A LONGITUDINAL STUDY OF FAMILIES FACING CANCER

Dissertation

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By

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Introduction

Review of the Research Literature: The Impact of
Cancer on the Family System

The estimated number of new cancer cases diagnosed in this
country in 1984 will be 870,000. Predictions indicate that cancer
will eventually appear in three out of four American families
(American Cancer Society, 1983). Because serious illness often
precipitates a crisis within the nuclear family (Olsen, 1970;
Bruhn, 1977), the impact of cancer upon the family system is an
important issue for health care professionals.

A diagnosis of cancer has generally been viewed by members of
the general public as disabling and eventually fatal (Currier,
1966; Giacquinta, 1977). Although there have been many anecdotal
accounts of the family's experience with cancer, there has been
little systematic research in this area. The purpose of this
dissertation is to present a viable theoretical framework with
which to view families facing chronic and terminal illness, and to
apply this framework in a longitudinal study of cancer patients and
their families. Thus an attempt is made to address the need stated
by Weisman (1979),

"There can be no reliable information without an
appropriate conceptual structure. Theories and
hypotheses came together and provide a basis and
an impetus for further research and rational care. Suppositions help no one. What are required are data gathered from many cancer patients with different types of cancer at various stages over an extended period." (p. xv)

It is becoming commonly recognized that cancer affects the entire family system, not merely the individual patient. Many of the effects of cancer on the family are a result of the changes in family role structure necessitated by the disease and its treatment. As early as 1958, Hill described stress within families facing serious illness in terms of the problems associated with role reallocation and the attendant loss of family unity. Although the bulk of psychosocial cancer research has focused on the individual patient, a few subsequent researchers (e.g. Cohen, Winget & Dizenhus, 1977; Giacquinta, 1977; Orcutt, 1977) have expanded on Hill's original contribution, and have suggested characteristics of the family system likely to influence role reallocations and adaptation to the chronic or terminal illness of a member.

Communication

When illness forces the patient to abdicate his or her usual roles within the family, other members may resent the increased duties they are charged with as well as the patient's release from former responsibilities (Oppenheimer, 1967; Power and Dell Orto, 1981). Perhaps the most important structural component of the family system in terms of role reallocation is the communication structure, (Aldous, 1978). It first becomes important in
determining the degree to which family members can express their feelings related to the illness or death. It is generally believed that a more open communication structure, wherein members are relatively free to express feelings of sadness and loss as well as anger, guilt, and relief, is an important factor in the success of the adjustment process of the individual family members and in the readjustment of the family role complex (Vollman, Ganzert, Picher, & Williams, 1971; Silverman & Englander, 1975; Bowen, 1976). Later in the adjustment process, open communication allows for the negotiation of roles which best fit the capabilities of the remaining family members (Giaquinta, 1977).

In contrast, a closed communication structure restricts the reallocation and reorganization process. A "conspiracy of silence" may develop in the family, in which everyone is aware that the others have feelings but no one knows how to talk about them and in fact prefers that they keep their feelings to themselves (Bonnard, 1961). Further, closed communication regarding roles may cause the reallocation of the patient's roles in such a system to be settled by default, often with no clear decisions made about how they should be played or by whom (Silverman & Englander, 1975). This can lead to role reallocations which do not best suit the available family resources or cause undue stress on certain family members. If role assignments are not made explicit, the resulting perceived inadequacy in role performance may further increase tensions within the family system. The importance of explicit role performance expectations is highlighted by Elliot (1948) and Bruhn (1977), who
point out that if incompatible conceptions of the new roles are held by family members, conflict can produce decreased solidarity and increase marital conflict within the family system. An open communication structure can prevent such incompatible role conception from developing by allowing for the negotiating of clearly defined role reallocations with mutually agreed upon norms.

Power and Dell Orto (1981) argue that one of the strongest determinants of family reaction to chronic or terminal illness is communication of disease related information. When family members fail to clarify matters regarding the illness, added anxiety is created. The authors recognize that many patients and family members are ambivalent in their desire to acquire information regarding the disease. Yet when they continue to avoid the facts, and/or neglect to share this information with each other, family members may be prevented from gaining necessary family support. The quality of family relationships may also suffer, "since tensions and fears felt by the patient are not understood by those close to him" (Rakel, 1977, p. 375). Cassen (1974) describes a potentially vicious cycle, whereby poor communication patterns among family members leads to a lack of response to the patient's needs. This precipitates further emotional difficulty for the patient which, in turn, adds further tension to family relationships.

