 yr.	Yes	Yes	Small Town

* between injury and interview

† ( ) denotes pre-injury condition

constituents of this experience"; also "our basic assumption is that the core of such common experiences is the same in different individuals" (Van Kaam, 1959, p. 67).

> A necessary constituent of a certain experience is a moment of the experience which, while explicitly or implicitly expressed in a significant majority of explications by a random sample of subjects, is also compatible with those descriptions which do not express it (Van Kaam, 1959, p. 68).

In consideration of the sample size, for the purposes of this study, necessary constituents or major themes were identified as those expressed by five or more of the subjects. Any theme expressed by at least three subjects was deemed a minor theme, worthy of examination.

The terms "major" and "minor" are in no way intended to be indicative of greater or lesser importance of the themes. These terms merely represent the <u>frequency</u> with which the themes occurred across participants. Indeed, a theme to which only three or four women subscribed may have included several statements of that theme from each woman, indicating that, for them, it was extremely important. Any theme with less than three subscribers was considered non-essential to the description of the phenomenon, while still recognizing their importance to some individuals.

The method of analysis outlined below represents a synthesis of the methods described by Collier and Kuiken (1977), Giorgi (1975) and Van Kaam (1959).

<u>Step 1</u>

The transcribed interviews were read repeatedly with a view to re-acquainting the experimenter with the general tone and nuance of each interview. When this had been accomplished, usually after the second reading, each interview was examined for specific statements or ideas which related directly to the experience of the subject. All descriptive expressions which did not pertain directly to her experience of adaptation to this new situation were eliminated. Lengthy descriptions were reduced to the essential idea, taking care to retain the meaning expressed by the subject.

Step 2

The lists of descriptions or meaning units were then typed onto three by five inch cards, one description per card, for a total of 335 cards over the 10 subjects. A card-sort was performed, placing together cards which seemed to be expressing the same essential idea. When this was completed, each pile was examined in turn with two purposes in mind: the first was to identify the basis for the grouping together of those cards, and the second was to examine each card to ensure that it belonged to the group. The basis for grouping was identified as the theme of the expressions. This procedure yielded 16 major themes and 15 minor ones, as defined previously.

Step 3

In this step, an effort was made to organize and synthesize the results of Step 2 into a complex and meaningful description of the experience as expressed by these women.

Step 4

The interviews were further examined with a view to answering the specific questions listed at the end of the literature review.

Reliability of the Analysis.

Phenomenal reduction of interview data to the essential elements of an experience is, of necessity, conducted with a minimum of guidelines and a maximum of openmindedness. Under these conditions the question must certainly be asked of the experimenter, how does one know that bias and pre-judgement have truly been suspended, or that those elements earmarked as essential to the experience are the same as would be suggested to another individual examining the same data? In other words, is it possible for two persons working independently to glean from the data the same essential elements or themes?

In order to answer this question, an independent psychologist undertook the task of identifying themes. This person was apprised of the purpose of the study and the method of data collection and analysis but was naive regarding the actual data themselves before commencing the analysis. Instructions were given to sort the cards as outlined in Step 2 of the analysis. There were no instructions given with regard to the number or nature of the categories, or the number of cards which might be expected to form a category.

The results of this independent analysis matched almost identically with those of the experimenter. Differences were attributable mainly to differently worded descriptions of the themes but also to slight differences in the breadth or narrowness of some themes. In other words, the independent analyst sometimes grouped two or three closely related themes together under a more complex description than the experimenter had done, and vice versa. This occurred in five or six cases and accounted for the 31 versus 25 themes discrepancy in the independent listings. Only one minor theme listed by the experimenter failed to emerge in the independent analysis.

The strength of agreement between these independent analyses was taken as evidence of the reliability of the method and to a certain extent, of the validity of the themes which emerged from the data.

Chapter 4

Description of the Experience

Several research questions were posed at the end of the literature review. The first question was: What are the predominant features or constituents of the adaptation process for these women? The following chapter examines the data with respect to this question bearing in mind that the data must be allowed to speak for themselves rather than being interpreted by the investigator. Therefore, following the overall description, use will be made of quotations from the interviews in order that the reader may understand precisely what was said that led to the description of each theme or constituent of the experience.

Overall Description

Many elements of the experience of adaptation to life with a disabled spouse were common to most or all of the subjects. Initially the experience was characterized by shock, fear, and uncertainty, fear of his death predominating all other reactions. This fear was based on "not knowing" and imagining the worst possible situation until there was "knowing". For some, the thought of brain damage leapt to mind and conjured images which seemed worse than death. Although all received fairly blunt, but medically explicit, descriptions of the injury from a doctor, genuine recognition of the severity of the injury and its implications, both broad and specific, came slowly and gradually over several weeks or months.

Of paramount importance during the months of hospitalization was the assistance of family and/or friends. This assistance took many forms: just being there, listening to her concerns, assisting with business operations, providing transportation, babysitting, prayers. In general, however, there was rarely an atmosphere in which she allowed herself to let go, emotionally. Work and private tears were the permitted forms of emotional release. It was at this time that the negative reactions of family and close friends toward the injured spouse were most keenly felt. She now had to deal not only with her own concerns but with their reluctance and discomfort in his presence. Expectation of their support and acceptance was implicit here.

The early weeks were a time of emotional control in public, especially in his presence. This behavior was controlled both internally, by a sense of his inability to deal with her emotionality, and externally, by hospital personnel who counselled that she must be strong, not letting him see her cry. Thus began a pattern in which she took on the role of protector--of his comfort, self-esteem and emotional well-being--at the same time dismissing or denying her own needs. In retrospect, these women recognized value in having an emotional outlet other than their husbands, whom they sensed were too wrapped up in themselves for a time to give emotional support. There was an often expressed regret that there was no contact with someone who was perceived as truly understanding, "perhaps someone who had been through it".

In establishing themselves in the role of protector, certain patterns emerged. The predominating theme was control of both the physical and the emotional environment. Beginning with the ordering of their lives into routines, only some of which were established before the injury, changes were made to accommodate hospital visiting, to take on tasks which the spouse had previously performed, and to acquire new skills, in some cases (e.g. learning to drive a car). Routines brought a measure of stability to the situation.

As a couple, they did not discuss their feelings about the injury. Although the relationship was frequently described as cooperative, there were clearly areas which were left untouched, at least for several months. Much of what these women felt the situation required them to do was done with resignation or passive acceptance-- "you do what you have to do". Commitment to the relationship came early on, usually within three months, but often with a tenor of obligation, and again, passive acceptance-- "I never thought of leaving". Not surprisingly, though, at some point feelings emerged of being unappreciated. A certain lack of sensitivity in others, spouse included, to the fact that she also was suffering, that she also had given up a great deal, was alluded to time and again.

Commitment to the relationship for most of the women meant accepting reponsibility for the physical care of their spouses as well as for household tasks which he could no longer perform. The burdens of responsibility weighed heavily at times, there being recurring references to feeling pressured with the workload. Varying amounts of time passed after the injury before each acknowledged the need for some "relief time", a part of her life which could be separate from him, in which she could feel free of her responsibility for him. Conflicting emotions around this issue and others, coupled with lack of an empathic contact, often led to feelings of guilt, resentment and frustration before a satisfactory solution was found.

Another major theme was the issue of sexuality and the resumption of sexual relations. An awkward topic for most of these couples to deal with, it was, nevertheless, not a source of much frustration once dealt with. Both a physical and an emotional adjustment were required which was accomplished more or less satisfactorily through talk and experimentation. The importance of sex was reduced in the overall scope of their lives but many admitted it may have been more important to their husbands.

Despite the feelings of pressure from the burdens of responsibility, emotional upheavals, and an occasional sense of loss or missing something, this experience was viewed as a time of emotional growth, a time of positive changes in which the couple came closer together. Many of the women spoke of feelings of increased emotional strength and new found independence in areas which they had previously not explored.

Perhaps this is an appropriate place to consider the application of Maslow's needs hierarchy to the process of adaptation. In applying Maslow's theory to his crisis model, Fink (1967) stated, "in most instances an individual faced with a threat will be governed by his safety needs" (p. 595). This was very noticeable with most of the women studied as they attempted to re-establish a state of equilibrium in their lives through routines and resumption of a "normal" lifestyle. They did, indeed, as suggested in the literature review, direct their energies toward the care and protection of their spouses, often to the detriment of their own psychological and physical well being. In some senses, this undoubtedly served a need also, to stabilize the relationship, reducing the fear and uncertainty engendered by false or misleading advice from well meaning staff members. Clearly, however, this dominance of safety needs was replaced for these women, by the re-emergence of growth needs, well before their husbands had reached such a state. The frustrations expressed, for example, over his lack of appreciation for her role in his life demonstrated this. At a time when she was in need of friends, acceptance, esteem, and affection, some women were aware that concern was expressed mostly for the husband.

Maslow (1970) has suggested that a need may be deadened by experiencing life at a very low level for a long time. Certainly these women would not normally be described as experiencing life at a very low level; however, as many of them made great concessions to the situation, in terms of physical and emotional freedom, this might account in part for the air of passive acceptance which pervaded some of their lives. For others, at least within the confines of the marital relationship, cultural pressures which may have thwarted their needs for independence and self esteem were no longer operational. Reports of personal growth attest to this.

Maslow's framework for identifying and understanding certain human behavior cannot be applied in a ritualistic or simplistic manner to the complex situation under investigation. It does, however, provide a reasonable and rational basis for formulating strategies by which to facilitate psychological health in the individuals concerned.

Individual Themes

The overall description of the experience encompasses all of the 16 major themes and some of the minor ones expressed by the subjects. Each of the themes are expanded and discussed in the following pages, accompanied by representative quotations which exemplify the theme. Where two or more themes seem closely related, they are discussed together. The reader is reminded that the terms "major" and "minor" refer to the frequency of occurrence of the theme across participants and not to the relative importance of the theme for the women who expressed them.

Theme 1 (major) - initial reaction, fear of death
Theme 2 (minor) - uncertainty about the injury is more fearful than the reality

These together represent the predominant reaction to news of a serious accident, perhaps best described as a "worst fears" reaction. Only one of these women was present with her husband when the accident occurred. All of the others were notified by someone, often a telephone call from the hospital in which little information was given except that an accident had occurred. Only three of these women thought that it was "probably something minor". The rest related various panicked reactions, the details of which they could not recall. The initial fear for his life was sometimes replaced by concerns that he would be completely changed, either physically or mentally or both, that he might be a "vegetable". There was a sense of urgency to reach him, accompanied by dread at what would be seen.

> They let me see him first and I was relieved. In fact I couldn't believe his back was broken because otherwise there was no sign on him of having been in an accident. There wasn't the bandaged head and arms that you kind of expect (J.H.).

> When I phoned the doctor, none of it sank in, what she'd said. All I knew was that I had to get to Edmonton right away. That was all I thought about (B.G.).

> I asked him [the doctor] if he [her husband] was all right...he wouldn't say nothing, so I thought it must be bad...a train! He couldn't have been hit by a train! I just sat there and shook my head. I just couldn't believe it (V.P.).

<u>Theme 3</u> (major) - gradual recognition of the severity of the injury and its implications.

Some people with SCI require surgical treatment to stabilize the spine, others are placed in traction using skull tongs attached through holes drilled into the skull. The initial days and weeks, while the nervous system is still in shock, are ones of uncertainty. With some exceptions, the medical staff can usually make reasonable predictions about the amount of sensory and motor recovery which will occur with a particular level of injury. However, because other systems such as genito-urinary and gastro-intestinal also suffer, at least for a time, the period of overall stabilization can be quite lengthy and complicated. During this time, the injured person spends a great deal of time in bed, compromised in so many ways that the evidence of his disability is masked by the situation.

> Probably three days out of a week I was at the hospital with him and I fed him and brushed his teeth and did a lot for him there, and like once he started eating by himself I helped him with that (J.B.).

Under these conditions, it may be several weeks or several months before the loss of movement, in practical terms, becomes apparent.

> It's different visiting in the hospital and they're in a wheelchair. That's a hospital environment and wheelchairs and gowns and sickness. But when you bring them home, it's totally different (J.A.H.).

> It wasn't until he came home that I really went through a shock. I just couldn't believe it that he was so helpless, that everything he needed I'd have to get for him (J.B.).

> I don't think it really hits a person right away. You don't think about how bad it really is. I felt that way, anyway. I think it takes a long time to accept something like that (F.S.).

> I think as the days go by you just accept it, I guess. And go along with it, sort of, and just take each day at a time (J.R.).

Theme 4 (minor) hope and optimism of further recovery

Even small amounts of improvement sustain the hope that some couples have of eventual recovery. It acts as a buffer which allows the individual to delay the final acceptance of the disability as it stands, an acceptance for which they are not yet ready.

> You always have the feeling that it's still going to be better (F.S.).

> If he could just get his right arm going enough I think he could gain a lot more independence. He's started to write now, but its taken three years so who knows, it might go that far and it might go farther (J.A.H.).

> As long as therapy keeps up good, which it has for two and a half years, he will be fine and so will I ([illegible]).

Theme 5 (minor) - religious beliefs strengthen ability to cope

Belief that some Being more powerful than themselves is controlling their lives comforts some persons in times of great distress. It does not seem to be an abdication of responsibility so much as confidence that they will not be tested beyond their limits to endure. This knowledge that they are being watched over and cared for gives a certain strength which they feel would be absent otherwise.

> I believe God takes care of us and never gives us more trials than we can handle (C.P.).
>
> I think the Lord just gave me the strength to take it...the Lord really helped me through...He's been taking care of us (J.R.).

