A qualitative study of the effect of chronic illness on marital quality

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A qualitative study of the effect of chronic illness on marital quality

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A qualitative study of the effect of chronic illness on marital quality

by

Sandra Kay Thoman-Touet

A Dissertation Submitted to the Graduate Faculty in Partial Fulfillment of the Requirements for the Degree of DOCTOR OF PHILOSOPHY

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1992

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CHAPTER I
INTRODUCTION

Marital quality has been one of the most researched areas in the field of family studies over the past 50 years (Spanier & Lewis, 1980). It has been defined in a variety of ways and has been treated as both a unidimensional and a multidimensional construct. Numerous assessment devices have been created to obtain measurements. Yet, in spite of all this, it continues to be a limited phenomenon in terms of practical applications. For example, we have not been able to create a theory which is capable of effectively predicting the course and outcome of a given relationship or of satisfactorily explaining why some relationships are able to endure with high satisfaction levels and observable characteristics which are thought to be components of high marital quality; nor can we explain why others with similar qualities end in divorce. We do not know how specific aspects of marital quality combine to create a generally satisfactory and lifetime commitment for some, but not all, or how those qualities are also affected by other environmental or social factors. We know little of how specific life events affect individual marital relationships differently. We can not accurately predict which couples will be successful in their marriages, and often we are not able to intervene at crucial times to assist couples in trouble so as to alter outcomes. Thus, even though marital quality has been a much studied topic, theory development is still in the formative stages in terms of its functions to explain, predict and influence.

Both marital quality and status have been linked by several researchers to the level of health of the marital participants (Green, Folkman, & Lazarus, 1987; Kiecolt-Glaser et al., 1987; Kotler & Wingard, 1989; Renne, 1971; Schmidt, Pope,
& Hibbard, 1989; Verbrugge, 1979; Weingarten & Bryant, 1987). In the recent past, there have also been a large number of studies which have investigated the relationship between physical health, psychological health, interpersonal relationships, and environmental and societal factors. Numerous studies have now demonstrated the interactions of mind, body and social environment. Indeed, this area has seen a rapid expansion of interest in the past decade and will likely remain an area of focus in the immediate future. Williams (1988) found that the quality of marital interaction is more important than marital status for well-being, especially among women. Level of health has also been shown to be related to perceived locus of control, use of humor, and belief systems (Anderson & Arnoult, 1989; Kennedy, Kiecolt-Glaser, & Glaser, 1988), the amount of hostility expressed in daily living (Hardy & Smith, 1988), socioeconomic status, the life cycle and health practices, educational level (Slater & Carlton, 1985), and the number of life stressors present combined with the amount of support available (Holahan & Moos, 1987).

Marital quality has been used as an independent variable in most studies of the relationship between marital quality and level of health. Little research has been done on the impact of health impairments on the marital quality of those with illness and their spouses. There are many studies which discuss the impact of chronic illness on the person afflicted as well as the impact on specific other family members such as a spouse, child, parent or caretaker. There are very few studies, however, which report any information about how the illness of one person affects the interactional processes and the quality of the marital relationship when one spouse or a child is affected with a chronic debilitating illness.
Because chronic illness affects a large percentage of our population, and because that number of persons affected is likely to grow as our population becomes older and as we are able to treat more conditions which previously resulted in death, how those illnesses affect other areas of life will become increasingly important. Chronic illness touches on areas such as euthanasia and suicide, legal and ethical issues, social policy, financial concerns and certainly has a major impact far beyond the boundaries of the individuals afflicted.

The marriage relationship and other support systems can have a profound effect on when and whether a given individual becomes ill. Gannon and Pardie (1989) found, for example, that for both men and women there is a negative relationship between the amount of available support and the development of depression. The amount of support in a relationship may also impact on how well the partners are able to cope with the consequences of an illness after it has developed. Thus, if we are able to learn how chronic illness affects marital relationships, we may be able to find ways to improve coping with the stress and increase resistance to the development of illness so that significant others do not also succumb to the development of illness. Holahan and Moos (1987) found that both risk factors and resistance factors combined were linked to the development of future distress (physical and psychological) even when the initial distress is controlled and that the health effects of risk and resistance are additive. In other words, the number and severity of stressors can be modulated by the number and type of stress reductions or coping mechanisms available so that a given individual can maintain a higher level of resistance to disease/illness/accident. A quality marital relationship can function as a major resistance factor in the
prevention of further extension of the disease process in the ill spouse as well as in significant others.

This study explored the effect of chronic debilitating illness of one spouse or of a child on the marital relationship. Because there has been so little work done in this area, this research was exploratory and descriptive in nature and used qualitative methods. Hopefully, the information provided will develop specific ideas for further future research.
CHAPTER II
REVIEW OF THE LITERATURE

The Holistic Nature of Illness

By the 1940s, chronic diseases rather than infectious diseases had become the major public health problem (Slater & Carlton, 1985). Many chronic diseases are now coming to be understood as a result of a combination of effects of lifestyle, genetic predisposition, negative life events, personality characteristics, avoidance coping and amount of family support (Holahan & Moos, 1987), and social and economic environment (Slater & Carlton, 1985). The link between social and environmental factors and an individual's physical and/or emotional health is becoming better understood. While a full explanation of this link is beyond the scope of this paper, briefly, the major mechanisms by which external stressors affect the body appear to be through the immunological, hormonal, neurological, and biochemical systems (Cunningham, 1981; Jemmott et al., 1990; Kiecolt-Glaser et al., 1987; Kiecolt-Glaser et al., 1988; Kennedy, Kiecolt-Glaser, & Glaser, 1988; Pelletiere, 1977).

Cwikel, Dielman, Kirscht, and Israel (1988) constructed a path model to estimate the direct effects of psychosocial factors and health behaviors on indices of physical and mental health, controlling for demographic variables. They found that a combination of demographic, psychosocial, and behavioral measures were significant predictors of level of health and that psychosocial variables did have a direct effect for both men and women. Of the various types of social ties, the most intimate appear to have the strongest effects on health status.

Socioeconomic status is also highly correlated with health status. Lower classes experience greater health problems and mortality rates (Slater & Carlton,
Family support emerges as an important source of resistance to physical and psychological distress along with having an easy-going disposition and self-confidence (Holahan & Moos, 1987). Gannon and Pardie (1989) found that for both men and women, the best predictor of illness was the number of stressors present. The chronicity of the stress and the controllability of the stressors were also significantly related.

**Illness Within a Systemic Framework**

Although being married and having a high level of marital quality have both been found to be associated with lower rates of illness and mortality, it is certainly clear that there are many variables which interrelate to contribute to the development of illness in a given individual. Once developed, it is also evident that the presence of the illness becomes a stressor which can contribute to the development of other illnesses in the same individual and in significant others. However, care should be taken so that "blame" for the development of illness is not placed inappropriately and simplistic causes of illness development are not defined.

The individual who suffers from a chronic illness is most likely to be in need of some degree of caretaking. Caregiving has been the focus of significant research. It is found to be burdensome for many. Pruchno and Potashnik (1989) found care-giving spouses to have an increased risk for a host of mental and physical health problems. Sheehan and Nuttall (1988) found that increased strain was experienced in family caregivers when there was greater impairment of the ill member and when larger amounts of care were necessary. Less affection was shown toward the dependent person, and conflict in the relationship increased. The greater the amount of negative affect present, the greater was the incidence of
depression, anxiety, and somatization in the caregiver. Likewise, Moritz, Kasl, and Berkman (1989) found that living with a cognitively impaired elderly spouse negatively influences health and well-being and that financial difficulties appear to be more important than the spouse's functional limitations, the responsibility for household chores, or loss of emotional support from the spouse.

Some research findings lend support to the proposition that the effect of the illness on family members may be related to the role of the person who has the illness. Lewis, Woods, Hough, and Bensley (1989) studied family functioning when the mother was affected by chronic illness. They found that depression could be decreased and marital adjustment increased by the provision of alternative sources of services that reduce strain on the marital dyad. They also found that other family relationships were affected and that perceptions of family coping and marital satisfaction were affected by the level of depression in the "non-ill" spouse. Additionally, different results were found depending upon the type of diagnosis. Most likely, the effect of an ill child would be different from the effect of an ill spouse in terms of familial impact. Loss of the role of "breadwinner" would also have a different impact than would the loss of "nurturer," for example. Some illnesses have a more profound effect than others (Peterson, 1979).

Finkelstein, Finkelstein, and Steele (1976) examined the marital relationships of 17 chronic medically stable hemodialysis patients. There was a reported decrease in frequency of intercourse which was strongly related to the depression score of the patient. They found that the patients had high depression scores and that 9 of the 17 had scores on self-report measures of certain marital characteristics which were similar to the scores of persons seeking marital counseling, yet 88% reported their marriages as basically satisfactory. This may
indicate a difference between global ratings and multidimensional ratings of marital quality.

Woolett and Edelmann (1988) found no relationship between disability, life satisfaction, and marital satisfaction in 20 patients with Multiple Sclerosis and their spouses. There was a positive relationship between life satisfaction and marital satisfaction, however, and the non-M.S. partners were less satisfied with their marriages than were the patients with M.S. In patients with respiratory disease, the severity of the disease was strongly related to quality of life in patients with chronic bronchitis and emphysema (Moody, McCormick, & Williams, 1990).

Flor, Turk, and Scholz (1987) found that chronic pain patients and their spouses experienced a considerable change in their marital and sexual satisfaction. Chronic pain in the patient was also related to heightened distress and physical symptoms in the spouses as well. Women with rheumatoid arthritis married to healthy husbands were the focus of a 1990 study by Manne and Zantra. They found that the spouse's difficulties related to the partner's illness included the burden of providing care; disruption in social, sexual and recreational activities; and dealing with the partner's emotional distress associated with the illness. Healthy husbands did not experience an increase of psychological distress in this study, but the quality of marital interaction, particularly unsupportive, negative interactions surrounding the illness, was a major correlate of both the wife's and healthy husband's mental health.

Three studies explored the marital relationship in Alzheimer's disease. Morris, Morris, and Britton (1988) found that caregivers who experienced lower levels of marital intimacy both currently and before the onset of the dementia had higher levels of perceived strain and depression. Caregivers who experienced
greater loss of intimacy had higher levels of depression but no evidence of increased perceived strain. Kvale and Bohlen (1985) found that spouses of patients in early stages of Alzheimer's recognized changes in marital role patterns, especially the loss of egalitarian division of labor. Sharing sexual expression and communicating love declined early on. Blieszner and Shifflett (1990) found that intimacy was lower in the presence of Alzheimer's than before the onset of the disease and that a major decline occurred during the period of symptomatology but before the diagnosis was made.

Ulrich-Jakubowski, Russell, and O'Hara (1988) found evidence for a causal influence of depression on later marital adjustment. They found no support for the hypothesis that poor marital adjustment plays a causal role in the development of depression in a sample of 78 older men. Earlier, Briscoe and Smith (1975) reported that females become depressed during a discordant marriage, while Klerman (1984) found that men saw their depression as contributing to marital friction.

Peterson reported on the impact of physical disability on marital adjustment in a 1979 literature review article. Two studies, Renne (1970) and Palmer (1971), found physical disability to be related to marital dissatisfaction. DeLamata (1960) and Collette (1969), cited in Peterson (1979), reported the importance of clear generally sanctioned role definitions to marital harmony. Stone and Shapiro (1968, cited in Peterson, 1979) found family roles redistributed with the sick spouse often retaining decision-making functions while relinquishing other domains while Ludwig and Collette (cited in Peterson, 1979) found that husbands who were dependent on spouses for daily living activities had less decision-making power in the marriage regardless of the degree of handicap. In 1973,
Zahn (cited in Peterson, 1979) found that interpersonal relationships were better when characteristics of role impairments clearly indicated sickness and when they were significant enough that the disabled was not able to work. This was probably due to less role ambiguity. Peterson stated that, based on his literature review, cognitive and mental deterioration produced greater stress on the marriage than did physical disability. Clear and appropriate definitions with regard to role expectations were related to the performance of the handicapped spouse and appeared to be related to higher marital satisfaction for the couple. Overall impacts created by nearly any group of chronic illness include alterations in sexual function and activity, altered social activity, changed body images, and likely psychological, somatic, and occupational impacts (Lambert & Lambert, 1987).

Taken together, these studies still provide little information about changes which occur in marital relationships after the diagnosis of a chronic illness and as the disease progresses and becomes more severe. It is fairly evident that illness is a significant stressor and that marital relationships must respond in some fashion to such a major stress. It is also evident that overall quality of life will be significantly affected by chronic illness and that quality of life and quality of marriage are generally highly correlated when measured in the same study (Woolett & Edelman, 1988). It is not clear how the various concepts which are thought to be components of marital quality are each individually altered in the face of chronic illness.

**Components of Marital Quality**

Lauer and Lauer (1986) found the nature of the relationship (enjoyment in being together) to be the most frequent reason cited for couples staying together
for more than 15 years. Other reasons included the belief that marriage is a long term commitment and is better for the children. Mudd and Taubin (1982) found commitment, altruism, egalitarianism, and affection to be the most important characteristics of long-term marriages. Roberts (1979) found commitment, companionship with little struggle for dominance and high agreement on decision-making, and qualities of caring to be the characteristics noted in his sample of long-marrieds. Bentler and Newcomb (1978) found no difference in personality traits for married and divorced groups in a longitudinal study of marital success. Their "still married" group had a greater amount of ill health which seemed to have drawn the couples together. Homogamy of traits evidenced to a greater degree in successful marriages. Happily married males were introverted and vulnerable; happily married females were extroverted and invulnerable. This may lend support to the idea that non-traditional sex-role behaviors may be related to higher levels of marital satisfaction.

Communication has been a much studied aspect of the marriage relationship and is thought to be a major component of marital quality. Gottman and Porterfield (1981) found support for their hypotheses that a skill deficit exists in communication of dissatisfied married couples and that a "private message system" exists that enhances communication of satisfied couples; nondistressed couples are apparently able to decode messages from the spouse better than from an opposite sex stranger. In a 1980 study, Hawkins, Weisberg, and Ray found that wives preferred less controlling communication than husbands preferred in themselves and that husbands wanted more speculative behavior from wives than wives were willing to give. "Women want to move closer to their husbands . . . husbands still prefer to give less of this than their wives would like" (p. 591). In
1979, Billings (cited in Boland and Follingstad, 1987) found that distressed couples demonstrated more reciprocity of negative communication as compared to nondistressed couples. Koren, Carlton and Shaw in 1980 (cited in Boland and Follingstad, 1987) reported that distressed couples relied on criticism in attempting to influence their spouses while Boyd and Roach (1977, cited in Boland, 1987) found happy couples tended to make clear direct messages without hidden meanings, utilized active listening skills, and expressed respect and esteem for the spouse. Couples with higher rates of self-disclosure and expressions of love, support and affection tended also to experience greater marital satisfaction. Nondistressed couples laughed more, engaged in more touching and exhibited accurate sending and receiving and listening skills, clarity of speech and positive interpretation of the partner's behaviors.

Spiritual well-being or religiosity have been correlated significantly with marital adjustment (Roth, 1988; Wilson and Filsinger, 1986). Hatch, James, and Schumm (1986) found a high correlation (r=.78) between marital satisfaction and emotional intimacy. Scanzoni and Arnett (1987) found that the greater the religious devoutness, the greater was the commitment to marriage and the more devout the couple, the greater the love and caring.

Sex-role attitudes and congruence of beliefs about sex-roles have also been related to marital quality or marital satisfaction and marital adjustment. Li and Caldwell (1987) found that the relationship between marital sex-role incongruence and marital adjustment is a function of both the magnitude and direction of the spouses' disagreements about marital sex-roles. The greater the incongruence in the direction of the husband's being more egalitarian than the wife, the more positive is the estimated impact on marital adjustment. The greater the
incongruence in the direction of the wife's being more egalitarian than the husband, the more negative the impact on marital adjustment. Bowen and Orthner (1983) found similar outcomes. Marriages with the lowest evaluation of quality were those of traditional husband and modern wife. Modern husbands with traditional wives and couples who were sex-role congruent had greater marital quality. Likewise, Lueptow, Guss, and Hyden (1989) found that traditional sex-role ideology in women was positively related to happiness and that women at the nontraditional extreme were least happy. Nontraditional orientations of women are incongruent with traditional men's orientation and may create stresses in marriage.

Congruence between what is desired and what is occurring is also an aspect of high marital quality in terms of sharing of work, both inside and outside the home (Ross et al, 1983). Snyder (1979) and Orthner (1975) found that the amount and quality of shared time were related to marital satisfaction. Hill (1988) found shared time to be related also to shared stability. The greater the individual leisure time, the less the marital satisfaction, while high joint leisure time was related to greater marital satisfaction (Holman & Jacquart, 1988). They also found that low levels of joint leisure time was not related to husband satisfaction, but it was for wives. The total number of joint leisure activities was unrelated to either partner's marital satisfaction, but a discrepancy between the spouses or in the number of individual activities was negatively related to satisfaction. In the area of financial decision-making and handling, happily married couples reported more role specialization and less husband dominance (Schaninger & Buss, 1986). Further, they found that initial allocations of responsibilities for family financial handling in the first months of marriage was significantly related to subsequent
satisfaction or divorce. Establishment of equality and equity at an early stage of marriage is important for the survival of the marriage.

In a study which used physiological and affectional criteria to measure couple interaction, Levenson and Gottman (1985) were able to predict which couples would experience decreases in marital satisfaction over 3 years. Overall, their findings indicated that in dissatisfied marriages, husbands were more likely to withdraw than wives and withdrew earlier. Wives increased their affective behaviors. Men wanted to vent their negative affect and then be left alone while wives wanted to have their negative feelings responded to. Declines in satisfaction were predicted both by husband failure to respond and the wife's negative affect and by the wife reciprocating husband's negative expression of affect. The greater was the physiological arousal in the couple, the greater was the marital decline.

Eysenck and Wakefield (1981) studied psychological factors as predictors of marital satisfaction. They found that scores of both psychoticism and neuroticism had small interaction effects with marital satisfaction, but high psychoticism in one partner and high neuroticism in the other did decrease marital satisfaction. Marital satisfaction was lower still if only one spouse had high scores on psychoticism or neuroticism. They found that similarity between spouses on level of neuroticism, libido, tendermindedness, and several sexual behaviors were correlated with the level of marital satisfaction. Fincham (1985) found that distressed couples place blame for the problem on the spouse.

Franzoi, Davis, and Young (1985) found the ability to take the perspective of the partner was correlated with higher marital satisfaction for both partners. Greater levels of give and take were related with more marital satisfaction for both
wives and husbands. Higher satisfaction in relationships was related to self-awareness only through self-disclosure; self-disclosure was related to marital satisfaction only for the person doing the self-disclosing.

The level of marital quality over the life span of the marriage has been researched. Support has been found for a curvilinear relationship between number of years married and marital quality/satisfaction or adjustment. Franzoi, Davis, and Young (1985) found that longer relationships were associated with less satisfaction, especially for women. However, this sample dealt with relatively short term relationships, the longest defined as "greater than two years." Anderson, Russell, and Schumm (1983) found evidence for a curvilinear relationship between perceived quality of marriage and the family life cycle. Schumm and Bugaighis (1986) attributed that curvilinear relationship to the impact of children and income. In the group married longer than 25 years, value similarity appeared to have an impact on marital adjustment (Medling & McCarrey, 1989).

A final component found to be used as a measure of marital quality is the concept of power and decision-making. Godwin and Scanzoni (1989) found that decision-making may vary across content area and was contingent upon situational factors. Power is one component of decision-making (Godwin & Scanzoni, 1989). Blumberg and Coleman stated (1989) that women's relative economic power is held to be a key determinant of their relative control over the couple relationship and various other aspects of their own lives. In times of social or sex-role transition, female power is perceived as a threat and is likely to be treated with more repressive or violent male responses. Power is derived from money, education, occupational status, and personal physical and mental characteristics which are attractive to the partner (Jacobson, 1986). Jacobson
stated that how issues of power are defined and addressed greatly affects the success or failure of marital and love relationships. The success of a given relationship is determined by the degree to which each partner accepts the compromises that are made as fair and reasonable. Such perceptions are subjective and are based on each person's belief and value system.

In 1987, Madden investigated the association between marital power and satisfaction. Highly satisfied couples reported equal task control for husband and wife. Asymmetrical control over performing activities was particularly unacceptable and was related to low satisfaction with marriage.

In a literature review, Gray-Little and Burks (1983) noted that both self-report and observational studies of marital power led to similar findings. Generally, marriages in which the wife appeared to be dominant were the most likely to be unhappy. The highest levels of satisfaction were most often found among egalitarian couples. Coercive control techniques may be related to marital dissatisfaction.

This study attempted to explore the effect of chronic debilitating illness on the quality of marriage. It further attempted to discover how the components of marital quality are affected by chronic illness and how overall satisfaction with the marriage is altered as the specific components of marital quality are altered.
CHAPTER III
METHODOLOGY

Definition of Terms

The following definitions are used in this study:

1. The Commission on Chronic Illness defines chronic illness as "all impairments or deviations from normal which have one or more of the following characteristics: they are permanent, leave residual disability, are caused by non-reversible pathological alterations, require special training of the patient for rehabilitation, and may be expected to require a long period of supervised observation or care. It does create major alterations in one's lifestyle." For purposes of this study, chronic debilitating illness means those illnesses which are long-term with no expected chance of improvement but which are not yet in the terminal phase and which cause permanent impairment in the patient's life.

2. Marital quality is defined as those characteristics of the marriage relationship which contribute to the positive or negative nature of the interactions between the partners and to the level of satisfaction experienced by the participants. It was operationalized as an overall rating of marital satisfaction given by each spouse and a separate score of quality of interaction observed by the researcher. The measures observed by the researcher included the amount of eye contact made by the couple, the kinds of gestures (smiles, frowns, physical touches and proximity) made, the kinds of verbalizations made about the spouse, the amount of openness between spouses, the amount of hostility expressed plus the characteristics of their relationship identified by the couple during the interviews which have been found to be related to marital quality. Satisfaction was defined as the subjective feeling state in each spouse of contentment or happiness.
with the marital relationship when all things are considered. It was measured by asking each spouse to give a rating of the quality and satisfaction of the marriage on a scale from 0-10, with 0 meaning no satisfaction at all and 10 meaning the best marriage the individual can conceive of having, all things considered. Component parts of marital quality found in the literature include decision-making, conflict negotiation, sex-roles, financial handling, communication, division of work, time spent together, time spent in individual pursuits, expressions of warmth and affection, and sexuality. These qualities were identified as they were brought out in the interviews. Income, educational level, religion, occupation, and number and ages of children as well as the number of years married were control variables.

3. Power is defined as the freedom to decide what is desired and the ability to obtain it (Kantor & Lehr, 1975). It was measured in this study indirectly from information provided about who decides about various specific areas such as earning and spending money, child rearing, division of tasks, and how the couple solved problems. This researcher believes that chronic illness may alter the power structure of the marital relationship and therefore paid special attention to this component of marital quality.

Sample and Procedures

This study was conducted in urban and rural areas in the Midwest during 1991 and 1992. The research design was approved by the Iowa State University Human Subjects Review Committee prior to beginning interviews. Data was formulated from audiotaped interviews and observations of spousal interaction. Interviews were qualitative and questions were open-ended. After determining what the illness was, how it had physically affected the life of the patient, and
when it was diagnosed, the opening statement was, "Tell me what it has been like for you dealing with this chronic illness." Additional questions sought elaboration and clarification of the material shared by the subjects. The interviews continued until the subjects could provide the researcher with no further information.

Individual and couple responses were researched. Near the end of the interview, after the couple had told their story, couples were asked to discuss aspects of the history of their relationship with each other and of their current relationship. Individual interviews generally were not done because after the first few couples reported high levels of satisfaction and improvement in the relationship following the onset of the illness, it was determined that there was no new or conflicting information obtained in the individual interviews from the couple interviews. However, when there was indication that the communication between the couple was not open or that either spouse was reluctant to share thoughts and feelings in the presence of the other, individual sessions were conducted. One person was interviewed whose husband was deceased. She reported on her perceptions of her husband's reaction to the disability of their child and how it affected the marriage. Information was sought regarding the present and pre-illness states of the marriage relationship due to the researcher's interest in change as a result of the illness.

Possible subjects for the study were identified by physicians, hospital nurses working in discharge planning, a family therapist, newspaper "Personal" advertisements, and by other subjects who had already participated in the study. Eight physicians from small towns, 8 physicians from a major city, 4 small hospitals, 2 large medical centers, 2 health centers, and 1 family therapist were asked during a face-to-face meeting or via a mailed letter or telephone
conversation to assist in identifying possible subjects. Of those, 6 physicians from small towns, 2 small town hospitals, 1 family therapist, and 1 health center agreed to assist by mailing letters to potential subjects whom they identified. A total of 47 letters explaining the study were mailed to each of the identified persons who met the research criteria of having been married greater than 5 years with at least one spouse or a child afflicted with a chronic debilitating illness which had been diagnosed for at least 6 months but which is not yet in the terminal phase. Rolland (1987) defined three stages of the illness: crisis, chronic phase, and terminal phase. Each phase is characterized by specific needs and expected behaviors from the persons affected. The task requirements of each stage are different and require different adaptations. This study included persons who were in the chronic phase, but did not include persons in the crisis or terminal phases.

The letter which was mailed to the possible subjects identified the referral source, the qualifications of the researcher, and the purposes of the study. It stated that the identity of the reader was not known to the researcher and that the letter had been mailed anonymously by the referral source. Participation of the subjects was requested. Of the 47, 14 persons (30%) returned the stamped and addressed postcards to the researcher which provided their names and phone numbers and indicated their interest in participating. Each of the respondents was then contacted by telephone and asked to participate in an audiotaped interview conducted in their homes. Two couples requested that the interviews be conducted elsewhere and were interviewed in the researcher's office. Confidentiality was assured, and subjects were asked to give their written informed consent. This form and copies of the letters mailed to each possible subject and to
those persons asked to assist in the identification of possible subjects are included as appendices.

Additionally, 8 other persons were identified by participants in the study. All of these persons were contacted by telephone, the referral source was named, the study was explained, and participation was requested. Of these, one couple agreed to participate. A newspaper ad was placed in the "Personals" classified section of a nearby major city's Sunday newspaper on two consecutive Sundays. This yielded five more interviews. The total sample for this study was 20. However, one interview was deleted because the couple was caring for a dependent relative, not a child of the couple, and thus did not meet the criteria for the study.

It is recognized that retrospective data collection is not without problems. However, since baseline information was not available, recall of past behaviors was all that was available against which to measure change. The unit of analysis is the couple relationship although some of the data was provided by individual responses.

Interviews were transcribed to written form verbatim and content-analyzed according to procedures described by Lincoln and Guba (1985) and Spradley (1979). Each interview was subjected to domain analysis. The goal was to identify themes or domains, how the subjects organized their behavior and interpreted their experience of coping with the illness, and to identify the relationships among linguistic symbols used.

A cultural theme is a cognitive principle, tacit or explicit, recurrent in a number of domains which serves as a relationship among subsystems of cultural meaning. Themes are symbols linked into meaningful relationships (Spradley,
(1979) which connect different subsystems in a culture. They serve as a general semantic relationship among domains. The terminology used by informants was utilized by the researcher to identify the domains. Each interview was read three times in order to identify the major themes or domains. Prior to the first reading of the transcription, audiotaped interviews were played and reviewed. During the first level of the analysis, the interviews were read through from beginning to end with no attempts made to categorize meanings. During the second level of the analysis, each interview was again read in its entirety; cover tems were underlined and notes were written in the margins to identify the major themes. During a third reading, segments of each interview were categorized according to similar topics of discussion, clustering key words together to create the cover tems or domains. These domains or themes emerged from the mutual shaping and interaction between the researcher and the subjects and the researcher's interpretations of the subjects' meanings (Lincoln & Guba, 1985). Subjects' meanings were verified by way of phone calls to the subjects following completion of the researcher's third reading of the transcribed interviews.

Reliability was checked by comparing the researcher's identifications of themes and meanings with those of a research assistant who held a masters degree in counseling education. Forty percent of the transcribed interviews were read by the assistant for analysis. There was 90% agreement between the researcher and her assistant in the identification of the domains/themes. Demographic information obtained included ages of respondents (spouses), number of years married, religion, educational level obtained, occupation, income, sex, time of onset of the illness, the diagnosis, and ages and number of children.
This author believed that the level of marital quality would be changed when challenged by chronic illness. The questions explored were: 1. In what way does chronic illness affect the marital relationship; 2. Does the current level of marital quality vary directly with the quality of the relationship prior to the onset of the illness; 3. Does the current level of marital quality vary with the power arrangement of the relationship before and after the illness onset; 4. Does the quality of the marital relationship vary with the specific diagnosis and nature of the disability and amount of loss of role performances; and 5. Does current marital quality vary dependent upon whether the illness is present in a spouse or in a child.

Data analysis was primarily descriptive rather than inferential. Narrative reports of the open-ended interviews are the main method of reporting the data. Excerpts from various interviews are included in sufficient length to convey the subjects' experience within each domain. *These are reported exactly as stated with no corrections for grammar or syntax.* Levels of marital quality were analyzed for differences in the "before illness" and "after illness" time frames.

Ages of the subjects was 25-84 for the husbands and 29-79 for the wives. The number of years married ranged from 6-57. Three husbands and 3 wives had less than a high school education (16.2%); 4 husbands and 6 wives had high school diplomas or GEDs (27%); 3 husbands and 3 wives had some college (16.2%); 4 husbands and 4 wives were college graduates (21.6%); and 3 husbands had Ph.D. degrees while 3 wives had master's degrees (16.2%). Educational level was not obtained for 2 (5%) husbands, but it likely that it was not beyond high school.
Four couples (21%) had a family income of less than $15,000 per year; 8 (42.1%) ranged between $15,000-25,000 annually; 4 (21.1%) had incomes of $25,000-40,000 annually; 3 (15.8%) had incomes of $40,000-55,000 annually; and none reported an annual income exceeding $55,000. Seven couples (36.8%) held mainly blue collar jobs; 5 (26.3%) had white collar positions; 2 (10.5%) had one partner with a blue collar job and the other with a white collar position; 2 (10.5%) had one spouse with a white collar occupation and one with a professional position; 3 (15.8%) held professional positions. Persons who were mainly homemakers but who had worked at some time outside of the home were categorized according to the paid employment. Respondents who were homemakers, never holding any paid employment position, were classified as blue collar. In several instances, one spouse did not work consistently outside of the home. Several couples were retired or disabled so that they did not currently work, or the disabled spouse did not work. Five couples received some form of public support as their main source of income; only one of those couples consisted of spouses with a dependent child. Two persons had federal retirement income; 7 had some private retirement income. The others were currently working for their source of support.

One couple stated their religion was Catholic; 1 couple consisted of one partner who was atheist and the other was humanistic; 2 couples and 1 individual spouse were non-active in any religion but stated they were Protestant; the others were Protestant. Ten (53%) of the respondent couples considered religion to be very important in their lives; nine (47%) did not consider religion to be very important especially as it affected their response to the illness.
Six (32.6%) of the subjects interviewed had a dependent child with a chronic illness/disability. Of these, two involved remarriages with children from a previous marriage. One of these had the spouse who died; she was interviewed individually. Thirteen subjects (68.4%) were couples where one or both spouses had chronic debilitating illnesses. In each of those couples there was clearly an "identified patient" or one who was clearly labeled as more disabled than the other by the couple. Nine of those couples were in the only marriage for either partner and only one had a child currently in the home; this was a granddaughter who was adopted by the couple. Four remarried couples participated; none of these had children who were still living at home, but one had a daughter who had recently returned home temporarily. The length of the interviews ranged from 45 minutes to 3 hours. The average length was 94 minutes. The most frequent interview length was 120 minutes.

Couple number one was in their 50s, with less than a high school education for each spouse. The husband had received disability payments for 9 years and has had severe health problems for over 25 years. Both were or had been blue collar workers with less than high school educations. He had chronic degenerative disc disease which caused chronic pain and severe coronary artery disease which had required balloon angioplasty. They had been married over 29 years and had two grown children who were still living at home when the back problems began but who are both out of the home now. They were highly stressed with financial worries their main concern. Their annual income was approximately $10,000. They were highly satisfied with their marriage which was characterized by open communication, sharing of affection, respect, trust, and commitment.
Couple number two had an 8-year-old child who was severely affected by Cerebral Palsy from birth after an uneventful pregnancy. He attended school, but was severely handicapped in the areas of speech and developmental abilities. He was learning to walk with a walker and braces but mainly was carried or wheeled in his stroller. This couple had been married for 11 years and had another well child, age 10. The husband was 30; she was age 29. He has had 6 months of college; she held a high school diploma. They were both blue collar workers; she worked only part-time when the handicapped child was in school. They were coping quite well and defined difficulties with the extended family and lack of support from family members as their major stressors. They were highly satisfied with their marriage and worked together to achieve their goals. They valued each other and the family and were highly committed. Annual income was $38,000.

The third couple was college educated, ages 79 and 84. He was injured with a head injury from a fall and later suffered a stroke. The wife has had arthritis for many years and was also diagnosed with cancer since her husband's injury 1 1/2 years ago. They had been married 48 years. He was a retired government employee. She was mainly a homemaker. They were coping well at the time of the interview. She was the most stressed during the time when her husband was mentally confused and disoriented shortly after the fall and stroke. Their income annually was about $20,000. This couple was also highly satisfied with their marriage which had a long history of shared experiences and affection. She was having some difficulty adjusting to his mental and sensory impairments and assumed a bit of a "mothering" role toward him at times. Their verbal expression of
affection was not always very articulate, especially the husband's, but there were obviously strong bonds and great loyalty between them.

Couple number four had been married for 37 years. He was 61; she was 58. Neither had a college degree. He was retired from the military and currently worked at odd jobs. She had been mainly a homemaker. Their youngest son was diagnosed at age 11 months with neurofibromatosis, a disorder which produces pigmented spots and tumors of the skin, tumors of peripheral, optic and acoustic nerves, and subcutaneous and bony deformities. He also had a seizure disorder. They had five children, ages 15-35. They experienced on-going stress as their son continued to develop new problems, and they lived in a constant state of "not knowing what will happen" because the course of this illness is quite unpredictable. Their marriage has had many "ups and downs" and some conflict regarding power and role definitions. They were strongly committed to one another. They were perhaps less satisfied with the marriage than they would like to be, but they perceived it as a good marriage. Their annual income was about $22,000, and many of the medical bills were covered by his military benefits.

Couple number five had been married for 45 years. He was 69 years of age, and she was 64. She was diagnosed 4 years ago with coronary artery disease and cardiomyopathy, a weakened heart muscle. She fatigued easily and had medically ordered limitations on her physical activities. He had an eighth grade education; she completed high school. He was a retired railroad worker who currently held part-time employment caring for the church lawn and driving a school bus. She had mainly been a homemaker, but did sell real estate. They had two grown children. They were coping well and were financially stable. Annual income was $22,000. They had a history of sharing responsibilities and working
together, and they formed an alliance against intrusive family members. They were content with each other, highly committed and very respectful of each other. They had a high quality marriage which was satisfying to both partners.