In addition to reducing the disruptive effects just described, open communication related to the disease offers several other advantages. Rakel (1977) notes that families that were able to
make positive adaptations to the disability of chronic illness were characterized by effective and constant communication which allowed for flexibility in family roles. Cohen, Dizenhuz and Winget (1977) also report that the families of cancer patients in their study which were rated as open in disease related communication were more flexible in role reallocations and experienced less difficulty in post-death restabilization.

In their description of a hospital-based psychosocial unit to meet the needs of oncology patients and their families, Krant, Beiser, Adler and Johnston (1976) recommend, whenever possible, the rehearsal of roles which other family members will need to adopt. Such behavior requires that the family can engage in open communication about illness related issues. As Orcutt (1977) points out, the dying member who supposedly does not know he is dying cannot participate in family planning and role realignments.

Another advantage to open communication regarding the disease is an enhanced sense of closeness among family members. Patients who are not talked to openly about their disease and its impact on the family often feel isolated (Glaser and Strauss, 1966; Orcutt, 1977). Conversely, patients who can openly discuss their condition and its ramifications with significant others often feel that their families have become closer (Power and Dell Orta, 1981). In his study of 80 patients in the later stages of progressive cancer, Hinton (1981) reports that significantly more couples who openly shared their awareness of the patient's condition felt that their relationship had grown closer, in contrast to those with limited or
no such sharing. Hinton concludes that "fuller communication was more successful as judged by increased affection between wife and husband". This supports an earlier study (Gerle, Lunden and Sandblum, 1960) suggesting the beneficial effects on the quality of relationships when the patient and family could share the knowledge of the prognosis.

Approximately one third of Hinton's (1981) sample had said nothing to their spouses about their prognosis and another third had only made tentative comments which were outwardly ignored or denied. The author describes three patterns by which these couples avoided direct communication. One was an "automatic" communication of only positive messages, and an attendant reluctance to face the truth. The patient and spouse essentially colluded with each other in voicing no pessimism.

A second, related pattern was a more conscious avoidance of negative facts. It was ostensibly enacted to protect the other from distress, but obviously served to protect the self as well. This pattern, however, often put the couple in the paradoxical position of being unable to share important feelings with the loved one in order to protect him or her, thus precluding the closeness otherwise sought after.

The third pattern of sparse communication appeared to be a continuation of communication patterns established over many years, in which the couple had rarely spoken about important issues. The fact that one of them was dying did not change their long established pattern of exchanging few words.
Hinton warns that it is incorrect to consider many of the couples employing the three patterns just described as failing to communicate. Instead, their reluctance was often based on an understanding of the husband's or wife's reactions and their need to avoid distressing topics. The author further notes that it would therefore be incorrect to presume that open communication is best for all couples. Yet for those that possess the requisite skills, open communication appears to offer a number of advantages to the chronic or terminally ill patient and his or her family.

**Family Norms: Position vs Person Oriented Families**

Rogers (1973) describes serious illness and/or death within the family as a form of disjunctive change, whereby the current normative structure of the family may be inadequate. Such situations are termed "anomie" indicating normlessness, and necessitate a series of interactions which serve to redefine the norms for family roles. Several authors have noted the need for established family norms in dealing with crisis (Bruhn, 1977; Vollman et. al., 1971). On the basis of the following, it can be argued that certain types of families will have an advantage in the process of norm redefinition and role reallocation.