Theme 6 (major) - control of her emotions

Theme 7 (major)- need for emotional outlet other than husband

Beginning almost from the moment that their husbands were admitted to hospital, these women were counselled by hospital staff that they must be strong and not let their husbands see them cry. Some of these men were very ill from other injuries sustained in the accident and the sentiment was expressed that they had enough to cope with in coming to grips with their own problems. For most of the women, this seemed to be good advice--they stated their unwillingness to burden him further. However, no substitute was offered as an outlet for their own feelings. Some had a very close friend or relative with whom they could share their fears and frustrations, although they felt this person frequently did not really understand. Many wished there had been someone available, especially someone who had had similar experience and could, therefore, "really understand". Realization of the need for an emotional outlet was almost unanimous.

> Hopefully that person has a very close friend. I have one and I've been able to talk to her a lot, although she doesn't understand the medical part of it, just being able to talk to someone helps...the doctor told me to have a good cry and get it out of my system then not do it after because he [her husband] would need me to be strong...but you also have to think about yourself (J.H.).
>
> I would never say anything about how I was feeling or anything. I never talked to anybody, and that's a really bad thing to do...I kept thinking I have to be strong, I can't break down (B.G.).
>
> When he first got hurt they said to me, now you mustn't let him see you cry, you mustn't let him know you're upset...but as soon as we decided not to listen to anybody else, then everything was just fine, because he was wondering what the heck was wrong with me because here I am not crying and he's laying there (J.A.H.).

<u>Theme 8</u> (major) - she takes on role of protector

It is not uncommon for persons with SCI to go through a period of time during which they feel useless to those around them and may express a great deal of negative emotion (Wright, 1960). That coupled with the awareness of his physical helplessness may be what leads these women to shelter and protect their husbands by bolstering egos and generally placing him first in their lives. While a certain amount of this may be considered normal and healthy in any relationship, in this instance the impression was sometimes created that he was not strong enough to face the world by himself. Control in the face of uncertainty may also be viewed as a manifestation of her safety needs.

> He became hostile, angry, depressed, he lashed out at me...I treated him differently, very delicately, wanting to protect him...I wanted at times to force an argument so the next days would be less pressured...I decided I would never leave him alone, and I still don't (C.P.).

> He'd get down and get upset when he couldn't do things for himself...I always tried to reassure him that we'd be there to help him...I tried to let him do as much as possible when it came to the farm so that he felt he was doing something for us, and then he didn't have to feel that he's useless (J.B.).

> I felt I had to shelter him from any further harm...they used to get angry with me because I'd check his pills before they gave them to him...you see, I didn't give him a chance to stand up for himself when I was there (J.A.H.).

<u>Theme 9</u> (major) - denial of her needs, secondary to his

This can take many forms: going to the hospital to visit when she would really like a day to relax, giving up a job to devote herself to his full time care, leading a restricted social life because he feels uncomfortable in public, or restructuring her days to accommodate his needs. Whatever form it takes, these women seem to have their husbands' comfort foremost in their minds. Extra work is just done because it has to be done and any additional strain on her is seen as minor because he is the most important person in the relationship. Conflicts between need levels begin to become evident in the following quotations.

> I time everything so I can spend all my time with my husband and daughter...I think sometimes the accident has made me too responsible, and sometimes I just can't unwind and relax (C.P.).
>
> I gave up babysitting after he was home for a while...because I've been taking him to the hospital everyday and that takes time...seems like you don't get time to do anything else (J.R.).
>
> We always went dancing, all the time, and we don't go that often yet because it really hurts him ... go so far as to take him somewhere, he'd rather not go because he thinks he's being a bother to somebody (V.P.).
>
> It gets really hectic sometimes, especially in the morning when I'm getting ready for work. There's so much to do...but I just decided I'm going to get up earlier...give up a few things in the evening (J.B.).

<u>Theme 10</u> (major) - importance of support of family, friends

<u>Theme 11</u> (major) - negative reaction of family and friends is an additional burden

Not all families were as supportive as some were, for a variety of reasons, but the feeling was generally present that they helped as best they could. Without family and friends rallying in some way, either giving emotional support or physical labor, these women would have had a much more difficult time, especially those with farming operations. Implicit in their expressions was the expectation that this support would be forthcoming and subsequent hurt or disappointment when it was not as expected. This was particularly true when the reaction of family and friends suggested lack of acceptance of the husband with a disability.

> Our friends didn't handle it quite as well...all they could see was that now he couldn't walk, now he was in a wheelchair...some of them were honest enough to say we just don't know how to talk to you...I could see how he was hurt by it (C.C.).

> I found that our friends were more of a help than my relatives. It seemed they called to see if I needed help or to see how I was, more than family, but maybe that's just how some people are (F.S.).

> Most people did feel better after they saw him. Of course it was difficult for everybody the first time to have to see him, knowing the extent of his injury (J.H.).

> They really stood by us. They were very good, going to see him, and taking me up whenever they were going...and I don't think he'd be alive today if it wasn't for the prayers of people (J.R.).

> It would have been really hard to do it without them, for anyone to handle it without family around them (B.G.).

<u>Theme 12</u> (major) - need for sensitivity in others, appreciation that she also is suffering, that she gives a lot

Although others pitched in to help with work and give support, once the initial crisis was over and her husband's condition had stabilized, some of these women were aware that all attention was still focussed on their husbands. Queries of "how are you" were seen as perfunctory, automatic, rather than a demonstration of genuine concern for her well being, or recognition that she might be suffering. Later, the same feelings were expressed about the husband who focussed on his own losses and frustrations and failed to express any appreciation of the fact that she also had given up a lot as a result of his injury. When appreciation was expressed, it made the workload seem lighter. Apparent here is the emergence of the growth needs, notably for acceptance, esteem, and recognition of her competence.

> Well everybody phones and says hi, how are you, but I wonder if I answered something really, really nasty if they'd even realize I had (J.H.).
>
> I always think like I'm trying to do my best and I get mad because he's getting frustrated with me (B.G.).
>
> Well, he doesn't seem to think I've got anything to beef about (O.S.).
>
> There are times I'd like to just backhand him. You know, wake up, you're not the only one going through this (V.P.).
>
> There's a different appreciation for each other, especially my husband for me. He appreciates me in a different way now than he did before (J.B.).

Theme 13 (major) - importance of routines for stability and control

The first days or weeks after the injury can be chaotic since everything is dropped to be at the hospital. Arrangements must be made for the children, time is taken off work, family notified and so on. There does seem to be a need, however, to return to some sort of ordered style of living. This exemplifies the predominance of safety needs which propel the individual to seek stability, structure, and freedom from anxiety and chaos (Maslow, 1970). Later, when the husband is home, the additional workload requires more planning and development of new routines. All of this decreases spontaneity but appears necessary if the work is to be accomplished with a minimum of strain, both physical and emotional. This organization extends to social outings and vacations as well, the feeling being that she cannot cope with uncertainty, hence the need for control of events, even if this limits the lifestyle.

> It was a big chore at first. It took me a long time to be able to do all these things in a short time like I can now...you always have to plan ahead so far (J.B.).
>
> The most frustrating thing is little stresses such as a car breakdown and all the hassles, or a disruption in routine ...I don't allow people in my life, like casual friends that disrupt my routine (C.P.).
>
> For the first month I didn't really care. My whole life had gone 'poof' ...after that we just sort of settled back into a routine family life (J.A.H.).
>
> And if you go anywhere you always have to remember to find a place where the bathroom is big enough or a motel that's accessible (J.R.).

<u>Theme 14</u> (minor) - his feelings about the injury not discussed

Even though some of the husbands were depressed or angry, there was sometimes no open discussion of his feelings about the accident and his disability. These women did not know if their husbands talked to anyone about these feelings and seemed reluctant or afraid to do so themselves.

> We talked somewhat, but not a real lot. We never really dwelt on it (J.R.).
>
> He couldn't talk to me as he couldn't even begin to sort out his own feelings (C.P.).
>
> He never says anything...so I don't know what he thinks (B.G.).
>
> He's not a very open person. He tends to stay within himself...I try to talk to him (J.H.).

<u>Theme 15</u> (major) - strong sense of commitment to the relationship

<u>Theme 16</u> (minor) - importance of cooperative relationship

Treischmann (1980) has told us that there is very often a period of "testing the relationship", a time when the injured spouse either says outright that the partner should find someone else, or implies through his actions a wish for the relationship to end. This can be a crucial point even for a strong marriage. Many of these women made the commitment to stay even before this testing occurred, if indeed it did, and some felt hurt at his suggestion that he was no longer good enough for them. For some, however, the commitment had overtones of resignation rather than choice. Since only one of the women was financially independent, the alternative may have been too anxiety provoking to warrant serious consideration. The price of loss of stability and security may have seemed too great. They emphasized their desire for a close and cooperative relationship, one in which they shared decision making. Some were particularly aware that their husbands had a special place in raising the children.

> He told me one time that he didn't expect me to stay with him, he wanted me to leave...I got mad at him and he's never said that to me again...I have never thought of leaving so I don't want him to always have that in the back of his mind (B.G.).
>
> I believe marriage is a lifelong commitment and I don't like praise for my attitude...our daughter needs her Daddy and so do I (C.P.).
>
> I've been really thankful that he's been around to help me with our youngest daughter...I think it's my responsibility [to stay with him], and also he's my husband so I just couldn't leave (J.R.).
>
> It was one of the hardest things I ever did in my life, but...I said 'I cannot handle all of these things by myself. You have a perfectly good head and arms and either you help me or I shut everything down and forget it.' And that kind of snapped him out of it (J.H.).

<u>Theme 17</u> (major) - resignation, passive acceptance

Many of these women conveyed the impression that much of what they did, particularly things which were necessitated by the disability, they did without making a choice. Something needed to be done so they did it. Sometimes they did not see themselves as having a choice to make, and at other times the alternatives were not very attractive so they carried on as they have been. There was an air of resignation about some of them.

> I think as the days go by you just accept it, I guess...some things are kind of upsetting, but you just learn to take it...I just went ahead and did what I was supposed to do (J.R.).

> I'm resigned...getting along as well as can be expected ...and what other alternatives were there (O.S.).

> I think it gives you a different outlook on life...and this was one thing I had to teach myself--not to think ahead and plan ahead...you just have to take one day at a time the way it comes (J.B).

The preceding quotations came from women who differed in some respects from the majority. While the others seemed to function from a realistic recognition of the situation they were in, these three women plus one other gave the impression of living unnecessarily meagre lives, narrow in scope and outlook beyond that which might reasonably be required by the situation. The interviewer was left with feelings of optimism about six of the women, yet these other four seemed to have retreated or resigned from much of what life had to offer them. The reasons for this were not entirely clear but seemed to be related to an unwillingness to take risks (either physical or emotional) and somewhat to the lack of an appropriate role model. When faced with choice or decision-making points in life, one may either focus on the course of action which will maximize the gains to be made or on that which will minimize the potential for losses. The former course seemed to characterize the majority while the minority chose the latter course.

<u>Theme 18</u> (minor) - uncertainty about her ability to cope

At times, some of these women experienced doubt or concern about their own abilities to deal with the extra work of having their husbands at home. These doubts seemed to be most predominant before the first weekend passes were taken. The concerns included emotional factors as well as the physical environment and her own physical abilities. A feeling of confidence usually replaced these fears when his visits were successful.

> There was nobody else there. At the hospital there were so many people doing everything and here there was just me...it just seemed like such a terrible impossibility that I didn't know how I was ever going to cope (J.B.).
>
> I remember the first time he came home simply because it was a trauma for days before. I was worried about that first home visit. At that time we didn't know if we could get him through the doors in the house (J.H.).
>
> It was really nice having him home. It was very tiring...but it was worth it...I had a lot more confidence...I had wondered, would I be able to take care of him if something went wrong, or wouldn't I? (C.C.).
>
> I was really nervous because I hadn't done it before, looked after him. I had learned it all in the hospital and I was doing it in the hospital but it's different when you don't have a nurse standing over you, telling you what to do (B.G.).

<u>Theme 19</u> (minor) - conflicting emotions

There are times throughout the process of adaptation when some women questioned whether the things they were doing were really the best under the circumstances. These were most often situations where there was no right answer in any absolute sense, but perhaps in a moral sense.

> I felt guilty as a mother living in such a tiny

> apartment where she couldn't play outside, but good because every second day we spent together with my husband (C.P.).
>
> He was getting the feeling he should go to an auxiliary hospital for the winter. I didn't want him to go and yet I thought, well maybe if he went I would have a rest. And so you have kind of mixed feelings about it (J.B.).

<u>Theme 20</u> (minor) - sense of loss

<u>Theme 21</u> (minor) - uncertainty about the future

The impression conveyed was that the injury and subsequent disability must, of necessity, alter their vision of the future. The loss included more than mobility, it included a sense of knowing what could be expected out of life, a certain sense that their lives could never be quite the same again.

> I think anybody that goes through something like this has to go through a normal set of feelings. It's almost a sort of grief, for what was, and isn't anymore (C.C.).
>
> Life was supposed to become much easier...I was so looking forward to this point in our lives, and now, yeah, I'm a little resentful because I don't know, now, what's going to happen (J.H.).
>
> If you were to think ahead a few years, maybe you would get panicky, but I think you just have to take a day at a time, whatever happens (J.R.).