The sixth interview couple had been married for 23 years. She was 52; he was 48 years old and had a history of back problems, ulcers, severe diabetes as a result of a pancreatectomy for the removal of tumors in 1989, bi-polar affective disorder controlled with Lithium, a past (and probably incorrect) diagnosis of schizophrenia, and was impotent. He had also developed coronary artery disease. They had one grown son who recently moved out of their home. Neither was college educated. They were blue collar and had owned their own business in the past. Their main stress was financial with an annual income of approximately $11,000. He was disabled and received public assistance. She worked part-time. This couple gave their relationship a higher rating of marital quality than did the researcher. Bonding was very strong, but there were persistent communication problems and a stated feeling of the wife that her needs were sometimes not met.

Interview number seven was deleted due to not meeting research criteria. Couple number eight was college educated, age 78 for both, and married for 57 years. They had two grown children. He had prostatic cancer, diagnosed about one year ago, and congestive heart failure which was diagnosed 4 years ago. He also had a pacemaker and his physical abilities were severely restricted. He was a retired businessman and rancher. She was a homemaker. They had adequate financial resources ($25,000-40,000) and maintained that they experienced little stress. They stated that their marriage is calmer now than before the illness onset.

Couple number nine consisted of a college educated 62 year old female and 65 year old male. He held a Ph.D. She had a college degree. He was a
minister and a college professor. The wife experienced the onset of chronic depression following a hysterectomy in 1971. About 5 years ago, she was also diagnosed as schizophrenic and she had arthritis. The husband was diabetic. Four children were all grown. Annual income was in the $40,000-55,000 range. Their marriage went through a period of great stress and discontent but was rated by the couple as quite satisfying at the time of the interview. He was protective of her, however, and would have still liked a somewhat "stronger" wife. They had been married for 42 years.

Couple number 10 held graduate degrees; hers was a masters; his was a doctorate. They were 72 years old. He was a retired university president, while she had been mainly a homemaker. He suffered a stroke 4 years ago which left him a hemiplegic. They had been married 46 years and had grown children. Annual income was adequate at the $40,000-50,000 range, so there was little or no financial stress. This couple was highly satisfied with their marriage which was characterized by very open and honest communication, great respect for one another, and consideration of the needs of the partner. They worked together on many projects but also maintained individual pursuits.

Couple number 11 held graduate degrees; hers was a masters degree; his was a doctorate. He was a retired vice president of a university, 78 years old. She was 77 and taught school for a short time during their 57 year marriage. They also had grown children. They were coping well after the onset of his blindness from macular degeneration 12 years ago. Income was adequate, estimated in the $25,000-40,000 range. This couple delighted in engaging in activities together and had open and respectful communication patterns.
The twelfth couple had been married 7 years. They had a 3 year-old-child diagnosed 2 years ago with Hurler's Syndrome, a fatal genetic degenerative endocrine and metabolic disorder, and a 2-year-old normal child. Both were college graduates; he worked for an insurance company; she was a homemaker who worked before the children were born. He was 31; she was 30. The marriage was unstable and highly stressed, yet was characterized by honest and open communication of thoughts but was less open regarding emotion. Husband and wife also dealt with stressful situations differently and did not always understand the other's position. Annual income was $40,000-50,000.

Couple number 13 had less than a high school education. He was 44; she was 46. They had been married for 26 years. He had been a very brittle diabetic complicated with severe diabetic neuropathy for 14 years. Both were blue collar workers; he was, of course, disabled and received public assistance. Their children were grown. They also raised his younger brothers and sisters when his mother died shortly after he and his wife were married. Their marriage was highly unsatisfactory and had been for many years. They were also highly stressed financially with an income of less than $15,000.

Couple number 14 had been married to each other for 32 years. Each had been married previously. She was 50; he was 59. He had been disabled for at least 4 years with severe chronic obstructive pulmonary disease. He had some college; she had attended a Vo-tech program and currently ran the family business. He was retired from a career in law enforcement. Together, they had one grown child, and each had children from the previous marriages. Their marriage was currently very strained, and individual stress was high. Their
financial situation was adequate at around $25,000, and most of his medical bills were covered.

Interview number 15 was with the mother of a physically and mentally handicapped 15-year-old son who was also diabetic. The father was deceased. Their marriage was a first for him and a remarriage for her. Together, they had two children, and they incorporated the three children from her previous relationship. This family was currently without any funds. In the past, this family's income had come from public assistance and both blue and white collar employment and businesses. She was a physical therapy assistant. She remarried and divorced again after the death of the handicapped child's father. Her exact age is unknown.

Couple number 16 was in a stable common-law remarriage. He had a college degree; she had a masters degree. They had been together for 6 years. Three and one-half years ago, he suffered a severe head injury after a fall. This left him with short and long-term memory deficits. He was comatose and severely impaired immediately following the accident. He was also amnesic for the 25 years of his life prior to the accident, for the accident, and about 3 months following the accident. They both had grown children from previous marriages. He was 57. Her exact age is unknown but is estimated to be close to his age. Neither was currently employed. The wife also had coronary disease. They were coping well, and stress levels were currently rather low. Income was in the $15,000-25,000 range.

Couple number 17 has a 3-year-old daughter with severe asthma which required respiratory treatments several times daily, a 10-year-old son from her previous marriage who was developmentally delayed, and a normal son from her previous marriage. He was 25; she was 30. Both were blue collar workers with
high school or GED educations. They had been married for 6 years. They appeared to be coping adequately with help of family. Income was $15,000-20,000. Medical care for the children was provided free of charge by a federal health care facility.

Couple number 18 had been married for 15 years. Each had grown children from a previous marriage; her daughter had recently returned home temporarily. He was a retired federal employee; she had had blue and white collar jobs. Both had suffered from alcoholism in the past, but were recovering. He was diagnosed as having schizoaffective disorder three years ago, but it is likely that the onset was much earlier. He was 52; she was 42. Both have had some college education. Their relationship was very strained, and her stress level was very high. Financially, they were barely able to meet basic expenses. Income was around $20,000.

Couple number 19 was ages 41 and 37. They had been married for 20 years. He had worked in the oil industry while she had only recently taken paid outside employment. They both had high school educations. They had two sons, ages 18 and 15, who had endocrine disorders which cause significant growth retardation. This was complicated by psychological problems secondary to their small size, especially in the older son. Their marriage was stable but not without unresolved conflict. Coping was adequate, but the mother experienced high levels of stress. Their income was between $15,000 and $25,000.

The last couple, number 20, was in their 50s and had been married for 35 years. They had one grown daughter and had adopted a granddaughter who was living with them. He had Multiple Sclerosis which had likely existed for many years even though only diagnosed 3 or 4 years ago. He was forced to retire 2
years later and has been restricted to a wheelchair and bed for most of the time since he retired. They have held both blue and white collar jobs. She currently worked; he received disability income. Their marriage was very strained at the time of the interview; stress levels were high and marital quality was low. Income was between $15,000 and $20,000, annually.
CHAPTER IV
FINDINGS AND ANALYSIS OF DATA

Several themes emerged from the interviews. Individual, marital, and family responses to the illness/disability and to the person with the illness were varied and appeared to be dependent upon other psychological, sociological, and economic variables as much as to the particular illness itself. No matter the circumstances, virtually everyone interviewed acknowledged a significant amount of stress experienced at some time following the onset of the chronic illness or disability. The grieving process was involved for each respondent but was experienced differently by specific individuals. Some couples pulled apart; other couple relationships were strengthened as an outcome of dealing with the illness. Roles were changed, but few power shifts occurred. The roles of religion, social support systems, social institutions such as public schools, health care delivery systems or welfare programs, and economic factors all influenced individual and marital interaction patterns and the amount of stress experienced. Areas of unmet needs were identified.

Responses to Illness: Individual and Marital

A feeling of stress was the predominant feature for every person in the family of the affected individual. This stress was present in various forms and to various degrees, but was a universal, no matter the severity or type of the illness. Although information about family response was not sought, many couples did indicate that their children also would have liked to be involved in the interviews, that they also experienced significant stress, and that parent-child relationships were altered.
Each family interviewed went or was going through a crisis phase and the grief process as a host of losses was dealt with. These included loss of plans or dreams, loss of bodily functions or image, loss of power or status, loss of identity, or loss of significant roles. Individual members often grieved in different ways and were in different phases of the adaptation process at any given time so that the spouses were not able to be understanding of or responsive to the needs of the other. The severity of the illness or disability itself also played a significant role in how the couple was able to adjust, but that was less of a factor than how the illness was perceived. For some, the stress began before the actual diagnosis was made. The following couples provide examples of difficult adjustments where adaptation to the illness contributed to the creation of significant intra-couple stress and tension.

**Loss and grief**

As described by Kubler-Ross (1969), the grief process consists of stages which persons go through as they adjust to a significant loss. These include denial, bargaining, despair, anger, and acceptance. The onset of a chronic illness is a major life change which involves many losses, all of which must be grieved. Individuals go through the grief process in different ways and at different paces. The following couples demonstrate examples of early responses to the illness and how they handled grieving.

The parents of a 3-year-old girl diagnosed with Hurler's Syndrome (a degenerative and ultimately fatal enzyme deficiency affecting the endocrine and metabolic systems) 2 years prior to this interview gave this report.

Researcher: "What was it like for the two of you getting this news?"
... It was devastating. Uh, I guess I likened it to a, to running as fast as you could into a brick wall. . . ."

Wife: "... Having a sick child, your life's an emotional roller coaster a lot. . . . The pediatrician was saying that 'There's something terribly wrong here; we don't know what it is. It might be physical; it might not be; we don't know, but it's something we definitely, we need to look into now.' So quickly we were in [hospital]. The doctor there, he was very compassionate and didn't want to upset me, us, anymore until he was sure. But the impression he gave was that 'This was fine.' . . . A week later when I go back to take M [daughter] for a recheck he said, 'Well, I've gotten the results and she does have this rare disease'. . . and we were, like, 'Okay, she's gonna die'; then 'Nothing's wrong'; then all of a sudden, 'Oh, he was right' [she will die], and then we were angry at the doctor at [hospital] because why did he, you know, why did he let on like there really probably wasn't anything wrong, when all along he suspected that's what it was?"

Husband: "... The process of even finding out was very difficult and very maddening. We were very angry and, uh, we felt like we'd been betrayed and miscommunicated to. The question about how did it feel to finally find out that she was, had Hurler's and probably wouldn't be with us for a long time . . . and the feelings there were probably different for both of us, but, um, for me it was immediate avoidance, I think. When we first found out that something might be wrong, . . . I just, uh, had an uncontrollable flood of tears and despair and emotions . . . and shortly after that . . . I just started kind of saying, 'Well, okay, let's accept it now; okay, it's fine' and finding out as time goes by that was more just a way to try to deal with that on my part, and somewhat of a defensive way, because it was
overwhelming. Yeah, denial because it was overwhelming and I couldn't deal with it. And, [my wife], I think, on the other hand, proceeded to deal with it.

Wife: "I feel like I'm a little bit more in touch with my feelings than [my husband] is, for whatever reason. I was in shock, I think; I mean, I don't remember a lot . . . as far as just the day to day, in and out of that time. I, you know, it's just kind of a blur. I think I just went through the motions and I had two babies to take care of . . . so it was a very busy time for me and an emotional time in a lot of ways, a lot of very opposing emotions: you know, the joy of a new baby [wife was pregnant and delivered shortly after diagnosis of Hurler's in the first child was made] and the grief of the impending loss of our first child. I think I am still grieving. I cried every day. I do think I kind of went through pretty much the normal stages of grief that you hear about or you know of. Um, the anger stage I have just now come out of. I wasn't angry for a long time, but earlier last year . . . I found myself becoming very negative, angry, and I just got to the point where I was just mad at everything and, um, . . . I guess I was cursing and saying things that I never said; it was like 'What is this coming out of me?' My children would do things that should not have upset me, and I was just like exploding. . . . I feel like our grief is different from some in that it will be repeating itself until we actually lose her. I will grieve when she quits walking; I will grieve when she quits talking--"

Husband: "If any of those things ever come."

Wife: "Yeah, I think they will, but yeah, maybe they won't occur. She may die of heart failure before she quits walking. . . . What I'm saying is I feel like I dealt with the anger that I have so far in the process, but I can't know that I won't ever have it again."
Researcher: "So you [wife] dealt with your feelings of grief differently from how you [husband] did. You were or are in the stage of denial. How did that affect your relationship then?"

Husband: "Well, the first thing I think it did was intensify any areas of distance that were already there, and it also intensified any other problems or concerns that we have. I think of an analogy of the gas tank, if you will. That it provides an energy vat of energy juice that goes to dealing with any problems there are, and just day to day conflicts in marriage take a part of that; conflicts at work take a part of that; stress and strain from other things take a part of that; and then all of a sudden, in our situation, M's [daughter's] illness takes a part of that. And not only does it take a part, but it now takes a large part, and it takes a large part and it takes a first part, so I think what it did was it zapped our ability to, uh, pass off any concerns or problems that we did have. So, it got, brought them all to the surface. And so it doesn't necessarily create problems, but if you don't have a good-- If you're not doing well in an area to begin with, then this makes it worse..."

Wife: "... My husband is not comfortable with showing or sharing feelings. ... I was frustrated a lot... and felt like I was held at arm's length emotionally.... When this happened, he just kind of shut down... so not only did I feel alone, but I also did not feel that my feelings were even validated in his mind.... It has caused me to do my own thing and him to do his own thing. We were not sharing the pain...at all."

Each partner in this marriage dealt with the certainty of having a daughter with a fatal illness by grieving. However, the husband's rather lengthy period of
denial did not blend with the wife's stages of despair and anger. The result was increased marital estrangement.

A couple in their 50s reported the following. The husband was diagnosed with Multiple Sclerosis 3 years ago and has been disabled, confined to bed or wheelchair, for nearly two.

Husband: "I hated to hear I had it. I've always been so active all my life. I didn't know really what to feel."

Wife: "We'd tell everyone what was happening to him, and they [the doctors] couldn't find anything wrong. We thought he was losing his mind or something. I thought he was just getting lazy... I couldn't understand why it [the disease] affected him that way. It doesn't affect other people that way. When he quit work, he just all of a sudden quit everything."

Husband: "I didn't have to push myself anymore. I worked for a year after I first found out about it. It was hard on me when I quit, getting used to not working. At least I had something to do every day. When I quit, I didn't have anything, and at first I didn't have disability. For 6 months, we didn't make a penny. I was worried about that, and I felt bad because I was sick."

Researcher: "Did you tell your wife that?"

Husband: "No, I kept it to myself. She knew about the money problem though."

Wife: "I got resentful because he wouldn't try. The neurologist said, 'It's your attitude and how you face it,' so I kind of blame it on him. If they told me that different people would react differently, it never reached me... I quit being a wife. I became a nurse."

Husband: "And I became a patient. I stopped being a husband."
Wife: "I don't think he really did care about anything at that time."
Husband: "Yeah, I didn't at that time."
Wife: "I felt like life was over."

This couple also responded to the diagnosis of the husband's M.S. by grieving. The wife denied the seriousness of the illness and blamed it on the husband's attitude or even on his laziness. He responded to the diagnosis and his forced retirement with despair and feelings of uselessness and hopelessness which sent him into a rather lengthy depression he was just then coming out of.

An additional couple was in their 70s. The husband had a stroke four years ago. They said:

Husband: "Uh, it has been, uh, of course it was traumatic, and it, uh, we, uh, it shocked both of us and until both of us learned to adapt to it a little bit and began to realize what was involved in this stroke, it was very stressful. And, uh, very, uh, uh, stressful on the marriage because she was inclined to think that I was, that I wasn't-- She resisted the idea that she was going to be married to a man who was going to be severely handicapped, which is natural, and so I sometimes say that when a man has a stroke, the whole family has a stroke. And so she, uh, she had a hard time accepting the fact that I was really disabled and that would make her, her-- and she acted in good spirit, I mean in good, with the best of intentions, but she would make harsh demands, I mean harsh demands of me that I couldn't fulfill in terms of walking or being independent of the cane or doing things that I couldn't do, um, because I was giving it my best shot."

Wife: "Well, I wanted him to walk. I still think he can. [laughs] I, I still believe he can walk better than he walks, but this bothers him, so I've quit talking about it to him. You know, I mean, you know, he says he can't, and maybe he really can't.
The therapist thought he could, and I thought he could, and I tried to continue what they were doing when we got him home and so he resented that. . . . He felt like I was demanding the impossible for him to really work at this walking like they had been training him to do. . . . He said 'I can't do it. . . . I've tried the best I can,' which may be true. But anyway, so we finally just, I just, you know, I don't push it anymore because he doesn't want to be pushed anymore, so we called a peace treaty on that."

Husband: "Well, we, um, we've had by way of background, put it in perspective a bit. . . . We've had a very contented fulfilling marriage, a very happy marriage, very good marriage. . . . I just got bitter and hostile at this. I'd try to walk around the room and it was a constant flow of negative criticism of, 'Why didn't I do this this way, or why didn't I do this this way', and so a man wants love and support and tenderness and endorsement from his wife and, uh, all of a sudden I was kind of married to a First Sergeant, you know?"

All three of these cases demonstrate examples of the husband and wife's being in different stages of the grief process at a given point in time. The denial of one spouse clashed with the despair of the other one so that the result was increased marital friction or withdrawal.

The parents of a 15-year-old blind, deaf, and developmentally delayed diabetic child had very different methods of coping. This husband is now deceased, so the information was provided from the mother's point of view.

Mother: "R [son] is very severe; he probably functions from a 3 to a 6-month level, you know, but through the years we went to the Child Study Center for about 2 1/2 years, I guess. Well, he started there when he was 9 months old and then he went there 'til he was about 2 1/2 or 3 years old . . . and a group of us parents, well
they-- Then they switched us over to the public schools so we had a homebound program the first year. . . Then a group of us parents got together and decided we wanted a classroom for these, you know, so we all converged on the schoolboard. . . ."

Researcher: "Was your husband involved in this too?"

Mother: "Well, off and on. I mean, now he, he had a lot of problems dealing. R was his, his only son. [Husband] was the last boy in his line, in his name, you know, his family. So, virtually, it ended with him. You know what I'm saying?"

Researcher: So R was the first child for both of you together; he was an oldest son, the only person to carry on a line?"

Mother: "Right, and that was very very hard for [husband], for his Dad. He, uh, he just, you know, he couldn't handle it."

Researcher: "So, what did he do?"

Mother: "Well, he would drink. He, uh, which he drank before we were married, but he, uh-- I got involved in the Child Study Center and was going, like, to a parents' group; tried to get him to go. He just, he just refused. He said, 'Ah, you're going to see your shrink.' I said, 'Well, call it what you want to,' you know, 'It's probably what's helped me keep my sanity.' But he would not get involved. . . ."

Researcher: "So, instead, to cope, he turned to just sort of getting away, escaping through alcohol?"

Mother: "Right. . . . We were going down hill fast. [laughs] You know, 'cause here I was, I mean I had to take care of R. He was total care, you know . . . round the clock care. . . . I'd have to set the alarm like every 4 hours 'cause he had
episodes of low blood sugar and I'd have to get up . . . and feed him so it didn't leave a whole lot of time for me and [husband]."

Researcher: "So, was that part of what it was; he felt neglected? All your attention was going to this baby?"

Mother: "I think maybe that was part of it."

Researcher: "Do you have any sense of what else maybe contributed?"

Mother: "I think it was a combination of everything: the financial aspect, the fact that, you know, it was becoming more evident how severely involved R was. And I remember one time, in particular, we took R to the doctor and the doctor said, 'Well,'--How did he say that about his testicles? Something about-- Well, what he meant, in a sense, was that, you know, he would never have any children, which looking at R, you'd know he wouldn't anyway. . . . But that really preyed upon [husband], you know, 'cause he mentioned it several times, you know."

These couples clearly were faced with grieving losses. Each handled the grieving process differently. Despair, denial, and anger were all present. Each partner may also be grieving different things, for chronic illness creates many losses. One such loss has to do with the image an individual holds about himself. Someone who views him/her self as being a specific type of person in terms of activities performed, job performed, appearance, or status may be devastated when chronic illness robs that from him/her. A spouse who values those characteristics may, likewise, feel the loss. Restrictions of one's physical activity seems to be one of the most frequently mentioned losses, although not necessarily referred to in those terms.

One older couple is coping with the husband's congestive heart failure and cardiac electrical conduction abnormalities as well as with prostatic carcinoma.
This man may be in the stage of denial regarding his illness, although the heart disease was diagnosed 4 years prior to the interview. He and his wife lead nearly separate lives and, in fact, did not really interact much during the interview itself. Both were strong-willed individualists who have finally simply agreed to disagree about many issues after having been married for 57 years. The main problems they acknowledged involved his physical limitations, his reaction to that loss, and his wife's reaction or concern regarding his loss.

Wife: [reporting on the visit to the doctor and initial hospitalization] "I said, 'Doctor, how important is this?' and he said, 'Well, we know what's going to happen; we don't know exactly when it's gonna happen, but it will happen.' He said, 'It may be a week; it may be a month, but I don't think he can make it a year.'"

Researcher: "We know what's gonna happen?"
Wife: "Well, he's gonna die."
Husband: "Well, I just needed a pacemaker."
Wife: "Well, that's it if he doesn't get something done."
Researcher: "So, prior to that time, you both had been healthy, hadn't had any health problems at all?"
Wife: "No, we hadn't had any trouble at all. We'd just had routine physicals. . . ."
Researcher: "So what was it like finding out suddenly that--?"
Wife: "Well, we were just going to do what the doctor said."
Husband: "Well, it didn't bother me. I didn't think I was going anywhere."

[later in the interview]
Wife: "The electrical system to his heart was worn out . . . but we learned later that the heart muscle was about gone, too."
Husband: "Well, I put fertilizer on my lawn today, so I'm all right."
Wife: "Ah, it just kills ya; it just wore ya out."
Husband: "Yeah, it wore me out; I don't have any energy."
Researcher: "How do you deal with that?"
Wife: "You take one day at a time, and you do what you've got to do that
day and wait 'til tomorrow, and you go right on from then on and never look back.
. . . I don't think we worry. I know I--"

Husband: "I never did worry too much about it, no, I just-- What's going to
happen's gonna happen, and I never have worried about it."
Wife: "Well, it was a worry. Well, it was for me, but I knew I just was gonna
do what I had to do. . . . You get tired, but you don't think of stress connected with
it. . . . I was physically tired, but I didn't have time to be stressed out. . . . He kept
pushing himself and doing what he could, but he was very discouraged a lot of
times because of his lack of strength, and he worried about his lack of strength."

Husband: "Worried because I couldn't do anything. I didn't worry about it,
but I, I just couldn't do anything."
Wife: "Well, it bugged him. I don't use that word 'worry'; he doesn't like
it. . . ."

Husband: "I'm 78 years old, about 78 years old, so I'm not supposed to do a
lot, I guess."

The researcher inferred from this that this husband considered himself to be
strong and capable and downplayed his illness and limitations and his emotional
responses to these limitations. His wife, likewise, minimized her worry and "does
what she has to do." This couple spent little time together. He still spent 3 to 4
days at his ranch while his wife stayed in the city. They were together in the same
house on weekends but appeared to interact minimally, yet they still reported engaging in some activities together, and they did go out with friends.

Wife: "This is just how we choose to live, and so he just goes his way and I go mine. He likes the cattle and the land and stuff, and, well, I'm involved in church work a lot and have a lot planned. I'm involved in what I do and then we see each other on weekends. I don't think we worry; I don't think there's a lot of stress."

As stated earlier, this couple may deny their stress and he may deny the seriousness of his illness, yet this denial, or perhaps fighting spirit is a better term, may also contribute to his longevity. His doctor told him he could only expect a year; he has lived four.

The wife of a diabetic with neuropathy stated:

Wife: "... He's mad 'cause he can't work like he wants to; he can't do things he used to."

Husband: "That's true, I am mad. I'm not denying that."

Wife: "He can do things if he does a small amount at a time and rests. But he won't do it; he wants to do it all at once. He won't do a little bit at a time and rest."

Husband: "Yeah, you know why? I don't know if tomorrow's gonna be there for me. I may not be around."

Wife: "Uh-huh, but you can't do that..."

It's difficult for a person to give up one's way of living and to adjust to being sedate when one has previously been active or to being dependent when one has been capable and independent. In our society, working is equated with value. If one makes his/her own way in the world, then he/she is an adequate person. The more money one makes, and the more status one has, the more valuable one is
seen to be. While the sick-role relieves one of responsibilities (Parsons, 1951), it also alters one's status in society, an enormous loss. It may be that some or much of the "noncompliance" which frustrates health care providers may be attributed to the difficulty patients and couples have in adjusting to this loss.

**Giving up the dream**

Various couples discussed how dreams and plans were altered as a result of the illness. Often couples have dreams: of having children, of retiring to a country home, of traveling, of living their life with an adequate income which would allow them to live at their planned or desired standard of living, etc. The list of altered dreams or expectations is nearly endless. The following couples discussed their illnesses in terms of some of those losses.

The couple who has the child afflicted with Hurler's Syndrome is one such couple. The wife reported, "... One of the two decisions we had to make, or I felt we had to make, was the part of not having any more children. We both carry the gene. I knew I could not have another child. The chances were-- There was a 25% chance that any child would have this disease, so I don't really think I fully grieved that, but added to the grief, I, I no longer could conceive and have any more children on top of the fact that I'm losing one..."

One couple spoke of being unable to enjoy their vacation home. He had a head injury and a stroke in the past year; she had surgery for colon cancer. "We own a place on Lake Texoma and up until this year, we went back and forth a great deal during the year. We had a boat down there and we loved to fish... We have friends down there who are retired and do the same thing that we have always done, but as I've said, we haven't got to enjoy that this year."
Another man dealing with the loss of his sight said, "I had really prepared myself for retirement. I had several hobbies going. One was woodworking; I really enjoyed woodworking, but after I lost my vision, I couldn't use my power machinery, so I had to give that up." His wife added, "One of the things that when he retired we had made great plans to borrow, I mean build a home in Colorado. We have five children, and grandchildren married so there's . . . 34 of us, so we decided that we wanted to have a home in Colorado and that would be the kids' main inheritance. . . . So immediately after he retired in June, we went to Colorado and built this home. So each summer we go up and spend the summer. We also go in the wintertime; used to be twice we'd go, but we haven't the last couple years. . . ."

A man, 4 years after his stroke, described it this way; "You're projected into a whole new realm psychologically, and in my own mind, I divide my life into before stroke and after stroke. And there are certain roles that I used to play, certain activities that I used to enjoy that I just think about now and I just say, 'Well, that was before stroke, so forget about it. Why that's out of my life.'"

Another woman who has severe cardiac disease and who loved to go to garage sales said, "There are a lot of things I can't do that I used to do. . . . My hobby is garage saleing. Well, I've lost that. And he [husband] has no patience with my garage saleing at all, so there's not much chance of him helping me garage sale, and my daughter don't like it so, so far, I haven't been able to. Come spring, I know I'm gonna miss it. . . . You can't-- And if you think of something at the store, I can't jump in the car and go for it."
Sexuality and intimacy

Some respondents mentioned the loss of physical expressions of affection and sexuality as a loss associated with the illness. However, this was not a major concern for most, perhaps due to the older ages of many of the respondents. Some couples did, however, discuss the loss of this aspect of the relationship as a major concern.

One wife stated, "A year back or 2 years back, I talked with his case manager and his doctor there, and we sat down and had a session one day. So for different reasons, medication I assume is one of them, our relationship has been platonic for a number of years now. And I expressed that day that maybe, that part of how I was feeling-- Do you remember when I talked when we had that meeting?"

Husband: "I know the meeting; I don't know what you said."

Wife: "Well, I expressed to some degree of what I'm saying here today, [pause] that I felt I needed a little more. And it seemed like [husband] didn't quite understand what I was saying, . . . what I was all upset about."

Husband: "I still don't know what you're upset about."

Wife: "I wish there was more closeness. I think the medicines that control the mania and so forth have caused a quieting of the emotions. 'Cause I get all excited about this or that, you know; this is going on and, you know, and it's like I get no response, you know, to what I'm feeling . . . and, dammit, I want some kind of response." She is 42 years old; he is 52.

Another couple, now in their 60s, reported that the quality and frequency of their sexual relationship and their display of affection for each other decreased greatly during the early phases of her illness. She stated, "Everything became
difficult. I would cry because he just didn't understand, and he would be angry. We pulled away from each other."

Another wife (50 years old) stated that the loss of the sexual relationship did not bother her.

Wife: "We always had a very active sex life together before he got sick, but that [giving up the sexual intercourse] really doesn't bother me. What I miss is the loss of the intimacy and the physical affection."

Husband: "I miss the sex and the affection. The doctor told me I probably couldn't have sex because the illness [M.S.] will affect me." For this couple, not only did the physical illness affect their sexuality, but the husband responded to his illness by becoming severely depressed so that all affection and even communication between them ceased. For the wife, it was the loss of the intimacy, not the sex, which was devastating enough to precipitate the onset of a depression for her, also.

Likewise, another wife in her 40s stated that their marriage had always been "kind of unique, less physical and more a meeting of the minds, intellectual. The biggest loss has been the intimacy, not the sex."

One of the couples (in their 40s) who has been affected by severe diabetes with complications gave the following rather lengthy report on the nature of the sexual complications of the illness and how they cope with it.

Husband: "We used to have a pretty good sexual relationship, but because of my diabetes I have problems with impotence. I've had surgery, but I got infection and they had to remove the implant, and I have to wait 'til January 'til they can try again. Because I came from a family where the word 'sex' was forbidden, the things I've learned, I learned on my own, and because of that I'm not really that
sexually motivated. We had a good sex life. Since I've had my heart surgery, that's when it really started. I think a lot of times, she gets frustrated because we can't have a normal sex life. We try the best we can... but because of me not knowing what it was like to discuss sex in my home as I was growing up, I don't know how to do things that I guess married couples are supposed to. I'm old fashioned."

Wife: "But he thinks that it bothers me, and it doesn't. I think that's what attracted me to him maybe to begin with, was that he, he really wasn't that sexually oriented because that always went with-- My ex-husband was the type that, you know, every night, and it was just one of those things that when [husband, J] and I met, and he wasn't that way, maybe it made me feel that I had some freedom, and so now, I mean, I enjoy everything the same as everybody else, but you know it doesn't bother me now."

Researcher: "So he's more worried about it than you are?"
Wife: "Yeah, he's more worried about how I feel. And another thing, I feel like I'm getting older and it's not as important as it was like when we were younger."

Researcher: "So are you able to talk about these kinds of things, then? So you both know if you are or are not bothered by something?"

Husband: "I don't have any problems discussing it with anybody. I've discussed it with the nurses in the hospital, and with my doctors.
Wife: "Now, I don't."
Husband: "I feel like it's a natural part of our life. I feel I'm inadequate, at times, because I can't have the kind of sexual relationship that I would like to have."
Researcher: "Sounds like it bothers you [to husband] more that it does you [to wife]."

Wife: "It bothers me at times, but not all the time, you know. It, it does bother me at times because sometimes, you know, there are times when I just really get bothered over the fact that, that we can't do anything, but I'm not that way all the time, because I try to, I try to just put that in the back of my mind and just go about my business and do other things and forget about it, you know, because I know that he can't do anything, you know, and so I just try to, you know, forget about it."

Researcher: "So this is another area where there could be a wedge formed between you, but it isn't happening."

Husband: "She realized that I can't do anything about it. Uh, I am trying, and we are going to have a different relationship, but it's going to take time. Even if I have surgery the beginning of January, it will be March before we can have any kind of normal sexual relations. It isn't a situation-- Like some people would probably say 'Well, he can't perform, so hit the road.' Well, that's not the way it is. We have to accept the facts. We do have a sexual intimacy, a few moments, that they suffice. It's not the best in the world, but it shows that she loves me and I love her. We're capable of having, let's say, a love affair without the sexual intercourse."

Researcher: "So you're saying that love is more important than sex?"

Wife: "Oh yeah, as far as I'm concerned."

Husband: "I think that's the biggest thing, that you love each other. If you don't love each other, you might as well hang it up."

Wife: "But see, you have to understand that this wasn't an immediate thing. It didn't just happen all of a sudden like this. It was a gradual thing because from
the time he started getting sick, his sexual ability started going down hill too, and so it wasn't something that just kind of came on immediately. Had it been that way, maybe I would have had a different attitude towards it because I wouldn't have understood it, but I did understand it because of the fact that I knew he was ill, and I knew that these things were affecting him."

Another elderly wife put it this way: "If you have faith, you know things are going to be okay. It keeps you close together. You, uh-- In your later years you don't make love like you did in your younger years, but it seems as though that's a part of growing older. But that doesn't mean we still don't hold hands and kiss and, um, love each other and respect each other, you know." For this couple, the alterations in the sexual relationship were attributed to aging, not to illness, and were accepted.

Many of the couples did not even address the area of sexuality as a part of their concerns around chronic illness. A few stated that sex was adversely affected as the entire relationship was adversely affected. It did not seem to be a major issue for any of these couples interviewed, even those whose sexual relationship was entirely gone. It was the loss of physical affection and/or intimacy which was the most important factor. Perhaps these findings would have been different if the couples had been younger or had fewer years together in the marriage. Or, it may be that when the issue is compared to the continuance of life itself, it may pale into the background. Several couples addressed the issue of dealing with life on a day to day basis, very aware of the fact that their life together is very likely in its last phase and that death may likely occur in the near, if not immediate, future.
Thoughts about death

Several couples brought up the issue of death. No one really expressed a fear of death, but many expressed a hope to put it off for as long as possible. Death was treated as an inevitable and as one of the many losses which must be prepared for.

A woman, ill with cardiac disease, stated, "[The doctor] said that they'd expect me to go anytime just like that. Well, you know that we're all going sometime, and you don't know how soon, so I really didn't, I did a few things that I knew needed to be done. I still got things that I need to get taken care of. . . . I don't think I have ever dreaded death. . . . Of course one-- I did-- I wanted-- I always wanted to live long enough to see that my children were raised because I didn't know of anyone else that I would rather have raise them, you know. . . . So I've raised 'em, and they've got their lives good and settled. Of course, I'd like to see those grandkids get a little older, but whatever's to be is to be. I know at a church meeting this one time, they discussed the fear of death and all of the ladies that talked said that they had a definite fear of death, and I said I didn't, and they acted like I was a weirdo, so I didn't say anymore about it. But I don't know, heaven is supposed to be so much better than here on earth, but sometimes I wonder why we struggle to stay here on earth so long."

Husband: "I know I can't see being scared of dying. I mean, you're going to someday."

Researcher: "Okay, so death itself isn't something that scares either one of you."