Families differ in the method of role assignment which they employ. The basic distinction is between achieved and ascribed roles. An ascribed role is one that is assigned to a family member by virtue of some characteristic over which he or she has no control, such as age or sex. Achieved roles, in contrast, are acquired by the individual's own efforts and abilities.
Given this distinction, roles within the family can result from one of two processes identified by Turner (1967) as "role-making" versus "norm-playing." Norm-playing is analogous to ascribed roles in that there exists a cultural or societal normative prescription for a particular position to fulfill a given role. For example, it may be that the societal norm prescribes the role of provider entirely and invariably to the husband-father position, and the roles of housekeeper and child-care entirely and invariably to the wife-mother position. These ascribed roles would therefore be assigned to the individual occupying these positions, regardless of the individual's abilities or interests.

Role-making is more analogous to achieved roles. In this process roles develop from the day-to-day interactions among family members. This process results in role content and role assignment that more closely reflect individual differences because individual preferences and abilities are taken into account in the negotiation of role assignments. Such differences are ignored by the more rigid role prescriptions of the norm-playing process.

The interrelatedness of family communication, power, and affection, and the distinction between ascribed and achieved roles, are illustrated by Bernstein (1970), who distinguishes between what he terms position oriented and person oriented families. Roles in position oriented families tend to be ascribed, based on the age and gender of the member, instead of his or her individual characteristics. As Aldous (1978) describes these families:
"Socialization is unilateral from parents and other elders to children with accompanying one-way communication channels. The children have two-way communication channels with their peers who serve as role models and information sources in matters adults do not concern themselves with. In the vertical power structure, associated with position oriented families, parents' control of children is based on parental force or on their appeals to norms that regulate the status of children rather than oriented to the person and verbally explained. The factor of gender typically makes the husband-father the final authority." (p. 71)

The affection patterns in position oriented families are more rigid and restrictive than that of person oriented families. Based on cultural stereotypes, the expressive role of affection giver is assigned to the female family members. Males in position oriented families tend to consider signs of affection, especially toward other males, as effeminate and inappropriate. This tendency may have significant consequences in families facing cancer, in that cancer patients and their spouses have been found to desire greater affection and physical closeness after illness onset (Leiber, Plumb, Gerstenzang, and Holland, 1976). If family members are unable to respond to the increased affectional needs, disruption of the psychosocial environment may result.

Position oriented families thus engage in the norm-playing process described earlier. In contrast, person-oriented families utilize the role-making process. In these families, roles are allocated on the basis of achievement, not ascribed according to age and gender. Communication channels are two-way to allow for the extensive communication necessary for the role-making process. The parents' power is based on greater experience, not on rigid
normative prescriptions. The power structure in such families is also more flexible, so that as children's competency increases or the patient's competency decreases, the structure may become more horizontal in nature.

In the less rigid person oriented family there are fewer culturally prescribed limitations to showing affection. Since roles are based on the unique characteristics of the individual family members rather than on societal norms for a given family position, members are freer to express affection to whatever degree they are comfortable. Role changes may also be much easier in person oriented families because affection is used to soften confrontation and misunderstanding while new roles are made and new interaction patterns developed (Aldous, 1978, p. 73).

Because of open communication, less restricted affection patterns, and their experience in the role making process, person oriented families may be better equipped to deal with the changes in family functioning imposed by chronic or terminal illness. Such families are less likely to experience anomie under these circumstances than those families who have relied on cultural norms to guide their family interactions. Referring to an essentially person oriented family, Vollman, et. al. (1971) note:

"In such a case, role assumption is usually explicit and well understood by all family members. When a member of this type of family dies, the critical period of reorganization is not likely to be experienced as a crisis because the family already has a built-in process which allows it to reallocate the role functions of the decedent with minimal difficulty". (p. 104)
A Conceptual Framework: The DRA Model

To understand in a systematic way the differences among families with a chronic or terminally ill member, the clinician/researcher needs a conceptual framework. The one proposed here combines Duvall's (1977) eight stage family life cycle model with the family role delineation proposed by Nye (1974). The result of this integration is a developmental role analysis (DRA) of the family system (Vess, Moreland & Schwebel, in press).

Nye identifies eight primary roles in the family system. These include: provider, housekeeper, child care, child socialization, sexual, recreational, therapeutic and kinship. Having identified these roles by reviewing the family literature, Nye went on to test them empirically. Nye and his colleagues obtained data on 210 couples using questionnaires designed to measure the existence and enactment of roles, the competency of the role players, sanctions used to enforce norms, role identification, role strain and role conflict. Despite the relatively small sample, this study is the most extensive of its kind in the literature and forms the basis for the present model.