<u>Theme 22</u> (major) - feeling of pressure and the burden of responsibility

<u>Theme 23</u> (major) - need for some "relief time" from his care

For the most part, these women did not work outside the home and their husbands, with one exception, did not expect to return to their previous jobs, or any job in many cases. This meant that they would be in each other's company 24 hours a day. Prior to his discharge, all of the women had been managing one way or another to look after the home and children, but having him home on a full time basis introduced new concerns. Apart from the increase in physical work to help him with personal care, transfers from bed to wheelchair, and so on, they found that they had to organize their time, and the household to a much greater extent. Coupled with his boredom and inability to do commonplace things for himself, this often led to feelings of never having time for herself, and never seeing an end to the workload or the worry. Eventually, most came to the realization that some of his needs could be met by someone else, and that she should take regular breaks from the pressures she was feeling. This represented a real breakthrough for some, as they finally acknowledged that they had needs which were not being met within the relationship, needs which had to do with freedom, confidence and importance in her own right.

> That's the thing that's beginning to get me down is not having any time at all for myself...so far we kind of tend to wait on him but you want to get to a point in the house that he can be totally self-sufficient and somebody doesn't have to be with him 24 hours a day (J.H.).

> We had to come to an agreement on that I would have a chance to take a day off now and then so that I would have a break. At first my husband couldn't see this...but he finally agreed and it works out good (J.B.).

> He wants me to do it all right now and I'm afraid to ask anybody else to help...I'm scared...I can pretty well do it all myself, but 24 hours a day, everyday ... (B.G.).

> We enjoy being together...once in a while I start climbing the walls...it's just one of those days when I'm not feeling up to snuff and I've just had enough and when's someone going to take care of me, so I just go out for half an hour, and I'm fine (J.A.H.).

<u>Theme 24</u> (minor) - simple activities missed

When asked if there was anything they particularly missed, these women listed ordinary everyday activities, those things which "normal" people do.

> I'd like a hug (J.A.H.).

> Activity, like going out for a walk, the fun times, like ball games with the kids and stuff like that (J.B.).

> I sometimes think it would be really nice if he could walk so we could just go for a walk. Like ordinary people (J.R.).

> Dancing. I love to dance. Or just go for a drive on the weekend (V.P.).

<u>Theme 25</u> (major) sexual adjustment required

<u>Theme 26</u> (minor) - importance of sex downplayed

<u>Theme 27</u> (minor) - discussion and resumption of sex is awkward

Sexual function following SCI in males may be as varied as the individuals themselves, and is determined by the extent (complete or incomplete lesion of the spinal cord) and level of injury (cervical thoracic lumbar or sacral)

In general, the higher the level of injury, the greater the remaining sexual function. This means, for example, that many quadriplegic males but fewer paraplegics, will be able to achieve an erection. Production and emission of ejaculate are frequently affected even in those who can achieve an erection, with the result that very few children are sired by SCI males. Finally, due to sensory loss, few persons with SCI experience orgasm in the physiological sense, although they may experience some of the changes associated with build-up and release of sexual tension. More detailed discussion may be obtained from Comarr (1974) and Eisenbert and Rustad (1974).

In the final analysis, each person must find out for herself what is possible and how best to find enjoyment in a sexual relationship. Willingness of the couple to experiment and explore alternatives is necessary for satisfactory resolution of this somewhat delicate problem. Fear of hurting their husbands, both physically and emotionally, made these women hesitant at first. The presence of urinary drainage devices also made things awkward, yet they were aware of the importance of sex, especially for their husbands. Very often these women found that for themselves, sex became less important than it had been, at least partly because of other pressures. For some, a satisfactory solution was found; for others the matter was simply shelved, but unresolved. Either way it was a major

> It's going to be a matter of waiting until exactly the right time...I don't think he's physically ready and I'm not sure I'm mentally ready for it (J.H.).
>
> You have to do things differently but our feelings toward each other haven't changed...I think it's very important especially when you're as young as we are (F.S.).
>
> One thing he had a real problem with was worrying about functioning sexually afterwards. He felt he wasn't a man anymore...I realized our sex lives would be different now and I felt that I could adjust...we've talked a lot about it and he knows that sex does not take priority in my life (C.C.).
>
> Well, your sexual life is sort of gone...we talked about it a bit, but not a lot...I've got so I just accept it (J.R.).

Theme 28 (major) - time of growth and positive change

With one exception, all of these women expressed the sentiment that the injury and subsequent disability of their husbands had produced positive changes in their lives and relationships. Some of these changes, such as the feeling of being emotionally stronger, may be not so much changes as increased awareness of one's ability to deal with the seemingly unbearable. Also responsibilities were relegated to them which they may never have had the opportunity to handle before, things such as finances, accommodation or transportation. There does seem to have been a breakdown in the barriers to communication which was perceived by the women as increased closeness to their husbands. The fact of his reliance on her for some of the most basic of personal care--washing, dressing, and so on--means that they must be more communicative, at least on some subjects. There seems to have been spillover to other areas as well. Finally, there is the sense that having come through this very trying ordeal together, they have matured, "grown", in their approach to one another.

> Since the accident I've become stronger, confident, organized and responsible...I love meeting challenges now (C.P.).
>
> We lost a lot of things but we gained a lot of things. There's a different appreciation for each other (J.B.).
>
> He's more open to talk to me now than he ever was before...I think it's brought us closer together in that sense (B.G.).
>
> That's one thing I did learn through the accident, is total independence. It suddenly dawned on me that I had to be able to decide what color socks to wear today without him telling me [illegible]).
>
> I think I'm a lot stronger now...I see our lives in a lot different light now. It did bring all of us closer, much closer. And we're not afraid to share our feelings about each other now (C.C.).

<u>Theme 29</u> (minor) - financial concerns have negative impact

Finances were only seriously strained for one couple to the extent that they had to seek social assistance. However, even those without problems were quick to point out that financial worries would have put yet another strain on an already tense situation. Since home renovations, special vehicles, and other equipment may be necessary if the husband is to have any measure of independence, those who do not have the support of Worker's Compensation or other insurance benefits are likely to feel some financial strain.

> We're going to have to build on...the only thing we're sort of thinking about is whether we'll have enough money to keep things going the way we'd like to (F.S.).

> I don't have any problem financially, but there are a lot who do. They've got little children at home, and they have no income suddenly (J.H.).

> Things were piling up and I knew it. I tried to get assistance because it got to the point where I didn't even have money to pay for transportation to go visit him...they said he wasn't eligible for assistance because he was eligible for C.P.P. However, 10 months down the road he hasn't seen a cheque from C.P.P. (C.C.).

Theme 30 (minor) - love to be needed

For a minority of these women, having someone dependent on them for nurturance brought out the best in them and they happily accepted the role of caregiver.

> I really enjoy being a homemaker, taking care of my family, seeing to their needs...I like being a housewife and mother for a change...and I don't really feel a need to go back to work (C.C.).

> I guess I'm kind of a nursing type of person. The more someone needs me the better I like it (J.A.H.).

> I do love my life. I love being responsible for 2 people. I love being needed (C.P.).

Theme 31 (minor) - lost control of elimination functions requires special adjustment

With almost any level of SCI there is lost sphincter control. Various urinary devices are available to deal with urinary incontinence but problems can still arise from leakage or clogging. No devices exist to deal with bowel incontinence, and for many persons with SCI this is not a problem so long as they adhere to a regular schedule. No system is failsafe however, and occasional problems require the assistance of another person. The lost control of these most personal of functions can be a difficult thing to accept for the spouses as well.

> He feels like a little kid to begin with because he can't do anything about it...it isn't his fault really...I always try to put myself in his place (B.G.).
>
> I can't imagine not having control over your bladder or your bowels...that's actually the more difficult part as opposed to being in a wheelchair (J.H.).
>
> He still has those [bladder and bowel] problems all the time. It's kind of upsetting, but you just learn to take it (J.R.).

Summary

In essence, these women have described a process of adaptation to their new situation, as wives of disabled men, which encompasses many positive and negative features. Most would probably agree that the accident was unfortunate but not that it was devastating to their lives. There have been many changes for some of them but few insurmountable problems. Apart from their descriptions of various aspects of the experience some of them were quite clear on what made life easier or more difficult for them, some changes they felt should be made, and what sort of help they wish had been available to them. These areas will be explored in the following chapters. Rather than separating the results of the data analysis from the discussion of the findings, these two shall be be discussed in tandem to facilitate clarity and cohesion of thought in dealing with the remaining research questions.

Chapter 5

Results and Discussion

This chapter examines the data with a view to answering specific research questions. The literature review provided speculative food for thought about the emotional reactions to disability which might be displayed by the wives of SCI males, and also suggested some factors which might influence the ways in which these women reacted.

Before examining these, a look will be taken at the process of the study and the impact it may have had on the women involved, with a view to sharing the insights gained by the researcher into the experience of conducting clinical research.

The conduct of clinical research

Research which focuses on gaining in-depth knowledge of the subjects, particularly through extensive observation and/or interviews is frequently termed "clinical" research. "Clinical" may also be defined as analytical or detached, and herein lies one of the difficulties in conducting such research: the subject is asked to disclose personal and sometimes painful thoughts and experiences yet these are not "counselling" sessions in the strictest sense and the tendency to want to "do something" which might help the subject must be curbed or redirected to another time and place quite separate from the research interview. One cannot discount, however, the benefit which may be derived by the interviewee from the experience of talking with one who really listens.

Another difficulty lies in the nature of the methods used to gather data, most specifically the open-ended interview. Phenomenology had its origins in philosophy, a field of study whose followers are generally noted for their highly developed verbal and reflective skills. Phenomenological psychologists such as Colaizzi (1978), Giorgi (1975), and Collier and Kuiken (1977) have, through their writing, attempted to raise the consciousness of their colleagues toward the principles and practice of phenomenology by demonstrating and explicating the technique and the varied subject areas to which it may be applied. Their subjects are usually university students, often at the post-graduate level. It is assumed, often erroneously, that such students are representative of the population in general.

In the present study, the specific educational level of the subjects was not determined, however, only one woman had completed a university degree (B.Ed.) and one other had taken some Arts courses. All were married to blue collar workers or farmers. When confronted with the task demanded by the research, namely exploring and describing their feelings and reactions toward their husband's disability, most experienced great difficulty. This is not meant to suggest that educational level was the prime factor but it, coupled with lack of experience with such tasks, may have had some influence on the degree of comfort which they felt with the task at hand. Many stated that they had "never really thought about it", yet it became obvious throughout that some had spent considerable time thinking about the effect of the injury on their *husbands.* Time and again, throughout the interview, it was necessary to refocus the discussion toward themselves and *their* feelings.

In addition to the difficulties encountered with the focus of the interview, the relative lack of structure or direction to many of the questions also posed problems. When faced with questions such as, "Tell me about ...", or "How did you feel about ...", the interviewer was frequently given responses such as "What do you mean?" Or "I don't know". Other responses included single word or simple phrase answers followed by silence which usually was only broken by the interviewer probing with another question. The questions thus became more and more directive as the situation demanded.

What, then, was the effect upon these women of participating in the study? For some, it provided a form of release, as if, once give permission to talk about themselves, everything just came spilling out. Only three in number, these, nonetheless, provided real insights into the emotional pain and anxiety which they had experienced, some of which remained unresolved. Following the interview itself, these women probed the interviewer for affirmation of their experience, seemingly until their anxieties about the future were relieved. One subsequently requested formal counselling and was referred to a therapist knowledgeable in the areas of counselling and rehabilitation.

Five subjects in the study, plus one in the pilot study, were perceived as really committing themselves to the task. They frequently began with statements such as, "Since you first called, I've really been thinking about it." Although they still experienced difficulties verbalizing satisfactorily, they seemed pleased with the opportunity to explore and reflect upon their experience, and particularly with the notion that their contribution might ultimately help others. Some offered additional information several days or weeks later, indicating that the process of examination continued.

The remaining two subjects were the most draining and least satisfying to interview as there seemed to be some resistance to verbal reflection. The reason for this was unclear but may have resulted from general uneasiness about the demands of the task and a stated concern that they had little to contribute. There was no indication whether each of these subjects was affected, either positively or negatively, by the process of the study.

In summary, these subjects generated a sense of optimism and admiration for the ways in which they coped, although they did not view themselves as special or unusual. The researcher was left with new insights into the difficulties of doing verbal-reflective tasks with essentially non-reflective persons. For further explication, the reader is referred to the Epilogue.

Each of the questions posed at the end of the literature review will now be discussed on the basis of the data gleaned in this study, beginning with the second one. (Question one is considered to have been dealt with in the preceding chapter.)

<u>Research Question 2:</u> Is there evidence of a sequential "stage" process of adaptation as outlined by Bray (1978)?

Bray (1977, 1978) suggested that the families of severely injured persons experienced similar reactions to those of the injured person, following roughly the same time frame. To review, his "stage theory" of adaptation to disability encompassed three distinct stages: anxiety, lasting for about nine months; accommodation, seen in the 10 to 24 month post-injury phase; and assimilation, beginning after the second year and continuing through life (see Table 2). Since the women studied here were interviewed at varying times post-injury, ranging from two months to 10 years, it should be possible to see the progression through stages, if in fact this occurs.

A. Anxiety stage

According to Bray (1978) this stage has several phases. The first, fear, is present in the acute phase following injury. The family (spouse) is immediately fearful of his death, then, when reassured that he has not died, manifests continued anxiety through an obsession with his care, criticism of hospital staff and feelings of inadequacy, frustration and despair.

Only six of the 10 women in this study expressed fear for their husband's lives, initially. Two of the remaining women experienced the possibility of his death from complications developed at a later date but this differs from the initial reaction Bray described. Of the six who expressed the classic reaction, only one became obsessed with her husband's care (J.A.H.). Feelings of inadequacy and frustration tended to manifest themselves later, usually at the time when he began coming home on weekend passes, and resulted quite naturally from uncertainty about management of many of the physical demands of the disability, i.e. transfers, dressing, bowel and bladder care. For most, however, these feelings disappeared and were replaced by confidence when they successfully managed home visits.