Wife: "I think it's sad when somebody young goes, but then they say that if uh, uh, that there's, that if they had lived, hard telling what had been ahead of
them, a lot worse than death. And I think that could be true, that a lot of times when
they go, it's sad, but it could be a blessing that you haven't seen. . . ."

Husband: " . . . He [doctor] said she could have one of those attacks again
just anytime. There's just no, nothing we can do. All we can do is just try and
control her heart rhythm and her heart the best we can. . . . He said she could go
on and live for a long time, or it could happen anytime."

Wife: "You can't just think 'Now today's my last day.' That would be
miserable. 'Cause I'll probably make it past today, you know. Your attitude
controls a lot."

So, although this couple did not fear death, each was interested in
postponing it for as long as possible by seeking medical care and maintaining an
attitude believed to be conducive to promoting life. One of the couples dealing
with multiple health problems stated:

Husband: "It bothers me when I, when they tell me something, and I wonder
how long it will be before I go. How long is it going to be until I end up with another
life-threatening situation that will be another life-threatening problem? How long
will it be before I get cancer, before I have another heart attack? Tension and
more anxiety--"

Wife: "I have to think in my mind, 'Just live each day at a time'; that's all I
can do. That's all I can do because if I sit around and dwell on it, I'd go crazy!"

Husband: " . . . I think we're closer to one another because we never know
when we, when it will--"

Researcher: "So you appreciate each day and are closer because you
don't know when it will end?"
Wife: "I think so, and I think you have to live each day to the fullest. You have to get up in the morning and say, 'This may be the last day,' in your mind say, 'This may be the last day that you see each other and Lord, if it be thy will, give me another day,' and that, that's how you have, that's how I feel about it. And that's what we do and we seem to get along better that way."

Husband: "... I'm not afraid to die. If today is my last day, then I've had a good life with her. And if I wake up tomorrow morning, and I'm allowed to get out of bed in the morning, I'll have a good day. It's still a good day. I can't-- I don't sit and dwell on it either, because if I sat and dwelled on it, it would kill me. It absolutely would kill me. And every time I go the the doctor, I just-- Sometimes I get angry every time I go the the doctor and they tell me I've got something else going on. If I live for ten more years with this diabetes, I've already been told that chances are that I will end up with kidney problems. . . . Chances are that I'll be on a dialysis machine . . . I'm not going to sit for the next ten years and worry about it. I can't. I turn around and take each day like she says. I don't worry about it. I don't try to make plans for anything in the future because I don't know if I'm going to be here. I just take one day at a time."

Death was also mentioned by some of the other subjects, for example the parents who knew that their children would not live a normal life span but did not have any clear idea about when to expect death. For them, it's something that was always there at the back of their thoughts. Anticipated grief is a commonality for all those where the chronic illness is going to result in death after a probable shortened life-span. When the illness causes severe disability and discomfort, some even look forward to it. This was not acknowledged in a direct way, but was indirectly "thrown out" in passing. One woman stated, "If it's going to be like this
the rest of the time, then I hope it can end soon." Another man affected by respiratory problems said, "I get-- Even though I don't think, I don't think I would ever do it, but I-- There's always that fleeting time when you get so disgusted that you'd like to, you know, get it over with."

Attribution of blame was another important consideration for some.
Decreases in the level of intimacy and in marital satisfaction correlated with attributing blame for the illness or disability to one partner. This is the focus of the next section of this paper.

**Attribution of blame**

Attribution of blame appeared to be a factor for some in how well the couples were able to adjust to the changes necessitated by the illness. Attribution of blame was a theme which emerged for every couple who had an ill child. The couple with the child disabled by cerebral palsy spoke of being questioned by health care providers about life style patterns which may have contributed to the problem.

Wife: "Well, they came and took samples of me and they sent the placenta off and everything, and the only thing they found out was that his blood only circulated 20% of what it was supposed to of. I don't know. The cord wasn't pinched. They just don't know what happened. We don't smoke. We don't drink."

Husband: "There wasn't no bacteria."

Wife: "There was no bacteria, no holes in the placenta. We don't drink; we don't smoke; we don't do drugs. We're about as square as you get. And they told us then it was just a freak thing, you know."

Researcher: "Essentially, no known cause."
Husband: "We never did anything to make him like that because there was nothing we could have done, you know, like smokin' or drinkin.'"

Wife: "They're times--"

Husband: "We might of, but we never did."

The couple with the little girl with Hurler's Syndrome stated the following:

Husband: "We have never blamed each other for M's [daughter's] illness, nor have we blamed anybody else. Like at times, I question God, but I don't blame Him for it. I mean, we blame sin, but that's not an ingredient that we have had to deal with. And I think that--"

Wife: "We were very thankful."

Husband: "I think that would have been very difficult."

Researcher: "Okay, do you think that [the issue of blame] was avoided because that's a recessive trait so that you both needed to bring--"

Wife: "Right."

Husband: "And we-- Yeah."

Wife: "Some diseases the mother carries; the mother is the contributor . . . but there are some diseases that the problem gene, or whatever, comes from just one person, and M's is just not that case, and, uh, there is no, absolutely no way of knowing you have this recessive gene . . . so I really honestly don't feel like that anyone could take any more blame than the other for that. . . . You know I don't, I don't feel guilty. Uh, I don't think I-- There was nothing that I could do or I-- We neither one had any control over it that I know of. . . ."

And one mother with a mentally handicapped child may place blame with her ex-husband or the physician who delivered the baby for her child's problem.
Wife: "[Son, C] has had his situation since, since he was born. They really couldn't figure out, you know, if it had to do with his natural father being on drugs or whatever-- if he was, it was unbeknownst to me-- and, or if it was, you know, a physical attribute or, I want to say organic but that would not be the right word, or, or if it was done by outside interference. We're still having problems with that because the doctor that delivered him came into the delivery room in an interesting state. . . . You can feel the forceps' indentation on each side of his head."

The mother of the teens with growth hormone deficiency stated, "Sometimes I blame myself saying, 'Well, if I hadn't had the kids, maybe I wouldn't have to have put them through this,' you know, that it's unfair for them to suffer all the time. I want them to be, like, you know, like all the other boys you know, big and strong."

Researcher: "You feel guilty and depressed sometimes because of the problems they have to handle. [To husband] How do you handle it when she's feeling guilty and depressed?"

Husband: "Well, really we kind of both, because of our--"

Wife: "I'm not going to blame it on him. I blame it on myself and he doesn't like that. . . ."

Husband: "It's something neither one of us could help, you know, but we feel a little guilty about it, but there was nothing we could do about it so--"

Wife: "And he [son] blamed us. That's what hurts, you know. Your kids say, 'Well, it's all your fault.' You know, that's what's really hard to handle when they say that and mean it with that anger, when he's mad."

The other mother with the child who has severe mental and physical handicaps, likewise, looked for what or who is responsible. "We went for genetic counseling and for the genetic tests, but evidently it was not genetic. I think when I
was pregnant with R, I had the Swine flu vaccine. That's the one that killed all
those people and paralyzed 'em, but I can't prove that."

Researcher: "But it was something prior to birth?"

Mother: "... They feel like he was born with some of his problems. ...

The couple with the teen with neurofibromatosis stated:

Wife: "I think we have pulled together instead of, you know, instead of well,
you know-- Well, if it hadn't been-- Well, I don't know how he feels, but I could
blame him, you know, for the child being in that condition if I thought, well,
somebody in his family had it. I could say, yeah, you knew that it could--"

Husband: "Well, I could do the same thing, too."

Wife: "Well, I knew that nobody in my family had it either. See, he could
blame me; we could blame each other. But I haven't; I don't feel like it's his fault.
It's just something, a birth defect that happened."

Researcher: "Was that a part-- Was that a stage that you went through
wondering if the other one was responsible for the problem?"

Wife: "Yes, because my oldest sister, she was-- Oh, and I asked my aunts
and uncles, you know, when we found out what he had. Well, some of my
mother's people were still alive and some of my dad's were still living, and they
couldn't tell me anything; and his mother is still living, and she said she didn't know
anybody that had this disease. And, of course, we didn't know anybody that had
this disease.... There wasn't nothing."

Researcher: "So the blaming was something you sort of explored but there
wasn't anything so you never blamed each other?"

Wife: "There wasn't nothing, so no."
Attribution of blame or responsibility for the illness also played a part of the process of dealing with the illness for some of the couples with an ill spouse. Two marriages in which the husbands were brittle diabetics demonstrated a contrast on this issue. There are many similarities between these two couples in terms of the number of years married (23 and 26), their ages (48 and 52 versus 44 and 46), the severity of the illness itself and the complications which accompany it for each of them, and even some aspects of their psychosocial histories. Yet, in terms of marital satisfaction, there is an extreme difference between them, more than the differences in the scores of marital quality given by the researcher. Both husbands are quite focused on their illnesses, but the wives responded to the illness and to their husbands quite differently. The husbands also responded to their wives quite differently.

The first of these couples dialogued in this manner regarding the issue of blame or responsibility for the illness in its present state:

Husband: "I feel like nobody even tries to support me, you know. My wife, she doesn't. I'm not asking her to make me well . . . ."

Wife: "I go to work, I come home so you can bitch. . . . That's all he does is complain 24 hours a day. . . . He bitches about his past too. . . ."

Husband: "I have no future and there's nothing nobody out there can help do."

Wife: "But like I told him, what time you've got left, why don't you make it happy instead--"

Husband: "Yeah, why don't ya all, why don't ya--"

Wife: "Live one day at a time."

Husband: "What she's--"
Wife: "He says you can't do that."

[later in the interview]

Husband: "Look at my blood sugars yesterday [shows the researcher a list of values].

Researcher: "They go up and down; they're real erratic, aren't they?"

Wife: "That's 'cause he don't eat what--"

Husband: "I can't eat; it's not because I don't eat. I can't."

Wife: "He gets up and eats sweets; he ain't supposed to do that."

Husband: ". . . I know what I'm doing with my diabetes. I've had to learn to take care of my own self."

[he takes a blood sugar reading]

Husband: "You know how low it is? It's 40. That same thing happened last night."

Wife: "Why don't you take something for it instead of talking. . . . Do you know what his problem is? He knows everything and nobody else knows nothing."

This couple argued throughout the entire interview. They did not listen to each other, but instead attacked and counter-attacked. Yet, it seemed evident that the wife was concerned about her husband. She believed that there were things he could do differently to improve his condition. She attributed responsibility for his difficulties at least partly on him and believed he had some control that he did not exert. Her good intentions came across to him in a very negative way, however, and he felt attacked instead of supported. This was a long standing pattern between them.

The other couple, however, exhibited a different pattern. Although she sacrificed many of her needs in favor of his, she did so because she believed this
man to be "a saint." The following provides a glimpse into the process of their relationship as it pertains to the illness.

Wife: "He can't help it that his health went down hill. I mean that's not his fault that that happened, you know. . . As far as I'm concerned, this man's a saint. I mean, as far as I'm concerned, he's a very good man. He may not be able to go out and go to work, but he's never laid a hand on me in the 23 years we've been married. . . . I will say that I do get tense and I get stressed out over his illness . . . I just love him. I mean, his, uh, his sicknesses don't have anything to do with it. They don't have a bit of anything to do with it. I'd love him if he wasn't sick, you know, that doesn't, he can't help that. . . ."

Throughout this man's many depressive episodes, his surgeries, and his numerous illnesses, this wife never once questioned whether there were any things her husband might do which could improve his health status or at least maintain it at its present level. She was not critical and had consistently offered positive emotional support.

Attribution of blame could have played a role in other cases where it did not. Certainly the woman whose husband suffers from chronic obstructive pulmonary disease could be angry because he continued to smoke even after he began to have symptoms of difficult breathing and shortness of breath. She had also been a smoker but quit, while he continued to smoke. Yet, there appeared to be no blame for the illness associated with their current marital difficulties. Rather, she grieved the loss of the relationship which had resulted from his significant physical limitations as well as from the difficulties they had in communication of emotional and relational issues even prior to the illness. He stated, " . . . When we first got married, she had asthma real bad. . . . She can sympathize with my physical
She knows how it is and can't do anything more than what we're doing, and that kind of gets her frustrated, so it gets her kind of stressed out and upset. Then I get upset. I'm usually the first one to start it. We'll have one of those loud, uh—Well, I'll tell ya, I get to bawling and squawling; I break down... the mental stress gets me."

She said, "I understand where he's coming from, but I get frustrated. He thinks of his needs first. We always had kind of a unique relationship; it was more intellectual, less intimate, more a meeting of the minds, less physical. The biggest loss is the lack of discussion about topics of interest. I don't tell him that I miss him."

He said, "I feel I have a total dependency on her to see to all my comforts... but that's not really all of it. It's personally just being there, being with her to sit and talk. We don't get to do that very much, but I guess—Well, we never were very—I never was a communicative type person. I didn't know how to communicate to my family. I could talk all day long... but I don't know how to talk to my family. And that's what hurt us all these years... I just didn't have the ability to communicate with my own children... my own wife."

Blame was not a factor for this couple; it was the inadequate communication skills which prevented their intimacy. When blame or responsibility was attributed to one party, however, it appeared that it made adjustment more difficult and marital satisfaction declined.

**Role and power changes**

When the spouse is the person with the chronic illness, especially when that spouse has been the primary breadwinner or decision-maker or manager, role changes are significant and sometimes difficult or challenging for the couple. The
end result frequently is advantageous, offering the spouses a new respect for the partner and opening up broader ranges of sex-role behaviors for each partner even though initial adjustment may have been stressful. However, there appears to be fewer changes in the power structure of the relationship for many of the couples, even when role performances changed quite dramatically, than one might anticipate. According to resource theory (Blood & Wolfe, 1960), one might expect that the person in control of making decisions, earning the money, or responsible for the care-giving might hold more power or that the power might shift as the person in charge of those aspects of the relationship changes, but this did not appear to be true. The following interview excerpts demonstrate.

Husband: "I've become more, much more dependent...on her and she has had to assume a lot more personal, I guess, responsibility of handling me and working, you know, ... and she's had to take over the duties that I, uh, basically I was performing, you know, as the breadwinner, and running a business, and our daily personal life; she has to maintain everything... And if I get out and go anywhere, I can't drive, so she has to take time off from her job or time that she needs to rest or something... and, uh, look after me."

Wife: "Everything revolves around him. I do what he needs or wants. It's like a mother/son relationship: his needs, his wants. My needs come last."

For this couple, each partner (who was interviewed separately from the spouse) believed the other has the power. Because he was dependent upon her for care and because she had assumed all the responsibilities, he felt guilty or humbled to ask for assistance from her; she felt she had lost much freedom in her personal life because of a duty and commitment to care for her husband.
A man with heart disease and back pain stated: "We don't get out a lot; she just works and, uh, my daily routine is to get up in the morning and take her to work 'cause she doesn't like me to stay at home without a way to go someplace and get help if I need it."

Wife: "If I didn't do that, I'm afraid he would just, just stay totally at home."

[This man has had a significant depressive episode in the past after the onset of his illnesses.]

Husband: "My daily activities are I get up in the morning and I take her to work and go home and then pick her up in the afternoon."

Researcher: "So your position in your marriage changed. You went from being the breadwinner to being the dependent one and you [to wife] became the breadwinner, so you reversed roles in that respect."

Wife: "Um-hum."

Researcher: "Was that also difficult for you to adjust to?"

Wife: "[laughs] Yeah, I worked usually twelve hours a day, sometimes more, and I guess I really got to the point where I just couldn't go any longer. I had to give up one for a while anyway. But, you know, like I said, Social Security is not all that great. I'm glad we've got it. I don't know what we'd do if we didn't have it, but I still don't know how we're going to make it with it, you know. . . . For a long time I worked two jobs. That made it hard on him too, because it was hard for him to handle."

Husband: "Well, it works on you in a lot of ways. I went so long with, uh, with doctors acting like that I was faking all my pain and stuff. . . . It wasn't bad enough that she was having to work and to help support us, it got to the point where she was having to work two jobs and that really worked on me. I grew up
old-fashioned. I'm supposed to be the head of the household and take care of my wife, not her take care of me, know what I mean?"

According to this couple, power in this relationship was 50/50 before the onset of the illness and it continued to be that same way in the presence of the illness even though the traditional male/female roles had been reversed for them. They continued, "We've always-- I mean I've never went to town and bought anything that I didn't talk to [husband] about it and he's always talked to me . . . even with little things. It probably sounds silly, but even when we discuss buying-- I'm going to have to get me some new clothes or something like that-- we usually sit and talk about stuff like that."

An elderly couple also adjusted roles when the wife became ill.

Researcher: "Okay, so your activities and what you can do as an individual decreased and now you [to husband] have started taking up a little bit of the slack doing some of the things she used to do around the house."

Husband: "Oh yeah, yeah. I keep the house."

Wife: "He had already taken over two or three years ago-- well, no, even before that-- paying the bills and things, and uh, and when I came home from [hospital] the first time and the first bills came in, I said, 'I don't want to hear about them; I don't want to see them; I don't want to know anything about them,' so he's took care of all that headache. And it's a headache. . . . Well, I might as well say one thing, it makes a-- If it had to happen to the family, it's a lot better to happen to me than for him. He couldn't handle the inactivity that I have to handle near as well as I can. . . ."

Husband: "Yeah, I can't sit around. It drives me nuts."
Wife: "And there too, he has picked up the slack for me, but I couldn't pick up the slack for him. If it was reversed, if he was unable to do things that I am able to do, I couldn't do all the things that he needs, that needs to be done. . . . 'Course I get a little resentful; the kitchen ain't mine anymore. I truthfully think I can get that back. There are some things I can't get back, but I think I can get that kitchen back."

This couple also had a history of working together, making decisions together, and sharing power. This had not been altered by the illness.

The man who had a stroke 4 years ago stated, "As you get a little bit older . . . you kind of appreciate how her whole world is limited by my limitations and that the fact that none of my stroke friends-- Now some of them, you know, their marriages have broken up and all, and she's remained steadfast and, and uh, I'm very dependent on her, and uh, she's had to shift roles, and I've come to see in her qualities that I didn't see before. I was a, I guess, a very strong leader in the home and so all the financial planning, uh, anything to deal with the well-being of the house-- she's had the car, the plumbing, heating, whatever-- she's had to take the initiative and learn to wear that mantle, which is not very inviting. And so, uh, I think I'm capable of feeling toward her now a greater sense of tenderness and affection."

Although this woman had taken over several responsibilities formerly performed by her husband, she continued to remain her husband's helpmate, assisting him with publications, lecture notes, and so forth which he continued to undertake and giving his "career" priority. Another older couple said:

Husband: "Well, one thing that the illness has caused is that she's had to take over the business, take care of all of our business. I used to write all the
checks and keep all the accounts and, consequently, she had it all to learn, which is bad. If we could have anticipated this, we could have had her learn it along as we went, but uh-- [laughs]

Wife: "I was taking a business course. [laughs]"

Husband: "That part has been a little tough for her, but she does a good job."

Wife: "That part's very difficult 'cause I didn't ever balance the checkbook and I still don't exactly, but I get it near. Well, I had always written the checks and that type of thing, but business is like, well like last night I went in there and got all the checks out. He doesn't even know I did, but I've got them down there getting ready for income tax."

Several other couples also spoke of how their roles changed in the marriage following the development of the illness. The role changes between the couple were, of course, much greater when a spouse became ill than when a child had the illness. The patient typically had to give up some instrumental roles, but also frequently learned to take on other roles in the relationship, many times in the affective domain. Spouses discovered abilities they did not know they had and were typically proud of their accomplishments. Generally the ill spouse was also proud. The researcher found little or no evidence to indicate that the power structure of the relationship changed or that power conflicts occurred when the illness developed in most situations. When it did occur, it seemed to be for only a short duration while in the early stages of adjustment to the illness.

Withdrawal or battle

For some of the subjects, it appeared that the marriages were not without significant dysfunction even before the illness. Although the couples or one
spouse in these examples viewed the illness as the "cause" of the conflict, it appeared to the researcher that dysfunctional family patterns of interaction may have existed apart from the illness itself. This next set of couples experienced stress which was quite possibly not precipitated solely by the illness.

One couple who had two teenage sons, both of whom had a growth hormone deficiency only recently diagnosed and who were both extremely small for their age and had been since early childhood, reported the following when they were asked about how the boys were handling being much smaller than their peers.

Wife: "He didn't like it! [laughs]"

Husband: "He was the smallest one in the room, you know, in the class. It was pretty tough."

Researcher: "Get picked on by the other kids?"

Husband: "Yeah, always being teased about being small."

Wife: "... And then another problem we don't think much about it, finding clothes, clothes that he wants to wear like the other boys have. They don't make them. ... They wanted to hold him back in the fifth grade because he was small. He had the highest grade point average, but it didn't matter. They wanted to hold him back because of his height. ... J, our youngest boy, doesn't seem to have the problems like D [older son]. It doesn't bother him. ... D doesn't cope with things at all. He has a low stress tolerance; he gets mad easy. When things don't go his way or something's hard, he'll give up. When we realized that he was having trouble, that he just wasn't like the others and he was getting put down, then his grades dropped. He wouldn't participate at all in school. ... I went ahead and held him back in the 6th grade 'cause that was the year he made all the D's and
wouldn't do any work. He went from all A's to all D's... back into his temper
throwing, being mean, not liking anyone, himself, or anyone."

Researcher: "And so you two were dealing with stress then?"

Wife: "With him. Yeah, that's where we have mainly our main fights is over
the kids, that's all. We don't have fights about anything else much. ... I argue with,
with the kids, and he doesn't like it."

Husband: "I don't think there's no need in arguing with them. If you tell them,
that's it. That's the way it ought to be. And she'll argue with them. And D will
argue 'till he turns blue in the face."

Wife: "To get his way. Yes, he's stubborn; he's not gonna--"

Husband: "I can't handle it with her, and that's when I just-- I listen to a little
of it, I say, 'It's over with,' and then she gets mad at me. ..."

Wife: "He [son] usually wins with me but he don't with him and then-- And I
know that's my fault, but it's just-- He [father] loses his temper."

Husband: "After so long, you know. That's why I think, you know, just
usually it's whatever he's asking for is, sometimes isn't always the worst things, it's
just, it's the way he says it. ... Well, D is pretty regular about causing fights."

Wife: "If we go a week without some kind of clash--"

Husband: "It's one thing or another. I just bought him a car. He has to pay
his insurance and I'll make the payment. But then two weeks later he quits his job.
So we fight about that. ... We don't fight 'til he comes in and starts something with
her. ... He usually always starts it with her. He'll try to wait till I'm out of the house,
then when I'm out in the flowers or whatever, I can hear it all out there. ' So here I'll
come back in the house, and I'll put an end to it. [laughs]"
Wife: "I don't really know what brings--I know what part of it is. I'm real protective of the kids. I guess I'm afraid something's going to happen to them, you know.... I guess it's because I do not know what to do; I know that. It was because of the way I was raised.... I was sheltered, protected.... He [husband] protects me; he does the same thing to me as I do to my kids."

Here the physical problems seemed to be the focus of a pattern of dysfunctional triangulation among the mother, the father, and the son rather than a "cause" of the dysfunctional pattern. The same behaviors manifested themselves around other topics involving the son such as the payments on the car insurance, for example, but the parents saw them as caused by the son's chronic handicap. Of course, it is also possible that the overprotectiveness would not exist if the physical problem and the emotional sequelae did not exist.

For the next couple, the illness certainly created some dramatic changes in the relationship between the spouses, yet a great deal of the change in roles was created not just by the illness, but by the inability of the couple to communicate their feelings and needs to one another directly.

This next couple was dealing with the development of severe chronic obstructive pulmonary disease in the husband who had been disabled for 3 years. He used oxygen constantly, and his physical mobility was limited to his wheelchair. I initially contacted this wife by phone when she answered a newspaper ad. She was willing to speak freely, but seemed somewhat reluctant to have her husband speak with me because she didn't want him "to get stressed or tired." When I explained that I needed to talk with both of them, an appointment was made to meet both at their home, but the wife was not present when I arrived for that interview. I interviewed her later in more detail on the telephone after I
conducted an individual interview with the husband. It appeared to me that the wife wanted to speak separately from her husband.

Wife: "There is no marriage. It's like a mother/son relationship. Sometimes we can communicate and sometimes he's so self-centered with his illness that he can't focus on anything else. The biggest loss for me is the intimacy. There's no one to talk with and no one to put their arm around me and say 'Okay.' I understand where he's coming from, but I get frustrated. He thinks of his needs first."

The husband said, "As far as our personal relationship . . . I guess in a way it's kinda deepened that bond in a sense as far as feeling, I guess, more responsible to her than I have in the past. Uh, of course she comes in from work tired, and she wants to sit and rest, and a lot of times, I, I gotta have something done. Of course, she gets aggravated at that point, if she's tired, and she'll-- To me that sounds like she can answer me in a resentful, which means she resents having to get up and do something for me. . . . It's the tone of her voice is the main thing. I, I, I-- She may not even be short with me. It's just that she can say-- I can say, 'Honey, do this for me' so she'll say, 'Okay' in kind of a sharp tone that sounds like she's doing it in a resentful tone. . . . I'll tell her, 'Well, if you don't want to do it, forget it. I'll do it myself' or 'I'll get somebody else.' Then she really gets mad [he laughs]; then she'll, yeah, you know, comes back like, 'Well, you misunderstand everything I say.'"

Researcher: "Your feelings are a little hurt when she uses that tone of voice?"
Husband: "Right. That's what I'm trying-- I guess that's what I'm trying to say. I just feel-- It makes me feel like well, she don't really care whether she does it for me or not . . . like she's, 'Well, I just wish you'd go away.' . . . Well, you really get in-- I get-- Well, stress boils, breaks up in me where I, I'm frustrated and I cry, and at that point I become totally stressed where I-- 'till I wish-- I sometimes make the statement, 'I'll go ahead and blow my head off and get it over with and you won't have to worry about it.' You know, it drives you to that, to that feeling, and I guess I say it more to hurt her and look for sympathy . . . but I'm darn sure not gonna do nothing like that."

Both the husband and wife identified long-standing problems which existed prior to the illness with communication and in the amount and quality of time spent together in their marriage. Yet, they remained with each other because the most important need each had was fulfilled. She wanted an "intellectual relationship." He wanted someone he could trust implicitly and who he knew would always be faithful and "there" for him. Their lack of ability to communicate their feelings and needs to each other certainly contributed to the difficulties which seemed to be present with the illness.

The next couple had been married for 26 years. He had had diabetes for 14 years, currently had a gastrostomy tube, was being treated for depression, and suffered with diabetic neuropathy. He attributed his marital problems to his illness. This is their report:

Husband: "I feel like nobody even tries to support me. You know, my wife, she doesn't. I'm not asking her to make me well . . . ."

Wife: "I go to work, I come home so you can bitch, and I go to work and I come home and listen to ya; that's all you do. That's all he does is complain 24
hours a day. . . . He bitches about his past too. He brings up his past, his brothers, his sisters, my brothers, my sisters, what all they've done. I've told him, he can't live his past. You got to live for today and tomorrow, and whatever's behind you is already gone; you can't correct it."

Researcher: [to wife] "So when you say something like that, you're trying to be helpful to him, but it doesn't seem helpful to you [directed at husband]?"

Husband: "When I get low sugar like I did yesterday, yes ma'am, I do get mad. And with the combination of pills, she thinks it's too much. . . . I've been addicted to some type of medicine, oh, I believe, since I was 29 years old. They've had me on every different kind of thing imaginable . . . but when I get like I am, I'm-- My blood sugar's dropping, I can tell you that. You want to know what a bearing illness has on the family. The problem is, if your family don't stay with you and learn the same things that you do about diabetes, they can't help you and they're not going to."

Researcher: "Okay, in the last 20 years, have you gone together to take any classes or go to any support groups or something like that?"

Husband: "No. Well, there was one, or a couple. She did, or I did too, counseling; I, I don't know where they [the agency] moved to. But when I get low like this, I'm goofy. I don't, I didn't know-- All I can remember her last night is hittin' me."

Wife: "I didn't hit him; I was trying to check his blood sugar."

Researcher: [to wife] "What have you learned about diabetes, its complications, its behavioral changes?"

Wife: "It affects your attitude; it affects your personality greatly."

Husband: "At this point she just don't understand, I mean--"
Wife: "Like he is right now, he was that way yesterday. I tried to check his blood sugar and he fights me."

Husband: "I do anybody when they hurt me now."

Researcher: "Has anyone told you that diabetics can behave like that when their blood sugar is low?"

Wife: "Yeah, it wasn't his blood sugar; it was only 68 . . . and last night about 11:00, he was still this way so I took it again and it was still 68."

Husband: "So, Sandi, what what I'm trying to tell my wife--"

Wife: "It took 10 units."

Husband: "Once your, your blood sugar goes down and you're taking medicine to bring it down, you're gonna bottom out and then you gotta come right back up, and it's not easy to do that."

Wife: "Yeah, it was low, like at three something yesterday, and I gave him some apple juice and it got back up to what, I think it was 131-- I can't remember-- or 168. And he was still talking this way!"

Researcher: "So are you thinking that it's not the diabetes as much as--?"

Husband: "Yes, maam, that's what she is. She's trying to say it's the medication that's doin' it, and--"

Wife: "Yes, because the psychiatrist he's going to is just increasing his medication instead of decreasing it."

Husband: "They sure are."

Wife: "They just keep giving him more and more."

Researcher: "Have you talked to the psychiatrist?"

Wife: "One time. She won't talk to me. He told me that she told him that she could not doctor him and talk to me too."
Husband: "What she meant is she can't take people being angry at her because of something she don't have no control over."

Wife: "I'm not angry at her. I'm just trying to tell her how you are so she'll know, 'cause she's not with you; I am."

Researcher: "So when you try to talk to the psychiatrist because you're concerned about--"

Wife: "Him, like today."

Husband: "Sandi, this is something! I had one brother that told me that he couldn't stand to be around me because this tube [gastrostomy] was gross. Wouldn't that hurt your feelings just a little bit?"

Researcher: "So you're having some problems with your family?"

Husband: "I have problems with almost everybody."

Wife: "He brings it on himself. . . . They come around, he calls 'em on the phone. They stay away because they get tired of listening to his whatever . . . ."

Husband: "Whatever, yeah, whatever."

Researcher: "You've been together now for a long time. Why--?"

Husband: "Why now split up? 'Cause I can't take her bull crap every morning. She blames everything that happens on me, not her. . . ."

Wife: "He's getting worse."

Husband: "I don't know what I'm doing. I know my health's getting worse."

Both partners seemed to care very much about his physical condition but the caring did not come through because the blaming and attacking stance was so strong. Again, it appeared that the problems here were not so much related to the illness as to the inability to communicate clearly and supportively. Each
perceived an attack by the other and answered with a counter attack. The illness became the fulcrum around which the dysfunctional interaction patterns moved.

A third couple reported the sudden onset of problems after the wife had a total hysterectomy. She then became depressed and at one point was diagnosed as schizophrenic. They both described severe problems between them during this time. She attributed that to the differences in their backgrounds.

Wife: "His mother was very strong. . . . Mine never talked back. I had a problem with standing up for myself and have a problem with arguing. . . . He just didn't understand what was happening to me."

Husband: "We would talk over and over, the same topics with no resolution. She didn't even remember we had talked about it."

This couple sought out professional advice to help resolve the problems with communication and to help the wife learn to be more assertive with her husband. They attributed the cause of the problems to the hysterectomy, but acknowledged that the stress created in the marriage revolved around the depression which resulted "as a side effect" of the hysterectomy. Additionally, what appeared to be a significant part of the problem was the issue of power as she became unhappy about how the relationship was structured. He expected a more powerful wife; she believed she must be submissive even though not completely satisfied with that position.

**Alliances and protectiveness**

Some couples, although acknowledging individual stress as a result of dealing with the onset of a chronic illness, were able to keep that stress from having a detrimental effect on the marriage relationship. For these couples, the stress associated with the illness became something which teamed them up
together against a common foe. Although for some of them the relationship was not one of complete openness or honesty, what was withheld was for what was believed to be the good of the other. Protectiveness of the spouse and an alliance formed against the illness were major themes in the relationship dynamics.

The first couple exhibiting a pattern of protectiveness had a son with neurofibromatosis. He had also had a brain tumor surgically removed 2 years prior to the interview and a leg amputated when he was 10. The son was 15 when the study was conducted. Each spouse in this couple was protective of the other; when stress is high, each withdrew from the other so as not to "burden" the partner or worry him/her. This is their story of how they responded to the illness and its many complications.

Researcher: "How did that affect you two?"

Wife: "Well, it just absolutely floored me, I didn't know what to do."

Husband: "Well, any time you have a crippled child--"

Wife: "Know--"

Husband: "With a disease, you have crippled parents."

Wife: "Yeah, we felt, and we didn't know, you know--"

Husband: "If affects ya; it affects your life in every way."

Wife: "You don't know--"

Husband: "In every way."

Researcher: "Tell me more about that."

Husband: "Okay. It affects your nerves. It affects your sex life. It affects you, uh, it affects every part of your life. I mean that, you normally-- Like I say, if as parents we could take him to a doctor and get it fixed and take him home and he'd get well, you see--"
Wife: "Or tell something, that knows something--"

Husband: "You're living from day to day: nerves, nerves, nerves!"

Researcher: "So, high stress?"

Husband: "Yes! . . ."

Researcher: "You've both experienced a lot of stress because you've been worried about [son, J]."

Wife: "My weight goes up and I have a problem--"

Husband: "And you ignore each other because you don't want to worry the other one--"

Wife: "You don't tell them your problems."

Husband: "Yeah, I'm okay, no problem."

Researcher: "So you both tried the 'stiff upper lip,' huh?"

Wife: "Yeah, like it was-- I found out either Wednesday or Thursday that he had this, so I thought, 'Well, I'm not gonna say anything to him [husband] 'til I get home.' [She's talking about a time when the child was hospitalized for routine exams in an out-of-state hospital, but it was discovered that the child had a brain tumor which would require surgery.] J called his Daddy and he spilled the beans.

. . . Yeah, and I had to sit there and tell him on the telephone, and I kept saying, 'Are you okay?' and I could tell by his voice that something was wrong."

Researcher: "So you were worried about how he would be?"

Wife: "Yeah, I was real worried, and then we were down in [the hospital] and I got kind of perturbed at my oldest son because he didn't come down and check on his daddy . . . 'cause I had gotten a letter [from a friend] and she told me that this man I know had died of a heart attack, and I thought 'Oh, my God!, if someone was
to go in and find"-- I didn't know what to think, and I called him [husband] once a week and wrote letters, and uh [wife starts to cry]--"

Researcher: "So you were concerned about his health while you were gone with J? Did you tell him you were concerned?"

Wife: [shakes her head "no"]
Researcher: "You just tried to be strong?"
Wife: "Yep."

[Later during interview]

Researcher: "During this time [now we are talking about after the surgery when the husband has joined his wife and son in the hospital], were either of you aware that the other one was trying to be strong and protective?"