Denial of the seriousness of the injury is the next phase of the anxiety stage. Bray asserts that the family may become angry and frequently turns to religion, often looking for that "miracle" which will eliminate the necessity of coming to grips with the injury. Only one woman in this study appeared to engage in denial (J.B.), although this did not take the form of hostility or unreasonableness when faced with reality. Rather, she seemed not to have recognized the signs for what they were. She did realize that her husband would never walk again, but seemed to avoid seeing that the extent of his physical helplessness was real and not merely a function of being hospitalized. By her own admission, she had done many things for him in the hospital but simply hadn't realized "that everything he needed, I'd have to get for him". This is not representative of "denial" as described by Bray (1978) or Wright (1960) but may be important to recognize since J.B. is the only woman who really manifested signs of depression during the early months. Of those who turned to religion, none prayed for miracles. Religion was already an integral part of their lives, and they prayed for emotional and physical strength, guidance, and some divine assistance which would help them to "ma[illegible]

Depression is described as "the most noticeable behavior" which occurs during the anxiety stage (Bray, 1977). For an emotion to qualify as a phase through which people pass, certain characteristics seem necessary. The emotion must be sustained over a period of time, it must characterize the individual throughout this time, and it should have behavioral manifestations which set it apart from other times and emotions. In this sense "depression" is an emotion, rather than a behavior, but one which is recognized by certain behavioral characteristics such as lowered motivation, withdrawal, and decreased activity, particularly that of a goal directed nature. Only one woman in the study (J.B.) seemed to have gone through such a phase in the early months following the injury. Others, at times, felt saddened or overwhelmed but certainly would not have been classified as having gone through a phase of depression.

More appropriately, these women might be described as having gone through a phase of mourning, the final phase of the anxiety stage. Bray lists, but does not describe this phase as it applies to families. For the injured person, mourning is said to occur when identifiable hopes, aspirations or goals are mourned as lost--mourning is target specific. Few of the women interviewed mourned specific losses, although some did. Typically, they expressed a sense of loss of their lives as they had been. Only J.H. described specific goals and plans which she felt would not be achieved as a result of her husband's disability.

It is apparent by now that the women in the present study did not consistently react in accordance with the Bray model, at least in the anxiety stage. They certainly experienced anxiety, some more than others, but rarely did this take the form of denial or depression, two phases which have been declared by some (Bray, 1978; Wright, 1960) to be essential for successful adaptation. Moreover, staff expectations concerning the emotional reactions of both the injured male and his spouse frequently caused additional difficulties for these people. More will be said about this later.

B. Accommodation stage

This stage is described as having two phases: compromise and reconstruction. Together they point the way to full acceptance of the disabled family member: "The client is once again an active part of the family but is only that and not the focal point of life itself" (Bray, 1977, p. 163). Using the time frame established by Bray, at least seven of the women in this study should have been either functioning at this stage or through it at the time they were interviewed. In fact, all 10 seemed to have begun this stage. This is a time when changes are made in lifestyle to accommodate the disabled spouse and seemed to begin for these women prior to their spouse's final discharge from hospital. Taking into consideration housing renovations or even relocation, what he would do with his time, if and how much they (the wives) would be free to work, these women had already begun the processes of compromise and reconstruction. The most difficult task for some seemed to be taking that final step in which their disabled husband ceased to be the <u>focal</u> point of their lives.

It would seem that part of successful transition through this stage would require a change in attitude of the woman toward her disabled spouse. In the previous chapter it was seen that very often there was some sense of needing to protect these men, to treat them differently, make them feel useful or productive in some way. Until the disabled spouse is accepted and treated as a <u>person</u> first and disabled second, this stage cannot be considered complete. Using this change in attitude as a yardstick then, only two of the women whose husbands had been discharged from hospital (C.C. and J.A.H.) appeared to have made the final transition. In the case of C.C., it was a mere 10 months after the injury, yet she quite obviously saw her husband as a person first, an attitude which she attributed to having had positive contact with SCI students while she attended school years before. This reaction is highly consistent with the research literature on changing attitudes toward disabled persons (Donaldson, 1976; Evans, 1976). J.A.H. was well beyond the suggested time of 24 months to reach this stage but she was the only one of four women in the study meeting the time requirement who had successfully achieved the level of acceptance described above. In the Bray (1978) study, families were given assistance by the rehabilitation team to explore and deal with issues which kept them from final resolution of this stage, whereas the women in the present study were left to their own devices. The importance of continued support and intervention will be discussed in the final chapter.

C. Assimilation stage

Assimilation, in the Bray model, is less a "stage" than a way of life. For the family it involves total reintegration of the disabled member into the family structure while, for the individual, it is described as a stage of "cultural incorporation into an expanding society" (Bray, 1978, p. 76). These goals are akin to Maslow's self actualization: most assuredly worth striving for, but rarely realized. To do so would require changes in individual and societal values surrounding such things as physique and mobility, productivity, and other measures of personal and social worth. The women studied here were still involved with their day-to-day functioning, dealing with interruptions in routine, architectural barriers, and the insensitivity of a society designed for the young, good-looking and able-bodied. The state in which many of them may ultimately reside is best described as "resignation", a state in which they have released their old lifestyle but have not established a new orientation to life.

The value of a theory or model lies in its ability to explain and predict outcomes in a parsimonious fashion. The evolution of Bray's (1978) model of adaptation to disability is somewhat/unclear but it appears to have been developed from observations of persons <u>in treatment</u>. Although he described the families of SCI patients as following "a natural and logical progression" (Bray, 1977, p. 237) through the stages, apparently the stage model emerged from his study of the family involvement program in the institution where he worked. This suggests that his families were guided through a process rather than merely observed, making his a treatment model, not a stage theory.

Examination of his model and its applicability to the women in this study has demonstrated that , except as a very rough guide, there is little congruence between Bray's findings and those of the present study (see Table 5). Myriad explanations for this incongruence suggest themselves: the women interviewed for this study may have forgotten to report certain emotional reactions which occurred in the early months, they may have censored their revelations for a variety of reasons; they may simply not have experienced denial or depression; being in treatment, the focus of a research project, Bray's subjects may have had a different experience; or finally, reactions may have been attributed to them which were incongruent with their own perceptions. This would support Cook (1976) who suggested that some emotional reactions are attributable to staff attitudes and expectations rather than anything inherent in the patient or family member. Trieschmann (1978) also subscribed to this view based on her review of studies purporting to demonstrate the existence of emotional stages in the rehabilitation process.

We cannot know, in this instance, the precise reasons why the women in this study failed to follow the Bray model.

Table 5

Summary of the Present Study Versus Bray's Stages

Bray	Present Study
I Anxiety (0-9 mos.)	-anxiety occurred at various intervals but as a general state lasted only about 2 - 3 mos.
Phase A. Fear of death	-present in 6 of 10 subjects
B. Denial	-no evidence of B or C, instead there was a recurring theme of uncertainty
C. Depression	
D. Mourning	-mourned the loss of life as it used to be rather than specific losses
II Accommodation (10-24 mos.)	-evidence of accommodation seen as early as 3 mos.
Phase A. Compromise	-lifestyle changes evident but husband still the focal point of life several years after injury
B. Denial	
	-evidence of strong commitment to the relationship, sometimes with an air of resignation toward accepting an unpleasant situation
III Assimilation (25 mos. - life)	-evidence pointed more toward varying degrees of withdrawal than toward assimilation

It does serve to point out, however, some of the difficulties with such theories. They function to create a "mental set" or a series of expectations which can color one's view of reality, and in some situations act as the impetus for a self-fulfilling prophecy. As an example, one subject (C.C.) related an incident in which she was approached by a team consisting of a social worker, a psychologist, a doctor, and a nurse. This team suggested that she would ultimately leave her husband as a result of his disability and made it clear that it would be better for him in the long run if she left sooner rather than later. She found their somewhat callous approach upsetting:

> They were so concerned with him at the time but my feelings and the fact that they might have hurt my feelings when they were asking me questions and probing my psyche or whatever didn't seem to bother them at all (C.C.).

Instead of offering emotional support to this woman, opening the door and allowing her to voice and deal with any concerns she may have had, an assumption was made, probably based on some literature on SCI, that because other such marriages have tended to fall apart, hers would too. When she assured them otherwise they simply left her alone.

J.A.H. and her husband suffered a similar experience at the hands of well-meaning staff. Independently, she was told that he would no longer want her, and he was told that she would not want to stay with him. Had it not been for the forthright manner in which they approached each other, this couple might well have begun to act in ways which communicated these very ideas, even to the extent of fulfilling the prophecy.

The women in this study certainly shared some common reactions and experiences as they adapted to life with a disabled husband. To say that they followed the same pattern of reactions would be a gross misrepresentation of the situation. An outside observer may have attributed certain emotions to these women which they themselves did not report but as the concern here was their representation of their reality, these women's views can hardly be discounted.

Emotional reactions may be examined outside the context of a stage theory of adaptation. In large measure this has been done in describing the experience of adaptation in the previous chapter, however, as we examine the next research question, emotional reactions will again surface in the discussion.

<u>Research Question 3:</u> What factors were identified by the women as influencing the ways in which they reacted or how they felt about their new life situation?

Personality, lifestyle, and age were among a number of factors on which these women differed. Each story was unique in some ways, yet many common reactions and experiences were reported. From these, six factors emerged as the most powerful influences over these reactions. Each will be discussed in turn, as they are presented in their approximate order of importance. The order is not invariant, however, and several factors might be given equal weighting.

A. Support systems

The presence of adequate, functional support systems was clearly the single most important or influential factor in the ways these women reacted. The system was broad and far-reaching, encompassing emotional, physical, child care, financial and religious areas. When these support systems were active and functioning well, the effect was positive; when they were absent or functioning poorly, the effect was negative.

1. Emotional support

Emotional support took different forms and therefore had different effects, largely dependent upon the source and the expectations of the recipient. Family members were not always the most instrumental in providing emotional support, some because of physical distance and others because of affective distance. While absence of family support was frequently excused, a certain sadness was detected in those whose families were not especially supportive emotionally. Having a close friend or relative with whom one could really let down emotional barriers allowed some of these women to carry on with life when it seemed they could not. Some who had no one (O.S.) or whose families were perceived as increasing the emotional strain (V.P.) were bitter, angry, and/or disappointed, seemingly because they expected something more positive than they received. Still others were pleasantly surprised when support came from unexpected sources.

The unfortunate aspect of emotional support was that it tended to be somewhat shortlived, grad[illegible] easing off after the first weeks of hospitalization. By the time each husband reached the rehabilitation unit, the "crisis" aspect of the injury was well past, at least in the view of outsiders. Conspicuous by its absence was any form of emotional support specifically directed towards the wife by either the acute care hospital or the rehabilitation unit, neither while the husband was a patient nor afterwards. The hospital's mandate for care ends with final discharge, yet there was no outside agency recommended to assist with post-discharge problems, of which there were many.

2. Physical support

Physical support encompassed everything from getting time off work to be at the hospital to assistance with farm work to home care services. It was initially offered freely and abundantly to most of these women, giving them "breathing space" to deal with immediate demands on their time and energy without the additional worries of keeping a business going. Later it took the form of helping with renovations, transporting her husband in his wheelchair, and generally relieving some of her workload. A few women found the services of a part time homemaker necessary, while others would have felt trapped were it not for special forms of subsidized public transportation for the disabled. Unfortunately, there seems to be a time when one no longer wishes to ask friends for assistance, for fear of taxing the friendship perhaps. Some women stubbornly refused to seek outside help, wishing instead to maintain their independence after such a long period of dependence.

> We had to ask people for help so much to begin with that the thought of asking anyone for help now just chills me right to the corners...[others] just couldn't understand that it was personal. It was our life and I didn't want someone else doing it (J.A.H.).

Still others would have happily accepted outside help from an agency had such been available to them.

3. Child care

Since all of the women except one had children living at home, child care of some sort was a concern. Women like B.G., C.P., and J.A.H. who had tiny children to care for relied heavily on others to take good care of their little ones for hours each day, or sometimes days at a time. This was an especially big concern when it was necessary to take up temporary residence in the city to be near the hospital. Living in a new and strange location was already a strain without additional concerns about finding adequate child care. These women all counted themselves lucky to have found suitable help. They felt badly enough about the upheaval and worried about possible negative effects upon their children. One woman, C.C., was forced by the circumstances to place four of her five children in temporary foster care until she was sufficiently recovered from her own injuries to care for them again. None reported any serious difficulties in this area but it was obviously a concern as they emphasized its importance time and again.

4. Financial support

Financial support was a major problem for only one couple but for that one couple it affected not only long range plans but basic day-to-day functioning. Others experienced periods of uncertainty as they waited for cheques to begin arriving from Worker's Compensation. Persons with severe disabilities require special equipment for mobility and to enable those around them to do whatever lifting and transferring may be required. It is important that some source of funding be available for these devices, for without it, many more severely disabled persons would have to live in institutions with the manpower and equipment to assist them. At the present time, the Government of Alberta does provide funding for many kinds of equipment and several women indicated that they would be reluctant to move elsewhere for just that reason. The quality of life can be severely reduced when the major breadwinner can no longer fulfill this function. Therefore it is of major importance that whatever funding an individual is entitled to be readily forthcoming.

5. Religion

Support through religious beliefs is a special, though ill-defined form of support. For those who subscribe, it seems to provide some source of peace and acceptance which these people cannot attain otherwise. None claimed to have given up their beliefs as a result of the injury to their husbands, rather they saw their belief in God as a source of strength. For those with no professed religious conviction, it was simply not an issue.