Wife: "No, no."
Husband: "Well, yeah."
Wife: "Well, in a way we did, because I wouldn't, you know-- 'Course we'd say, 'Yeah, we're okay, let's, you know--""

Husband: "That's after we'd lived together for what, 20 years or so? [laughs]"

Wife: "Well, it was well over 25 years; this was ten years ago and we've been married over 35 years. So, but you know, we tried to put up a front, you know. I did with the kids, you know, not let them know how worried we were and how, you know, I was feeling, or how he-- I don't know whether he-- But you never know, you know, how one person's feeling, not 'less you tell your, say something to 'em. 'Course we don't do it. 'Course we argue a lot and--"

Husband: "But I do feel that the parents', uh, welfare is grossly neglected."
Another couple discussed how they "teamed up" to take care of each other. This 84 year old husband suffered a head injury in a fall about one year prior to the interview and, shortly after the fall, also suffered a stroke. He also suffered from arthritis and had had one knee joint replaced. The wife also was diagnosed with colon cancer and required surgery during this year and she also had arthritis. This is the story of how illness affected them.

Wife: "We have managed to overcome all the hurdles, and there have been lots of them because when you're ill, things are not normal, and you don't see things the way you should, but, um, I told him the 8 months that he was so bad and no doctor thought he'd ever overcome the illness, the brain damage, I told him that it was horrible, but I enjoyed taking care of him, and I did, because each day it was different and yet some things were similar."

Researcher: "Different and similar?"

Wife: "Well, the ailments that he had, the conditions, the falling, and the, uh, the way he responded to everything because he was off in another world and he didn't know what he was doing. I was telling him the other night that the towel rack in his bathroom he had completely pulled out of the wall. Well, he doesn't remember that, and he doesn't think he did that, but you couldn't control him when he was in those kind of states. He'd sit on the stool, and he'd get a hold of the towel rack and pull himself up or something, you know, and just little things like that."

Researcher: "That was the different part?"

Wife: "Oh, that was the different part, but then you learn to cope with all of that and, um, because of all of the strong affection you have for each other, you overcome those things and you put your life together, you know. 'Course he didn't
know what he was doing and I realized he didn't know what he was doing, and even though it made it hard for me to accept some of the things that happened, it still made you a little more compassionate because, after all, you're dealing with someone who doesn't know what's going on or if he's being ugly to me, which he was a lot of this time."

Researcher: "One of the things that was different, then, was that some of his behavior changed."

Wife: "You bet, you bet. The good thing was that when he began to realize that, when he began to get better, was that he begun to realize that he hadn't been maybe the husband that he should have been, but everything so far has worked out." [At about this same time, the wife developed symptoms and visited her doctor. The excerpt continues with talking about her illness.] "But anyway, . . . when they found out that I didn't have any blood, then they had to do tests to find out where this blood was going and why was I without blood, so they did several tests and . . . found out I had a colon tumor . . . so we had to go to [hospital], and he went with me. . . . Then when we came home, of course, I think it did something to him 'cause he got better. . . ."

Researcher: "What do you think happened?"

Wife: "I don't know. I think maybe it was-- The doctors said that he was afraid; he had a feeling I would never come home."

Husband: "She had this colon trouble. . . . I stayed at the hotel there in the hospital."

Wife: "I told her about that."

Husband: "Oh, you did?" [husband is also hearing impaired]

Researcher: "What was that like for you?"
Wife: "What was it like for you? What did you think? How did you feel about me being in the hospital with cancer?"

Husband: "Well, it's like I have always been. I've been through several deals with her, and uh, I know how I feel, yes, but I don't know how to express it."

Wife: "Well, you've said that you didn't think I'd ever come home."

Husband: "Oh, well, we never had cancer before. . . . When this cancer deal came along, that scared me 'cause we've never had cancer in our family. Well, her daddy, he died with cancer."

Wife: "Cancer of the colon."

Husband: "Yeah. But, yeah, that kind of floored me. . . . I didn't give up or anything. I felt like we'd come on through with it, but it's just kinda surprising to you. . . ."

Researcher: "Were you afraid she might die?"

Wife: "Were you afraid that I might die, that I might not come back?"

Husband: "Well, that's always a possibility. Yeah, yeah, it's a possibility, naturally."

Researcher: "And were you [to wife] also afraid earlier in the year that he might not make it?"

Husband and wife talk simultaneously]

Husband: "]Course, like this, any doctor would--"

Wife: "But if you had seen him like I did, you wouldn't--"
Husband: "Any doctor would tell you anytime you open up even a minor incision, it's a chance, see?"

Wife: "He had therapy after his, uh, stroke. But it didn't seem to help him much so we didn't stay with that too awful long. . . . When he had his knee surgery . . . I was right in the room with him all the time he was in the hospital."

[She had back surgery at the same time]

Researcher: "Was that helpful, that you could be in the same place, in the same room?"

Wife: "Oh, yes, I don't think that he could have made it without me being there--"

Husband: "I just checked in like a patient."

Wife: "Because he was too, uh, he was in--"

Husband: "Well, here's what it boils down to. It's just about as expensive to get a double room in the hospital as it is to . . . get a motel room, or whatever. . . . And it's a whole lot better if you want to be with her . . . where I was with her constantly, all the time 24 hours a day, it makes a lot of difference. . . ."

Each spouse perceived that he/she took care of the other; each desired to take care of the other; each wanted to give of self to help the other feel better or receive better care. The illnesses, although stressful to the spouse, were used as a way to be attentive to and needed by the other.

In the next couple, the husband suffered a severe head injury after a fall. The injury left him with a permanent amnesia for the 25 to 27 years of his life prior to the accident and some problems with short and long term memory.

Wife: "Right in the beginning there was coma, so it [pause], you-- I received the bad news from the neurosurgeon, you know, that . . . they really did not expect
him to survive. So I think we were just dealing with day to day things, hoping that, um, that it would come out all right, but I really full well knew the, the injuries were serious. . . . He was blinded in one eye, and of course, in the beginning he couldn't focus or see or do anything, and, nor talk, nor swallow, nor walk, nothing. He just had to start over from scratch. . . . I think my background probably made it easier for me [she had a masters in psychology and worked in neuropsychiatry]. . . . Of course, there's a great loss when that happens, and I think that's something that I worked through day by day with him, but at that point in time he needed someone to really be there. . . . He was frustrated once he started to come around a little bit; he was very frustrated. . . . He couldn't remember anything from one moment to the next which, in a way, was a blessing because he didn't remember a lot of the really rough times." [Husband still has no memory of the accident or the first few months after the accident.]

Husband: "The only-- During the time of the three or so months after the injury and for the 27 years before the injury, total zero. . . . There is no guarantee of the memory recovery. . . . I realized one-- I was always kind of wanting-- Prior to this time I don't remember anything I did, but I remember the fact that I was a party boy kind of guy. . . . I don't remember what or who, but I've-- But one day, this is all-- It sounds a little melodramatic to take the time to say this, but this is a fact. It affects and has affected me ever since. One day I sat down and in one of my, what do you call them S [wife], uh, the spells I can't drive because of it?"

Wife: "Seizures."

Husband. "Seizures. Because of seizures, I can't drive. . . . All of a sudden I just stare off and all of a sudden just be in the-- mentally lost for a period of time in something that I may not even remember what it was. But it's a mental, uh mental
effect that it's had on me. One day, I sat down and, not in one of those seizures I don't believe, but otherwise I was, uh, God himself honestly talking to me. It sounds a little dramatic for an adult sitting here like this to say this to you, but it is a fact. And I was told that S was the girl for me, that no matter what I'd ever done or what I think I should do, forget it. She loves you; she's faithful to you; she was with you when you were ill the most-- and remember I didn't even remember she was there-- she uh, she uh, is the girl for you, and I made the decision right then for life with S. That very moment bound me in that. So in a sense, the injury, the life since the injury has caused a, caused a, a tremendous, has become an asset to us. I also learned to rationalize about my memory loss and . . . live day to day. . . ."

Researcher: "... Let me see if I'm following this correctly. Because now you recognize the importance of today and tomorrow, you're not dwelling on whatever happened in the past whether good or bad, and you're appreciating the relationship you do have with her, again on a day to day basis. Did I follow that correctly?"

Husband: "That's correct."

Researcher: "Okay, were you able to notice any changes then in him?"

Wife: "Oh, yes, dramatic changes!"

Researcher: "What kind of changes did you see?"

Wife: "Um, well he was, uh, more compatible, more compassionate, a lot of feeling was not-- He didn't take time for feeling before a lot, and he, uh, didn't let a lot of people get very close to him. I think that, you know-- Now he enjoys being with people a great deal. He enjoyed being with people, but didn't let too many get too close. You know, no commitment kind of thing to anything: pretty face, free kind of person. . . ."
Researcher: ". . . What was the relationship like for you before that? You [to husband] have no memory of that? [He nods] So, S, what was it like?"

Wife: "Well, at times it was really nice, and other times it was difficult. Uh, T [husband] had a drinking problem which caused chaos often times. Um, I think there were many many beautiful times and then many tense times."

Researcher: "Okay, so some of both extremes?"

Wife: "Yes, uh-huh, extremes."

Researcher: "What kept you together through that?"

Wife: "Well, I cared a lot for him, and, uh, we did a lot of interesting things together and we enjoyed things very, you know, the same things . . . ."

This woman used her training and knowledge to help her cope with a partner who was brain damaged and went through the very demanding and frustrating tasks of having to relearn walking, talking etc. She acknowledged great stress on herself but was able to seek help from professionals to deal with her feelings. The couple also went for intensive counseling together. The illness did not cause this couple to be at war with one another; they were able to work together to overcome or adjust to the limitations which were created. In fact, in this situation the mental/emotional changes which occurred after the head injury were advantageous to the couple; the husband altered his values and behaviors and became more committed to the relationship with his partner.

This next couple also aligned themselves together to try to adjust to or cope with the illness. In this particular case, the wife sacrificed her needs many times for the sake of not causing her husband increased stress and additional health problems. This man suffered a severe depressive illness following a fire that burned their home, their business, and took all their belongings. He also had a
history of multiple health problems since childhood including a brain tumor, later pancreatic tumors which required surgery resulting in diabetic hypoglycemia and diabetic neuropathy, peptic ulcers, and several illnesses which have required several surgeries including fairly recent triple bypass surgery following a heart attack.

Husband: "She means something special to me and if she dies, I don't know how I'll go on, because I'm not that type of person. I'm a very, I'm a very emotional type person. I can cry at the easiest things. . . . I would have to go very quickly if, if I could bring myself to do it. If I didn't sit there and withdraw again. . . . I know I will be losing something or someone who is very special."

Wife: " . . . And I would feel that way about him. And that's probably the attitude that I took, plus the fact that everyone told me, you know, you've got to be the strong one; you have to be the strong one, and I've always had to do that in my life."

Husband: "Well, I think she became the-- I think because she was the strong one is because she was streetwise. She grew up in a hard atmosphere; I didn't. . . . I actually almost died at birth because of problems, and I was protected over and over and over again. . . . Losing our home was a disaster in my life. After the first attempted suicide, they diagnosed me as being paranoid schizophrenic and I was being treated accordingly. They kept putting me on . . . those kinds of medicines that set you out on cloud nine. . . . In and out, in and out of the hospital all the time to keep me from going suicidal again. . . . And she had to put up with all of that . . . in the sense of having to-- She stayed with me and because she stayed with me, she put up with it."
Wife: "Well, not knowing, you know-- I knew that he had problems, and I think that if for one minute that I would've thought that he was doing it just for attention or something, I probably would have left him years ago, but I knew that he had problems and the doctors weren't doing anything. I knew that what they were doing wasn't what he needed because they had diagnosed him as being paranoid schizophrenic and they gave him medicine that wasn't doing any good. . . . Well, they didn't do anything with him the first four times; the stages of suicide that he was in, they didn't do anything. They would give him medicine and send him home. The last time, I told the doctor 'You have to do something this time. If you have to turn around and put him in the hospital, do it, but something has to be done because I'm not getting any younger, and it's starting to affect me.' So they put him in . . . and told him these other doctors were crazy, that he was . . . manic depressive. So, they put him on Lithium. He hasn't had any problems since."

The next couple appeared not to have conflict about the illness. The illness was accepted as it was for the previous couple, and this husband and wife were also joined in a common battle to achieve financial and emotional survival. He was disabled with heart disease and degenerative disc disease and had been on disability income for 8 or 9 years. The onset of the problems was about 20 years ago.

Wife: "I think the worst part started probably in '83 and he had problems before then, but we never could-- Uh, he went to the doctor with his back, or something. They were always telling him this was because he was too heavy and he had just pulled muscles, or what have you. We went like that for, I don't know, for 5 or 6 years before we ever found a doctor that finally could see what was wrong with him."
Researcher: "Which was?"

Wife: "He has a ruptured disc in his back. In fact, he has two of them in his back. And so, I guess it was probably in '83 that we started trying to get him on Social Security disability because the doctor had wrote a letter saying that he was not physically able to do the kind of work that he was doing. And he couldn't seem to find anything that he could do because he can't really sit very long at a time or stand very long at a time. And so, when you have a back problem, you know you go someplace to work and you put down that you have a back problem, they aren't going to hire you anyway. . . . But then he was on Social Security dis-- We finally got him on after 3 years, I guess, of fighting with them. And then he was on for, what, 7 years, 6 or 7 years anyway, and then, I think it was '89 when they cut you off?"

Husband: "I'm not sure. It was something like that."

Wife: "They sent a letter saying that-- They sent him to doctors again. He, uh, went to the doctors, and stuff, and I was with him every time he went in to a doctor for an examination. They did not examine him. I mean, just for little minor things and then they would tell him, you know, 'Okay,' and then when we got the denial they said he had improved and that he was able to go back to work. So then, we started fighting it again. And it took us until this year to get him back on it again. . . ."

Researcher: "So, the back problem started how many years before they diagnosed the deteriorated discs?"

Wife: "Probably, I would say it has been a good--"

Husband: "I have had it ever since, uh--"

Wife: "Probably he was in his 20s."
Husband: "In my early 20s."
Wife: "And he is 50 now."
Husband: "But, I would hurt it off and on way back then, you know. I would spend 3 or 4 days a week in bed before I could get back on my feet. And then the last year that I worked--"
Wife: "Which I think was in '83 . . . ."
Husband: "I averaged about 2 to 3 days a week missing work. And that was real hard because I was having to lie, you know, that there was something else wrong with me. But I was trying to keep my job, because I seen them fire other people for having back problems. It was in a machine shop and it was a heavy job. And just that was a lot of stress. But, then, when you start fighting the system trying to get something done--"
Wife: "They humiliate you."
Husband: "You-- Well, for instance this last time that we were fighting with them, I was called everything from a hypochondriac to just crazy, you know. My doctors--"
Wife: "And judges--"
Husband: "And after a while, you start believing that these people might be right, you know. They work on your mind a lot."

Never during the interview with this couple was there any indication that this wife thought her husband might be malingering, that she had any questions at all about the validity of his complaints, that he was not working because he was lazy, or that he was not doing the best that he could for her and for himself. There was no indication of any split between them at any time, only of a very strong
alliance between them against the Social Security system and other social systems, even family, as will be discussed later.

Yet another couple provided evidence that the disability of the husband had created no conflict between him and his wife. This man had a sudden onset of blindness at age 66, 12 years previously. Four years prior to that, he had lost the vision in the first eye. This is how they responded:

Husband: "The loss of vision, of course, was a traumatic experience, and uh, it affected me very adversely at first. The fact is, I thought at first that life wasn't worth living anymore. But I soon decided that I should, I was going to emphasize the things that I could do instead of the things that I couldn't do. After that, I got along much better. . . . The adjustment, of course, is still going on, but mainly it took me probably 6 or 8 months to psychologically prepare myself for what I knew I had to live with. . . . I remained active. I'd been active in the Chamber of Commerce and Rotary Club. . . . I still maintained my connections with those organizations, still do. . . . It's a little bit difficult to go to those meetings where you eat because I, I can't really tell-- And they always serve buffet. . . ."

Wife: "But you like everything, so that's an advantage.[laughs]"

Husband: "[laughs] I just eat what I get . . . fill my plate, and it's all good, and I can eat fairly well. I make a little bit of a mess sometimes, but--"

Wife: "No, you do really well. . . . He's also increased the use of his peripheral vision through efforts. Since he has kept busy and done all these things, he's brought that vision around."

Husband: "The doctor told me that, oh, I couldn't see anything straight ahead. He said probably with use and practice that this peripheral vision would come around a little bit. . . ."
Researcher: [to wife] "What was that like for you then, having this happen?"

Wife: "Well, I don't remember what it was for me. [laughs]"

Husband: "Been pretty hard for her, actually."

Wife: "Well, it hasn't. I mean I don't look back on it. You know, there's times, I'm sure there were times that it was, but when you've lived together for about 45 years, or 40 some years up to then. . . ."

Husband: "Well, it's 57 years now, so--"

Wife: "Yeah, 57 years now."

Husband: "So about 45 years."

Wife: "You've lived that long, why, uh, you've made a lot of adjustments in that time. You have to make them a little faster in this case, but, uh, since I had never had my own career anyway-- I was a homemaker-- so it was not anything just out of, out of reason to, it-- I had to shift priorities somewhat, but that in itself's what one should do anyway, so I don't think of that as being particularly heroic or anything. . . . Once you get to look at it 'Don't have to do it, you get to do it,' that makes it a little bit--"

Husband: "That makes it more acceptable."

Researcher: "You said shifting your priorities is um-- Driving him is one of the ways you did--?"

Wife: "Yes, and arranging my work so it fits in and keep my activities that I like to do. And he's very considerate of them and will arrange his if need be. So, all in all, well, its had its many negatives; its also had some positives."

[later]

Researcher: "So you never went through a stage where you were kind of resentful about having to do some things for him? That never happened?"
Wife: "Oh, I'm sure that maybe there may have been some feelings like that, but once I realized that I was not a caregiver, that I was a wife, once I realized that, it was entirely different."

Researcher: "So a way of thinking about it that's positive."

Wife: "Yes, on both our parts."

During this interview, this couple demonstrated much positive regard for one another and pride in the spouse's abilities and accomplishments. They worked together and supported one another in joint and individual endeavors. This couple described a very positive marriage in the many years before the disability occurred. They also both had a positive attitude about the illness and about life without being "Pollyanna." The researcher, however, did not ask specific information about how the husband behaved during the time when he thought life wasn't worth living any more, how his wife responded, and what happened to the relationship during that short time.

The next couple also formed an alliance to cope with the severe disability of their child, birth injured and now 8-years-old. This dialogue provides an indication of the way in which the husband was able to provide support and share the challenge of caring for this son.

Wife: "We knew right when he was born that something was wrong. The doctor said-- And then he flew him to [pediatric specialty hospital]. And then they made the diagnosis."

Researcher: "You were still here and your new baby was taken someplace else. . . . What was that like?"

Wife: "It was pretty devastating. We had no idea there was going to be anything wrong with him."
Husband: "They worked on him for about an hour still trying to--"

Wife: "About two."

Husband: "His lung collapsed. His heart wouldn't beat."

Wife: "They couldn't find a tube small enough to go down his throat, and they called in two other doctors and three other nurses to come in here and just left me on the delivery table, and I was real fortunate that D [husband] got to go in there with me."

Researcher: "So at that time you didn't know what was going on?"

Wife: "No, we didn't know what he was. We didn't know if he was a boy or girl for about a couple of hours.... They'd come by--"

Husband: "And say what they was doing--"

Wife: "And pat your arm, and 'It's going to be okay.' You know, I think that scared me more than anything.... He [husband] kept saying, 'K, it's going to be okay; they're working on him,' 'cause he was out where he could see and I was laying flat.... I just remember crying and wanting to scream and stuff, and he calmed me down.... [later, when the parents are visiting the child in the children's hospital] Three neurologists came in; they checked him.... and said, 'Well, he's going to be deaf and blind and that's why you should put him in an institution.' We just looked at them.... and so we just left; we just had to leave. We just couldn't handle it."

Researcher: "How did you decide you weren't going to take the neurologists' word and put him in an institution? How did the two of you decide?.... Were you in agreement?"

Wife: "No, I don't think we ever disagreed on anything about [child]. We were just wondering if we would physically be able to handle him. We know that
sometime in his future, far future, that he might have to go to a home, you know. . . .
He's got brain damage in every area; not an area's untouched. He [neurologist] told us there would come a time that he would stop progressing any further. We have fought the school system, doctors, and everything in pushing his learning."

[Much later in the interview]

"He [husband] gives him baths and he's here and he does things with [child], you know, just so I don't have to do it all. He helps with the housework. . . . It might not have been done like I did it. . . ."

Researcher: "How did that happen?"

Wife: "Well, because of B [the handicapped child]. Uh, he [the husband] was real young. He didn't know how to take care of kids. . . . He'd never been around 'em, and so I done a lot. I did 99% of it, but when B came, we couldn't take him out, so he either had to stay with him or do the grocery shopping or take care of whatever had to be done. . . . I said this is what we gotta do and I showed him how to do it, and I had to come to the realization he's not gonna do things like I do. That don't mean he can't do a good job and, uh, and a lot, I think, of why he didn't help or why he didn't do anything [at first], he really didn't know what to do or what I wanted done or what."

This wife was forced to ask her husband for help and to serve as his teacher in the area of child care and home-making so that he could assist her. They developed a collaborative approach to parenting with both children.

Stress is the state of experiencing being strained or pressured. It can be created by a variety of situations or stressors. Clearly, it was a predominant state for those persons interviewed as the following section demonstrates.
Stress

This section of the findings provides an indication of how chronic illness can create great stress for those persons who are afflicted with it and also for those persons who care most about them: the parents, spouse, and children. With the exception of only a few individuals, each respondent indicated a significant experience of stress as he/she was faced with learning new roles and ways of interacting with the partner to accommodate new limitations in physical and/or mental and emotional functioning.

Each person was asked to give a score from 0-10 of the amount of stress he/she believed was caused by the illness and its effects on them individually and as a couple. Individual scores ranged from 2 to 10 on a scale of 0-10. Zero meant no stress and 10 meant the greatest stress one can imagine ever having to deal with. The individual who reported a score of two was the person who had schizoaffective disorder and was medicated so that he was "numbed." The average score was 7.36. The modal score was 10 with 29.7% of the individual respondents rating their individual stress level at the highest rating possible.

The amount of stress placed on the relationship was considerably lower with a range of 0-10 and an average of 4.63. Several couples, although individually stressed to a high degree, did not believe that it caused stress in the relationship between them. Others, as mentioned, attributed the cause of all or most of their problems to the illness and gave a high couple stress rating. Table one summarizes these scores.
Table 1. Stress Ratings: Husbands, Wives, and Couple

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<td>(W) 0</td>
<td>(H) diabetic</td>
</tr>
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<td>#8</td>
<td>(H) 3</td>
<td>(H) 1</td>
<td>(H) cardiac; cancer</td>
</tr>
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<td>#9</td>
<td>(H) 6</td>
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<td>(W) schiz/ dep.</td>
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<td>#10</td>
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<td>#12</td>
<td>(H) 7</td>
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<td>(H)10</td>
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<td>#14</td>
<td>(H) 8</td>
<td>(W) 8</td>
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<td>#15</td>
<td>(H)na</td>
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<td>child(devel. delay)</td>
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<td>#16</td>
<td>(H)10</td>
<td>(H) 3</td>
<td>(H) head injury</td>
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<td>#17</td>
<td>(H) 3</td>
<td>(H) 0</td>
<td>child(2)asthma,MR</td>
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<td>(H) 2</td>
<td>(W) 5</td>
<td>(H) schizoaffective</td>
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<tr>
<td>#19</td>
<td>(H) 5</td>
<td>(H) 7</td>
<td>child(2) GH defic.</td>
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<td>#20</td>
<td>(H) 8</td>
<td>(W)10</td>
<td>(H) M.S.</td>
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Three couples reported that the illness caused no stress in their relationship. The first of these was a couple who had a child handicapped with C.P. Although there were high levels of individual stress, the illness and its associated hardships did not create any tension or conflict between them.

One couple denied any significant stress in response to the development of illness. This young couple with children saw little of each other. They worked different shifts, and she attended school. Both minimized any problems or difficulties and just "do what has to be done." She had one mentally handicapped child from a previous marriage; together, they had a severely asthmatic child. This couple was not able to verbalize how the illness or disability of either child
affected their relationship, and seemed unable to think in terms other than individual responses.

In another couple, in order to protect the husband who has had to battle depression, numerous surgeries, diabetes with complications and heart disease, the wife was willing to take on more individual stress so as not to increase the couple stress or her husband's stress. This is their story.

Wife: "I told him [husband] that the next time, if he tried to commit suicide again, that I'd leave him. Because I just couldn't take it anymore. . . . I love him dearly, but it takes a piece out of me every time he does it. . . ."

Researcher: "What kind of piece?"

Wife: "I don't know, it's just hard to explain. . . . I got mad. I got angry. I got angry that he wanted to leave. . . . that he wanted, you know, to do this. . . . I don't believe I really got depressed. Sometimes I feel like, like I could go through the roof. . . . a lot of tension and a lot of stress. . . . A lot of times it still happens when he has a hypoglycemic attack. I get real tense and I get stressed, you know, real stressed over it. But, there isn't anything I can do about it because I know that's not his fault; . . . he can't help it that his health went downhill."

[Later]

Husband: "There have been moments when we've had disagreements and I have tried-- If we have an argument, I say what I have to say; I try to let her say what she has to say, and then I want it to stop. I mean stop. And I can tell her that I don't want to talk about it anymore, but she just won't shut up. She keeps right on going which, unfortunately, just fuels the fire. . . . I get up and walk out. . . . I want it to stop even if we don't agree because the arguing doesn't make it any better, and if she won't shut up, I'll take a walk."
Wife: ". . . I believe that, that lately, I, I just mainly give in I think, because I know his illness and I know that if it keeps going and keeps going that it's just going to make him worse. I think everything is really good with J [husband] and I. It's really better than the average person. Sometimes I feel that if I'd just keep my mouth shut, things are better. It bothers me, and I've told J this time and time again that he doesn't seem-- and I know he does-- but it seems to me that he doesn't seem to listen to my problems. My problems are probably very minute compared to his, but you know, when I have a problem and I want to talk to him about it, it all goes back around to his sickness. And someway or other during that conversation, it will end up with his sickness, and I get so frustrated over that, you know, it just makes me feel as though he thinks that I am, that there's nothing wrong ever. I should be this smiling little C [wife's name] all the time. And I can't do that all the time, you know, and I'd like to try to make him understand that I can't be that way all the time. If I get up in a bad mood or something, you know, in about two hours he'll look at me and say, 'I sure hope you feel better this afternoon or you're in a better mood,' and I'm thinking, 'God, you know, 20 years I've put up with you, and I have one bad day, and you think I'm having PMS or something.'[laughs] . . . But I've just given that up, you know.

"I've given up even thinking about that. I mean, one of these days if I ever end up in the hospital, it's going to be a reality to him and he's going to have to make a decision what he's going to do, you know, but I've just given up. . . . I don't really know how to explain it other than the fact that, yes, I will say that I do get tense, and I get stressed out over his illness. . . . I just shut up and I don't say anything anymore, and it seems like for us it's better that way. I don't know about for him, but for me it's better that way . . . if I don't say anymore about it, if I don't
complain or I just go ahead and be the good and faithful wife like I'm supposed to be, so to speak, that things are better. . . .

"I believe that, that lately, I, I just mainly give in, I think, because I know his illness, and I know that if it keeps going and keeps going, that it's just going to make him sicker, and I don't want that, so I just hold it inside and I don't say anymore about it. I feel bad, and I feel like I have not had my say or that I cannot get him to understand the way I feel, but I also think that if I continue with it, it's going to get worse."

Perhaps one of the most powerful demonstrations of the amount of stress experienced individually was expressed by this next couple. This couple had not been at odds with one another at any time during the illness, but had each helped support the other as the levels of individual stresses became nearly intolerable.

Husband: "But I've talked to a lot of people. Another fellow who lives here that we grew up with sort of as kids, uh, he has heart problems and he told me the other day that he went through some of the things I've been going through, and they finally did the bypass on him, and he told me that I was probably never going to get to feeling real good, so I don't know, I just keep hoping. I'm hoping that I don't have to have it [bypass surgery], but sometimes it looks like the only recourse. When they ballooned the arteries the first time, they told me that you get past the first 6 months that everything would be okay. Well, I'm past the 6 months, and I had my heart attack because they blocked up, and then--"

Wife: "Well, what's been so bad about it, up until just this last heart attack he had the medical bills and, I don't know, getting depressed. I don't know. I couldn't get N [husband] to go the the doctor, you know, like he really needed to because he had so much problems for so long, you know. The doctors told him they
couldn't find anything, and he said, you know, 'What good did it do to go because they're just going to tell me the same thing,' and he got so depressed and everything, and the first time he went there they sent him to the City. It ended up costin' like $600.00 for the ambulance ride, uh, about $13,000.00 for the hospital, and $3,000.00 for the doctor, not counting what we owed the doctor here, and just that brought him down real hard, you know. So he kept putting off going to the doctor 'til he had the heart attack, so it gets to the point where you think, 'What are you going to do?''

Researcher: "So, your reaction was, 'I can't deal with the medical system any more; that hasn't helped; there's no point in going 'til you had to go, and another effect was getting depressed trying to cope with all this for so long?" 

[This man had been struggling with many symptoms for which the doctors could make no diagnosis; he had been unable to work and could not get disability payments; physicians and the Social Security Administration had labeled him a hypochondriac and malingerer.]

Wife: "Real depressed."

Researcher: [to wife] "What happens to you when he gets depressed?"

Husband answers: "She does too, but she hides it and just keeps trying to talk to me and-- This is unusual for me, I don't usually talk this much."

Wife: "[laughs] He doesn't!"

Researcher: "How is it?"

Husband: "All right!"

Wife: "But I worked so-- For a long time I worked two jobs. That made it hard on him, too, because it was hard for him to handle."
Husband: "Well, it works on ya in a lot of ways. I went so long with, uh, the doctors acting like that I was faking all my pain and stuff, and one doctor even made a report to Social Security that as far as he was concerned, I was a hypochondriac and exaggerated everything, and my true nature is just the opposite and I know that, and she knows that; everybody who knows me knows that, [sighs] but Social Security takes his word over everything else and uh--"

Wife: "Social Security is really really--"

Husband: "The fact that--It wasn't bad enough that she was having to work to help support us; it got to the point where she was having to work two jobs and that really worked on me. I grew up old-fashioned. I'm supposed to be the head of the household and take care of my wife, not her take care of me, know what I mean?"

Researcher: "So that was a big blow to your self-esteem?"

Husband: "Right. The old male ego."

Researcher: "So a lot of financial stresses added."

Husband and Wife: "Right. A lot of them."

Researcher: "So your position in your marriage changed. You went from being the head of the household to being the dependent one, and you became the breadwinner, and so you reversed roles in that respect."

Husband: "Um-hum."

Researcher: [to wife] "Was that also stressful for you to adjust?"

Wife: "[laughs] Yeah. I worked usually 12 hours a day, sometimes more, and I guess I really just got to the point where I just couldn't go anymore. I had to give up one for a while anyway. But you know, like I said, Social Security is not
that great... I don't know what we'd do if we didn't have it, but I still don't know how we're going to make it with it, you know?"

Husband: "Well, it boils down to if anything happens to where she can't work any more, we're dead in the water... Well, when I first got Social Security, our daughter was still at home."

Wife: "Our son-- Well, when he first got sick, we had both kids... And N [husband] was going through real bad times because he wasn't physically able, but he kept pushing himself, and it caused a lot of tension and pressure then because the kids couldn't understand because N had always been such a gentle and easy-going person, and he was losing his temper and was sharp at the kids for no reason, and they couldn't understand because that wasn't their Dad... He's really a good person. I mean anything that he can do to help me, he always has even when the kids were home."

Researcher: [Illness began with chronic back pain] "How do you cope with the fact that there's always pain?"

Husband: "Well, it's just something you have to learn to live with. I, uh, I don't know. It gets to a point where I don't know what I'd do without it, you know what I'm saying? You get so conditioned to it... I just kind of push it back and let other things take control."

Wife: "He has a-- One thing about him, he has a real strong, I don't know, inner strength or something, because I've seen him go through things that I know if it would've been me-- and I feel like I'm a fairly strong person-- I know that I couldn't handle it and, um, most people probably think it's just that I love him and everything, but he has an inner strength that I've never seen in anyone... ""
Husband: "Because there for a while, this heart thing is a really scary thing. Everything else I've been able to deal with pretty good. But this thing scares me, you know? And, uh, before they did the last ballooning, I didn't know if I was going to live 'til the next morning, and it's something to deal with."

Researcher: "Do you two talk about that?"

Husband: "Oh, yeah."

Wife: "We didn't at first. [crying] I guess we didn't want to upset one another, but we do now."

Husband: "Yeah, we finally realized that we were both worrying about the same things. . . ."

Wife: "We started out, really, I guess, protecting one another. . . . At first, it was like I didn't want to talk about it because I didn't want him to know that I was scared, and I didn't want to make him worry about me because I would make it worse on him, so I tried not to say anything other than asking how he was feeling because, like I said, I've lived with him for a long time and N has never complained. Even now he doesn't, but I know by looking at him. I can read his pain; I see it on his face. I know when his back is bothering him; I know when he's having chest pain because I've learned to read him because he never has been one to, you know, complain. You might be around him and think he's doing just fine, there's nothing wrong with him. In fact, I know from my family that for a long time, I don't think my family thought N was sick. . . . I think they thought he became lazy. . . ."

Husband: "Like I didn't want to go to work."

Wife: " . . . When N at first was so bad, he kind of went into depression; he didn't want to go anywhere; he didn't want to be around anybody; he didn't want to
talk to anybody on the phone. I would just go to work and come home and he'd be his quiet self, and when we were first married he was basically a real quiet person anyway, and I guess we grew with one another talking and stuff like that, and he opened up a whole lot more and stuff and then, when all this happened, it was like he, uh, sort of closed up in a shell by himself, and I kept telling him we need to talk. . . . I was scared, I guess, because I wanted to help him and I couldn't [crying]. . . . I guess I was afraid of losing him mentally, like.

Husband: "Depression works on ya. There was a time when I wouldn't have cried for anything. You know, the old male ego again. But when things got so bad with Social Security and everything, things got really bad and I guess I was really more depressed and everything than even she knew."

Wife: "I knew."

Husband: "There were times I could be sittin' all by myself and I would just start cryin', and I couldn't control it. And even now-- I'm not like that now-- but even now, for some reason, it's easy for me to cry. . . . I don't know if that's good or bad, but I know it's a change. Sometimes it feels good; sometimes it's like opening a pressure valve."

The effect of chronic illness is enormous stress, such that one illness may become compounded by the creation of additional illnesses, both physical and emotional and often in both partners. The mind-body connection becomes very evident as do the connections between partners in intimate relationships. Illness alone is significant enough to cause decompensation in the individual and relationships, but many times illness is accompanied by other stresses simultaneously. Then the situation can become overwhelming, perhaps leading to divorce.
Although the persons who agreed to participate in this research had not reached that point, perhaps because of the research criteria of requiring participation of couples, there is evidence provided which indicates that relationship distress, apart from or preexisting the illness, contributes to overwhelming stress in the face of illness which can lead to divorce. These couples also discussed how other stresses contribute to the difficulties in adjustment. The next section of the paper will discuss some additional stressors.

**Additional Stressors: Vulnerabilities**

**Relationship dysfunction**

The couples who were interviewed had the following comments to offer about how marital problems which were present before the illness were exaggerated when the onset of a chronic illness occurred. Some couples made the report about their own relationship; others made observations about other relationships they were aware of.

A mother with a handicapped child stated this about another family she was aware of: "Like I say, I've gone down [to the hospital] with the people that have Cerebral Palsy real bad, you know; some of 'em are not as bad as others, but I've been down with two families that did have-- their kids had it, and the man always took this one little boy down and the woman went down [this hospitalization], and I asked her one day about her husband. 'Oh, . . . he went his way because he blamed me for the child being like that,' and he just walked off and left them. . . ."

The father of a child with a degenerative fatal illness stated the following about the marital response when illness strikes. "Well, the first thing I think it did was intensify any areas of distance that were already there, and it also intensified any other problems or concerns that we have; . . . it brought them all to the surface."
And so, it doesn't necessarily create problems, but if you don't have a good—If you're not doing well in an area to begin with, then this makes it worse, so, J [wife] and I had some, uh, baggage from even before we got married that we never settled, so it brought it to a point where we had to get it settled. Um, other problems were we didn't communicate very well; we didn't understand each other very well. She had some anger towards me for some things before our marriage and it, it made all those intensify to the point that we had to deal with them. Other areas—Another significant area is, as J mentioned, the difference in how we deal with emotions and feelings...."

His wife stated, "I do think that our biggest struggle is making yourself or finding the energy to invest in a relationship when so much of your energy goes to dealing with your pain and the things that jump out and shout at you and say, 'You have to deal with me.' Like you have to feed the kids, and you have to change diapers, and you know, um, our relationship doesn't do that as much, so I think that we just have unconsciously—In a lot of ways, it's easiest to let it go by the wayside...I just don't have the energy and...you just kind of throw up your hands and, well, I don't know where to get the energy. I mean, it's gone...A good relationship takes a lot of energy, a lot of time, and a lot of effort, and that scares me to a degree, because, you know, I don't know where you get it when you're using it dealing with what life has hit you with [the illness]."

In talking with an elderly couple about what had made their marriage a success and how illness had affected it, the husband stated that they had the qualities which contribute to a good marriage even before they married. Then his wife stated, "I don't think at our age that if you didn't have some of these qualities, I don't think that you could develop it with something like this [his chronic disability]
happening. I think you have to have those qualities. If they weren't there, the person would have self-- the person who was affected would have self-pity and would not try to go and be independent. And that could be very demanding, I could see."

Husband: "Well, the lack of probably the qualities we're talking about probably accounts for most of the divorces."

The qualities mentioned by this couple were the ability to know and honor the other's desires, consideration for each other, forgiveness, and "understanding" love. Another wife whose husband had a brain injury from a fall followed by a stroke stated that, "I think that people who would, say, be farther apart [as a result of an illness] would be people who maybe were not strong within themselves to begin with. And they let these things bother them to the point that it pulls them away. I can't see, if there's real love and concern and caring in a family, how illness or anything would make you farther apart."

A wife of another husband with a head injury stated, "Within the head injury group, I've witnessed so many divorces and so much selfishness with the spouses, and I thought, especially in the beginning when T [husband] was still having such great problems, 'Lady, be happy for the fellow that you have because, you know, T can not do this; T can not do this; your husband's able to do these things; he walks; he talks; he drives. . . . He can clean house; he can, you know, just so many things,' and here they are, some of these women, thinking they're in such bad shape, and you know, they're the ones that are carrying the whole burden, like nothing happened to their husband. Their life has changed so drastically that they're almost blaming the other person for this, you know? 'If this
hadn't happened to you, it wouldn't have happened to me,' and these women are able to work, too. . . .  

"I think to go through this that people need to be pretty stable, and so if they're not, and if they've been very spoiled, it's going to be very difficult for them; it's easy to give up. And, uh, you can just see the marriages fade away, the ones in the group, and that's hard. It just, you know, when you're normal and can cope with things, it's one thing. But when you've had a massive head injury, and you're trying to cope with your life, yourself, and then you see you're losing everyone around you, [it's devastating]. . . . They [the people who are not doing well in their relationships] can't talk; they don't know how, and they might not really be aware of, uh, uh, well number one what there is to say, and number two, how their illness is."

Another victim of a stroke attended a support group and observed, "There is a man who came in and is in our stroke support group and uh, he is, his reaction pattern has been so apparently to berate his wife so much that uh, you wonder if the, how much more the marriage is going to take. It just triggered that pattern. He, uh, he berates her, then he will reference it and cry about it. He has some language limitations with his stroke."

If these observations are correct, one might say that in a marriage which is not strong before the onset of a chronic debilitating illness, it is quite possible that the individual stress which heightens any preexisting couple stress may precipitate the onset of marital dysfunction which is significant enough in scope and duration so as to lead to the termination of the marriage. However; the couples in this sample, with the exception of one remarried couple and three couples with small children who had been married for only 6 to 8 years, had been
married for 15-57 years; only one of those couples was married less than 20 years. For the most part, the illnesses had also existed for several years. It is likely that these couples either had agreed to tolerate and maintain a less than desirable relationship or had worked out the relationship sufficiently before the onset of the illness so that they were able to withstand the stress associated with it.

In fact, the largest number of the couples in this sample (37.8%) stated that they believed the quality of their marriage was actually improved as a result of the illness. Twenty-six percent stated that the quality of the marriage was decreased because of the illness; 10.5% were only two years into the illness and were still in the "working out" phase of dealing with the grief and stress (currently each of these couples was experiencing decreased marital satisfaction); and 26% believed that there was little or no effect on the relationship, while 0.5% had a mixed review with the wife seeing a decline in the marriage and the husband believing the marriage had improved. For some, perhaps for the reasons given by these research participants, the stress of illness does play a part in the termination of the relationship through divorce.

For some couples, the extended family system was a source of stress in relationship to dealing with chronic illness. A couple with a handicapped child stated:

Wife: "The biggest stress that we have-- and he mentioned it before-- we don't get any help from our family."

Husband: "Either side."

Wife: "Either side."

Husband: "Dad does with him [speaking about normal child]."

Wife: "He [husband] lost his Mom when he was--"
Husband: "Nine."

Wife: "Nine, and so there's just his Dad, and he'll watch him [handicapped child]."

Husband: "Not overnight, but he'll watch him."

Wife: "Not very often."

Husband: "Not often."

Wife: "But he will. And then my folks just live 20 miles down the road and she's a LPN and, uh, I don't know, like you said, we could count--"

Husband: "On both hands. Used to be one hand, now we got up to two."

Wife: "... We can't even go out to eat, just him and I. For an example, okay? For an example, I had major surgery this January, had a hysterectomy. Uh, I was making plans-- Thank God, I've got two really really close friends; I don't know what we'd do without them-- but I was making plans, trying to get everything, you know, figured out on how we was gonna do everything and he was getting his shifts all regulated and I talked to Mom... telling her what I was doing and she said, 'Don't worry about it, it will take care of itself.' I said, 'Mom, no it won't... With B [handicapped child], I can't just say 'Okay, you and [brother] walk over to someone's house or walk home, fix y'all a sandwich.' I mean I can't do that with B. He's like a two-year-old and in some ways younger than that, and she [mother] was just sayin', you know, 'Let it happen.' Thank God I made plans because she was going to take the kids for the weekend or for however long. She comes in on a Friday after school and she had 'em here Sunday at noon."

Husband: "She gets upset if you don't ask her and if you do ask her, she usually makes an excuse."
Wife: "Just like-- Our church, I'm the church piano player. I was playing for a funeral, and uh, this was before B's school. It was at our church and we had to go serve and so I asked Mom-- there wasn't anybody else; both my friends go to the same church, so they were going to be there, too. So I said, 'Mom, can you watch B 'cause I'll be busy?' 'Yes, okay'; she didn't have anything else to do. 'But you gotta be back at 4:00.' The funeral was at 2:00 and I had to clean up, so I had to leave everything, go get him-- she didn't have anything else planned-- and take him back and finish help cleaning up. I have never taken advantage of my Mom. Now when my brother was married, they would pawn their kids off on my Mom, and that was okay, and they never griped about it or done anything. We have never taken advantage of Mom and Dad. We have never said we was going to be there at a certain time-- If and when they have watched 'em, I have been there early. They always talk about 'our grandkids' and uh, 'We're going to be good grandparents. We're going to do this, and we're going to do that.' They've not done anything. . . . They'll watch [normal child], but they won't watch B."

Husband: "... She gets real defensive [if you try to tell her about how you feel about not taking care of B]."

Wife: "I just got fed up with her. Yeah, Mom and I got into a big old fight. I'm just shocked. I've gone through shock and hurt. I still feel hurt and still cry about it, but . . . like we make plans-- Our ten year anniversary and we wanted to go back to where we had our honeymoon. Mom had to offer [to take care of the kids] but when it came time to pick 'em up, she didn't feel good; her back hurt or something so we didn't get to go."

This couple seemed to feel as if the family was unwilling to take care of this child because of his handicap. This was another source of stress and hurt. A
diabetic who also experienced hurt and rejection by his family of origin because of 
his illness stated, "This is something. I have one brother that told me that he 
couldn't stand to be around me because this [gastrostomy] tube is gross. That's 
exactly what he says. Wouldn't that hurt your feelings just a little bit?"

A wife with a disabled husband had this to say about family: "I have to be 
honest. Even my own family still pass our house everyday and never stop and 
say 'Hey, sis, you need some milk or you need some bread?' or whatever, you 
know, and uh, I don't know, maybe I made it a little hard sometimes too because I 
was determined that if they couldn't stop and see if I needed something, I wasn't 
gonna crawl on my knees and beg; we'd do without first, you know. And maybe 
that's being hard hearted or a little bit stubborn or too proud or whatever, but it just, 
it hurts to think, you know, that it wasn't like they had to go out of their way, you 
know. They could at least have stopped and said, you know, 'Do you guys need 
anything?' or 'Can we help?' Even if I'd said 'No, thank you,' at least they would 
have asked, you know, but that's-- There's a big problem out there that there's 
nobody that really cares and think they're doing okay themselves, you know. 
Well, the heck with it, and it makes it really hard, you know?"

The father of a handicapped child stated, "I wish he was friends with more 
cripples. Because of the kids that are in good sound condition, you've got the 
lame duck syndrome, the lame duck situation. He's never been treated like he was 
anybody by other kids. They run off and leave him; they use him, call him names 
or whatever. They don't ever play with him; they won't play with him. He's always 
left alone. And so all his life he's been alone as far as other kids go. And believe it 
or not, that's the heart breakingness part of this whole thing. That's the hardest part 
of the whole thing is the way the other kids treat him, you know."
The child did not convey this same idea about being totally left out or rejected by other children. It was the father who seemed to suffer the most by his perception of how his son was treated. They continued:

Wife: "Yeah, well he's learned to cope with it, and he's learned to entertain himself."

Husband: "Probably a lot worse on me than it is on him."

Wife: "Yeah, it is."

Husband: "It's made me feel bad ever since he was born, or ever since he was old enough to play with other children."

Wife: "Well, I've noticed, too, that other people don't understand what he's got and, uh-- Just like down there at his [husband's] mother's one time, J [handicapped son] was, he was a little over a year old, and one of his nephew's wife had a baby and she was-- I don't know how old she was-- but anyway, J started over-- I remember he had a brace on-- but anyway, he started over toward her, and her mother snatched her away from J. . . . J's brother looked over there and said, 'What he's got ain't catching.' You know, it just made him so mad to see."

It seems that far bigger than the illness itself, for some of these couples, were other stressors including responses from family and social networks (friends, peers, etc.), financial stress, and even dealing with social systems. The apparent lack of understanding from family or friends and lack of acceptance and concern created hurt feelings and increased stress for some of the subjects. Financial stresses were devastating for some. This is discussed in the next section of this paper.
Financial stress

Financial stress was mentioned as one of the biggest parts in the overall level of stress experienced by some subjects. Some couples had military health benefits and pensions or had retirement and insurance plans so that the onset of the chronic disability did not produce an undue hardship. Many however, were faced with financial stress of varying degrees from mild to catastrophic. This, like most financial stress, correlated to a large degree with educational and occupational status. Excerpts from selected interviews provide a picture of this hardship.

"The financial part is the hardest of all. You get all these bills coming in and you can't pay them. N's [husband's] medicine runs $200.00 to $300.00 a month. By the time you pay for that and the rent-- N's check alone might pay the medicine and the light bill, and someone who works minimum wage, what do you do?"

Husband: "It's hard to make people understand that there are X number of dollars coming in. Without Social Security, I've got nothing. With it, I've got almost nothing. I realize that everybody doesn't have the doctor bills I do. The last hospital bill from [hospital] was $13,000. The one before that was $20,000. I didn't even have Social Security then."

Wife: "Medicare now pays a percentage except for $629 deductible. They never pay the limit, and what they do pay on, you're left with 20% of what they do pay on. N had insurance when he worked, so when he got to where he couldn't work, he no longer had insurance. Now he can't get insurance, and I can't afford to take out insurance on me."

Another couple reported, "We live on one of the tightest budgets you've ever seen in your life. I get Social Security. I retired; I was forced to retire."
Wife: "He draws Social Security and I'm working."

This wife also worked at near minimum wage and his medical bills were large and ongoing. Yet another couple said, "We live day-to-day financially. It's not overwhelming but when, when things happen like the car, like our car went, you know, transmission went, then there just wasn't the money for that. So that's frustrating. It's, um, frustrating for me in that uh, when something like that happens, we don't have the extra cash to fix it, so-- Like one time we had, we had to have a radiator, and I had to pay it out over four or five months. We just couldn't do it any other way. So I think things like that are the things that bother me. Day-to-day regular things I can budget. I can still operate within that budget but sometimes it's hard because, you know, T [husband] might want to do some things and just, we just can only do so much; that check only goes so far." This illness forced complete retirement for one spouse. The other was limited due to cardiac problems.

In this family with a handicapped child, the mother worked part-time and the father was a blue collar worker. The child had special needs and frequent illnesses. They provided this picture of how they sought out aid to purchase expensive equipment needed, etc. "Everything we checked into, we either make like $40 a month too much, or didn't make enough or something. We make payments. We say we can't pay it all. We make payments and--"

Husband: "We were getting help from SSI at one time."

Wife: "Yeah, at one time, and now we're paying them back after they'd been giving it to us for months."

Husband: "We have to pay them back now."
Wife: "And like, we have to turn it over. They said they want $1,100.00. [laughs] I told you about this check. [anxious laugh] I knew it wasn't going to be this amount. I knew the check wasn't supposed to be that big, so I called 'em and said, 'Where can I send this check back to; it's too much.' [They said] 'Well, we can't do nothing about it now; just cash it and next month we'll make it up.' Well, next month come and they didn't make an adjustment, so I called them, you know? They go, 'Well, you must be eligible to make the full amount,' so okay fine, you know. But now they say, 'You owe us.' .."

Another wife stated, "Our financial situation is such that we can't afford to go out to do anything. You know, it's such that we can't afford to go out for a movie. You know, it's basic right now, you know: food, clothing, shelter, trying to keep the bills taken care of. We had to file bankruptcy this past year because of the tremendous medical bills."

And a final couple, very strapped financially due to his disability and her low paying job, provided this accounting of why the wife does not seek medical care for her own illnesses.

Wife: "He's got Medicare and he's got Medicaid, which pays for 80% of his illnesses plus Medicaid which pays for the other 20%. Now, they don't pay for medicine. We have over $500 a month in medicine for him. I make $518. Now you tell me how we can afford to pay electric and pay our rent and pay everything else. I can't go to the doctor because if he gives me a prescription, I couldn't afford to have it filled. . . . We spend it and do what we have to do with what we have. We didn't have this attitude when we first got married and he was working. We felt that everything had to be paid, and we still feel like everything should be paid. We don't want anything for nothing. But we feel now with all his medical bills..."
and everything that we pay what we can and the things that come first are shelter, food, utilities, things to live on and the bills. The medical bills and that come next. Well, his medicine has to be paid. That's got to be one of the very first things, you know, but when those things get paid, if there's money left over to pay doctors and hospitals, then we do it. If there isn't, there isn't anything we can do about it, and we give them what we can but we don't--"

Husband: "Most of the time they don't get any. And most of the time-- Just like my medicine, I don't know how we're going to pay what we have to pay in medicine before I'm out again. We've got enough medicine to last us a month. . . . It's getting worse instead of better because some of those medicines-- Like when we first started getting them they were like, oh, $20 and $30, and now they are $20 and $30 higher than they were. One medicine I've got up there costs $139 just for the generic. I'm going to have to quit it. I don't have that kind of money. They tell you to see a doctor; I know I need to see a doctor, but when I go to the doctor and they do like he did today-- he gives me these medicines that you have to take-- how do they expect you to do it when you don't have anyplace to go to get help and it's a strain?"

Researcher: "Have you asked them that question?"

Husband: "Yes, and they say 'Well, go there or go here.' I go there and they don't have it or it's too expensive or they can't get it. I don't qualify [for assistance] because I'm getting this already, and I make this amount of money so I don't qualify."

Wife: "That's what I think is the funniest thing in the world is that you go-- He makes $489 a month and they say we make too much money--"

Husband: "It's $18 more a month than you're allowed."
Wife: "I mean that's what, it's what really really--"

Husband: "... On Medicaid they will buy me my three most expensive medicines, but I qualify for financial aid for Medicaid and I get it for 4 months at a time. ... We can handle each other. We can do without things. It's the illnesses and having to deal with the expense of the illnesses, having to deal with doing without things that I need or she might need for our illnesses."

Wife: "Having to deal with maybe not being able to pay the rent the next month or pay the utilities because this is what happens, you know, because you get into a situation like this. You've got, you have medicine that you have to buy, and that comes first, and then so you're taking away for that. Your rent, so your rent gets behind; your utilities get behind and so, finally, it gets to the point to where they say we're going to shut off your utilities if you don't pay it, so you have to make a payment and then leave the medicine go because you had to use that money to make a payment of your utilities, you know, or whatever the case may be. That's what is so stressful, is not having enough money to buy the medicine you need and to pay all of your daily living. ... What I bring home is nothing, you know; it's really nothing. But it will buy medicine that he needs, or it will pay the rent which is two months behind, you know, something like that. It will pay on those things, so I do it."

This couple stated that the marital stress between them was a zero, but the individual stress related to the financial aspects of the illness was a ten on a scale of 0-10. The two couples who were the most severely financially affected were not living extravagantly. They lived in modest apartments, one bedroom, and quite small. When I attempted to locate these two couples at the time of my follow-up call after completing all of the interviews, they no longer could be reached at their
phone number. I could not locate them and suspect that, financially, they were forced to leave.

Social institutions: health care, welfare programs, and education

It makes sense that nearly every respondent in this sample made comments about the health care system. Chronic illness, at least in our society, necessitates ongoing interaction with health care providers. The range of comments was quite varied from the extremely positive to the extremely negative. A few either had no comments about the health care system, or their responses were neutral and matter of fact, with neither a negative nor positive emotional reaction to the care received. This section deals with the health care system as an additional stressor, an enemy or adversary to be dealt with in addition to the illness or, at best, a necessary but uncaring entity.

This first example was provided by a 64 year old woman who had been hospitalized several times with coronary problems in the past 3 to 4 years and also had problems with other assorted illnesses. Her reaction to the care she received was mainly negative. "I've had a lot of different health problems that I didn't have before. . . . The doctor here says, 'Well, that heart attack brought down your system' . . . and, well, my first heart medicine went against me. I got so that I couldn't use my hands. . . . They took a blood sample and what it turned out to be was the heart medicine that I was on. And so then I had therapy for my hands off and on, and it just didn't get better. . . . They was gonna do surgery on that. . . . Well, then in the meantime-- I had had a bad back for better than 20 years-- the doctor said I should lose some weight. I didn't lose the weight, which I should've, I admit, but he should've looked into it more, and when he didn't I should've went to another doctor because then while I was gonna have that surgery, my right foot
just started flopping . . . so I went out to . . . see the doctor, and she said I was all right for the surgery, but she had a fit over that foot. So she said to tell the doctor when he did the surgery for my hands, tell him about your foot. Well, I decided not to wait, so I called the doctor and told his nurse about it. Well, she was kind of hateful, but she called me back shortly and said they wanted me over there . . . and they sent me on to [the hospital] to run some tests, and they told me it was from an old injury . . . so then I had back surgery. And then I had laser gall bladder surgery . . . and then surgery for hammer toes . . . but then I had bronchitis that drug on and on, so [the doctor] sent me to the hospital and it turned out to be pneumonia. That was at the first of July.

"By the end of July, I couldn't get my breath, so I went back in the hospital and my lungs had filled with water. So, they sent me back over to the cardiologist and he did another arteriogram on me, and what it turned out to be was the heart muscles had gotten too weak to pump the fluid to the kidneys, and so it backed up to the lungs. So he said that they'd expect me to go anytime. . . . Well, he had changed my medicine. . . . I just got so deathly sick and she [another doctor] said to go back to the hospital. . . . I was on ten different medications from three different doctors. Of course I was very careful that each one was aware of everything I took. I said I thought it was some of the medicines not agreeing with me, and she said, 'We'll have to put you on a cardiac monitor to find out.' Well, while I was out there doing that, I went out, completely out. My heart completely stopped. . . . They gave me electrical shock and CPR and rushed me to [larger hospital]. . . . When I received the arteriogram, I found out those heart muscles was weak.

"Well, of course, I had it [arteriogram] three times before that. The first time was at [hospital] Intensive Care . . . and that nurse was a very pleasant, very sweet
person. . . . The second one didn't make even an impression on me; she just did her job and went on her way. Well, this time, they didn't have room for me in the outpatient, so they kept me in the holding ward to go into surgery. Well, this young girl come in there and said she was going to apply pressure. [After an arteriogram, pressure must be applied constantly to the catheter insertion site to avoid bleeding.] Okay, I'd been through it before. It wasn't two minutes when she traded off with a man, then they traded back. Then they had another man involved. Now you're not gonna trade off with the flow and not keep, and keep the flow going. One time there were three pressing on that leg at one time. . . . Well, you can't imagine the leg I come out of there with. I still got the marks.

"Well, anyhow, down in the outpatient ward, when I got moved down in the outpatient late in the afternoon . . . she told me if that leg starts hurting, be sure and get ahold of the doctor. Well, it was all right that day and the next, and the next night I woke up and I, and that thing was killing me. And so I called the doctor that was on call . . . and he said 'Put some cold packs on it.' . . . The next time I got up I had a knot the size of my fist sticking out on that leg. . . . By that time I had a pain in my toe. You don't associate that with the heart. It seemed like a silly thing to complain about, even if it did hurt like the devil. And I forget what else it was, but anyway I had two items so I went out to the doctors . . . and that toe upset [the doctor] a lot more than I expected it to. I'm pretty sure now she thought that the blood clot had come from the damage they done with that leg. . . . It was a blood clot that traveled down my leg to my toe. If it had went the other direction, it would have went to the brain and caused a stroke. . . .

"I told [the doctor] what I thought of the people [at the hospital where they did the arteriogram]. I don't think they should be allowed on that kind of work.
whatever. I'm very angry about that. It was so uncalled for because I know how it can be done. I can't remember what words he [she has referred to two different doctors] used but what it amounted to was 'Doctors' nightmares; they can talk to them and talk to them and they do their own thing.' But, he said, 'I know the time and date and I can find out who it was.' Well, I don't often wish people bad luck, but I hope they burnt the tail off of 'em. I really and truly am bitter about it because it was so unnecessary, and it did cause me a lot of problems, and I didn't need no more problems.

"I don't like [hospital's] cardiac floor because the nurses-- Now the aides were nice, you could survive with them, but their nurses come in bitchin' and bitchin'. They were underpaid, and they were overworked. That's all you heard out of them. And one nurse bitched so one day that I told her, asked her, I said, 'What do you, how many patients are you responsible for?' 'Six.' Well, I thought, 'Whoop-de-doo,' because I know that my roommate and I, sometimes it's 2 and 3 hours when she didn't need to come in there. Of course, I may, I realize she maybe had some very severe in those six, but I still don't think that needed to be laid on us, and that's the darn truth..."

Then this same woman spoke of the first time she was in the hospital to have an arteriogram. "I could not move that leg because they told me that if I moved it the least little bit, there would be a spear there, kind of like a spear that would hit a main artery and cause a lot of problems, so I was immobilized. Well, I did a lot of vomiting in Intensive Care and those ladies acted like it was their privilege to clean it up. They clean me up and clean the bed up. So one night, a little girl come in. I told her, 'I got bad news for ya; they're having to clean me up from vomiting' and she said, 'We'll take care of that,' and she just handed me my dish pan, my water
basin. Well, you know what those spit pans do; you vomit, it goes flooey. So when I went down to the ward room, I insisted that I have that pan [the large water basin] in bed with me. Well, they argued with me over it... Well, everytime I dozed off, it was out of the bed. Well, there was no way I could get it. So, I ended up, the only thing I could do when I was vomiting was throw my head. Well, that made them angry. They did not like that a little bit. And I never did get the bed changed or me changed; I got a wipe job. . . . So when they took me down to do the balloon-- Well that's another thing, and I've often wondered if that had something to with the second blocking again-- When I got out of there, they took me back in the holding place, and you know those cots are miserable... my back was hurting."

This lady's perception of her care was very negative. Lay people have little knowledge of what, from a medical standpoint, constitutes good care. But they do know how they are treated as persons, whether they are treated courteously and respectfully, and that has a great bearing on how they perceive the health care they receive.

Another woman with an ill child reported an account of learning her son had a brain tumor shortly after two friends and family members had died of cancer. "The doctor told me that, uh, it was cancer. He said, 'I know it is,' and he gave me all this crap that could go wrong. And, um, he [son] was on, he was on the operating table over ten hours. 'Course we knew that that's what, that it would take long and then, um, we didn't really know what was going on, but they were coming out ever so often and telling us that he was still in surgery and he was still, you know, they would get word to us."

Her husband said, "'Course you imagine it's a lot worse than it was. . . . It looked a lot worse than it probably was 'cause when he come out his head looked
like a lop-sided pumpkin, you know, great big huge. . . . They had him bandaged up. They wasn't going to let us see him."

Wife: "But, you know, there in [hospital where years earlier there had been another surgery] they didn't even let us know what was going on; not a person came out and told us, and I think he went in at 5:00 and came out at 8:00, and I didn't know whether he-- They let us see him, and I wished I hadn't of 'cause he had tubes in. . . . Now down there [other hospital] this nurse came out . . . and said, 'Now, he's got a catheter, he's got all kinds of monitors' and he had an IV and blood. She explained to us what he had, and you know, everything. . . . It helped me to know. . . ."

Husband: "But I do feel that the parents' welfare is grossly neglected because everyone is concerned with the sick. And they don't realize that the parents are also sick. . . . Sometimes just talking to the parents can help, you know what I mean . . . maybe even before the operation . . . maybe try to find ways to put 'em at ease."

Wife: "And try to explain what might happen to you, [not just what might happen to the patient]."

Husband: "Yeah, and uh, they might even be concerned about some kind of a pill that a person could take if he got too nervous or too upset, something like that, you know."

For this couple, a lack of information and preparation of what to expect, not just for their child, but also regarding their own emotional responses, added stress at an already stressful time. Another wife reported on her perception of the care given to her husband while hospitalized for cardiac problems.
Wife: "And the medical profession has gotten so bad that I can't afford to, you know, to put him in the hospital and not stay there with him, because I don't ever know what they're gonna do to him. That's like he was transferred from here to the city and had such a bad ordeal with the catheterization, you know, that-- I told you about with the balloon in there and all that, and I-- After they had him in there the second time and brought him out and I was standing there with him, uh, he said his head was hurting him real bad. Of course, we knew it was from the nitroglycerin patches that they had on him, and so she went to get him something for his head and she come back over there and she told him, she said, 'Open up. I got you some Tylenol with codeine' and I started hollering at her, you know. 'Wait, wait, he's allergic to it.' He had this big red band on his arm that says 'codeine' in great big letters, but she never looked; she was just gonna pop 'em down him, you know.

"It's like they, you know, you're scared to take 'em-- You're scared to leave 'em, and you know, I mean it's just unreal to me. And the first time that they had him up there and they had him in ICU, I went in to see him. You know you can only go in every so often for ten minutes. And, uh, three times I went in there, and every time I went in there, I had to call somebody to come to him, and there was supposed to be a one-on-one nursing in there. She was paying no attention whatsoever. The first time the monitor was all crazy because he was half unhooked from the monitor. The second time, the IV had come out and was dripping all over the floor. The third time the bag that they have, that they have to keep so much pressure and keep the fluid going in where they do the catheterization, they hadn't; the pressure was off of it, and it was pumping blood out of him all over the place. And you know, it's just stuff like that, and I told my
sister that one more trip and I'm just gonna lose it. They won't let me stay with him, but yet they won't take care of him either, you know. It's just all scary."

Researcher: "So you don't feel safe to have somebody in the hospital that you care about. Were the nurses supportive, did they recognize that you were angry or afraid or upset?"

Wife: "No. I guess it makes you angry because they charge for that stuff, and you're supposed to be getting good medical care, you know, and I feel like if I hadn't have been there, he might be dead today... And if you say something, you know, it's like, 'Well, everybody makes mistakes,' you know. But that's his life, or my life, or whose ever's life, you know. It should be more important than that."

These were probably not life-threatening incidents although without correction, they might have become so. While lay persons may not know what is potentially dangerous and what is not, again, they can tell when something is not as it should be, and it creates a mistrust, especially when the fear is not recognized and dealt with by the health care providers. This next woman spoke of her feelings about the mental health care system.

"After a certain time you get treatment sick. You get sick and tired of counselors; you get sick and tired of psychiatrists; you get sick and tired of it all. That's kind of the way I feel. I went to see a private counselor, and uh, the way they were set up, their funding was set up on how many alcoholics and recovering alcoholics they put into the program. So I felt that instead of addressing the problems I had then, they were addressing them as a recovering alcoholic to make their funding and their number of projective customers that they need to put in the program... I felt like they were missing all this, this other."
This wife is a recovering alcoholic married to another recovering alcoholic and drug abuser who is now diagnosed with schizoaffective disorder. It would appear that this woman's counselor did not make a connection for her between the alcoholism and her current problems if he/she believed there was one, so that the therapy offered made some sense to this subject.

A mother with a child physically and mentally handicapped from birth stated, "They come in that night-- there was three doctors-- and said, 'Well, we've done all these tests and we've found out that your son is blind, and deaf, and mentally retarded and probably will never do anything, but we want you to take him home and treat him normal.' And they discharged us right then. I cried all the way home. Fortunately, J [husband], his sister, and her husband had come up to visit, so they drove us home. A few days later I thought, you know, 'Well, if this kid's got all these problems, I need to find out where to take him so I can learn how to help him learn or learn how to take care of him or whatever,' so I called one of the doctors back. He said, 'I don't think it will do no good no matter where you take him.' Well, that didn't set too good with me, you know? I thought, 'Well who are you? You're not God; you don't know what this kid is gonna do.' So, fortunately, I had a friend at [clinic] and I took him in to neurology because he had siezures and . . . they kinda showed us how to work with him."

Researcher: "So if you had not had a friend there, you might not have known it existed, and nothing else was offered in terms of resources or places you could go to get information or help?"

Wife: "Nothing. Nothing. . . . The doctor was very rude. 'I don't think it'll do no good no matter where you take him' which we've come across that a lot 'cause
R's [son] very severe. To me, they need to have a little more tact or finesse or compassion or something."

Later in the interview, she talked about the time they were faced with making a decision about whether to have a gastrostomy tube inserted when this child was about nine years old. "He was in the hospital, had pneumonia. They wanted to do a feeding tube right then, and he was out at [hospital] and, of course, we didn't want it done, you know. We don't want to take this [his ability to take oral nourishment, which he enjoyed] away from him. Uh, we had a little intern come up to me and say, 'Well, you're aware that you can't withhold medical treatment from a child just because he's handicapped.' She come this close to gettin' her ass whopped. I mean, you know, and she even went so far as to call our regular pediatrician, which I've used for 20 years, and he told her, 'Look, don't underestimate this woman,' you know. But yeah, I think they should be taught from day one that, you know, a lot of us parents-- Maybe some of us are stupid, but not all of us. But after the head surgeon out there talked with our pediatrician, you know, we all agreed that maybe it wasn't the time to do the feeding tube, you know. I mean, eventually I had to have it done."

Later in the interview she said, "They're making the kids live longer, and there's got to be resources for parents to go to. I mean, you can't just-- I've seen parents bring kids home from day one with-- I mean R's even more involved now with his trach and his feeding tube, you know; they're just brought home cold, know what I mean? I mean the parents don't know what to do. The first week after I come home when R first had this trach and his feeding tube, I slept on the floor by his bed, scared to death I wouldn't hear him."
One final couple was very satisfied with the medical care they were receiving at the present time but had this to say about previous providers for their sons. "Dr. X has been our God send. He has been the one that's really-- If we had him all along, but none of the other doctors ever treated him psychic-- physically, but never anything mentioned about emotional, even the doctor from [specialty hospital], you know. It was just a very cold and-- But never any emotional help... for anybody. All the money that we spent, and we spent thousands of dollars... They told us what was the matter, and put him on medicine and that was it... No one ever asked D [older chronically ill child] any questions, emotional questions. Nothing!... That's what makes me so angry; to know that well, maybe it wouldn't have been so hard if we'd have known that there was a doctor that did stuff like [our present doctor], that helped emotionally."

This couple had gone to several clinics around the state and the country, seeking answers and help for their sons. Ironically, they found the kind of total person care they were seeking in a local federally funded health care program.

When health care was viewed as an added stress, it was because workers in the system did not pay attention to the needs of the individuals and the family members, but, instead, focused only on medical problems. Sometimes it appeared to these respondents that even these were not attended to very well.

Several subjects were also very stressed out by their attempts to find help from the very social programs designed to provide assistance for persons who are in situations such as these subjects were contending with. Finding financial assistance from disability and Social Security programs was extremely frustrating and humilitating for some.
Four couples discussed their feelings of frustration and anger regarding trying to work with the social programs designed to provide assistance. Two of these couples had an ill child; two were couples with an ill spouse. These are their reports.

Wife: "We have to fight to get his rights. There's been a lot of battle for him to get what he's supposed to have. We don't even get what he's supposed to be getting. How other people can do it, I don't know. I've learned-- We don't lie, but you don't offer information unless it's asked. I don't lie; if they ask, I'll answer truthfully, but I'm not going to say anything and offer it to them."