B. Commitment to the marital relationship

This factor is broad and difficult to define for it includes in part the preinjury relationship, the sense of commitment to the spouse and the ways that these manifested themselves in this situation. Yet it was not entirely any of these. A few of the women stated that it was their love for each other which helped them to deal with this change in their lives, indicating that the relationship had not changed noticeably. Others commented that they had been brought closer to their husbands through the accident, partly through the realization of the importance of the relationship and partly through necessity to discuss and resolve issues which were disability related. Still others claimed that they had found it easier to accept and adjust to the new situation because their husbands did not react with much anger, hostility or depression. On the other hand, V.P. had considerable emotional stress which she related to her husband's inability to accept himself as a worthwhile person once disabled. Two women (D.S. and J.R.) described a type of commitment which seemed to be based on some well ingrained idea that whatever life presented to them was to be accepted, not questioned or examined with a view to changing it. This was the only instance in which the age of the subjects seemed to account for some difference in reaction. These women were 57 and 63 years old respectively and seemed to represent the views of women and marriage which were prevalent 30 to 40 years ago.

C. Hope

> Hope, however unrealistic in terms of probability of its actualization, does not necessarily interfere with the practical and sensible care of the [disabled person]. On the contrary, it provides the needed encouragement to continue with the interminable demands of rehabilitation whereas the recognition of stark reality can so deplete one's emotional resources as to make one ineffectual in the job ahead (Wright, 1960, p. 301).

The preceding describes the role that hope seemed to play for the women in this study. None who expressed hope of further recovery seemed to be living in a world of unreality; they merely needed more time to consciously accept that which they already knew to be true. One subject (C.P.) stated that she would not find it hard to accept if no further recovery occurred but feared her husband's reaction would not be positive.

D. Staff attitudes and advice

This factor is closely linked with the preceding one for it is the medical personnel, in imparting information, who ultimately control the harshness of reality as it is presented. The large majority of the women in this study had no contact with their husband's doctor after the initial brief explanation of the injury, often presented in a coldly clinical fashion, usually in a small cubicle in the emergency ward. After this one encounter, information-giving sessions were not experienced again until they reached the rehabilitation unit where structured classes are held dealing with the anatomy of SCI, skin care, bowel and bladder care, and sexuality. Some women found these helpful but incomplete and often coming at a time when they did not feel comfortable discussing such delicate matters in a group setting. Timing, then, seems to be a key aspect of information and advice giving. There is, first of all, a period of some weeks when nothing is really explained except that her husband will never walk again. Secondly, a certain lack of sensitivity in the staff is perceived by these women when they do start to receive information.

The other aspect of this factor has to do with the perceived attitudes of the staff toward the women themselves. Incidents have been reported elsewhere of unsolicited advice-giving ~~by~~ various staff members regarding expectation of marital breakdown. Apart from this, however, several women reported a general lack of concern for <u>their</u> feelings and reactions. This was manifested in several ways: failure to report serious complications which their husbands developed, annoyance with her desire for information about tests or medications prescribed, casual comments and dire predictions made to her about his eventual outcome including his early demise. (These were expressed as the opinions of the staff involved, based on what they "knew" about SCI, not on the facts of the particular individual's case.), and a general feeling conveyed to these women that they had little right to be upset since it was the husband who was suffering, not them.

To be fair, it must also be reported that some women identified certain individuals as helpful, sensitive and understanding. Unfortunately, these appeared to be the exception rather than the rule. Often the women were simply ignored, especially in the acute care hospital, and felt themselves to be quite outside the sphere of concern.

E. Architectural/societal barriers

Following upon the preceding factor, this is perhaps an extension of it, to the "real" world outside the hospital, of which, after all, hospital staff are members too. This factor had its primary effect when the couple began to appear in public. The first series of architectural barriers encountered were generally those in their own residence: narrow doorways, small bathrooms, and stairs. It soon became evident, however, that these barriers existed in abundance in all manner of public places including the homes of friends and relatives. Even long after the couples had settled into their new lives, these considerations continued to plague them and, for some, restricted their social lives to a greater or lesser extent, especially spontaneous social activity involving unfamiliar settings.

Early on, many of the husbands found it difficult to participate in the social world not only outside their own homes but in them as well, perhaps sensing the discomfort of others. It is also possible that, as recent members of the disabled community, they had not yet rid themselves of the negative attitudes so prevalent among the non-disabled, a group with which they identified prior to their accident. While the wives frequently commented that these men were "still the same person" there was a tendency on their part to comply with the husband's wishes, at least for a time.

F. Children

All of the women interviewed had had at least one child, and only one no longer had children at home at the time of the accident. None reported any serious difficulty with the children in relation to any aspect of their father's injury or following months in hospital. They had, by and large, close relationships with the father. There was a general feeling of the children having contributed something positive to the time of adaptation, generally expressed as some reminder of reality, a sort of stabilizer of emotions. "I sort of think I have to really control myself because I've got three kids to raise yet" (F.S.).

The preceding six factors were those most frequently identified as influencing the ways these women reacted, whether positively or negatively. The major one, support systems, was alluded to, in part at least, by many of the studies reviewed in an earlier chapter. Reactions of depression, feelings of helplessness and frustration, the sense of having a full time burden (D'Afflitti & Swanson, 1975; Santopietro, 1975), financial problems, health problems resulting from disturbed sleep and worry (Berezowsky, 1979; Malone, 1969), feeling trapped by the situation, and social and emotional isolation (Lezak, 1978) all have their roots in failed support systems. The women in this study showed themselves to vary greatly in individual resourcefulness and ability to adapt, yet even the most outstanding of them relied on others to provide some special support at some point. It is a factor which has been underemphasized not only in relation to the non-disabled spouses and significant others of SCI victims, but in the whole health care delivery system.

The factor described as loyalty to the marital relationship is not one which has been discussed in the literature, at least not in those terms. In her study of marital adjustment in couples with a disabled spouse, Peterson (1979) encountered four typical patterns of marital sociability and companionship (one of her indices of adjustment) which she labelled fighters, hiders, interactionists, and resigners. Fighters were typified by high levels of sociability and companionship, were flexible and variable in their social engagements, and tended to downplay the disability as they oriented themselves around "normalcy" as a lifestyle. Hiders were low on sociability and high on companionship. They tended to hide their feelings from each other, their shared time together being low on affective involvement and high on form. Interactionists experienced a gradual decline in social activities with a concomitant increase in interaction between them. Their social lives contracted as a result of "cumulative but subtle frustrations [which] occurred in finding places to go which were wheelchair accessible" (Peterson, 1979, p. 53). There was a greater appreciation of exchanges between the couple but a tendency existed for the non-disabled spouse to compensate for decreased social activity as a couple by arranging time away, alone. "Empty shell marriage" described the resigners. They gave little emotional support to each other, had no outside interests and experienced little companionship. These were styles of interaction between the couple, the unit of study in the

Peterson report. In the present study, only the non-disabled wives were involved, yet similar lifestyles were described by them. Three women tended to follow the pattern of the fighters, three were interactionists, two were resigners, and none were hiders. Two could not be categorized because of the recency of the injury but seemed to be favoring the pattern of the fighters. This does not explain the basis for the loyalty but perhaps suggests reasons for the varied forms of commitment expressed.

Colaizzi (1978) stated, "Our preconceived meaning, or approach..., of an undertaking regulates all of our involvements in it" (p. 55). While the women in this study were not always able to articulate the basis of their commitment to their husbands and marriages, this factor seems to warrant further investigation and may even provide the key to understanding why some of these (or any) marriages succeed while so many others fail.

Hart (1981) emphasized the need by significant others for hope and information in the early weeks after injury. The present study supported this finding yet demonstrated that, in the role of information giving, hospital staff often lacked sensitivity toward the non-injured spouse, thus adding to her stress rather than alleviating it. This suggests a necessity for staff training which will be discussed later.

Physical barriers to mobility have a large nuisance value, not only for the person in the wheelchair but for others who must be called upon to assist. They also represent a greater problem--that of non-acceptance by the public of persons with disabilities. Some of this is mere thoughtlessness but much has to do with fear of the unfamiliar, and discomfort in the presence of those who are different. The effects are felt by the couple when they venture into public places and are greeted by overt stares or covert examination, and embarassing interactions such as oversolicitousness or outright rejection. Closer to home, they also may witness these reactions in close friends who simply cannot see past the disability. These reactions are well documented and researched (Kleck, Ono, & Hastorf, 1966; Park, 1975; Pulton, 1976; Siefert, 1979; Westwood, Vargo & Vargo, 1981; Yuker, Block & Younng, 1966). Some of these women overcame the discomfort experienced in social situations with their husbands fairly quickly by putting on a "tough skin"; others preferred to be safe from negative reactions and restricted their social lives.

The effect of the presence or absence of children on the marital relationship where one spouse is disabled has never really been investigated, particularly in relation to the stability of the marriage. Nagi and Clark (1964) found "number of children" to be a factor in marital adjustment after disability but the context was somewhat unique: post-disability siring of children was taken as an index of sexual relations. Where impairment existed, this tended to contribute to marital breakdown. Their subjects were mainly polio victims whose sexual functioning is generally not affected by the disease <u>per se.</u> A surprising finding reported by El Ghatit and Hanson (1975) showed that the presence of pre-injury and additional post-injury children tended to be related to greater rates of marital breakdown. No explanation was proffered but, as this finding was based on 333 respondents, it is unlikely to be spurious. Too little information was reported by these authors to enable alternate explanations to be considered. David, Gur, and Rozin (1977) investigated couples where the male was paraplegic and the marriage took place <u>after</u> the injury. In this situation, the women reported their major dissatisfactions to be the inability to conceive and bear children. Children are the elements which turn "marriage" into "family" and there is no reason to suppose that couples with a disabled spouse would have a different perspective from other couples. The three youngest women in this study expressed a desire for more children in the future but were thankful to have at least one already.

The women in this study saw their children having a positive effect upon the marriage but some researchers are concerned with the effect upon the children of having a disabled parent, particularly a same-sex parent. Two groups of children, one raised with disabled fathers and the other with able-bodied fathers, were extensively evaluated in a study reported by Buck and Hohmann (1981). They concluded that the children of the disabled fathers were well adjusted, emotionally stable and had attained normal sex role identities. Health patterns, body image, recreational interests, interpersonal relations, and family relations were not adversely affected. The women in the present study did not express any concerns that their children were being negatively affected.

Factors other than those discussed have been suggested by other studies: education (Franklin, 1977; Nagi & Clark, 1964), occupation (Nagi & Clark, 1964), roles (Berezowsky, 1979; Franklin, 1977), and the ability to obtain and sustain employment (El Ghatit & Hanson, 1975). None of these was isolated as having special importance for the sample in this study. All of the men were blue collar workers before their injury but concern was expressed not in terms of employment but rather as a question of filling their time. Some of these factors might have had greater importance in the face of financial need which required at least one member of the couple to have full time employment. This was not generally the case for these subjects.

<u>Research Question 4:</u> As a result of the injury to their husbands, what changes have the women identified in themselves and what meaning do these changes have for the ways in which they view themselves and their marital relationship?

Adulthood, for women, is associated with taking on responsibilities, independence, unexpected confrontations with reality, and exposure to new experiences (Spricer, 1981). It is characterized by learning to cope, having to make decisions, making commitments, increased self-confidence and broadening one's viewpoint. These are also characteristics of the positive experience of a crisis identified as an event with growth producing potential (Liburd, 1980). If "crisis" refers to one's emotional reaction and not the situation, as Liburd (1980) asserts it does, perhaps the first question asked must be: did these women view the injury to their husbands as a crisis in their own lives? Eight of the ten women responded to the event in a manner which suggested that they experienced a crisis during the early weeks of hospitalization. The other two spoke of the event in very matter-of-fact terms, denying emotional involvement to any great extent and minimizing changes to those of the physical surroundings (ramps, renovations).

Liburd (1980) described changes resulting from major experiences as being three main types: 1) a dramatic shift in lifestyle, 2) clarification and/or change in values, and 3) interpersonal changes. This typology will be used to examine the reactions of the women in this study to the crisis involved in the injury to their husbands. In a few cases, the "crisis" aspect of the event occurred not with the initial injury and hospitalization, but with his return home.

A. Dramatic shift in lifestyle

Included here will be consideration of the reconstruction of social life and any role changes made in response to the husband's injury. Social life, by definition, is constructed around persons and activities but for couples where one spouse is disabled, there is an added dimension, that of accessibility. This includes transportation as well as mobility in respect to the physical surroundings. For these subjects, their social lives contracted to include a narrower range of activities, engaged in at less frequent intervals than before. Some friendships gradually terminated due to the general level of discomfort experienced on both sides around the disability itself. New friendships were slow to form for the very reason that fewer opportunities presented themselves in which to meet new people. Time which the women spent out on their own was viewed as "relief" time rather than socialization. Some denied that their social lives had changed appreciably but for the rest, they had gradually reduced their sphere of social activity until it included mainly planned, as opposed to spontaneous, activities with a few close friends or relatives. It was "just easier" that way.