Researcher: "So, in order for a handicapped child to be eligible for Social Security disability benefits, it's based on his parent's income?"

Husband: "Yes, it is."

Wife: "And he's more than qualified."

Husband: "Yeah."

Wife: "They told us he's more than qualified."

Husband: "Well, we need to go through it again. They passed a law again or something where they're more eligible."

Wife: "We gotta begin the fight again. . . . Welfare told us one time, if D [husband] and I were divorced, they could get all the help in the world. I said, 'You mean to tell me if I divorce him, my son would get taken care of?' I said, 'All I ask is for a little bit of help.' So I said, 'Well D, let's get a divorce; you can live with your dad, which is next door, and just make trips over here. [laughs] . . . I guess everything you hear on TV, you know, supposed to be for handicapped people, I look into it. Well, it's not what it's cracked up to be. One person's criteria will be fine; another person's criteria will be too much, you know. Well, we found one
place that helped us get his stroller; that was expensive, and I called them to find out about it 'cause [social worker] had told me about it. They go, 'How much money do you make?,' and I go 'Here we go; here it goes.' But it was a bombshell. They said, 'No problem.' I can't believe it."

This couple was blue collar, not living at poverty level but certainly not well-off, either. He was employed full-time; she part-time. They lived in a small mobile home in a small town with their two children. The youngest, the handicapped one, was 8 years old, unable to speak, not toilet trained, just learning to walk and crawl up on the couch, and totally dependent upon others for his care and nourishment. He needed special equipment, which was costly, and special care, which was provided totally by the family. This meant that all other family members had to sacrifice for the handicapped child. There was no money for paid providers to assist with even the physical care or to provide respite services.

Another mother was comparing her current state of residence to another where she had previously lived. "Well, if I can compare A with here, A has what's called ALTCS. It's a Long Term Care System which kids like R [handicapped son] automatically qualify for because of their medical condition. Okay, here we do not have that. In A, I could get that out there and still work and still make, you know, a fairly-- enough salary to support me and the kids. Here, when I go to work, I lose everything, I mean everything.

"I think A's program should be nationwide. I mean, I realize that R or these other people are not like your responsibility or their responsibility, but if you pick the lesser, it's cheaper to keep 'em at home-- they're better taken care of--than it is to put 'em in an institution. . . . He doesn't have Medicaid now. I'm trying to get it,
but they're fighting me [laughs]. Oh, I can't believe they cut it off. Oh, do you know how frightening that is? It costs $1200 a month to get the stuff that R has to have. That's not counting the doctor bills and, you know, hospital bills. That's just tubes and trachs and formula and, you know. . . . That guy said to me, he said, 'What's the matter with you going back to working?' [She is a physical therapy assistant.] I said, 'Not a thing, but who's going to take him to the doctor, and who's going to take care of him when he gets sick, and who's going to pay my bills when I can't work to do all this stuff, you know?' He said, 'Well, I understand your predicament' is what they kept telling me. Then they called and told me they'd buy R a toy, but they wouldn't give him his medicine. I just cried."

The wife of a man disabled with chronic back problems and cardiac problems stated, "It was probably in '83 that we started trying to get him on Social Security Disability because the doctor wrote a letter saying that he was not physically able to do the kind of work that he was doing. And he couldn't seem to find anything that he could do because he can't really sit very long at a time or stand very long at a time. And so, when you have a back problem, you know, you go someplace to go to work, and you put down that you have a back problem, they aren't going to hire you anyway. So, you either have to lie . . . but then he was on Social Security; we finally got him on after three years, I guess, of fighting with them. And then it was '89 when they cut you off [to husband]? . . . "Yes, they sent a letter saying that he had to go back to the doctors again. He, uh, went to the doctors and stuff, and I was with him every time he went for an examination, and they did not examine him. I mean, just for little minor things and then they would tell him, you know, that he had improved, and we got the denial. So then we started fighting it again. And it took us until this year to get him back on it again. Then
they said he never should have been taken off of it. And it has just been one long battle [laughs]. . . . He doesn't get enough Social Security so that he could survive by himself anyway and, uh, it's just hard."

Husband: "When you start fighting the system trying to get something done, uh--"

Wife: "They humiliate you."

Husband: "... Then we moved from [another state] here. I had one last appeal. Then before my appeal, I had a heart attack, another heart attack. I had one in [other state], but they said it was from too much medication and I was able to go back to work. And I knew if I went back to work, I was going to die. They just completely ignored it. So, anyway, back to this year. I had the heart attack and had a lot of medical bills that I took to my last hearing with me. The judge I drew here was very understanding, and he took the time to go through my records, and he knew everything that was in them, and it went like clockwork."

Wife: "That part of it went real well, but then when they sent him his medical card, they--"

Husband: "They did not hold out the money for the Medicare. Well, they paid payments, back Medicare payments that we have to pay each month."

Wife: "So we have to pay all that back."

Husband: "Well, see, they owed me back money, and they paid it in a lump sum."

Wife: "But they didn't hold out the money for the Medicare part."

Husband: "The judge declared that I had been eligible all along for my checks and my Medicare coverage, but they did not hold out the money out of my back pay to pay for the Medicare, and I was in debt over $13,000 from the heart
attack and no way to pay it without Medicare picking it up which they wouldn't 'cause I owed them money. So we had to fight with them for three or four months over that . . . so they finally told me if I would send the money to make the Medicare payments back that they would--"

Wife: "They would pick up the payments."

Husband: "All in all, it came out, but it just took a lot of time and trouble and fighting with them."

Wife: "It's still going like that."

Husband: "I think, personally, the problem is I have heart disease and I have arteries that are clogged up . . . and I think a lot of my problems with my heart originated from being under so much stress from Social Security and the doctors they sent me to."

The fourth couple made this report.

Husband: "At one time we had money in the bank. When I went on disability, that money was gone; not one penny [was left]. The account ended up being closed because that had to be done before we could go on disability because they would not help us with anything: food stamps, rent, nothing, not one dime until I did not have anything, until my money is gone and I have to beg for it. I have to beg for everything that I get from them. What will happen is, because she is working, we apply for food stamps next--"

Wife: "They will go down. We don't get that much to begin with. You know, you only get like $30 or $40 a month in food stamps, and that's not enough, you know, and now because I'm making the little bit that I'm making [less than $500 per month], they'll go down. Or we won't get any at all."
Husband: "It's degrading, and it's also depressing, and it's also frustrating. Emotionally it becomes sometimes-- Emotionally, it is the hardest thing when you sit over there in their office and they ask you things that they don't need to know anything about, and they tell you that you probably won't get X number of food stamps this month, you'll only get this or you may get that. Or if you ask for medical help and then they turn around and they tell you that you can't have it because you make too much money, but yet you-- They know, so help me as true as I am sitting here, they know that you will die if you don't have your medicine. They know I can die if I don't have my medicine, yet they won't give it to me because I make just a few dollars more than what the limit is, and that's frustrating. It's angering; it's emotionally upsetting.

"We try not to let what those fools do that are running the state, we try not to let them bother us to the point that it affects us. . . . I don't know if you've seen the paper today. . . . It had a big box on the front page 'Cut financial aid to DHS'. . . . They're cutting out free medicine all together. Those people who are already getting their medicine for free will have to pay. . . . They're cutting back on aid to dependent children and they are . . . taking the money away from the poor and sticking it in their pocket or they turn around and send it to Saudi Arabia so they can rebuild their oil fields and so forth. . . . There are too many legislators who are not taking care of the poor; they are not taking care of the medically disabled; they are not taking care of the old; they are not taking care of our children, the ones who are suffering. . . . They don't even begin to know the humiliation that people like me or my wife or somebody else when they have to go sit in the DHS office and be grilled over what you make and what you don't make and how much you spend here and what you spend there and so forth to see whether you qualify. I
shouldn't have to go over there to qualify. They know I am disabled. I have been disabled since 1982. They know I make so much money every month and it doesn't change. They know I am sick; they know I can die if I don't have my medicine, and yet I have to beg, and it's wrong. I get angry over that.

"That is one of the biggest frustrations in my life is having to live in poverty. I can't get life insurance. We can't afford it because she's a diabetic. She can get it even though she's diabetic. I can't get it. They won't even talk to me about it. I had life insurance. We had to let it go. And after I had my heart surgery, that was it. . . . She has this form to fill out. At [hospital], she can get reduced liability. You pay according to what your income is. But like she said, even if she went, she couldn't afford to buy the medicine if they gave it [the office medical visit] to her. . . . I don't even think most people realize unless they are in the same boat we are, they don't even begin to know the humiliation."

The public school system has been another social institution which has created stress for some couples as they have had to assert themselves to obtain special education programs needed for their disabled children. One mother stated, "We had sued [the public schools] for summer school and for therapy services, so I knew all about the rights and due process and everything that went along with-- I knew what steps to take if you couldn't-- [This state] does not offer the programs that [the other state] did. They don't have-- Well, out there they had a private school for handicapped kids, and they had preschool programs, and you know, lots of different things that they don't have here."

Another couple had this to say about getting their son's needs met by the school system.
Wife: "We have fought the school system, doctors, and everything in
pushing his learning. I mean just getting them teaching him things and, because if
there comes a time, [when he can't progress any further] I want to get everything
in, you know. . . . We had to fight just a little bit. I mean they're a really good school
system and they've really come a long ways. It's just they've never had any calls
for anything."

Husband: "This is the second year they've ever had a program, so they're
still learning."

Wife: "Yeah, I mean because just like some of these parents around here--"

Husband: "They don't know--"

Wife: "They either don't know or they don't care. I mean, I don't know what
the deal is. I don't understand it."

Husband: "They benefitted after we fought it. There's some families that
have benefitted after we--"

Wife: "Our pioneering all this. That's fine too, because someone had to
pioneer for a lot of other things that we've benefitted from so--"

Husband: "They was wanting us to take him to [another town] and they'd
reimburse us and all this, so we said, 'Well, you go down there and come back five
days a week,' and the first day they did it they said, 'No, that too far to drive,' you
know."

Each of these parents found it necessary to "fight" to obtain special
services from their respective school systems which were needed in order to
provide their children with educational opportunities which would optimize their
capabilities for learning. In some cases, new programs were developed which
now are a benefit not just to their own children but for others in similar situations. It
may be that without the "fight," such programs would not have been developed in those systems. It was implied that although there had been other handicapped children in the system before, no programs existed until these parents "took on" the system.

These couples found it necessary to seek public assistance in order to keep their heads above water financially, or to fight to obtain needed programs. However, instead of providing relief from stress, they found the process of applying for the aid to be an additional stressor added to the already near overwhelming stress they were already experiencing.

**Resistances, Supports, and Strengths**

Social supports: social organizations, health care providers, family, friends, church.

An important component of how an individual or family or couple responds to a stressor is the number and kind of coping mechanisms, resistances, and supports available at the time the stressor originates. This section of the paper will examine the support systems which help families survive and adapt during difficult times. Social supports including friends, family, the church membership and pastors, and other social organizations will be discussed as will the role of religion or spirituality.

Friends and family were discussed by several couples in this study as crucial to helping them survive the ordeal of living with a chronically ill or disabled family member. For example, two mothers, each of whom has a 15-year-old son with some disabling chronic illness, spoke of the support received from other grown children. The first stated, "Well, I have a 19-year-old daughter. She, uh, is a lot of help. She takes care of R [son] if I need to go somewhere, or you know, the
kids, the kids have been real supportive, all the kids. R weighs about 85 pounds
and right now his bath chair’s broken, so I carry him in there and hold him with one
arm and wash his front, and my 13-year-old daughter washes his back and
washes his hair. So, yeah, we kinda-- You know, they’ve all, all the kids have
been really wonderful. R’s trach tube has to be changed every week; sometimes
we have to change the feeding tube. I’ve insisted that all the kids learn how to do
that in case something should happen to me, you know. I was talking to [oldest
daughter] the other night and that if something happened to me that basically her
being of age, it would be up to her and [brother] to carry on with R and [underage
daughter]. . . . I worry about, you know, putting that burden on them. I mean, I don’t
think that’s quite fair either but, you know, there’s not any other choice. My family
wouldn’t take him.”

The current members of this nuclear family were supportive but, apparently,
the members of the mother’s nuclear family of origin were not. Another mother,
likewise, has her older children for support. She said, "When we were faced with
making decisions when J was small, the older brothers and sisters were very much
a part of that. In fact, when we took him to [city], the youngest girl was in high
school and the oldest girl was going to [college], so she didn't go to school that
year; they went with us to [city] to see what was wrong with him. And they have
just been a part of, uh, you know. And the oldest boy, he was always concerned
about J and he was still in high school, and he was really concerned about him
and he'd take him to school. Two years before he graduated, he'd take him to
school."

Another couple with one chronically ill and one mentally disabled child
stated very simply, "It helps to have a lot of good supporting family and a lot of
good friends. . . . His mother's just a hop, skip and a backyard away, and mine's about . . . two and one-half blocks away. Sometimes that helps; sometimes it gets in the way. It just depends on the subject. Like one of our problems we've come up against since he started working is . . . time. I work from 7:00 in the morning to 2:00. And he'll go to work anywhere from 3:00 in the afternoon 'til they close. . . . He, he will drive C [son] to school in the morning; my mother will come pick me up and take me to work. . . . Now if he [husband] has to be at work early, then we have to kinda depend on my mom, say, 'Hey, can you go get C 'cause S [husband] has to be at work at such and such a time' . . . and well, for instance, last night we, we just took time out and S took me out to dinner. My mom watched the kids and we just had time out for each other."

A couple with a disabled husband stated, "I don't know what we would have done without our families. He, he just has one sister left. She helped us get our van [specially equipped van with a lift which accommodates his wheelchair], and my family has been there to support me."

One wife who became ill herself while her husband still needed constant care following his head injury and stroke said, "[The doctor told me] you're going to the hospital, and I said, 'I can't do that. I have to call and cancel [husband's] appointment and I'll have to call and get somebody to stay with him.' He said, 'I'll take care of that.' Well, I knew that couldn't happen; I knew what he would do. He'd put him in a nursing home or something and that wouldn't work because of his disposition, so I called my sister in Amarillo and she said, 'I just got out of the shower. Let me get some clothes on, throw a few things together and I'll be right there.'" Later, this same wife stated, "We don't have any family here [in town] at all, but people have been so supportive of us this year. We couldn't possibly have
had more attention than what we've had. . . . We have friends in the city; they were there every day to see what they could do, and, uh, it's just been bearable because we have had so much love and concern from people."

A woman married to a man who suffered a severe head injury stated, "The kids were a support system for me, both his and mine. I'm very close with [his son] and his wife. And um, there were some friends."

The couple who was struggling to define and maintain their relationship as they tried to cope with the knowledge that their child will die of her chronic illness credited friends and family for the fact that they had been able to survive together this far.

Wife: "One thing that I just thought of that I think is vital is that we have-- Now [husband] may not agree as much as I do since he's not as close to many people, but I have some of the best friends in the world that have just, have filled these things for me that have been, I think, one of the reasons that we have made it as far as we have. They've cleaned my house; they've kept my kids; they've brought me food; they've taken me shopping. I mean anything that they can think to do that might help us keep on going, they've done it. I think that is a very important reason why we are dealing with this like we are. I am so thankful that we have friends that support us. And our family does. My folks and his folks, brothers and sisters, you know, they're here for us. And there's never a question when we call, and they never grudgingly do anything; they're here and they're happy to do it and they love, they love my kids, our kids, and they, they want to do what's best for them and they, they'll do anything, and I can't say enough about that. We are definitely not doing this on our own."

Husband: "That's true."
These couples had family members and/or friends who were available to help even on short notice. This help took many forms but usually meant physically providing some service, not just providing emotional support. Physical/behavioral assistance was a very valuable resource for these couples who were already pressed financially, physically, and emotionally.

Some of the couples who have made healthy adjustments to living with chronic illness spoke of the value of remaining active in their social or civic organizations or of staying connected to their social network of work, church, or volunteer activities.

A 78-year-old man, blinded by macular degeneration stated, "I remained active. I'd been active in the Chamber of Commerce and Rotary Club and other areas, and I was not affected too much there; I still maintained my connections with those organizations, still do. Little bit difficult, particularly that I can't take any assignments much, anything that requires reading. I can't do that, but I can do other things. . . . We both had lived here all those years also and we had so many friends, so many friends, and we're both religious people and that alone was the main solace. . . . Once you share a problem with someone else, well, it makes your problems so much lighter."

Another elderly couple coping with the husband's paralysis following a stroke reported the following:

Husband: "We have a community of involvement which has been very important. I was very active in work here at the university and still have some minor functions over there, but enough to say 'Well, I need to go over there and do thus and so.' And there's a church associated campus, and I've been, we've both been very active in that for 25 years so it always represents some telephoning or
some like circumstances that we need to become involved with. It's having something that pulls us out of ourselves and intends to weaken this preoccupation with self and with conditions that's been a lifesaver. . . ."

Wife: "... We do go out to eat frequently with various people. With people from his stroke support group . . . and, as he mentioned, the church situation, there are a lot of people who always need to be encouraged and counseled and whatever, and we take them out to eat. So we don't just sit here in these four walls all the time."

Researcher: "You're not just people who are receiving the support; you, it sounds like, are giving support to other people."

Husband: "We, uh, are kind of mentors of the little Loss Support Group at the church, [comprised of] people who suffer from any severe loss of several different kinds. And, uh, enjoy isn't the word, but we've had some fulfillment in it because we've seen some real healing take place in that group. . . . Kind of our standard operating procedure is, uh, weather permitting, we get out of the house at least once a day."

Rather than focusing solely on themselves and how the illness affected or limited them, these couples turned their energies outward, remaining useful and giving. They have used their ability to cope with his stroke to offer assistance to others who have experienced loss. This has provided them with a sense of purpose and usefulness.

Some of the respondents specifically mentioned the church as a source of support from the pastor or minister or from the congregation. One couple had this to say about their minister who, along with two other men from the church, goes to
their home to provide some physical exercise therapy for the husband who is severely weakened by M.S.

Husband: "I feel better now about myself. This therapy that the church gives me has helped a lot."

Wife: "I'd of never made it without the church. . . . This little guy [new pastor] didn't give up. He wouldn't let S [husband] give up. He said, 'I'm gonna make him see me."

Husband: "He's the one that started these exercises."

This man responded to his illness by becoming very depressed. He refused to see other people and virtually ceased all activity and involvement with others, including his wife. The previous pastor had visited, been rebuffed, and stopped trying to visit.

The same couple who spoke of receiving so much support from friends and other members of the community also spoke of being supported by their church and pastors. "We've had so much support that we feel like we were rich, not only from doctors, but also people from our church and from our civic organizations. . . . We are without a permanent minister right now and we were at the time, but the minister that we had was sent to [city] . . . but he came to see me in the hospital, and the minister that we had out here who was an interim, um, he didn't know me but he came to see me in the hospital anyway. And just things like that, you know. . . ."

Religion/spirituality

More than the pastors or congregation or church, per se, religious faith or spirituality was mentioned as a major factor in surviving the stress of the chronic illness for many of these subjects. These were comments made: "If a person
doesn't know God or doesn't have God or isn't an optimist or doesn't have something to reach for towards the future, doesn't have some reason outside themselves to live for, uh, I can't imagine how I could have, how we could make it or I could make it because almost every area of my life in the last two or three years has been extremely stressful. . . . God says that no temptation will be given to you that you can't stand. He always gives you a way out. And I believe that, and knowing that tells me that regardless of what comes to us, God is still there and He will still help us through, and He will still help us make it. It's not gonna overpower us because it's, He's helping us, and without that faith I can't imagine how somebody could live."

This man's wife stated, "I know that [my ill child] will be with God. I believe that to the very core of my being, and I'm happy about that."

A husband whose wife was ill with a weakened heart discussed how he prepared himself for the fact that his wife may die at any time. He said, "... You just live day by day. That's all you can do. And have faith in the Lord that He'll take care of you, you know, but you know He takes-- Whenever He's ready for you, He's gonna take ya. And in her case I mean, it could go like that."

When asked how they find support, a couple who had two ill children responded, "We read the Bible a lot. More S [husband] than myself. But, um, that's uh, that's how he'd encourage me, you know. He'd say, 'I read something really great in the Bible today during devotions' and, um, we'd talk to the doctors and you know, ... they wouldn't say a whole lot. . . ." For this couple, the Bible provided comfort and solice when science and the health care practitioners did not.
Another man coping with heart disease and a weakened heart muscle gave this statement as the way by which he copes: "We do the things-- We change the things that we can change and what we can't change, we leave it to the Lord."

Yet another couple, when asked how they have made a successful marriage and how they have coped with his stroke, stated:

Husband: "We both, uh, happen to have a strong religious faith and uh, that has been the very substance of it. Because uh, we tried to interpret this [the stroke] within the same philosophical set of, I mean our world view. Uh, we believe in the Supreme Being who wants, who is basically good, rather than trying to punish us and abuse us. We believe that in a way we couldn't comprehend, somehow or another good could come out of it, and uh, so uh, well, you answer her question."

Wife: "I think that's your basic-- The basic foundation for ours is, for our marriage, has always been our common religious faith."

A couple with a handicapped child reported, "We read books about the handicapped child and dealing with the handicapped child, but we love each other and we've got real strong faith in the Lord, and He's been like a glue [that keeps us together]."

Faith in a kind loving God, One who may provide challenges or trials but nothing that is unbearable or which does not have a positive purpose or outcome even if it is not readily or easily seen by man, provided these couples with a strength which allowed them to endure through many hard times when it would have been easier to "give up." Two respondents talked about their religious beliefs having been shaken by the necessity of dealing with the illness of a child or, for one couple with chronically disabled children, when the wife's mother died.
These individuals had a strong religious faith which was challenged as they attempted to make sense of the loss which had occurred for them, each within the past two years. Shaken religious/spiritual beliefs may be a part of the grief process of adjusting to the loss, whether that loss be a death which has already occurred or one which is anticipated at some future time.

This report is from the father of the 3-year-old child with the fatal degenerative condition. "I begin to question, uh, the people in the church and God in general. Because people don't know what to say. Uh, I lately have been--This is a passing thing I'm sure, but this is where I am now. I'm very mad at people because they don't know what to do or say, and because of that, generally they don't say anything. So, uh, I begin to think, 'Well, they don't care' and then God--On the same hand, I've always been told that He's a good God; He cares; He's loving. And Jesus, in the Sermon on the Mount, talks about, 'Ask and it will be given' and so forth. And so all my life I've prayed and I've heard people pray and ask for things, and I thought somewhat about them when they asked for something and it didn't happen. I thought some about it, but not much. And now there comes a time that I'm asking for things I really want, and I mean I really want more than anything else in the world, particularly after she was diagnosed, and they don't happen. So, what's the deal?

"So is God-- Then it makes me mad because I thought, I thought what I read-- In the Bible, it talks about how God will answer prayers. And then you ask people about that and they say, 'Well, God answers prayers, but it may not be in the way you want it,' and that just makes me even madder. . . . My relationship with God has been affected a great deal. And I think it will also end up stronger and better and more understanding of God and through that, I'll be able to help other
people, but I think there's a time, certainly, where, uh, I question not everything, but I question some things that I was raised with and trying to understand what does the Bible really say about God and who is He, how does He really see things."

The wife with children affected by growth hormone deficiency whose mother and grandmother had died within the past year stated, "I cannot believe the way that I was raised that He took her away from me. And I told my aunt, I said, 'I can't go back to the church having the feelings that I have.' That isn't right, just to go to church just because you're supposed to be at church. That is not the right way to be. None of us has gotten over the loss. That has been the most destructive thing that could've happened, and I guess that made me even more protective of my kids cause I never realized that something like that could happen, that He was actually going to take my grandmother and then my mother, you know. I couldn't believe it. And so then that made me bitter."

One couple reported that they were coping better after giving up their religious teachings from childhood. The husband had become an atheist; the wife had adopted non-Christian beliefs which are compatible with humanism. They each grew up with a view of God as "watching, punishing, controlling people's lives" and felt less guilt about their perceived weaknesses than when they held onto their previous teachings. Several couples did not believe that religion played much of a role in how they coped with illness, either positively or negatively.

In addition to religious beliefs, other factors which seemed to affect how well the couple was able to adjust to the illness were the individual and family characteristics and the couple's marital quality before the illness. The level of marital quality perceived by the couples was influenced by characteristics of the
families of origin and the couple's goals and beliefs about marriage. The findings in these areas are presented in the next section of this chapter.

Marital Outcome: After Illness Satisfaction and Quality

Couples gave numerical ratings to the quality of their marriages in the year prior to the onset of the illness, at the time of the interview, and in the first year after the onset and diagnosis of the illness (if different). Possible ratings of marital quality were on a scale of 0-10 with 0 meaning the worst marriage imaginable, and 10 meaning the best marriage imaginable. Table two provides a summary of those ratings.

Table 2: Marital Quality Ratings: Husbands, Wives, and Researcher

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Generally, the higher the quality of the marriage prior to the onset of the illness, the higher the quality of the marriage after the illness, although initial stress placed on the relationship early in the course of the illness was sometimes high creating a decrease in marital quality temporarily. The majority of couples in the study reported an increase in the quality of the relationship as a result of dealing with the stress of the illness.

**Marital quality: perceptions, evolutions, and effect of illness**

Some of the couples interviewed spoke of the effect of the family of origin on their couple relationship. A few talked at great length on the subject; others mentioned it only briefly. Couples were asked to identify what qualities had made their marriage more successful or less successful. They provided information about how they made decisions, how they evolved in their relationship, and how satisfied they were at various points along the way. The next section provides excerpts from the interviews which offer a picture of the quality of the relationships, how they have evolved, and how they have been influenced by illness.

A wife whose husband was ill and who believed theirs was as good as any marriage can be spoke of the impact of her past on this relationship. They had other financial hardships apart from those relating to the husband's illness, and attributed some of the cause of the illnesses to those losses.

Wife: "When our home burned, it seemed to start the whole thing."

Husband: "The suicides, the attempted suicides, peptic ulcers, the illnesses which actually started in '72 with back surgery, and a few months later I had hip surgery and then from '72-- March '74, our house burned."

Wife: "We lost everything but the clothes on our back. We lost our car, our business, our home; everything went."
Husband: "At that time people didn't think of insurance for replacement, just to be debt free, and that's the way I was. We raised Siamese cats and we lost all the cats. . . . I didn't handle it well. I mean I literally just-- I went into depression. It's hard for me to explain because at the time-- When you've worked so hard to gain something and you put so much money and you lose it, and you lose the items you put money into, you react sort of defensively and everything, and I went into depression because I felt wronged, so I sealed myself off from her and from everything so I wouldn't get hurt any more."

Researcher: [to wife] "And you reacted to the loss by--"

Wife: "I don't know. I [pause], I think it went back to the way I grew up and I was-- Probably that's what saved me was the way that I grew up because I grew up without anything. My parents were divorced when I was just a year old and I had to-- I went out on my own when I was just 13 and started my own life. I've been married before. I think probably that I felt these things are just material things. They can or cannot be replaced, and you know, as long as we come out of it all with our lives, that's all we need to worry about. . . . We have our son-- and the head of his bed was burning when J [husband] got him out of the fire, out of the house-- and so I was thankful that we had our son. And so I think that I just kind of centered myself around my son when, when he went into depression. You know, I was upset because of these losses and because we had worked for everything that we had, but I still think that . . . life goes on. . . ."

Husband: "See, I grew up different. I grew up where I didn't have to become streetwise. At 14 years of age, I had a brain tumor that I had to have surgery, so I was a very sheltered child. I didn't grow up in a home where there was a lot of love, because I can't ever remember my mother or my father either one ever
saying to us kids, 'I love you.' My mother went to her grave without saying 'I love you,' and Dad and I don't speak; very rarely have I heard him since I've been an adult say 'I love you.' So at any rate, whether there was any love there or not, we always had food on our table; we always had clothes on our back; we always had most everything we wanted, and so I led-- We were very sheltered. Those material things meant a lot. . . . I've talked with the psychiatrist, and they feel that because of the life I lived, the sheltered life, the protected life, because of my illness as a child, and uh, being ill from birth . . . I was protected over and over and over and over. . . . Um, losing our home was a disaster in my life. . . . She stayed with me. . . ."

Wife: "... I just knew there was something wrong, but I also told him that the next time, if he tried to commit suicide again, that I'd leave him because I just couldn't take it any more. . . ."

Husband: "I feel she stuck in there. Most women wouldn't have after the first attempted suicide. Very supportive in everything. If I was sick, she was there; if I wasn't sick, she was there."

Researcher: "How did you structure your marriage before the illnesses?"
Wife: "It all just came. [laughs] I can tell you what happened."
Husband: "I think that she's always been more of the decision-maker than I am. I can again reflect back to my childhood, because I've always been protected; I've never had to make decisions until I went out on my own, and I've never done a good job at that. But after we got married and she'd been the bill payer, she's made the decisions. I'm not saying I haven't made decisions, but I'm 48 years old and I hate to make decisions."

Researcher: "So, by agreement, you were willing to have her do this?"
Wife: "Well, when we first got married it wasn't really that easy, you know. [laughs] I mean the first couple of months was really hell for us because he was set in his ways, and this was his first marriage, and he was 27 and I was 31."

Husband: "25, I think, when we got married."

Wife: "I was 29 when we got married. So you know, both of us were older, and he was really set in his ways. Well, I was too, but I guess I just didn't realize it, and everything had to be his way. I mean the kitchen had to be put his way; the beds had to be his way; everything. And one day I couldn't take anymore, and I just blew. We were making the bed one day, and I remember it, and I just blew up. I said, 'This is it,' you know. I said, 'If we can't do this together then we're not going to do it at all.' . . . I mean it had to be done exactly the way he wanted it done, you know."

Husband: "I am a perfectionist." [wife laughs]

Researcher: "So you blew up. Did he adjust right away or--"

Wife: "I left and went to stay with his mother for two months and found out I was pregnant, and then he came over and we talked, and I think that while he was there his mother talked to him and she told him that he was going to have to adjust his life, that he had a wife now and that he had to allow her to come in and do the things that she'd like to do in her own home, instead of feeling like she was a slave to him. . . ."

Husband: " . . . At first my mother didn't approve of my marriage to K [wife]. Later on she knew that all the talking in the world wasn't going to change anything, so I think my mother learned to accept K and, because she did, she wanted the marriage to work."
Wife: "I just wanted it to be 50/50, you know. I didn't want him to have all the say so, and I didn't want to have all the say so. I just wanted it to be even. And so it got to be that way, you know, as time went by . . . nothing he does in the house bothers me anymore."

Husband: "They're more balanced now than before [the illnesses] because with me being sick a lot, waking up in the morning and being sick, I take everything in stride. Whatever happens, happens. . . . It's not that way now, but in her last marriage she had a husband who drank, who beat her quite often and almost killed her a couple of times. I think because of the way I was with being, uh, fastidious about the way things had to be, her and I had a lot of disagreements over that, and I think she put me in the same category as her first husband and, because of that, it caused an awful lot of problems with me being sick, trying to commit suicide and all of that. She put me in that category as her first husband."

Wife: "No, I really don't feel that way about J [husband], and I don't believe I've ever felt that way about him, but at times I think about my life and how I grew up and my ex-husband and the way he treated me and sometimes you just-- It gets to the point where you feel that maybe men are all alike, you know, because my father mistreated me; he sexually abused me when I was younger and that carried into my marriage, you know. I got married the first time to get away from my dad, and then I ended up with somebody that was just as bad, and sometimes I think that maybe when J and I have argued or something-- And this man's a saint, I mean as far as I'm concerned, he's a very good man. He may not be able to go out and go to work, but he's never laid a hand on me in the 23 years we've been married."

Researcher: "What has happened to the relationship since the illness?"

Husband: "Better than it was."
Wife: "Yeah."

Husband: "I think we're closer to each other because we don't know when one of us is going to keel over, and I think that brings us closer. Like she said earlier, we don't fight like we did. When we were younger, we fought like cats and dogs. But since I've developed these problems, we're closer to each other because we never know when we, when it--"

Researcher: "So you appreciate each other more?"

Wife: "I think so, and I think you have to live each day to the fullest. You have to get up in the morning and say 'This may be the last day . . . that you see each other and, Lord if it be thy will, give me another day,' and that's how you have-- That's how I feel about it, and that's what we do, and we seem to get along a lot better that way. . . . We've had to be closer. You know, now that he can't work, we're at home-- Until I went to work, we're at home 24 hours a day with each other, you know. And now we've been like this for years. I miss him when he goes to the doctor, you know, if I don't go with him. . . . If you love the person enough, their health problems are not going to make that much difference because people cannot help what life deals to them. . . . Your health is something you can't do anything about and you should never let your marriage go because of health. I mean a marriage can get to the point where you know the other one's thoughts, what they're thinking. We've done it many many times. We have said the same thing at the same time to each other. I mean, it's been the same words. To me, that's what marriage is."

Husband: "There has to be the love between her and I in order for her, especially, to stick around, so to speak. Because if she didn't love me, she certainly wouldn't be here."
Wife: "I don't really think there is a definiton for love because I think that it's all a conglomoration of all these things that we have mentioned. It's support; it's commitment; it's, you know, every word that we've spoken; that's what love is. He's my best friend. When I need something or when I want to talk about something, I can usually talk to him."

Although for some couples, coming from a dysfunctional background is detrimental to the creation of a satisfying marriage, this couple has allowed difficult early experiences and the absence of a sense of being loved to increase the bonding between them and the sense of commitment to making their marriage lasting and satisfying. The next couple, likewise, has been able to take family dysfunction and use it to increase the bonding between them as a couple.

Researcher: "What's your marriage been like over the course of its 46 years?"

Husband: "Fine. Oh, you know, I mean we have-- [laughs]"

Wife: "He snaps and I snap a few times."

Husband: "You know, I mean it hasn't been smooth sailing. What I mean--"

Wife: "Not any out and out--"

Husband: "But I mean just knock-down drag-outs, no."

Researcher: "Okay, how have you worked out-- How did you get that accomplished that you haven't had knock-down drag-outs?"

Wife: "I don't know. It might go-- I don't know how long this is going to run, and a lot of it probably won't do you a lot of good. My mother fought the marriage tooth and toenail, really and truly. It was a bad deal all around. Well, I think that maybe she forced me to make my decision, and I made it with him, and I have never changed back for it. And I never was going to admit defeat, and there's
been no reason to admit defeat at all, and of course-- And through the years-- with
Mom still living-- through the years the bridges, just got bigger and bigger between
us. I think of how nice it would have been if she could've accepted him like we
have accepted our daughter-in-law 'cause you know-- And we were scared when
he [son] was going to marry that little girl; you better believe we was scared. Uh,
for one thing, tell you the truth, I think it seems a shame-- Now [daughter-in-law]
says that she understands but I'll never, I know I'll never understand it. One of the
things I dreaded the most about was for [son] to be marrying into a family that had
so much background like mine. Although her father was living where mine wasn't,
there were too much things there alike. Now I would think that we have talked
about it. . . . [continues to talk on about her son and daughter-in-law]

Researcher: "You saw similarities between your family and her family, so
you were a little worried?"