Within the family unit, Nye (1976) identified eight roles which applied to the spouses. In all cases but one, the role of provider had been assumed by the husband. Following the accident, none of the remaining women saw this as changed although their major source of income was usually some form of insurance payments. Even those women who worked maintained the role of housekeeper but a few found it necessary to surrender some of the work to an outside agent. In no case was the husband seen as assuming any part of this role and every effort was made to involve their husbands in any way possible in some sort of "work", anything but house work. Child care was the primary responsibility of the women except in certain areas where they felt their husbands were more influential with the children. These areas would generally fall under the role of child socialization, a task which had been, and continued to be, shared in most cases. Sexual and recreational roles were altered but not in any systematic way. They were very much dependent on individual situations. Therapeutic and kinship roles were generally enhanced for the women, particularly within the period of major adaptation for their husbands. They have previously been described as protectors of their husbands' egos. Well aware of his many frustrations, they took on responsibility for alleviating these and directing his negative energy into positive lines of thought. If there was reciprocation, it was not mentioned. The kinship role was shared to a greater extent partly because of the social constraints imposed by the situation.

There was no evidence of major role changes for the women interviewed or of role ambiguity. The nature of the injury seems to have precluded this. Rather, Hilbourne's

(1973) position was supported wherein he asserted that freedom and flexibility are restricted by the additional tasks and responsibilities which must be taken on. It was not any task in particular, but the accumulation of small additional responsibilities which tended to create strain. When physical mobility is restricted for one spouse, there is a tendency for the other to assume the additional physical burdens without much opportunity for a trade-off.

B. Clarification and/or change of values

Major experiences in our lives often have the effect of causing us to sit back and re-evaluate our positions (Liburd, 1980). The meaning of marriage and the importance of sexuality were the two most often observed areas of re-evaluation for the wives of SCI males. Most did not engage in lengthy soul-searching but at some point made a commitment to continue in the marriage relationship with their husbands. The basis for this re-commitment varied but it was made on a conscious level and affirmed publicly. Several women claimed a new awareness of the meaning which their marriage vows held and of the importance of this man in their lives.

Sexuality seemed to be a larger issue for the husbands than the wives. Seven of the ten women still engaged in sexual activity with their husbands and although the physical nature had changed in varying degrees, it was the de-emphasis on the importance of sex in their lives which characterized these women. The affectional component held overriding importance over the physical component--"I don't feel rejected if we don't have sex, but I insist on hugs and kisses" (C.P.).

Value changes were also observed around future plans but these were made with greater reluctance suggesting that these women were security oriented. Now they found security in not making long range plans or looking too far ahead. "If you were to think ahead a few years, maybe you would get panicky, but I think you just have to take a day at a time, whatever happens" (J.R.).

C. Interpersonal changes

These included developing confidence, maturity, independence, becoming less self-centred, "growing-up". This was the predominant area of change discussed by the women in this study. Expressed generally as a feeling of growth and gaining strength in the face of adversity, it seemed rather to be a discovery of one's potential for confronting a negative experience and dealing with it in a positive way. Only two subjects felt they had been challenged in the past by major events in their lives but all felt that they would be better prepared to handle new challenges now. An interesting observation was made: while few viewed the satisfactory resolution of this crisis event as a personal triumph, they would have viewed the opposite result as a personal failure. Not all women were happy with the changes: some reluctantly accepted their new independence because ~~it~~ was accompanied by new responsibilities which they would as soon not have to deal with. Generally, however, the women emphasized the positive aspects of this negative experience as it related to interpersonal changes.

Summary and Conclusions

The preceding pages have described and discussed the data in terms of specific research questions. The findings are summarized as follows:

1. The stage theory outlined by Bray (1977, 1978) proved to be inadequate to describe the changing emotional reactions of the women in this study. It was shown to have the effect of all stage theories, namely that it tends to set up expectations in the treatment staff which may interfere with their observations and interventions.
2. Of the six factors identified as being most influential in guiding the reactions of these women, support systems stood out as the single most important factor. This has been hinted at and partially identified in previous studies but seems to warrant more attention than it has received in the past.
3. The type and amount of change which each woman experienced was quite individual but involved most

frequently some reconstruction of their personal and social lives as well as the clarification and/or change of some values, especially those around marriage and sexuality.

In conclusion, changes are necessary in the ways in which the health care delivery system views the significant others of some of its clientele, and its responsibility to these people. Specific recommendations vis-à-vis the wives of SCI males and our responsibility to them within the rehabilitation framework will be examined in the next chapter.

Chapter 6

Implications of the Study

To be worthwhile, a research study must have value beyond the mere completion of the task. It should add to the body of existing knowledge, outline new approaches, suggest changes, ~~or~~ point toward new directions for research. The implications of the present study will be discussed under the following headings: medical rehabilitation, rehabilitation counselling, and research.

A. Implications for medical rehabilitation

Because the nature of the injury is such that improper care and handling of the person may lead to further, even fatal, complications, SCI victims are generally transported to major treatment centres as soon as the injury is diagnosed. These centres are not necessarily designed specifically for the treatment of SCI but usually employ physicians and ancillary medical personnel with the specific knowledge and skills demanded by the injury. A major city like Edmonton or Calgary would usually have only one such centre for the long term, or rehabilitative, care of SCI, but this centre is fed in each case by several acute care hospitals within the same city. One implication of this study points toward the need for a central SCI acute care unit.

The establishment of such a unit would accomplish two things: 1) it would provide an arena for establishing good statistical records on the incidence and treatment of SCI, and 2) it would ease the task of training staff and sensitizing them to the needs of both patient and family. In the first case, apparently there are many unanswered questions having to do with early medical treatment of SCI (Reid, 1981), questions about the value of surgical stabilization of the spine, the varying incidence of kidney and bladder complications, and so on. In the second case, we have been told by the women in this study that they received little information or sometimes misinformation about their husband's condition, little support to alleviate their own anxiety, and often felt as if they were in the way. A central unit would have the advantages of early contact with others having similar injuries, and a well-informed and facilitative nursing staff. Hart (1981) has also emphasized the value of such an approach.

A second implication for the families in the acute care of SCI is the need for an early intervention screening procedure which would quickly identify the services needed by the family of SCI victims. This could be performed in the emergency ward or within the first two or three days following admission. The purpose would be to alleviate some of the more practical concerns such as where and how to apply for insurance or compensation payments if applicable, and would put the spouse or significant others in contact with psychologists, social workers, clerics, whatever the need might be. Early intervention is the key to alleviating unnecessary stress in a stressful situation.

Essentially then, this study has suggested that the medical team needs to pay attention not only to the needs of the injured but to those of the spouse as well. Two ways to accomplish this more efficiently would be through a central acute care unit for SCI and through use of a screening procedure which would direct the spouse toward appropriate sources of assistance early on in the adaptation process.

B. Implications for rehabilitation counselling

First and foremost, counselling should be seen as a regular part of the rehabilitation process, not just a crisis intervention strategy. Family members should be seen at least once, early in the acute care phase, and again in the extended care phase at which times they can be encouraged to seek assistance in exploring their feelings and dealing with their new situation. Not all families will accept or seek such assistance but currently they do not feel encouraged to do so. Jacus (1981) has provided a good discussion of the requirements for working with families in a rehabilitation setting.

Since many of the women in this study expressed a desire to communicate with others who had been through a similar experience, a rehabilitation psychologist could be instrumental in the establishment of peer support groups. Such groups function independently of the hospital staff once established, and provide a safe and comfortable forum for family members or even couples to share and deal with their fears, anxieties and frustrations. Successful outcomes have been reported using such groups for the wives of home hemodialysis patients (D'Afflitti & Swanson, 1975). For many of the women in the present study, such a group, offering support and encouragement, might have been all that was needed to put events in proper perspective. A group which included the disabled family member would serve another important function during the transition period following discharge from hospital. At this point, all ties are severed with the "community" within the rehabilitation unit, yet the couple may encounter a whole new set of problems once the injured spouse is home all the time. Many of these problems involve re-entry into the community, establishment of new friendships, and returning to old situations in which one must re-establish credibility. The experiences of others can be invaluable at such times.

For patients and families who require them, outpatient psychological services should be provided since these are not currently available through any other agency. Privately practising psychologists are, at best, ill-equipped to deal with particular problems which may be disability-related. In addition, there is need for liaison with outside agencies which may provide some form of service to the family, agencies such as various branches of social services and home care. The rehabilitation institution might prefer to designate some other team member to perform this task but it is a necessary one for several months following discharge. Contact must be maintained with the family either directly or through these service agencies in order that the treatment team be alerted to new problems with a view to early intervention.

The rather low correspondence between the reactions outlined in the Bray model and those reported by the subjects in this study raises another issue of importance, not only for psychologists but for all members of the rehabilitation team. A system which stresses the necessity of orderly and sequential changes in order to adapt to a disability, either one's own or that of a close family member, is no longer viable. Each client brings to the experience his/her own set of beliefs, values, and historical context and should, therefore, be viewed from this perspective. Certainly some reactions are common in the experience of many persons but too often stage theories are treated as if they were carved in stone and therefore inviolable. Such is not the case. Taken as a model of intervention, Bray's stages may serve as guidelines: if a particular reaction is observed, then a certain intervention may be required, not <u>when</u> the reaction is observed. The latter closes our awareness to the variety of possible attitudes which clients may bring to the situation.

Understanding stage theory of adaptation as representing potential, not inevitable, reactions is one aspect of training which should be provided to those wishing to work in the rehabilitation field. Presently there is no program available in Canada which trains psychologists for this specialized branch of the field but this study emphasizes the need for improved psychological services. Such individuals must be conversant in several special areas: the nature and course of neurological diseases, which behavioral and emotional changes are associated with the neurological damage itself as opposed to being person/situation specific, and the psycho-social implications for the individual and significant others when a disability is present. It is not the intent here to outline a training program but rather to emphasize the necessity for one.

C. Implications for research

More study is required in order that rehabilitation practitioners may provide service in the most sensitive yet efficient manner. Hospitals and governments can no longer bear the burden of ever increasing demands for staff and funding. While the notion of peer support groups has been presented as a viable alternative in some situations, a study of the efficacy of such groups in alleviating stress during the process of adaptation to disability is needed.

The present study has examined the process of adaptation to disability by the wives of SCI males. Is there a qualitative difference in the way husbands would react to SCI females? Women in surviving marriages have been studied; how does their experience compare with those wives of SCI males whose marriages failed?

We have seen that the women studied often felt uninvolved in the rehabilitation process. How is the perceived involvement of both partners in this process related to outcomes?

Finally, there were some difficulties encountered in carrying out this research. Most notable was that of identifying and locating potential subjects. Other difficulties included the reluctance some women had in focussing on themselves and their reactions; many had so much concern bottled up inside about their husbands and specific problems related to the future that they preferred to discuss these instead. Also many of them admitted to rarely thinking about themselves in the ways demanded by the study. All of these problems could be alleviated if this type of research was initiated and conducted internally, i.e. within the institution, where subjects could more readily be seen over a series of interviews. In this situation, participant-observer studies could be instituted to test the congruence of behavior and affect.

The scope of the present study has been confined to wives of SCI males. There is good reason to believe that generalizability to other situations is valid since considerable correspondence was found with the experiences of women whose husbands required hemodialysis. The most important feature of the study, however, is the evidence provided that disability profoundly affects the significant others of the disabled. This points to the necessity for the rehabilitation field to broaden its scope accordingly.

Epilogue

I have attempted in the previous chapters to describe the study and its findings; yet I am left with a feeling that I still have not provided a full account of what was learned from this endeavor. The purpose of the present section, therefore, is to offer some of the insights which I have gained in the hope that my experience may prove useful to others. In an attempt to make these insights as clear as possible, they are discussed in less formal language than that required for the core of the dissertation.

First, there is the issue of the phenomenological method versus the experimental method. For some this will be a non-issue but many of you will be aware from the reading of this paper that it was an issue for me. Books and articles dealing with phenomenology describe an ideal which is not always possible to achieve, yet I found its strength to be in taking a viewpoint which essentially validates human experience as a unit of study, and the personal expressions thereof as units of data. My training in measurement and statistical analysis prevented me from feeling wholly comfortable with the phenomenologist's disregard for such considerations as internal and external validity which are given such importance in experimental methods. The conflict which I experienced between the relatively unstructured methods of phenomenology and the structured ones associated with experiments and statistical analysis (with which I feel much more comfortable) was never completely resolved but was eased by a gentle marrying of the two. Thus, I imposed some constraints by focusing on one disability only and limiting the investigation to the female spouse. It seems to me now, that in designing a study one must not only choose the method most appropriate for the question being investigated, but one needs to be aware of one's own level of comfort with the methods. By this I do not suggest that anyone should avoid one or the other method for lack of knowledge, but should be aware of the constraints which may be imposed by one's training and personality.

Second, having devised my own quasi-phenomenological approach to this study, I found there were still a number of uncertainties and dissatisfactions which had to be faced in the data gathering phase. Some of the women were easily engaged in the dialogue about their personal experiences. Upon reflection, I realized that these women were the ones who, in my judgement, had made the most positive adaptation to their husband's disability and about whom I felt most optimistic. The others had me leaving the interview feeling one of two ways: if I had been able to draw them into the dialogue successfully, I often felt sadness at the apparent emptiness of many aspects of their lives; if I had not been able to achieve a comfortable level of openness, I questioned my personal adequacy for the task. It proved most useful to take a few moments to reflect on each interview and to make brief notes on my impressions of the person and the situation. These sometimes provided further insights not only into the individual interviewed but into my own style of engaging the individual. In this regard the pilot interviews were invaluable. So was the time spent after each interview in which I conversed with the woman, responding as best I could to the many questions which were raised by her anxieties and uncertainties. Although the interview was not intended to be psychotherapeutic, it is important to be aware that a cathartic effect may be achieved for the individual in any case, just by the very nature of the experience with the investigator.