Wife: "And the thing of it is, I wanted to put my husband-- Well, you might
literally think he saved my life out of that situation. I don't think I could've stayed
sane or anything else under the circumstances that I was being raised. With
years, you realize some things were child abuse, and basically-- Now it wasn't
beating and things like this, but there's a lot of different kinds of child abuse, and
one of the things was, with my mother, was when she didn't get her way, she
threatened suicide. Well, there was three of us girls who you better believe no
matter what she wanted, she got. Well, with the years, she knew better than that.
And of course, she lives here now. She never let my older sister go. She had
more bags, or tricks in her bags than you could imagine."

Researcher: "Your mother didn't accept him, so how did you pick him?"
Wife: "I didn't! [laughs] There's no answer. In fact, when he come home from the service, he was engaged to a girl down in Georgia. He told me that when he got home, although we was engaged when he left. But part of the problem was I didn't hear from him, and he didn't hear from me, and it turns out that Mom was stealing the letters. And do you know what her objection to him was? 'Cause he was of Russian background, and they are a narrow-minded class of people. It was the nationality."

Husband: "Yeah, that was her story."

Wife: "Couldn't be anyone more narrow-minded than that."

Researcher: "But you don't think you picked him?"

Wife: "I think that's just how it was supposed to be."

Husband: "Uh, because things have happened between us when we was still just going together."

Wife: "We had more trouble when we was going together than after--"

Husband: "I tell you what, it's a wonder we didn't kill each other. But, it's just, but I think maybe--"

Wife: "He has an extremely, extremely possessive sister. She was older than him quite a few years, even older than our daughter over our son, and so possessive. Well, he dated an Indian girl there that was a cousin of my cousin in Kansas where we lived. And he was definitely interested in [her] but she gave him the gate. . . . Well, my uncle passed away about six years ago. We went to the funeral. Well, it crossed my mind and I wanted to be sure and ask what had happened to [old girlfriend], and there at the house there was a lady that looked familiar, but I couldn't figure who she was so I went and asked her, and it was [girlfriend]. Then we got to visiting and so I told her, 'Well, I married L, you know,'
and she said, 'I knew he would make a good husband, but I didn't think anyone could live with him and his sister.' And I said, 'He didn't let her rule him,' and I said, 'He didn't let her take over our lives,' and he didn't.'

Husband: "We pulled away when we got married. Her mother lived on one street and my sister lived just catty-cornered across the alley from us. Well, if we'd spend more time at one house than at the other, then there was hard feelings saying you spend more time with them than you do with me. Well, I had started working for the railroad before I went in the service so I got myself established seniority wise. Then when I came back from the service, I had me a job. Well, that was when I came back in '46 and two years later, I got laid off. Well, the way things had been going, you know-- And of course, you know, we had a lot of trouble with her mother. In fact, she was fixing to-- Either I let her come back home or she was gonna shoot me. She [wife] worked at the dime store up there after we got married. Well, her mother had gone up there and threatened her with that. 'Course, I was just fresh out of the service and nothing scared me, you know, so she didn't let her [mother] bother her and then my sister walked in right after that, and when she saw my sister, she just collapsed. So they drove her home and then come over and got me, and I was just working just across the railroad tracks from where we lived. Of course, her mother followed her home. Well, when I got over there, we went in the bathroom to be by ourselves. Well, her mother pushed her way in. Well, I found out what had happened. I told her, 'You get yourself out of here and I don't want to see you here again.' I said, 'I married your daughter, I didn't marry you! . . . The best thing you can do is just get out of our lives and leave us alone.' Then there was a whole year there that we'd see her family up on the streets there, and we'd just walk right on by and act like they were total strangers."
Researcher: "And the two of you were together on this?"

Wife: "Yes. Now I'll admit it was hard for me where he never could see that or understand that, and then again I was raised with a guilt complex. Have you ever, do you realize how parents can lay guilt on children? And even to this day she'll let you know all the sacrifices she made to raise ya. Well, and she always-- Daddy had his first heart attack before I was born. I was 13 when he died. Now they were hard years, but they were hard years for the kids also, which never once was considered. Now like this here, that all happened so fast. 'Course with the years-- My mom lives here, which is a sad story. My older sister's husband is a nice guy, but he's milk toast. Mom picked him out lock, stock and barrel. Fact the gossip-- That was a little community up there, and I had more than one person say, 'Who did he marry, your sister or your mom?' Anyhow, if they tried to get out on their own, she come up with another trick and they never fought against it."

Researcher: "So maybe one of the reasons she didn't care for you [to husband] was she couldn't control you?"

Husband: "Uh-huh."

Researcher: "How have you two, with families that want to hang on to each of you, how have you managed to deal with that?"

Husband: "Get rid of them."

Wife: "I have a harder time than he does."

Husband: "She's got that guilt complex that I never had."

Researcher: "Have you argued about that guilt complex or--"

Husband: "Well, she kinda got aggravated at me for not understanding it, you know--"

Wife: "But I agreed that there's no way to ever make him understand it."
Husband: "You know, I just can't, I can't. To me, I just can't accept that, that some, your parents or someone else can lay something on you, like putting a thumb on ya. Huh-uh, I'm too hard-headed, you know? . . . She has pulled away more from her mother in the last several years due to her living here and the way she is. You can't have anything to do with that woman; she wants to still take you over."

Wife: "... Mom wanted to come here; she wanted to move. Now we had a 37-foot-yard and L [husband] had . . . built a 20 by 30 foot garage; that was his haven. If you wanted to be with him in the evening, you go out and sit in the garage, which was fine. Well, she wanted to move her stuff in that garage. I told her, I said, 'Mom, I don't think he'll let ya, but I'll ask him.' I went out in the garage and he said, 'Absolutely not' and so I went back in to the phone and told her what he said. Well, then she wanted an apartment, so then I went to, uh-- I had a friend, the one I ended up working for later, with an apartment. So I called and asked him 'Do you have an apartment available?' and he said, 'Yeah, who wants it?' and I said, 'Mom.' He said, 'I've got an ideal apartment for her.' . . . It was a one room furnished apartment, and she knew that. When she come in here, it was with a U-Haul. They'd [sister and brother-in-law with whom she had been living] hired someone up there to drive her up and then paid their bus trip back. Well, they almost-- The son-in-law had worked with a moving company once, and he knew how to pack things. That thing was packed. Well, the man was good enough about the apartment to let his stuff be put into storage for a while. Well, she packed that apartment full. What she did was she tried to get me, when L came'home from work, to unload that; she tried one more time to get it unloaded in our garage. And so she told me that she, if she couldn't do it that way, she was going to cut her
throat from here to here and tell people why she did it. And it just came all over me that, 'If that's the way it's to be, Mom, that's the way it's to be.' And that's what I told her. And you know, to my knowledge, she's never threatened it again. It was, like, all the time."

Researcher: "So that time it was your voice speaking, not your husband's saying, 'No, you can't do it.'"

Wife: "Well, there was no other way; that would've been the end to my marriage. I was fighting for my marriage. . . . I think in a lot of ways the family trouble made us stronger with each other, not that I would wish that family trouble off on anyone."

Husband: "There was family trouble on my side too. That's one reason I pulled away from my family. . . ."

Wife: "They worked in the harness real hard, you know, and that's why we moved [here] to get away from them."

Researcher: "You both came from families that wanted to control you. Did you do that with each other, try to control each other?"

Both: [simultaneously] "No!"

Wife: "I think we'd seen enough of it in our life time that we'd had enough of it and wanted no more of it in--"

Husband: "No, we haven't done that at all."

Researcher: "You broke away from your families and you broke away from that way of behaving, trying to control others. How did you go about deciding what was going to get done?"

Husband: "Just worked together."
Wife: "It's, you just worked together; you didn't want what you come out of; you just didn't want that anymore. . . ."

Researcher: "So before the illness started, it sounds like both of you felt like you had a pretty strong marriage."

Husband: "Oh, yeah!"

Researcher: "Has the illness done anything to change it, made it stronger or weaker or had any effect?"

Husband: "I don't think it's had any effect on it. I mean it hasn't made it any weaker."

Wife: "I wouldn't think it's had any effect. We keep going on day by day and all, and we just take care of the things that come up day by day. It's put more work on him and I know it, but he hasn't complained about it yet, so--"

Husband: "When the time comes that I can't do it, then-- I've turned down a lot of work that I used to do, but since the illness, I've quit, but I'm doing what I enjoy. . . . The meaning of marriage is work. . . . It's more or less a contract between two people of agreeing to live together until death do you part."

Wife: "Do things together."

Husband: "It ain't gonna work if both sides don't work. I look at it if it's one-sided, it ain't gonna work. Somebody's gonna come up with the short end of the deal and sooner or later, they're going to get tired of it."

Wife: "If the illness had happened earlier, it might have been harder."

This couple managed to change their family mythology and the rules and created a very different couple relationship from what might have been expected and also created a very different kind of parenting style with their children. They were resilient, very able to make changes which allowed them to adjust to altered
circumstances. Commitment to their marriage was always primary, and they created and maintained the couple boundary in the face of strong attempts from families of origin members to infiltrate that bond. The illness occurred later in life, after they had made a successful marriage.

One of the couples who was not coping well at the time of the interview and who was quite unstable provided this picture of their relationship. At this point in the interview, they were explaining to me the nature of the disability and illness. Disabilities began much earlier in the marriage.

Husband: "I have schizoaffective disorder . . . 3 years since it was diagnosed."

Wife: "... It's been there for a long time. And when A [husband] was treated for alcoholism and drug use, that this was really the primary underlying cause of the problems."

Researcher: "How long have you two been married?"

Husband: "... About 15 years."

Researcher: "What's it been like as you've dealt with these problems?"

Wife: "There have been lots of changes. [long pause] You think it's one thing that's going on, then you find out it's something else, then you have a different diagnosis, and it's just, uh, [pause] a lot of unknown. I mean things happen out of the clear blue sky that you never think about happening. It's been interesting."

Researcher: "When was the drug and alcohol counseling? How long had you two been together?"

Husband: "Just a couple of years when I went to, uh, that alcohol treatment center in [another state]. That one didn't work."
Researcher: "What was happening then with the two of you?"

Husband: "Well, pretty typical, I guess. We'd get along fine until I drank, and then we'd fight about this and that. I was smoking a lot of pot and doing some other drugs at the same time, and uh, we left [state] and moved, and I went to another treatment center. For a little while I quit [drinking], then I started again."

Researcher: [to wife] "Where were you at this point? What were you feeling at this time?"

Wife: "Tired! [laughs] I felt it was just never going to be any different. And I've had problems with alcohol myself and had drank, and when I went through their treatment program, I more or less quit drinking. I was just very tired of it all, you know. I wanted us to have a life without alcohol and drugs and everything that went with it. I just kind of gave up on a lot of things. I kinda withdrew from him, and I withdrew from myself, too."

Researcher: "Did you get depressed?"

Wife: "Yeah, oh, yeah. And it was kinda rough for me not to go back to drinking. It was a lot of frustration and hurt and wanting to fix it, you know. He calls me the original Mrs. Fixit, you know, and it-- I tried to learn to fix me instead of trying to fix him. . . . [finally] I realized you can't change other people; you can't do anything about anybody but yourself, you know."

Researcher: [to husband] And then what happened to you? Could you tell this was happening?"

Husband: "No. 'Cause I was still drinking and drugs, I didn't know too much. Then I retired."

Wife: "We separated for over a year . . . but I came back. I thought at the time that A had quit drinking and that, uh, things would be different. I missed him."
We had made plans about what we were going to do. One thing was to go to Spain and retire there. But instead of the money [from retirement] coming in a lump sum and so forth that would allow us to do that, it just kind of trickled in, so we never had enough lump sum cash to go ahead and make a move like that. And we got-- My grandmother was here, and her home had burned, and she was living with my sister and her three children. And my grandmother raised me and we was always extremely close, so she helped us get a house and lived with us 'til she died. So we all moved in here, our little house on the hill.

Researcher: "And what was happening to the two of you during that time?"

Husband: "Well, we was running around and drinking, going here and going there. She didn't drink much. I was doing most of the drinking and smoking pot."

Researcher: "How did you think that was affecting her?"

Husband: "Well, I thought it was all right. I didn't think that she was bothered by it."

Researcher: "Were you?"

Wife: "Very much so. I guess, uh-- A calls me an idealist. We were back home to a place that, the area that was the most home, felt the most home, you know, and I wanted us to be in our little house with the picket fence thing, and be a nice family. You know, we had my grandma here with us and everything."

This couple never had the communication or understanding of the needs of the other to achieve marital satisfaction. Finally, both stopped drinking, but then the husband was diagnosed with a chronic emotional/mental illness which was controlled with medication. The illness and the medications caused a very flat affect so that he showed little reaction to anything, either positively or negatively.
The wife began to change and was thinking of leaving her husband. She spoke of the health problems which her daughter suffered and attributed them to the family's stress and the dysfunction in the family. She said this about how her husband's emotional illness affected them. "It affects everything. It affects every aspect of your life. If affects every aspect of your relationship whether it's subtle shifts of power and a change in the priority, the thing that what's important then may be not as important now, you know. And it seems like, inevitably, things shift away from the family as a whole to being centered more on the person who's ill. I'm not saying that's a bad thing, but it can go too far. It can affect you financially because you've got to make the bills. But how their feelings are affects your social life, affects your sex life, affects everything . . . . The power thing has been an aspect of our relationship always: who was greater than, who was lesser than, wouldn't you agree [to husband]?

Husband: "No, never was with me."

Wife: "You've made that statement before that who was gonna be boss . . . and there comes a powerless, when you feel powerless about the illness and about how it's affecting you. . . . You feel like you don't have any control over anything. . . . That can be devastating when you feel like you have no control over your life. And any-- I think anybody contends with a long term illness, be it mental or physical either one, there's a weakening that goes on. . . . You can't get your coping mechanisms in place as much as you can. . . . I think a lot of it depends on how secure and how happy the marriage was before the illness took place. If the marriage had strengths and everything there before, then it will be easier for the two people to cope, you know. If it was lousy before, all this is just gonna make it worse. But I think after, uh-- I know for me, there's been a certain kind of bottoming
out and saying, 'Well, now this is the way it's gonna be. Nothing's gonna change
it.' I think there comes a certain amount of acceptance. I think there has to be or
you go mad yourself, you know, trying to rage against the windmill."

This message was given by nearly all of the respondents whether they were
satisfied with their relationship or not. Bad marriages get worse when faced with
dealing with a chronic illness. Good marriages get worse during the initial stages
of learning to adjust to the illness, and then come out even stronger as a result of
the experience. Those who had "average" marriages before the illness, in this
sample, experienced either a perception of an increase or decrease in the quality
of their relationships.

Two couples demonstrated how the illness can create a temporary state of
unstableness and dissatisfaction in the early stages of illness which may become
permanent. The parents of a 3-year-old who believed their child would
degenerate rather than progress developmentally before she eventually dies
provided this opinion about their relationship and its future.

Wife: "I don't feel like I can relate to him at all, because he doesn't show
any-- I know he's hurting; he has to be hurting, but there, there was no outside sign
of it; he just pretended it wasn't there. And so I was hurting and I showed it. I mean
I think that's just the way you do, to be honest with it. It has caused me to do my
own thing and him to do his own thing. We were not sharing the pain at all. We did
not share, really, any emotions. . . . It was never really there in the first place, but it
became-- It angered me, and that's probably-- I still have anger toward him and I
think that's a lot of it, because there was not any emotional support that we had for
each other. And I really didn't have for him either. . . . We're working on it."
Husband: "We need to refine this. We need to refine this area a lot more to understand. I think she's right in saying I don't, I'm not so much in touch with my feelings. Uh, that's true. Um, but at the same time, there are differences between us that we don't understand. Even when I get to the point where I am in total touch with my feelings, it may be that some piece is there, or some piece is not there that she does have."

Wife: "My point is that we were not sharing this pain and that is what our counselor has told us to do. . . . I was miserable knowing something is very wrong, and he's like, he's totally oblivious going, 'Let's just be happy' or something, and I just kind of knew there was more to it, but I felt like it was all my fault, you know. Why am I not happy and he just seems to be so content? . . . We're working on it."

Husband: "There's a lot of positive. And I, and I think we're both willing to work at it."

Wife: "We're both very level headed. I think we're both very mature . . . for our ages. . . . We haven't always communicated well emotionally . . . ."

Husband: "I have to say this, that when it's all over, not all over, when it, when we've recognized all these areas and we've taken care of them because they've floated to the top, then I think we will have a much stronger marriage, so in that sense, I think when it, when it's past, we can draw a conclusion that we will have a much stronger marriage. The difficulty is in getting through it, and I think the reason we're still married is because of our commitment to God and our commitment to each other to continue the marriage and continue to try to find ways to work it out. Divorce has not been an option in our upbringing."

Wife: "I refute that a little bit. I think that is possible. I don't think that will happen without a lot of hard work, not for a long period of time. . . . He has the
'sugar coating effect' on things and when I hear him say that it'll be okay someday, what I want to say is, 'It can be okay someday.' I think we have the raw materials to have a very good marriage, and we both want it. I really want to really honestly feel and say, 'He is my best friend,' but he is not right now because there is not the emotional support that I need. . . . I think that that is possible, but I think it will take a lot of hard work on both of our parts, and a lot of growing and changing.

Another couple in the early years of coping with illness had also become very estranged. They had a strong marriage before the illness and, with the help of a marriage and family therapist, were learning to adjust to the new roles and responsibilities required and were getting reacquainted after the relationship as it had been before the illness had essentially died. The final score is not in, but it appears that this couple is learning to appreciate qualities which were not demonstrated in the other before and has become "rejuvenated" to use the husband's term.

Wife: "Our therapist is really helping us. He [husband] is getting better. He's trying now. I'm beginning to feel like I have my husband back, although it's different now."

Husband: "We got to talking about sex. I'm starting to feel rejuvenated to think that maybe we can have some kind of sexual relationship again. I didn't think I could ever improve from how I was, and I just gave up. I didn't feel like even trying. But she's learned how to take care of a lot of things she couldn't do before. I'm real proud of her."

Wife: "He's never talked quite like that before."

The next excerpts demonstrate how marriages can become stronger and better in quality than they were before the illness. The first husband stated, "As
you get a little bit older-- I'm 72 now-- you kind of appreciate just a little bit how her whole world is limited by my limitations. . . . This is a very minor matter, but maybe it symbolizes something; I hope is does to her. Uh, on the day, uh, the anniversary day of my stroke every month, which is the seventh, I made a deal with one of the florists, and they send her a single long-stemmed red rose with a little note attached to it. That's a standing order. And so, that's just one little way of communicating to her that I, I love and appreciate her. And, uh, so I don't think it's hurt anything anyway." [wife laughs]

Researcher: "What kinds of things, what qualities do you think are important to having a good marriage?"

Husband: "Well, uh, we both uh, happen to have a strong religious faith and uh, that has been the very substance of it because we tried to interpret this [the stroke] within the same philosophical set of, I mean our world view. Uh, we believe in the Supreme Being who wants, who is basically good rather than trying to punish us and abuse us. We believe that in a way we couldn't comprehend, somehow or another good could come out of it [the disability]."

Wife: " . . . The basic foundation for our marriage has always been our common religious faith. But there are other things, too, that go along with that and that is, well, a determination. What makes any marriage work is you're determined to make it work. You're going to find the good in it, and you're going to make adjustments to the nature of your spouse and, hopefully, your spouse is going to make adjustments to your nature. I don't think you could ever make a marriage work without commitment. It's obvious that if you are determined to be committed to a marriage, when something like this happens, that doesn't shake that commitment, and if you don't have that commitment and determination, it would."
Husband: "Let me talk about one other ingredient. Seeing that [manuscript] on the table there reminds me of the fact that even though we've been a team before and, uh, working on various projects, we're even more now a team than ever. We've, worked-- for all practical purposes, co-authored a book together. And that meant that, uh, we had to agree on a whole set of ideas. . . . We have certain goals, objectives that we have: primary purposes, overruling purposes, and what we do is kind of under that umbrella. That means that the experience of life is fun because we are marching along toward that goal. . . . Chronic illness brings to the fore, as a catalyst to bring-- It precipitates whatever is there. That's it, a catalyst. If you could communicate before then you have-- In some ways, we're closer together now than we've ever been. We'll go on trips together-- which she'll do the driving-- and chatter like a couple of jay birds and you would think that after all these years we'd run out of things to talk about. But we still have a lot of conversational commonality, and we talk and don't have awkward silences in times together. . . ."

Wife: "I looked for a man that I thought was intelligent, and I looked for a man that I thought had the faith I had. Uh, those are the two main qualities. And I found them. [laughs]"

Husband: "I prayed about my marriage as much and with as much intensity as anything in my life and interestingly enough, we were both engaged to other people before we met on the campus where we were both employees . . . . I think we met because of a providing God. . . . I was scared of marriage, frankly, because I had seen too many middle-aged marriages where the people looked bored to death, but, uh, she was so pretty and nice and all, she convinced me otherwise."
[laughs] That was the best thing that ever happened to me, just about. I believe God gave us this gift.

Wife: "Luck is a pretty bad way to start a marriage. I mean, you know, to depend on that. You need to use your head a little bit. You've got to know that other person a little bit to make a commitment for a lifetime."

Another couple, equally satisfied with their marriage, when asked about the evolution of their marriage and the effect of the illness on it said:

Husband: "I feel more relaxed talking with her and I do know we have a more open relationship."

Wife: "I guess we're not afraid now."

Husband: "And even though she says no, I feel like we're closer now than we've ever been. [She thought they have always been so close that they couldn't become closer] Whether that was all of the stress or just after 30 years-- You know, you hear people saying after you're together so long, things get better, but you know, really, I feel like we're closer now."

Wife: "Maybe so."

Husband: "Before there was so much sickness and worry and stuff, we probably was a little happier, but, uh, as far a closeness and loving, I think it's drawn us closer."

Researcher: "How about the way you make decisions?"

Husband: "That's always been 50-50."

Wife: "... We've always just communicated about it."

Researcher: "Did parenting change in response to the illness?"
Husband: "No. As far as the kids, I feel like they're closer to us than they've ever been. And, of course, we're like any other parents; we still have to tell them what to do. They, of course, do what they want to."

Researcher: "Have there ever been times when instead of supporting each other, you were at odds?"

Husband: "Nothing in respect to the illness."

Wife: "No, it's just been the pressures. As far as, I don't know any time that I've had hard feelings towards him for any reason or anything."

Researcher: "So it really has been a supportive, working together? How did the two of you handle conflicts before the illness?"

Wife: "Talked them out. Most people don't believe me when I say I don't think N [husband] and I have ever had an argument or like a heated--"

Husband: "We've never really had an argument. What I've seen other married people-- what I consider fighting or arguing-- but we've never had any."

Wife: "I told him maybe we missed out on something by not fighting 'cause then you get to make-up [laughs]. I mean we've had our disagreements on things as far as not seeing eye-to-eye, but we've never hollered at one another or ever been the type to where we had to scream and holler. We'd usually, 'We need to talk about this,' you know.... We grew up together, I guess."

Husband: "I can remember when we got married. My side of the family told me it wouldn't be more than 6 months before we were divorced. I like to remind 'em of that once in a while. I can see where a lot of things we have went through could have caused problems for other people if they weren't as close or as comfortable with each other as we have been. I've known people who had serious problems over a lot less."
Wife: "N and I have had a good relationship and kind of come from the same background. We've both been through a lot and didn't want our lives to end up like them and didn't want our kids to go through the hurt we went through. N was quiet, but I knew I had to talk about my feelings and he'd say, 'I don't know what to say,' and I'd say, 'I don't care what you say, just talk to me.'"

A husband, suffering from cardiac problems, and his wife stated this about how his illness had affected their relationship:

Researcher: "Has it changed how you are with each other in any way?"
Wife: "No. Has it [husband]? Has it changed anything?"
Husband: "I don't know whether it has or not."
Wife: "We don't fight as much."
Husband: "We don't fight as much as we used to."
Wife: "Too tired to. Both have our own opinions. He's stubborn, and he thinks I'm contrary."

Researcher: "So after the illness, does that mean that you've given up some of the stubbornness and contrariness?"
Wife: "Well, I'm never gonna give that up. [laughs] We just got things settled."

Husband: "Well, you finally figure out that it's not worth fussin' about. She has a different opinion and eats my butt out about something, then I just try to figure it out and come to the conclusion that it's not worth raisin' a racket about."

Researcher: "How do you think you reached that conclusion?" [addressed to husband]
Wife: "He doesn't really like to delve into the reasons of why he is. Isn't this, isn't it the difference between a man and woman? Because uh, you know,"
men do not like to, um, be closed in on emotional issues and women often try to define theirs and know why it is as it is. The word 'feel,' he doesn't like to talk about that, 'feel.' It has to do with his mental attitude."

Researcher: "That's one of the ways that you've been different through the years? Is that one of the things that you fought about?"

Wife: "I don't really remember why we fought. We know it wasn't any worse than anyone else's, but I'm glad we pulled through."

Husband: "If you haven't figured it out by now, there's no use making a big issue out of it. Well, we might be a little calmer towards each other. She might be a little more tolerant towards me, and I might be a lot more tolerant to her."

Researcher: "Is there anything else you can think of to tell me about how the illness has affected your life or relationship?"

Husband: "Well, I don't know. The only thing I can say is that just the lack of energy. It just slowed me down so much, but as far as emotional and worry and stuff, I don't think it's affected me any."

Wife: "Well, I don't think I've changed."

Husband: "Well, yeah you have, I think."

Wife: "Well, Dad, I've told you over and over, if you're tired all the time, I'm just glad you're here."

This couple had argued a great deal about which of them was right. Only since the illness had they ceased to argue and let things ride more. They had been hit with the realization that their time together was limited, and they valued each other more and lived more harmoniously, although this marriage did not seem to have the togetherness and open communication and emotional support which was demonstrated by some of the couples. Another couple who did not share
much of their emotional lives shared this about their relationship and how it had been affected by coping with a chronically disabled child, now a teen.

Researcher: "You said that some couples might get split apart dealing with this, but it's helped the two of you to actually be stronger. How? How do you think that happened?"

Wife: "Well, I really don't know. I can't explain it. I know he's always here when I need him."

Husband: "I don't know. When you have a stressful situation you either, uh, it either drives you apart or closer together, and if you've got something to start with, I guess it pulls you closer together."

Researcher: "So, you felt like you had something to start with?"

Wife: "Yeah, 'cause we had been married over--"

Husband: "Well, you try not to over-do it, because you don't want to act like you're worried about, you know--"

Wife: "Nonchalant."

Husband: "Just ignore the other one. [laughs] I'm not worried, so don't you worry."

Researcher: "So you kind of got more distant in terms of expressing your feelings, protective but a little distant too?"

Wife: "Yeah, yeah."

Researcher: "You said that if you have something to begin with, then it kind of makes you stronger. What were the things you had after you'd been married 20 some years at that time did you say?"

Husband: "Four kids. [laughs]"
Wife: "Well, we had something else going because he was more of, I guess, a loner when we met and married. He started in the Air Force and he was more-- I wasn't-- I was living with my grandmother down in Texas when I met him, and I don't know, we just-- It was something that, uh, I guess we both decided that if we marry-- Well I did, I don't know about him, but I decided that if we marry, it's for life, not for uh, you know, just to have a place to live. And I wanted something that belonged to me. I guess I didn't want to share him with anybody else. He was mine, and that was it. So we started building our marriage and all. I wasn't as old as he was. Mama died in November and I was 14 in December, but anyway, he [father] took us to my grandmother's and she was about in her 60s and she didn't have any business trying to raise four kids, you know.

"I was the oldest, and I had a little brother that was three, and then there was three girls already married and away from home. But we'd ask him something, you know. We'd go, 'Daddy can we do something?' 'Well, I don't know, go ask granny,' so she just had the say of what went on at the house instead of him. It was just like, it seemed like he was relieved to get rid of that responsibility and give it to somebody else. I thought 'Good Lord, if I ever have any kids of my own, I'm gonna be responsible for 'em, and tell them what they can and what they can't do, and I hope their father does the same thing.' You know, when they asked me to do something, I never told them to go ask your daddy . . . ."

Researcher: "So you got married and wanted a man who was going to be all yours, and who was going to be responsible."

Wife: "Yeah."

Researcher: "Did he know that's what you wanted?"

Wife: "No, he probably didn't."
Husband: "I knew she wanted me to herself. [laughs] I knew she didn't want to share me; I found that out quick enough."

Wife: "Well, there's other things that I let him know right real fast, too. He knew what he was getting."

Husband: "I let her get away with just what I wanted her to, don't let her tell you any different. [laughs] You talk about the marriage. Picture this airplane trying to take off and it's coming back and bounces about 20 times; it finally gets in the air; it banks; it crash lands, but everybody lives, then it takes off again. [laughs]"

Researcher: "That's been your marriage?"

Husband: "This is the way it all starts; all marriages start like that."

Wife: "When we first met, we were talking, right after we first started seriously talking about marriage, and I told him, I said, 'Well, there's one thing that I won't put up with,' and he wanted to know what that was, and I said, 'Drinking, coming in drunk, spending money that we don't have on booze instead of things if we had a family, you know, and if you ever hit me, or anything like that, you better give your heart to God, because the rest of you belongs to me,' and he looked at me kind of funny. Well, I got a, my oldest sister--I didn't know what it was until several years ago, but she's a battered wife, has been, and the other two brother-in-laws drink quite a bit and you spend money--Well, all three of them drink but then [sister] got married to another man; he was right the opposite of the first husband, . . . but anyway, that was one thing I didn't like, I wouldn't stand for, so I just let him know right off the bat."

Researcher: "Did you also let her know what you wanted?"

Husband: "Yeah, then she learned to drive." [they both laugh]

Wife: "I didn't learn to drive until it was absolutely--"
Husband: "Then it was all out the window."
Researcher: So, she changed the rules?
Husband: "Yeah, she started wearing the pants."
Wife: "It didn't change that much. I had to learn to drive out of absolute necessity when we lived in [city]."
Researcher: "It sounds like there's been some changes then from how you started in the beginning."
Wife: "Yes. How we started out, I couldn't drive, and I stayed home and he worked. . . . I had to learn to drive 'cause I had to take [oldest daughter] to school."
Researcher: "So you got more independent?"
Wife: "Well, a little bit more independent. Well, I got kind of independent."
Husband: "A little bit?! She took over the car and the checkbook, so what does that tell ya? [laughs]"
Wife: "Well, I took over the checkbook before then. I started uh-- He was overseas in Germany when our oldest daughter was born."
Husband: "It really was a good deal, but you-- It's hard to get used to. You get used to her doing everything and telling you what to do, you know."
Researcher: "And you go ahead and do it?"
Husband: "If I want to."
Wife: "If he wants to."
Husband: "You got to give and take. She knew she can't go too far. She don't want to make me mad."
Researcher: "She knows that? She knows what too far is?"
Husband: "Yeah, she knows what too far is."
Researcher: "So this is part of this picture of the airplane?"
Husband: "Aw, we're already airborne. We're in a rut. I mean, we're gonna make it but it's--"

Wife: "When our oldest kids were small, I didn't, you know, I didn't work and--"

Husband: "We didn't have any problems like we do now. . . . You know, when you're young you don't worry much; you get old and you start worrying. [laughs]"

Researcher: "What were the positive things that you had before that made your marriage stronger?"

Wife: "Well, really a strong belief in God and, you know, that has helped a lot. . . . My great grandfather was what they call a hardshell Baptist, you know believing that what is going to be will be, . . ."

Researcher: "Do you have a common belief?"

Husband: "More or less."

Researcher: "If you were going to name the five most important qualities for a marriage to have to make it satisfying and lasting, what would they be?"

Wife: "Well, the first one, you'd have to love somebody to live with them, and you know, talk things out, not just be one-sided. You know, talk to your spouse or whatever, and I don't know, D, what can you say? [laughs] Share the responsibility."

Husband: "I don't know. Love, honor, obey? [laughs]"

Wife: "Don't get mad and call your wife a--"

Husband: "Oh, shut up. [laughs]"

Wife: " . . . I'll tell him what I'm gonna do and if he, he doesn't like it and he says, 'Well you're not gonna do it,' well sometimes I'll go ahead and do it anyway
and he don't say very much, but sometimes he does. I know what I can get by with and how far I can push and how far he can push me."

Researcher: "What other things have come out of coping with [son's] illness?"

Husband: "I don't know, it's just uh . . . . It can make it bad, it can make it bad or it can make it good. In our case, I think it's good because you appreciate each other more; you appreciate your family more; you appreciate the sunshine more; you appreciate being alive. You learn a little more about the value of some things."

Wife: "Well, you know, if you don't pretty well go along with each other, you're not going to work it out. . . . I think we have pulled together instead of, you know, instead of well, you know."

Husband: "I think the main thing, if it comes out good, is that you learn to take one day at a time. You just--"

Wife: "Well, you learn to take one day at a time. Take care of today and wait and see what tomorrow brings. He's here when I need, and I hope I'm here when he needs me."

Again, this was a couple who did not share a lot of their emotions verbally with each other and who had been through many ups and downs during the course of the marriage. There was a period, shortly after his retirement and the diagnosis of the son's illness, when this husband did start drinking heavily which placed a great strain on the relationship for a time.

It appears that the strain each has felt as they have dealt with the many crises involving the son's medical condition has resulted in a focus on the present and taking care of today's issues only without too much thought about the past or
the future. Each spouse has found support in the other's presence, and that has helped them survive.

An elderly couple responded to the question from the researcher, "What has kept you together for all of these 48 years?"

Wife: "Love."
Researcher: "That sounds easy."
Husband: "She fussed at me all the time, but I put up with it. [laughs]"
Researcher: "For 48 years she fussed at you?"
Wife: [laughs]
Husband: "I wouldn't trade her for any that I've met yet."
Researcher: "What makes her the best?"

[silence]
Wife: "What makes me the best?"
Husband: "I don't know. I'd have to dwell on that to answer that question, I believe."
Wife: "In other words, how am I different?"
Husband: "Uh, oh, we've had fusses and fights and all but nothing very serious, that is with me. I don't know how she felt."
Wife: "We've had love spats like every couple has, you know, but we've never had anything serious."

Researcher: "So both of you believe you've never had any serious troubles, any serious disagreements that you couldn't get through. What did you do? How did you handle it when you did disagree about something even though it wasn't serious?"
Wife: "You just go on and first thing you know, you've forgotten all about it, and you forget easy. I do. I overcome things. A lot of people hold grudges. I never do."

Husband: "That's the greatest trouble. They carry a chip on their shoulder, you know."

Wife: "We've never had that. In all of our marriage, I don't think he's ever been jealous of me in any way because I didn't give him any reason to, and I've never been jealous because he's been the sort of person and husband that you don't have a reason to be jealous. People will always say, 'You're so fortunate to have such a wonderful husband,' and he's always been handsome because he dressed handsomely, and people spoke of that, you know. He always had curly hair and perfect waves. 'Course now that it's grey-- And people would say, 'I love to sit behind him in church' and 'I want to get up there and put my fingers in those waves.' He's been highly respected and loved. He won $1,000.00 at one of the grocery stores one time, and he gave it to the church and, of course, that was something big in the papers, and he's done quite a few things."

Husband: "Well, all of the time I was in the service, I, uh, I-- Well, I've told you [to wife] about it. I walked a girl home one night in Palm Springs, California. My buddy was a son of the governor of New Hampshire. He was 22 years old and I was about 39 at the time. And, uh, he'd get him a date every once in a while, you know, so he run into these two girls and he wanted to walk them to the hotel. I don't know where-- His mother was already in town and she had flown out there-- severe winters in New Hampshire, and this was in February-- and uh, so I kidded her about I had to walk her friend home without him having to walk two. So we did; we walked the girls home, and that's all the date I ever had."
Researcher: "So trust, fidelity, and it sounds like respect, too."

Wife: "Oh yes."

Researcher: "What else has kept you together?"

Wife: "I think spiritual faith. I don't believe that families-- I think that families that we know anyway that have had so many problems, uh, have not had the faith that we have, and you can't go through what we've gone through, what we've gone through all the way back from service and losing two children, losing our parents, everything else, if you don't have faith because you have to have something to carry you through. And even during those years we've-- We'll say there were many times when I wasn't well. I've not been the healthiest person in the world, but I've been a person who overcomes things easily, seemingly. And that doesn't mean I don't have problems after I'm home, but I've not been one to feel sorry for myself. I've not been a person who wanted somebody to wait on me all the time, and I think those kinds of things are so helpful in your life and in your togetherness."

Researcher: "How has it been helpful in your togetherness?"

Wife: "Well, your love and your faith. If you have faith, you know things are going to be okay. It keeps you close together. You, uh, in your later years you don't make love like you did in your younger years, but it seems as though that's part of growing older, but that doesn't mean we still don't hold hands and kiss and, um, love each other and respect each other, you know. And we admire each other; I really do. I know that when he's all dressed up, I tell him so many times, 'You look fantastic; I'm so proud of you.' And he does the same thing for me."

Husband: "I don't like to dress up too much because some girl might take me away, see, and that would cause trouble."
Wife: [laughs and laughs]
Researcher: [jokingly] "She's very worried; I can tell."

[later]
Wife: "... We have done a lot of things [several civic organizations] that have kept us close and to enjoy the same things and people . . . . But we have never been people who had to go someplace to stay happy . . . and when we were able, I loved to fix up my home. . . . We’d never been able to travel because my mother passed away in '71, the year he retired. We had her a long time. I looked out after her and even though she wasn't here in our home at the time-- we had her in a nursing home. . . . I was gone quite a lot, so he retired so he could be--"

Husband: "I had reached what you would call early retirement. . . . I went on back to Texas where she was. Her mother was as good a friend as she could be to me."

Wife: "He thought my mother was a saint. He said if Mary was a saint, my mother was a saint. That's something to say about your in-laws."

[later]
Wife: "I think we usually talk about things. We don't-- [pause] I might sometimes say I'd like to do this or how would you like to do this or what would you like to do, and we just discuss things."

Husband: "The decisions are all made here."

Researcher: "Made where?"

Husband: "In her brain. That's where the decisions are made, so there's just one decision."

Wife: "He's teasing."
Husband: "No, I'm just joking about that. We've always gotten along. We kinda think down the same line, see what I mean? If you're on the same track and you're thinking in the-- like each of us is thinking like we should do, in all probability we'll come out as one decision, see what I mean? Do I make myself clear? Now if we was off on a deal where maybe we shouldn't be, then there's a chance for an argument on which way we should go. But we haven't had that trouble. We do it like we think it should be done, and that's all of it."

Researcher: "I've seen lots of couples where they do not think the same way. Each has a different definition of how things should be. How have you managed to come up with the same idea of what 'should' is?"

Wife: "Well, I think it comes from respect."

Husband: "Well, yeah."

Wife: "We respect each other's ideas, and I don't think we've ever really had any problems if I can remember correctly."

Husband: "A whole lot of it is your life, how you live, I think . . . ."

Researcher: "How has the illness affected your relationship?"

Wife: "You live in fear on what tomorrow is going to bring. . . . I think that our marriage is perhaps stronger, but I think that people who maybe were not strong within themselves to begin with . . . let these things bother them to the point it pulls them away. I can't see, if there's real love and concern and caring in a family, how illness or anything would make you farther apart. I would think it would draw you closer. . . . We're content to just sit here and have each other. We're not looking for something or have to have something in order to keep us together, to knit us together any more than what we are. We go to the grocery store together; we shop together; we just have a togetherness."
Husband: Well, my life with her has been on a level of honesty all the way through. It's never varied, as far as I'm concerned, on either side. And I have the same trust in her. The worst place in the world that I ever was, I believe, to be a grown man-- 'cause I didn't go in the service 'til I was 38 years old-- and I wound up there in Manchester, New Hampshire, and I was to report to the base at this town Monday morning. But it was Saturday night, so I had Saturday night and all day Sunday before I reported Monday morning. [laughs] [to wife] Where are they?

Wife: "I think they're in the living room."

Husband: "I walked by a curio shop and they had a display of a male and a female and two little ones. I was so homesick, I could hardly make it."

Wife: "He was always sending me something."

Researcher: So that was after you were married that you were in the military."

Husband: "There I was walking around by myself while the boys was out romping and tromping and drinking beer and getting them a date and so forth--"

Wife: "He was a, before he-- He didn't go into the post office until after he was out of service. He was, had the first airport that was ever in [name of town] and he taught flying; he taught, um, Army and Navy pilots to fly, and so he went into flying then. When he was in service, it was the first time he'd ever been away from home and our first separation. And it was-- We put the oldest boy in military school, and it was, it was the hardest thing, I guess. The separation was difficult, you know. But I still didn't, it didn't do anything to us like it perhaps did to a lot of families, couples. It separated you, made you go into another direction or feel like
maybe you found something more exciting. We were just here waiting for each other."

Researcher: "You let each other know that the caring was there while you were apart."

Wife: "Oh, yeah, we always did that."

This delightful couple took much pride in each other and in their relationship. They had numerous anecdotes about their life together and seemed to delight in their shared history with its joys and sorrows. A couple with an 8-year-old handicapped child very simply stated:

Wife: "Someone told me only one out of five marriages survives something like this."

Researcher: "What have you done that made your marriage one that survived?"

Wife: "Well, I love him!"

Husband: "We're buddies."

Researcher: "I've known people who loved each other who can't live with each other."

Wife: "I don't know. We've always gotten along. We love our family and both our boys. I mean--"

Researcher: "Do you think having him [the handicapped child] changed your relationship in any way?"

Wife: "Probably strengthened it."

Husband: "I know we--"

Wife: "It's made us appreciate a lot of little things. We don't take near as much for granted, you know."
The adjustment involved in accepting the chronic illness, no matter what form it took, was tightly interwoven with the quality of the marital relationship which existed prior to the onset of the illness for virtually every one of the couples. In spite of a strong relationship, however, several couples mentioned areas where they continued to have some needs which were still unmet and which deserve mention. Most of these involved human service programs and health care.

Unfulfilled Needs

Although there were good experiences with the health care system, nearly all of these couples reported incidences where health care providers, physicians or nurses, did not notice or did not attend to the psychosocial needs of the patient or of other family members. Fears were not addressed; education about the disease process, its course and prognosis, or about rehabilitative procedures was not given; information about resources available to help was not provided; and psychosocial needs of the family members received little attention. Some couples fall through the cracks and have problems qualifying for services. Incomes which normally would support a family in an adequate fashion in terms of food, shelter, and clothing are severely taxed when the cost of expensive health care items for the chronically ill member are added. Families must live in poverty or near poverty, yet they still may not qualify for services. Here are some brief comments made by subjects.

"We are trying to go through developmental disability, you know. We've been on the waiting list for a year and a half now, but not even-- See, the thing is, we'll hear about something; we'll check into it; he makes too much money, or he's [child] too disabled to go to a disabled handicapped place. I'll say, 'What's the deal? How can you be too handicapped to go to a handicapped place?"
The father of another chronically ill child stated, "I feel that the parent's welfare is grossly neglected because everyone is concerned with the sick. And they don't realize that the parents are also sick. I think that area is neglected. They need help. People need to talk to the parents and put them at ease. Sometimes just talking to the parents can help, you know what I mean? They might even point out and say, 'Hey, you're going to be sick, or you'll be nervous,' you know, talk to them about this. Maybe try to figure out ways to put 'em at ease. They might even be concerned about some kind of a pill that a person could take if he got too nervous or too upset, something like that, you know. Nothing's offered unless you ask for it, and it takes a long time to get in to even talk to a psychologist. Actually, I'd like to see a support group started for people like him and people like us. I wouldn't even know where to ask for help."

Another mother spoke of the need for health care providers to demonstrate caring and healing for the whole person, not just for the medical impairments. "Even the doctor from [hospital]-- it was very cold and never any emotional help, not for anybody. And we didn't know that there was 'cause no one ever offered it, and no one ever asked if there was any stress for us associated with it."

A middle-aged man with a chronic pulmonary condition stated, "... Mentally, no one's taken care of a thing. I don't even know if that would be helpful at this point. It would help a lot of people; it might even help me, I don't know. I get-- 'Cause, you know, even though I don't think, I don't think I would ever do it [suicide], but it, there's always that fleeting time when you get so disgusted that you'd just like to, you know, get it over with... ."

The mother of a handicapped son had to learn through trial and error what her son's rights were for education and financial care. She knew where to go for
health care, but no health care provider ever talked to her about programs which
might assist her in learning about caring for her son or finding the financial
assistance necessary to do so. "With medical science making these kids live
longer, they're gonna have to open up more doors, you know, making the parents
aware. I mean, I didn't know none of that stuff when we started. It's not an easy job
to fight the school district and whatever, and God, they think you're terrible. You
know, the first year we started that [the process of approaching school officials to
initiate special programs for handicapped children], I'd walk in and of course
everybody would just clam up. Nobody would speak to me, but finally, it got to
where I would just back my shoulders and walk down the hall like I owned the
whole damn school.

"Unless someone is strong, they're probably gonna back down and I'll tell
you why. When you first start going to the individualized education program which
every child that's handicapped is supposed to get, they'll make it real intimidating.
They would have like 10 or 12 people there . . . . You got the principal, the regular
teacher, the special ed. teacher, physical therapy, occupational therapy, the
nurse, speech therapist, three or four people from the board of education; it's real
intimidating. And it seems like it's you against all of them, like they think you're
trying to get something from them."

One wife, herself a health care professional, stated, "We were lucky. . . .
One of the things is I knew how to access the system and I tried to do it as nicely
as possible, but if there was anyone in the way that was not doing their job, I didn't
hesitate to talk about it right away, because there was not time to be lost with that.
If it was a nurse, a student nurse, whatever, social worker-- I even had a problem
with a social worker at [hospital], and I just went to the chief [of staff] and talked to
her because she was [husband's] main doctor and I said, 'This has to be worked out.' But I think that other people don't know how to access it. They don't, they don't-- They're coping with their own stress right now and their own loss. It's hard for them to function a lot of times.'

One other husband talked about possible discrimination on the basis of age. "Like when we first started fighting with Social Security for the first time to try to get me on, I had one arthritis doctor look me right in the eye and tell me, 'You will never get on social security.' I've had several doctors tell me that because of my age, because I was so young and everything, they couldn't see me getting on Social Security."

A feeling of some frustration regarding need fulfillment was a motivating factor for some of these participants. Several couples decided to participate in the research interview because they hoped to provide information which might somehow help someone else. One of these stated, "When I got your card, I said, 'Maybe it won't help us, but maybe it will help someone else.'" This was often repeated by those who were currently the most stressed either individually or in the marital relationship.

Coping with a chronic illness is an area that the respondents in this study believed was under-researched. Several mentioned that more resources, in terms of information, need to be provided to assist with individual and systemic adjustments. It is hoped that this study will promote additional research and that it may be useful to persons now trying to adjust to living with chronic illness. The next chapter summarizes these findings, proposes ideas for further study, and offers suggestions for persons faced with coping with chronic illness.
CHAPTER V
DISCUSSION AND CONCLUSIONS

Chronic illness is indeed a major stressor. Not only does it create a need for major changes in the affected individual's life, it also creates a need for major adjustments in relationships with significant others, often including children and extended relatives, but always including the spouse. The chronic nature of the disease or disability creates the need for permanent, not temporary, change. For some, the chronic illness may be progressive, characterized by unpredictable patterns, or it may fall into remissions and exacerbations so that there are variances in the amount of disability manifested over time. This necessitates ongoing need for adaptation; there are constantly new stressors added to the situation so that successful coping with the chronic illness is always being challenged. Resistances can become lowered, making coping more difficult as time goes on. Often, the spouse of the person with the identified chronic illness also develops health problems after the onset of the partner's illness. Several persons spoke of the development of new illnesses in themselves and/or in other family members as a "result of the stress" of coping with the illness or the associated stressors which often accompanied the illness.

Individual response to illness and marital response to illness varied greatly from each other. High levels of individual stress did not correlate with high levels of marital stress. In fact, high levels of individual stress coincided more with low levels of marital stress for many couples. The high quality of the marital relationship appeared to provide a kind of buffer and served as a resistance factor. Often the quality of the marital relationship was viewed by the study participants as improved in response to the stress caused by the illness. The majority of the
subjects in this study believed that the illness had made their relationship stronger, more honest, more accepting, and more appreciative of the spouse and of the relationship. Even some marriages which had considerable amounts of unresolved conflict were strengthened as a result of the illness, at least in terms of how the partners perceived the relationship and the degree to which they were satisfied with it. With the exception of 4 or 5 couples, the researcher’s rating of the quality of the marriage relationships approximately equalled that given by the couples themselves. For 4 couples, the researcher rated the marriage at a lower level of quality than the couples did. One couple was given a higher rating of marital quality than they gave themselves.

Any problems which were present in the relationship prior to the illness were exacerbated after the illness onset, at least during the adjustment phase of the response to the illness. Tension between the spouses was usually heightened initially. Characteristic physical or emotional behaviors previously present in the ill spouse were altered by the course of the illness. Roles characteristic of the couple were also altered. Following the adjustment phase, however, most couples either agreed to disagree, altered their attitudes about what was important enough to argue about, or they resolved those conflicts. A few couples did report an increase in the amount of marital conflict which they attributed to the illness, but which appeared to the researcher to also involve factors other than the illness. There were no couples in this sample who continued to express the conflict issues in the same way as they did prior to the illness.

Another outcome of dealing with chronic illness was the emphasis placed on the present, with less thought toward the future, especially for those marriages in which the progression and future course of the illness was uncertain. The focus
was on appreciating and living each day to its fullest, taking care of each day one
day at a time, and worrying little about tomorrow. For the most part, life was
appreciated more, although there were a few respondents who were, at the time of
these interviews, quite depressed and two or three who, at times, contemplated
suicide.

Death was a topic discussed by many. Generally it was not seen as
something to be feared; it was viewed as inevitable and something which each
couple was preparing for. However, this did not prevent the individuals or couples
in the study from appreciating each day and living to the fullest degree possible
within their physical limitations. Physical impairments were losses which most
adjusted to fairly well, especially when the deterioration was not progressive. It
appeared that the time necessary for a couple to achieve the level of acceptance
of the illness and reach a point of some stability was at least 6 months and often 2
to 3 years depending upon whether the illness was characterized by a
progressive or unpredictable course, or not. Those illnesses characterized by
ongoing change required a longer period of grieving and adjustment before
adaptation and acceptance could be achieved. Alterations in mental functioning
appeared to require more grieving and were handled less well than alterations in
physical functioning, contributing to increased stress levels in the well spouse.

Deteriorations in physical abilities necessitated grieving for the loss of
previous status positions in society, as jobs, careers, and normal social roles were
altered or ended. One's previous body image or level of self-esteem was also
altered with the changes in physical condition. Role performances were altered.
For some, these changes precipitated a significant depression which sometimes
required professional assistance. Often this depression affected the spouse
profundely, also. In its less severe form, this depression may be seen as one of the stages of grief which was experienced as a part of each spouse's adjustment and adaptation to the illness.

Other losses which required grieving included the loss of plans or dreams, loss of financial security, loss of employment, loss of a sense of purpose, or even the ultimate loss, the impending loss of one's own life or the life of a spouse or child. Often the impending loss of life was handled in a fatalistic way, accepting the inevitable and leaving it "in the hands of God" yet, at the same time, reveling in being given the gift of another day when life for the couple or family, as a unit, continued. In those couples who had been dealing with the limitations created by the illness for less than 1 to 3 years, the acceptance phase did not appear to have yet been reached. The stages of denial, despair and anger were more prevalent in these couples. Likewise, acceptance did not appear to be present in those couples who were not satisfied with the current state of their marriage. Certainly, they were less appreciative of each day and did not believe they were living life to its fullest.

Because the grief process involves several stages and because individuals go through the stages in different sequential patterns and with different time durations spent in the various stages, sometimes the process of grieving itself presented problems for the marital relationship. When one spouse was in the stage of denial and the other spouse was in the stage of despair, it seemed to be particularly problematic for the couple relationship. One spouse needed to protect him/herself from dealing with the loss; the other needed support and understanding from the partner and to express feelings. Each partner's needs of the moment clashed with the needs of the other; the result was strain in the relationship as
each wanted something the other was unable to give at the time when it was needed. It was here that professional psychotherapy appeared to be helpful.

Another area which seemed to contribute to marital discord was attributing blame for the illness to one spouse. If one spouse was seen as responsible for causing or contributing to the illness onset, severity or duration, marital harmony decreased. It appeared to be helpful to the marriage when both partners viewed the illness as something that was caused by fate, God, genetics, or an unavoidable accident, and not in the control of the person with the disease, the partner, or of either parent when it was a child who suffered the disability or illness. Marital quality also decreased when one spouse believed the ill spouse could do something to improve his/her physical, mental, or emotional capabilities after the onset of the illness more than he/she was doing. This belief sometimes resulted in battle between the spouses with one trying to coerce or manipulate the other to change behaviors. Other couples responded by one or both spouses withdrawing from the other.

Withdrawal did not always indicate a perceived problem in the relationship. Withdrawal was also used by couples relatively happy with their relationship as an attempt to protect the spouse from feelings which might cause increased stress for the other.

Role changes almost always occurred as a result of the illness and the changes necessitated in the person's physical and/or mental/emotional functioning. One spouse frequently became more dependent on the other than prior to the illness onset. Often the financial contributions of each were significantly altered. The social value or social connections of each spouse were sometimes changed as ties to work or other organizations were severed. Affective
expression and ability or willingness to be intimate often changed either due to psychological responses to the illness or to spouse's new behaviors or abilities.

Resource theory (Bloode & Wolfe, 1960) states that the person with the most resources in the relationship (what is valued by the couple, not just material goods and money) holds the most power. One would predict that as one's dependence upon the other increased, whether that be for financial support, physical care, emotional care, or connections to other resources, one's power in the relationship would decrease. This did not appear to be the case. It did not appear that the power arrangement in the relationship was altered, or at least it was not perceived as altered by the couple. A newly dependent spouse did not appear to relinquish any power he/she previously held in the relationship. Generally, decision-making and the power to obtain one's own desires did not appear to change after the illness. However, what did appear to occur was a change in the kind of resources offered by each spouse. Instrumental roles given up by one spouse were replaced with expressive roles in the successful marriages so that while the types of resources brought by each changed, the overall balance between them in terms of who held the most resources did not.

Even when physical dependence increased, for most of the couples, there were few alterations in the power structure although task performances were altered. The unhappy couples, however, did have ongoing power-struggles, sometimes in response to the illness but often present long before the illness. This power-struggle was one area of unresolved conflict which was exacerbated after the onset of the illness. The happily married couples generally had a perceived 50/50 power relationship before and after the illness or were in agreement about
how the power associated with their preferred gender-role performances was
distributed.

In addition to the power structure of the relationship, other factors which
appeared to correlate with perceived high levels of marital quality included
connections to others in the community, feelings of continued usefulness,
enjoyment of shared activities, a feeling of being accepted and supported by the
spouse, shared religious or spiritual beliefs, and particular attitudes or
philosophies about life and ways of behaving. An internal locus of control held by
both spouses appeared to be important. Each spouse assumed responsibility for
the quality of his/her life and made those changes in him/her self which promoted a
healthy adaptation. They did not try to change the other but did positively
reinforce the changes that the other was making in him/her self. They accepted
situations which were inevitable and out of their control, and believed that there is
a "good" purpose or possible outcome for the trials of the illness, either for
themselves or for others. They had high levels of commitment to the marriage and
demonstrated respect and caring for the partner. Open communication was
frequently, but not always, present.

The factors which contributed to or reduced the amount of couple stress
seemed to be far different from the factors which affected individual stress.
Individual stress, but not couple stress, was attenuated by extended family and
social relationships, the financial situation, and dealing with social welfare
programs and health care providers. Any or all of these factors were often seen as
additional sources of stress or as buffers against stress depending upon specific
situations. Each partner expressed some response as each stressor or buffer
interfaced with coping efforts related to the chronic illness. The majority of these
couples did not report that the individual stress experienced created a change in the stress level of the relationship. In other words, perceived individual stress of either or both spouses did not enter into the marital relationship by either spouse venting the stress experienced upon the other or taking it out on the relationship. On the contrary, in the couples who described a high level of marital quality, the partners each served as an understanding support of the other's sense of individually being stressed. Only in the couples who reported a decrease in marital quality was the stress experienced individually "dumped" upon the spouse or was support withheld.

The individual stress experienced as couples adjusted to illness sometimes resulted in the development of fatigue, however, especially when there were pre-existing marital problems. Other sources of stress, previously handled adequately, became accentuated. Marital conflicts previously unrecognized often became accentuated or took on new importance. Qualities in the relationship which may have compensated for the troublesome areas before the illness were sometimes lost due to the illness, or deficiencies became more significant as the previous balance of the relationship shifted.

Family typology appeared to play a role in the quality of the relationship and in both the individual and marital levels of stress experienced. Couples who were hardy, flexible, non-blaming, accepting of situations they could not change, philosophically or spiritually clear about life as meaningful and positive, committed to their marriage, trusting and respectful of the spouse, sharing of power and responsibility, and able to compromise were able to cope well with the hardships imposed by chronic illness. Totally open sharing of feelings or even of thoughts and beliefs was not an ingredient of every marriage perceived as highly
satisfactory by the couples. However, those who were quite closed in their emotional communication did not fare well because they were not able to understand the changes each spouse had to make in response to the illness onset. They were not able to understand the current needs of their partners and were faced with making their own changes alone without support or understanding from their partners. Support from extended family was helpful as were adequate financial resources.

There were some differences between the findings of this study and the findings in the literature reviewed in Chapter II as well as some similarities. There were no obvious differences between the findings in this study and those in the literature review regarding the levels of health and the locus of control, the use of humor, educational level, or even health practices (although there were not questions specifically asked about health practices or use of humor, some information in those areas was implied) and the development of or adaptation to illness. This may, however, be due to small sample size and the fact that many of the subjects were advanced in age and more likely than the general population to have illness regardless of life style factors. In a study where age was controlled, one would likely see stronger correlations emerge. There was some indication that living with an impaired spouse was related to the development of illness in the "well" spouse, although there were many cases where this did not appear to be true. Individual stress in the "well" spouse was experienced as greater when the spouse was mentally/emotionally impaired or when the physical impairment was great enough to require a great deal of physical care. A decrease in the sexual activity of the couples did not appear to influence the level of depression.
experienced. Again, this may be due, in part, to the age of the respondents and the long-term relationships involved.

A shared spiritual belief system stood out in this sample as a primary buffer to the stress of coping with chronic illness. This faith in God or in a philosophy of life which holds that all life experiences have some positive value was identified as the major coping mechanism by the majority of couples who were doing well. Those who were coping less well individually, not necessarily in terms of their relationship, did not place as much emphasis on the importance of spirituality in their lives.

The most outstanding additional stressor was financial deficiencies. Persons who experienced financial hardship to the point of having to live in poverty or near poverty rated their individual stress levels as nearly overwhelming, "the worst they could imagine having to deal with." Marriage often served as a support system against the fear and anxiety felt regarding the future.

As the interview transcriptions were analyzed, it became evident to the researcher that data could be described or organized according to the family stress model developed by Hill (1949) and recently elaborated upon by McCubbin and McCubbin (1989). Thus, the organizational scheme of this paper originated. Additional emphasis was given to the role of the health care system due to the researchers background in nursing, and recommendations for health care providers are made later in the paper.

There are vast amounts of research which demonstrate how the human body responds to biopsychosocial stressors which impact it. Over time, the immune, endocrine and neurological systems are altered. Biochemical changes occur. One result is the development of various chronic diseases: arthritis,
cardiovascular disease, diabetes, cancer, renal disease, etc. Chronic disability can also result from genetic factors and from accidents. It can, therefore, occur at any age, but the chances of developing one or more chronic conditions increase with age as the body has more years subject to wear and tear. It is not surprising, therefore, that a sample of chronically ill persons would have a large proportion of elderly persons included and this may approximate a representative sample. There were only four females among the person identified as the "patient" however, although as stated previously, some of the spouse's had also developed chronic illnesses.

Several conclusions were derived from this study which could be investigated in future studies. They are as follows:

1. Chronic illnesses which affect psychological and mental functioning to a significant degree produce greater marital stress than those which are more limited to physical alterations. This does not mean that "biological diseases" as opposed to "psychological conditions" will produce less stress. Persons can have severe psychological reactions to physical illnesses which alter psychological functioning more than some "emotional" illnesses might and persons who have "emotional" illness may experience physical symptoms.

2. The quality of the marital relationship will be less affected in couples who have been married for a longer number of years, other things being equal, than couples married only a short time before the onset of the illness. It was implied by many of the couples that one reason they were coping was due to the great number of years they had had together and their previous long history of rewarding experiences together.
3. Lower levels of pre-illness marital quality will be directly correlated with lower levels of post-illness marital quality.

4. Couples who attribute responsibility for the illness to one spouse will experience a greater decrease in the satisfaction with their marriage than couples where neither spouse is blamed.

A major problem in the design of this study was in limiting the interviews to still-married couples only. Meeting with couples who had chosen to divorce after the onset of a chronic illness may have provided further information into the dynamics of marital relationships stressed by chronic illness. It was interesting to hear reports given by couples in this study regarding relationships they knew of which had failed. For the most part, they were able to identify marital qualities which they had but which were missing in the couples who broke up, either in individual characteristics like self-responsibility or in couple qualities such as open communication. Of all the characteristics considered to be important to the quality of marriage, none stood out as more important than the others in terms of successful coping with chronic illness except for commitment. What was perceived to be crucial was the level of quality prior to the onset of the illness. Whether the illness affected physical or mental traits or both also appeared to be very relevant to the response of the spouse and to the quality of the marriage post-illness.

Suggestions for future study were given by some of the respondents in this study. They expressed a need for more qualitative research and, indeed, were invested in not having this study "turned into numbers and statistics." Several respondents stated a strong desire that the time and energy they were willing to invest not be minimized by conversion to quantities.
There is a perceived need for change in our health care system, both in terms of its affordability and in terms of the way in which health care is provided by the current practicing professionals. More attention to the person and the family is desperately needed and not often offered. Study participants generally were much more satisfied with the care provided them by small town family physicians and smaller hospitals than they were with larger medical centers and medical specialists. There were exceptions to this, however. One couple was very satisfied with care received in a large medical center and one was very satisfied with care provided by a V.A. hospital. Nearly all respondents perceived a need for greater support and education from health care providers regarding how their particular illnesses might impact other areas of their lives. This deserves additional research with emphasis placed on how and when patients and families want additional information and support and who would be most effective in providing it.

More information needs to be available for persons who have contracted a chronic illness or disability, and it seems obvious that health care providers are the most likely persons to be able to provide it. They are persons whom every chronically ill person will encounter. Others who need further education may include pastors, social service workers, and mental health practitioners.

A suggestion for future research would be to study all couples in a population where a spouse or child is newly diagnosed with a chronic illness and follow each couple over time (several years) to determine the process of their adjustments. This could be accomplished by someone working in a medical health care facility. Patients who are newly diagnosed with chronic illness could be interviewed or given a survey to determine possible problems in their relationships.
with significant others. Couples who had some problems areas identified could be
offered counseling. One of the respondents in this study suggested that this help
be called something other than counseling so that it might be more acceptable.
Another respondent suggested that it be presented in a positive way as a part of
the treatment program prescribed for everyone.

This researcher hopes that this exploratory study might encourage research
in this field and writings geared toward educating and preparing the lay public,
those with chronic illnesses and family members, who find themselves
experiencing situations they had not imagined and for which they could not
anticipate and prepare. Particularly vulnerable, in addition to those with prior
relationship problems, are those who are or will be financially stressed by the
illness and those who do not have a strong spiritual and philosophical belief
system to help them create some understanding of or belief in a positive purpose
for their difficult situation. Integrating family systems psychotherapy into the
practice of medicine and nursing would provide patients and their significant
others with a better chance of integration of the illness into an adaptive lifestyle
and a greater quality of life during their remaining lifetime. It is likely that
counseling would be more readily accepted, especially in some geographic areas
of the country and by some groups of people, if the "counselor/psychotherapist"
were presented as a part of the medical system and not as someone to help those
who are "not strong enough" to cope.

Medical practitioners can do a great deal in routine encounters to provide
emotional support and health/illness education as well as present a more positive
picture of psychotherapy, but more in-depth psychosocial services could be more
effectively provided by a mental health provider trained in family systems medical
psychotherapy. Physicians and nurses are too taxed, generally, providing for the physical needs of patients and completing legally required associated duties. It is therefore hoped that this study can be used to interest the medical community in offering a more holistic treatment plan for their patients and family systems with chronic illness by including family medical sociologists or family therapists as part of the treatment team.
REFERENCES


Dear Doctor:

I am writing to introduce myself and to seek your assistance in obtaining subjects for my dissertation research. I am a Ph.D. candidate in family studies at Iowa State University in Ames, Iowa. I am a registered nurse and nationally certified marriage and family therapist (Clinical Member of AAMFT since 1986). I am interested in studying how chronic illness of a spouse or child affects the marital relationship of the spouses or parents. To my surprise, there is little research which addresses this area although there is much research regarding the effect of chronic illness on individuals, especially caretakers and patients.

There is significant evidence which substantiates the relationship between mental, physical, emotional and spiritual factors in the relationship of any dysfunction whether manifested as biological or emotional illness or addictive behaviors. I hope that this research will provide information for further research and hypothesis testing and will also provide information which may be used to identify persons in need of psychological assistance and to develop appropriate interventions.

I solicit your assistance. I need contacts who meet criteria for this study. Due to the confidential nature of the health care professional/patient relationship, I realize that you may not be able to supply names or addresses to me. However, if your
office will search the files for patients who have a chronic debilitating illness and develop a list, I will supply cover letters, self-addressed return post cards, envelopes, and postage for mailing from your office. I am including a sample of the proposed cover letter and a brief abstract of the study design so that you can understand the study and sample criteria. What I am seeking now is your commitment to participate by identifying possible subjects and mailing the letters to them anonymously from your office. Please return the enclosed postcard at your earliest convenience marked "yes, I will" or "no, I cannot" assist. I hope that you will choose to assist me in the manner requested. I do believe that my study will provide useful information both for health professionals and for patients and families who are affected by chronic illness. If you have further questions or concerns, please contact me at (405) 772-6541 or 772-1805 or at the above address. Thank you for your consideration.

Sincerely,

Sandra Thoman, M.A., Ph.D. Candidate
APPENDIX II: LETTER TO POSSIBLE PARTICIPANTS

Route 5 Box 124
Weatherford, Oklahoma 73096
December, 1991

Dear Potential Participant:

I am a doctoral student at Iowa State University doing a dissertation on the effect of chronic illness of the patient on the quality of the marital relationship of the spouses/parents. I am also a registered nurse. You have met the study criteria of having one or both spouses or a child with a chronic illness.

Who really understands what you have been going through since the family has been affected by this illness or disability? Does anyone really understand the stresses or changes that have resulted in your lives? Is there anyone you can really talk to about your situation? What kind of supports do you have? What kinds of needs do you have that are unmet?

I hope to learn the answers to those questions as a result of my research. Although we are learning much more about how each of us is affected by stress in our lives and about how stress can contribute to the development of illness, relationship problems, and spiritual crisis, there is little known about how the development of a physical illness affects the couple relationship. Thus, persons who are experiencing much stress in their lives may go without much needed support and assistance. It is my hope that this study may provide beginning
information which can be used to improve the services available to entire families when chronic illness or disability strikes.

This letter has been mailed anonymously from the office of your physician. I am not aware of your name, address or any other identifying information. Your participation is needed. I need the participation of both husband and wife. I would like to conduct an interview in your home at your convenience. I want to listen to your story about your situation and to understand how the illness has affected your lives. All information will be completely confidential. At no time will any identifying information be released to anyone, not even your physician or the person mailing this letter.

Please talk this over with your spouse and return the postage paid enclosed card to me at your earliest convenience. This will indicate your agreement to participate in the study and will provide me with your name, your address, and your phone number. I will call you to set up an interview time and will be happy to answer questions you may have about the study. You are, of course, free to refuse to participate further at any time, should you change your mind. I hope to hear from you in the next few days. Thank you for your cooperation.

Sincerely,

Sandra Thoman, M.A.

I support Ms. Thoman in this research and believe your participation will provide a valuable service to others in similar situations to yours. I hope that you will
participate, but your refusal will in no way jeopardise your relationship with or treatment from me. I will not even be aware if you have participated, or not, and you will not be asked.

Sincerely,
APPENDIX III: RESEARCH CONSENT FORM

CONSENT FORM

I, ____________________________________________________________, voluntarily agree to participate in this study conducted by Sandra Thoman-Touet and her assistant for her doctoral dissertation at Iowa State University. I understand that all information will remain completely confidential. My participation will be limited to the couple and/or individual in-home interview and a follow-up phone interview to be conducted after Ms. Thoman has completed the initial analysis of the interview data. The follow-up interview will be for the purpose of validating her interpretations. I understand that I may withdraw from the interview process at any time.

There is little likelihood of risk associated with participation in the research. However, if I experience psychological distress as a result of the interview process, I may engage in up to three free hours of debriefing/counseling with Ms. Thoman.

A personal benefit which may occur as a result of my participation in this study may be psychological relief due to sharing my feelings, thoughts, and stress. A benefit to persons in similar situations and to health care professionals may occur as a result of the increased knowledge of the needs and stresses of persons who are living with chronic illness as an ongoing presence in their lives gained from this study. Greater support may be developed as a result of this increased knowledge.

(continued)
My signature below indicates that I freely consent to participation in this study.

Signature

Date