Finally, there are a few details which may be useful to note. The number of persons to be interviewed is always a concern, the impression created being that "more is better". The data from a single interview can run to staggering quantities and as the method of analysis is somewhat more wieldy than those for numerical data, one would be well-advised to do some pilot interviews and attempt at least a partial analysis before deciding on an ideal number of subjects. In this case, with 10 women interviewed, transcripts ran from 12 to 40 pages and analysis took about 125 hours in total.

This study was conducted using a single interview session, primarily because most of the women lived well away from the city (700 miles were travelled to collect the data). It is my opinion that at least two sessions would be better if distance permits as this allows the interviewee to become more familiar and comfortable with the process and the interviewer to retrace and clarify where necessary.

I hope that these remarks have served the purpose of highlighting some of the personal and practical details which were of concern to me while conducting the project and that my experiences may be of benefit to those who attempt non-statistical methodological approaches in the future.

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Appendix A

DEMOGRAPHIC DATA SHEET

Name..

Address...

Telephone.............................. Age.................

Date of present marriage..................................

Number of children....... Children's ages.................

Date of husband's injury..................................

Date of hospital discharge................................

Type and level of injury...................................

Do you work outside the home? ....

Full time? .... Part time? ....

Did you work before your husband's injury? ....

Does your husband work outside the home? ....

Does he receive any pension or disability benefits? ....

Do you make use of outside help such as orderly services, home care or the like? ....

....

Is your combined family income below $10,000 ....

between $10,000 & $20,000 ....

between $20,000 & $30,000 ....

above $30,000 ....

Appendix B

CONSENT TO PARTICIPATE

I, ... voluntarily consent to participate in an interview with Fran Vargo, a graduate student in the department of Educational Psychology at the University of Alberta. The purpose of the study has been explained to me and I understand that anything I say will be treated as confidential. The information given by me will be used solely for research purposes and all identifying information will be removed.

I also agree to allow the interview to be tape recorded with the understanding that the tapes will be erased when the research project is complete.

Date.................... Signed..........................

Witness.......................

Appendix C

INTERVIEW SCHEDULE

Begin by explaining the purpose of the study, confidentiality of information, etc.

Ask her to sign the Consent form and fill in the Demographic Data sheet.

Mention that I am married to someone in a wheelchair but that my situation is different...want to better understand what it is like for women who don't have that choice.

Review Demographic data...

Tell me about your husband's accident...
- how did it happen? where? when?
- how did you hear about it?
- what was your initial reaction?
- what feelings did you experience later?
- did you ever feel anger? at whom?
- did your feelings change over the next few months? how?

What it was like for you while your husband was in the hospital?
- did your life change? how?
- how did you feel about these changes?

-what kind of support did you receive from family? from friends?

-were you able to talk to your husband about problems that arose? about your worries or concerns?

-was he able to talk to you?

-was there anyone else you could talk to?

-what kind of information did you get about your husband's condition, and from whom?

-do you remember his first visit home? was it a good experience, or not? why?

What it was like when your husband was finally discharged?

-what were your expectations about what he would be able to do?

-did things differ from your expectations?

-how did you feel about this?

-what changes did you make?

-were you able to talk about your feelings with your husband? your friends? your family?

-what did you see as your principal functions before the accident? e.g. as wife, mother, lover, friend

-have your functions changed?

-how do you feel about this?

-how do you and your husband handle disagreements?

-is this different than it was before?

-are you a religious person?

-where do you turn for guidance? consolation? support?

Tell me about your relationship...

- what was your relationship like before your husband's accident?
- has your relationship changed? what do you think contributed to the change?
- what are the best things about your relationship?
- what are the worst or most frustrating?
- what are your reactions to these frustrations or bad times?
- with a severe injury or illness, one of the aspects of a relationship which often changes is sexuality--has your sexual relationship with your husband changed in any important way?
- if yes, how do you feel about this?

Has your life in general changed as a result of the accident?

- have you changed since the accident? in what ways?
- describe the way you see yourself as a person
- what is your general approach to any problem in life?
- is this different than it was before?
- how do you view your responsibility to your husband? to your marriage? to yourself?
- has this changed since the accident?
- have you experienced other crises in your life?
- how would your life be different if your husband could walk?

Is there anything you can think of which might be helpful to other women who find themselves in a similar situation to yours? any particular kind of help they should be given?

Is there anything else you would like to tell me which might help me understand what effects your husband's accident had on you?

Appendix D

CASE DESCRIPTIONS

These are intended to acquaint the reader with the prominent features of these women's lives as they relate to their adaptation to SCI in their husbands. More detail will be revealed by the actual analysis of the interview data as it relates to the research questions, in chapters 4 and 5.

Case 1 - F.S.

At the time of the interview F.S. was a 37 year old mother of three teenagers. Her husband is a quadriplegic as the result of a single vehicle accident involving a serious vehicle malfunction. The interview took place just prior to her husband's discharge from hospital, six months after his injury.

According to F.S. she was given a clinical description of the injury by the doctor who examined her husband but she did not experience the full impact of what this would mean and had not as yet. She denied any strong emotional reaction then or now. Her husband was treated in an active treatment hospital for six weeks before being transferred to the rehabilitation unit. During that time her daily routines were disrupted considerably by hospital visiting but the family soon returned to normal routines. At the time of interview, F.S. was spending one weekday at the hospital and her husband was home on a pass each weekend from Friday night to Sunday night.

Of the three children, only the eldest (the only daughter) reacted badly to her father's injury. F.S. explained that she (the daughter) had had difficulty going to visit her father but that since he had been coming home on weekends, her behavior toward him had returned to normal-- "now we just live our lives the way we always did" --and she denied any change in the relationship of the children to their father.

Friends and neighbors were particularly helpful to F.S. in maintaining the farming operation, moreso than family members. They also spent much time visiting her husband and continued to do so at their home on weekends, to the point of being overwhelming at times.

> Sometimes we'd just like to be alone, It's so bad some weekends that you don't even get a chance to talk to each other...I find it too much, but it's nice to think your friends are thinking about you too.

The focus of concern in virtually all aspects of daily living is her husband. F.S. described the need for major renovations of their house ("There's no place for him to exercise or anything."), concern for how her husband would fill his time at home ("that's our biggest thing on our minds right now"), and general concern for his emotional well-being ("Just because you can't walk, doesn't mean you're a different person." "I guess he has to decide what he wants to do - he has to be happy doing it, not me."). She demonstrated recognition that having him home all the time might create some problems which they had not yet experienced but these thoughts did not seem to cause undue concern on her part.

Nor was the concern one-sided. F.S. described a cooperative relationship with her husband and a mutual desire to maintain as normal a lifestyle as possible. "He doesn't want me to give anything up because of him being in a wheelchair." For his part, this included telling F.S. that "he's not much good anymore and that if I want I should find another man." Her response demonstrated confidence in their relationship and belief that this was a phase which would pass.

> I don't believe he wants me to go. He cares for me too much and I know he won't feel that way in a while so I just don't pay any attention.

F.S. was working part-time at the time of the accident and continues to do so. She maintained that this was one thing which kept her going throughout and she emphasized its importance then and now.

> A week after the accident, I went back to work and I got out in the public and kept myself really busy. Staying at home and moping around doesn't do anyone any good, and I think the sooner you get out and talk to people the better off you are.

Referring to the post-discharge period,

> I'd still like to work, maybe two days a week, just to get out...it might be too much of a change right off the bat, just to stay home and do nothing.

There were several aspects of their lives in the post-discharge period about which F.S. could not be sure:

the resumption of a normal sexual relationship, maintenance of an adequate income for their needs, requirement of outside help such as orderly service, and unforeseen difficulties in day-to-day living. None of these appeared on the surface to be causing much anxiety but F.S. did continue to talk about issues and concerns for about half an hour after the conclusion of the interview, which suggested some need for an emotional outlet. She seemed to be a person who does not express strong emotions, maintaining the appearance of a calm and unruffled nature. It seemed to be her style to take things as they come and deal with them as best she can, without expending much energy anxiously anticipating problems or engaging in non-productive activity such as worry or other forms of negative thinking.

Case 2 - J.H.

At the time of the interview, J.H. was a 37 year old mother of two teenagers. Her husband was injured in a two vehicle accident which left him a paraplegic. There is a possibility that he may be able to move about on crutches but it is unlikely that he will ever be independent of the wheelchair. The interview took place just prior to his discharge from hospital, about two months after the accident.

The frustrations and anxieties which J.H. experienced at first had abated, partly because of the additional responsibilities she has had to assume. She was already working full time when her husband was injured but now had the major responsibility for both family businesses. This left little time for herself or her children, a fact she much regretted.

Although family and friends provided much needed emotional support for both her and her husband, there was little they could do to remove the business pressures. J.H. also expressed the sentiment that while her husband needed and got a lot of support, there were times when she felt her needs were neglected.

> People phone and say, Hi, how are you?, but do they really mean that? The concern is always, of course, for the injured person.

The relationships between family members have remained very much as they were before the accident but J.H. felt a jolt of realization that one takes life and the people in it pretty much for granted.

> You haven't forgotten that you love that person but it really just made you think about how much you did depend on that person and you have a tendency to no longer take so much for granted.

Because the extent of her husband's injuries was such that he will be virtually independent, even in the wheelchair, J.H. expressed few concerns about their day-to-day lives. Instead, she wondered about long range plans including vacations, travel and their anticipated semi-retirement.

> I was so looking forward to this point in our lives. And now, yeah, I'm a little resentful because I don't know, now, what's going to happen.

This statement of uncertainty typified the state J.H. was in at the time of interview. Her approach to the whole situation was one of guarded optimism.

> I've always been optimistic that he would walk. The only thing I said right from the start was let's deal with the problem we have now and anything that happens after that is only good news.

In her view, the issue of walking versus wheelchair had diminished in importance, at least temporarily. It had been pre-empted by other, more personal concerns such as resumption of sexual relations, and bladder and bowel control, particularly the latter.

> I can't imagine not having control over your bladder or your bowels...that seems like such a normal function...that's actually the more difficult part, as opposed to being in a wheelchair.

J.H. described herself as a strong person and seemed capable of dealing with the changes and uncertainties the accident had brought about, so long as she could keep busy and continue to find emotional outlets in talking to an understanding friend and, occasionally, "have a bloody good cry."

<u>Case 3 - B.G.</u>

At the time of the interview, B.G. was 24 years old with one child, aged two and one half years. Her husband is a quadriplegic following a single vehicle accident. Because they lived in a farming community quite far from the city, B.G. and her daughter had taken up temporary residence in the city in order to be near her husband. The interview took place just prior to his discharge from hospital, eight months after injury.

When told that her husband had broken his back, B.G. responded as if in a state of shock, not remembering later much of what she had done, being concerned more for her husband's life than for the nature of the injury. Because the doctor had at first suggested the possibility of brain damage, B.G. sees the quadriplegia as relatively minor and therefore much easier to accept than her vision of a brain damaged husband who would not know her, would be confused and so on. She dealt well with the early stages when he was immobilized in skull tongs but noted that family and friends found this the most difficult time.

The adjustment of their families and close friends has been gradual but positive, much to B.G.'s relief. In her opinion, she could not have managed without them taking over the farming operation, visiting her husband, and generally being supportive. Having a small child to care for could also have created problems but she has been well taken care of by friends in the city, and "I couldn't have done it without her. She's been a lot of company to me."

Without the day-to-day worries of running the farm, B.G. was free to spend much of her time at the hospital. She expressed the belief that they have been brought closer together through this experience despite some unpleasant occurrences. She felt her husband had become more communicative and willing to share his feelings than he ever had been, but she saw many changes in herself as well. Primarily she described herself as stronger emotionally, better able to cope and make decisions, tasks which she had usually abdicated to her husband.

B.G. expressed several concerns about the post-discharge period. She was worried about how her husband would spend his time and what role he might be able to take in running the farm. The problem which seemed paramount to her, however, was that of her reponsibility for his needs on a 24 hour a day basis. The issue loomed large in her mind for two reasons: her fear that she wouldn't be able to cope, and her husband's reluctance to even discuss getting some outside help such as a visiting nurse. His ambiguity, "he wants me to do it all" versus "he finds it frustrating when I have to undress him and everything", only added to her dilemma. She anticipated that the first year would be difficult but was clearly prepared to make a go of it. "I have never thought of leaving so I don't want him to always have that in the back of his mind."

Having the opportunity to discuss her feelings and concerns with others who had experienced similar crises would have been helpful to B.G. as she had many unanswered questions about possible day-to-day problems. Following the interview, she continued to talk for almost an hour about their plans, their daughter, and a whole range of minor concerns.

Case 4 - C.C.

C.C., a 39 year old mother of five, was cohabiting with her spouse as opposed to being married to him. They had been living together for only two months at the time of the accident but have since made the commitment to stay together and to marry legally. A malfunction of the motorcycle on which they were riding sent both of them flying into the ditch at the side of the highway. C.C. sustained serious internal injuries plus multiple fractures involving both legs and one arm. Her husband became a paraplegic. The interview took place 10 months after the accident, five months after he was discharged from hospital. At the time C.C. was also in a wheelchair because she had recently undergone surgery on one ankle and could not tolerate crutches for very long due to the residual effects of her other injuries. She confessed that the outcome of the surgery might determine whether or not she would ever be free of the wheelchair.

This woman was not only confronted with the injury and possible death of her husband, but also with her own death. She expressed little concern for her injuries despite the semi-permanent nature of some of them. Because of her own long hospitalization, she was forced to place her children in temporary voluntary custody, suffered complete loss of income, yet felt that everyone, including the children, had gained in very positive and rewarding ways from this experience. United as a family once again, they were happily looking forward to their upcoming wedding.

Several years of experience in nursing meant that C.C. was familiar with medical terminology and hospital procedure so that the physical changes in her husband were not shocking to her, but she had only known him as a very physical person and knew what the loss might mean to him. Several weeks elapsed before either of them was really able to talk about it--C.C. finally broke the ice because she believed their relationship had been something special and wanted it to continue. C.C. spoke philosophically about the accident.

> God let this happen to him, but it also gave him someone that cares about him deeply, loves him very much, is very supportive physically and emotionally. So where He took something away from him, He gave something to him in return. Maybe something far more important than the ability to feel and to walk.

Family members and friends of their teenaged children were very accepting and supportive. Other support came from surprising sources--visitors in a waiting room and another young patient. Generally, however, they were alone much of the time, since their friends admitted openly that they just didn't know how to relate to this man whom they used to know. Their move to the city has afforded them the opportunity to make new friends.

> We feel a lot more comfortable, because people that socialize and associate with us now we know accept us. It's not like they feel obligated because they knew us before.

This couple continued to be plagued by financial concerns and medical problems (mainly hers) but C.C. denied major frustrations in her life. She was very much content to stay home, spend time with her children and share her joys and sorrows with her husband, things she had never been free to do, either in her first marriage or since.

> I feel like there's somebody up there looking down on us, and they're not going to tax us more than we can be. Things have really been working out quite well.

Case 5 - O.S.

At the time of the interview this woman was the 57 year old mother of two, both married and away from home. She described her situation as "unique" and in the the context of this study, it proved to be so. Nevertheless, she is a woman who has coped with serious illness and disability in her husband and some of her attitudes may not be that different from other women in her age bracket. The interview took place 14 months after her husband's injury which left him a quadriplegic, and six months after his initial discharge from hospital. At the time of interview he was re-hospitalized for a recurring infection.

Unlike the other women in this study, O.S. persistently described her husband as an "invalid", an attitude she may have developed from his long medical history beginning with a colostomy in 1964, and ending with quadriplegia. He had also had surgery for cataracts and suffered chronic alcoholism and a severe type of spinal arthritis. As she said, "We've had so many series of adjustments that we just go into 'Plan BX - Adjustment'."

O.S. and her husband have had a non-conjugal relationship for many years. They shared neither an intimate life nor a public one, living rather as two acquaintances under the same roof, yet O.S. maintained that their marriage had survived. She was unable to give her husband much physical care because she too suffered a chronic disability--one leg was considerably shorter and weaker than the other, a result of polio at age nine. They had stayed together as much for financial reasons as any other, with O.S. functioning as sole breadwinner these last several years. In her own words, "I don't think I owe him much...I've paid for services rendered."

Their two children were married and lived in another city. Although they visited their father at the outset, they have had little contact with their parents. O.S. received little, if any, emotional support through this latest ordeal but denied feeling the need either, as this was viewed as just one more in a long series of medical crises. The physical support which she received from community agencies such as the Victorian Order of Nurses had, however, been invaluable. O.S. did mention one friend "who is a consolation because she sort of understands how it is to live with an invalid." (The friend's husband had undergone heart surgery.) She had been somewhat of a loner most of her life because she felt her disability excluded her from many social activities and described herself, even in this situation, as "not like other women".

O.S. stated bluntly that she doubted her husband could live long in his present condition, and that, in any case, he would likely have to move to a nursing home at some time. She looked forward to the freedom she would experience following either of these events, describing her present situation as "pretty boring". In her own words, however, "You do what you have to do."

Case 6 - V.P.

V.P. is a 35 year old mother of two boys. Her husband is a quadriplegic as a result of a truck-train collision following which he was hospitalized for 13 months. The interview took place five months after he was discharged from hospital, 18 months after the injury.

As well as the spinal injury, V.P.'s husband also had a head injury which left him semi-comatose for several weeks, during which time V.P. spent most of her waking hours at the hospital. A sister and brother-in-law were particularly helpful but V.P. was angry and bitter about the rest of their relatives and what she perceived to be their total lack of sensitivity to the situation, then and now. She was and continued to be hurt and frustrated by the behavior of these people but had begun to realize that some of it stemmed from their inability to accept the permanence of her husband's disability. It became apparent through the interview that her husband was creating problems within the immediate family by his frequent self-deprecating talk and behavior, problems which she felt less and less able to handle.

V.P. returned to work two months after the accident, and continued to work until her husband was discharged. The decision to stay home full time was one she regretted as the responsibility for the care of her husband was too emotionally draining in light of his behavior problems. There had been a number of unpleasant incidents between father and sons in which she tried to mediate but it was clear that this family was in trouble. (The father has since been placed in a nursing home.)

As a unit, the family had always functioned well together, with a heavy emphasis on sporting and other physical activities. The inability of her husband to participate as he had in the past seemed to trigger an attitude of resentment on his part, the expression of which took the joy out of participation and achievement for the other family members. V.P. was highly resentful in her own right, feeling that she was unappreciated for the efforts she made on his behalf.

> I don't mind it [doing things for husband] one bit. The only thing I mind, that bothers me is after so much I get to feel what am I doing it for? Don't you appreciate it?

And

> There are times I'd like to just backhand him, you know. Wake up! You're not the only one going

through this.

There was some question by the hospital psychologist about brain damage which might have been precipitating her husband's behavior, but V.P. was of the impression that his inability to accept his disability was the main factor influencing his behavior. She was trying to function virtually without a support system, few if any of her needs were being met either within or outside the marriage, and she admitted that tranquilizers had become a necessary part of her life.

At the time of the interview, V.P. was stuck in a quagmire of emotions, a sense of responsibility, mingled with guilt, resentment, anger and helplessness. She was isolated from potential help, i.e. psychologist, social worker, because her husband was no longer a patient in the hospital and there was no continuity or transitional support through community agencies. It was only her personal strength and commitment which had kept her going this far.

Case 7 - C.P.

This woman, now 24 years old, was 22 with a six week old baby at the time of her husband's accident. He is now a quadriplegic as a result of a two vehicle accident between his truck and another. The interview took place two years after discharge from hospital, two and a half years after the accident.

C.P. described her pre-accident self as "a totally submissive wife and mother, and all the family responsibilities were on my husband." She could not drive a car, handle money, or make decisions on her own. Suddenly she was faced with all these responsibilities and more, a task which threatened to overwhelm her more than once. Nevertheless, she managed to move herself and her baby to the city, learned to drive, handled money matters and spent five to six hours a day at the hospital with her husband who had become hostile, angry and depressed.

Emotional support, so badly needed, came generously from family members and a minister at the hospital who provided guidance when her life seemed the bleakest. C.P. expressed regret that no assistance came from social workers or someone who could have directed her in matters such as applying for compensation and finding suitable accommodation.

The most difficult time for C.P. came in the first three months when her own frustrations were exacerbated by her husband's emotional outbursts and led to periodic explosions during which she wished for release - "I walked out the door, hoping to just fall down and have a nervous breakdown or be hit by a car...I was deciding if I was willing to try and handle this."

Belief in God and frequent prayers for guidance, plus the realization that she was afraid to face life alone, all contributed to her decision to remain with her husband. She described the time since then as a period of real growth for her, both as an individual and as part of a marriage partnership.

> Since the accident I've become stronger, confident, organized, and responsible...my approach to problems is frustration sometimes, yet confidence...it's been a strain sometimes, but always a challenge and I love meeting challenges now.

At the same time she became so protective of her husband that she refused to leave him alone even for a couple of hours. Her routines were so rigid that visitors were mildly resented because they disrupted these routines. C.P. described a very isolated, nuclear lifestyle which excluded casual friends and most socializing, yet declared "I love my life, I love being responsible, I love being needed." She admitted that there were frustrations and a sense of too much responsibility at times but could foresee a mainly positive future for them.

Case 8 - J.A.H.

This woman was 24 years old at the time of interview, but only 21 when her husband was injured. At the present time she was mother to five children--one of her husband's from his first marriage, one of hers born out of wedlock, and three from the present marriage, the youngest being three months old. Her husband is a quadriplegic resulting from an industrial accident. The interview took place three years after injury, two and a half years after his discharge from hospital.

J.A.H. was pregnant when her husband was injured. Her initial reactions of shock and fear caused her to start having contractions and she felt overwhelmed with concern for the other children, her husband's life and how they would ever manage. She spent the first two days crying, then calmed down and became, in her words:

> Very protective. I felt I had to shelter him from any further harm, I became very hard, and protective. I had no emotions, absolutely none. I was absolutely cold. No one could make me happy or make me sad.

In the first month her sister cared for the children but once her husband's condition had stabilized, she took the children back home. Each weekend, they travelled to the city to visit the hospital. J.A.H. did not know how to drive at that time and recalled feeling very lonely as most of their family members lived in England. While at the hospital she felt alienated from the staff partly because she insisted on knowing exactly what was going on with medications and such, and partly because she felt they were unnecessarily pessimistic when giving unsolicited advice.

> Well, you see, 'helpful people' would go in there and say, look, your wife will leave you. And they would come to me and say, you know, he's not going to want you anymore. Men do this when they get paralyzed.

She felt more anger at the hospital personnel for their attitudes than she did at the circumstances which caused the accident.

The main changes J.A.H. described in her life were greater freedom and more independence. Because her husband was often away for days or weeks at a time while working, she was left with the children and little adult company. Now that he is home all the time, they are happier, closer emotionally, and he is more involved with the children. She was also forced to learn how to drive and to make decisions on her own, something she now enjoys.

With five children and a disabled husband, J.A.H. admitted to frustrating days but denied ongoing dissatisfactions. Like some other women, she missed little things.

> I'd like a hug. But then I sit down and think about it, and if he could hug me, then I'd want him to walk, and if he could walk, then I'd want him home, so I may as well just stay wanting a hug.

As a couple, they always maintained a low social profile before the accident and have continued to do so. They go out a great deal at times, but not much with other couples. They have shared some rather unique experiences (he was hospitalized in the same room at the birth of their last child) and seemed happy with life. J.A.H. believed she found a new respect for her husband and new meaning in her marriage vows following the accident. She credited this crisis with giving them a happier life together.

Case 9 - J.B.

J.B. was 40 years old at the time of interview, conducted six and one half years after her husband's injury. Two of their three children were in their early teens at that time but have now finished school. Her husband is a quadriplegic as a result of a two vehicle accident. The interview took place six years after his discharge from hospital.

Because they ran a dairy farming operation, the accident was devastating to business. Unable to manage on her own, J.B. was forced to liquidate that part of the farm, but neighbors freely assisted with crops and heavy work, which allowed them to stay financially solvent. Emotional support came partially from neighbors but most particularly from J.B.'s sister and another female friend. All the time that her husband was hospitalized, J.B. assisted him with everyday activities like eating and brushing his teeth yet seemed to have an almost dreamlike belief that it was all temporary.

> It just didn't seem to me like it was that bad. I always thought he's going to get better. He's just going to be up and gone one of these days. It wasn't until he came home that I really went through a shock...I just couldn't believe that he was so helpless, that everything he needed I'd have to get for him...it just seemed like such a terrible impossibility that I didn't know how I was ever going to cope.

She credited her sister with having rescued her from this sense of helplessness, giving her time to organize and "get into the groove."

There were very few problems with the children. Their willingness to cooperate when help was needed, plus her husband's skill in guiding the boys contributed to successful maintenance of the farm and family. J.B. went to work as much for her mental health as for the necessary financial assistance it provided, although not without paying a price in terms of energy.

Belief in God and the teachings of the bible were the most important factors in helping J.B. and her husband deal with many of the emotion-laden aspects of their new life, as they prayed frequently for guidance. She described one major change which occurred as a result of the accident: they have developed a mutual appreciation of each other, something which obviously meant a lot to her.

Despite the passage of more than six years since the accident, some issues still loomed large, such as her right to some time on her own, versus his expectation that she would provide for all his physical needs. The impression created by J.B. ~~was~~ one of reluctant acceptance of her life as it was.

Case 10 - J.R.

At the time of interview J.R. was a 63 year old mother of seven. Her husband had been a paraplegic for 10 years, the result of an industrial accident. At that time only one child remained at home, an 11 year old daughter who has since finished school and college and now lives on her own. The interview took place nine years after J.R.'s husband was discharged from hospital.

Apart from the initial shock upon being notified of her husband's accident, J.R. denied any strong emotional reactions either at the outset or later.

> I just took it, I guess. I don't know that I really thought too much. I just seemed to say, well I guess this is the way it's going to be.

She was unable to drive a car at that time, although she has since learned, so she depended on family and friends to drive her into the city to see her husband. Both she and her husband leaned heavily on their religious beliefs for support and felt that their friends in the church had been instrumental in seeing them through this crisis, by means of prayer and more tangible forms of assistance.

Prior to the injury J.R. played a somewhat passive, restricted role within the family. She felt responsible for housework, laundry, meals, and such while her husband supported them financially and took care of business. When suddenly faced with responsibility for banking and paying bills, J.R. felt uneasy and unhappy with her new roles. Her approach over the years has been one of passive resignation to an unpleasant but, in her view, unchangeable situation. She had to learn to function somewhat more independently but did not enjoy the responsibility. The following statement is a typical expression of how she felt:

> I never really thought of not doing it. I just went ahead and did what I was supposed to do. But, of course, you have to learn to do these things.

Their social life was somewhat restricted by the inaccessibility of many buildings and their mutual reluctance to ask for assistance, yet it was small things which J.R. missed the most, like walking in the fields. She has had no special friend or confidante over the years except her bible and the Lord, and it had not occurred to her that any response was possible on her part except acceptance.