Nye (1976) considers the child socialization and child care roles to be the definitive elements of the family. Although other functions may vary, "that which appears as the irreducible element of the structure known as the family is the nurturant socialization of children." Gecas defines the socialization role as concerned with the social and psychological development of the child, and
involves those processes within the family which contribute to developing the child into a competent social and moral person. The role requires the specific activities of teaching children right and wrong, developing in them a sense of responsibility and competence in such areas as eating and dressing properly, doing school work and other required tasks, and how to conduct general interactions with others.

In contrast to socialization, which involves development of the child's social and psychological capacities, the child care role involves the physical and psychological maintenance of the child. Accordingly, the specific activities required in the child care role include keeping the child clean, fed, warm, and protected from physical danger and frightening experiences. Behaviorally the child care and socialization roles may overlap, in that socialization may take place in caring for the child and vice versa. Yet Gecas argues that they refer to conceptually distinct activities and may even be segregated according to who is responsible for each. The object of the socialization role is to produced a socialized person, whereas the object of the child care role is to enable the development of a healthy organism.

If the child care and socialization roles are the definitive elements of the family, also among the most traditionally well-established family roles are those of provider and housekeeper. Specifically, Nye defines the provider role as that in which goods and services needed by the family are produced or are obtained by an exchange of goods and services. Conversely, the housekeeper
role uses the goods, once obtained, by preparing and maintaining them for family use. The roles are thus complimentary in the sense that they involve the same goods at different points in obtainment, preparation and utilization. The provider role is essentially instrumental in the sense described by Parsons and Bales (1955). However, the housekeeper role also includes instrumental tasks in the form of food processing, cooking and serving, cleaning, laundering, repairing clothing and household equipment, marketing, and perhaps keeping the relevant financial records. Nye distinguishes between the housekeeper role as he defines it and what could be termed the housewife role, noting that the housewife role is potentially much broader category. The housewife role might include the child care, child socialization, and housekeeper roles mentioned above, as well as the therapeutic, recreational, and kinship roles described below.

The kinship role results from an apparent consensus that "people have an obligation to keep in touch with kin" (Reiss, 1962, p. 336). Farber (1964, p. 196) lists norms for ideal kindred relations related to 1) participation in rituals and ceremonies, 2) promotion of the welfare of family members, 3) making personal resources available to family members, 4) trust in the kindred, and 5) maximizing communication.

The activities included in such a role, as conceptualized by Nye, are obligations to aid financially one's relatives and to maintain communications by phone, letter or visit. His results showed that a large majority of his sample affirm that an
obligation to kin exists, and that there are sanctions regarding the performance of this role.

The recreational role has been defined in the literature as "activity, apart from the obligations of work, family and society—to which the individual turns at will, for either relaxation, diversion, or broadening his knowledge and his spontaneous social participation, the free exercise of his creative capacity" (Dumazedier, 1967). Nye, however, allowed his subjects to define for themselves what they felt to be recreational activity. An earlier conceptualization of recreation as a role was presented by Bates (1956) who included "playmate" as a role of the mother and father positions. The primary responsibility associated with this role, under Nye's conceptualization, is to organize and initiate family recreational activities, whatever they may be within a given family.

Nye appears to be the first to examine marital sexual behavior within a role framework. He notes that although several writers discuss the relative duties of husbands and wives concerning sex, none conceptualize it as a role (Nye, 1976, p.102). The sexual role is based on concern for the sexual needs of one's spouse, and involves the initiation of sexual activities as a result of this concern.

Finally, Nye discusses the emergence of a new role in the social structure of the nuclear family, that being the therapeutic role. Similar to Blood and Wolfe's (1960) concept of the mental hygiene function of the marital couple, the behavior required in
this role involves assisting the spouse to cope with and resolve the problems with which he or she is confronted. Recognizing that some problems originate in the interaction between spouses, the therapeutic role includes dealing with these interspousal problems as well as those involving other family members and non-family individuals and groups.

Nye addresses the relationship between the therapeutic role and the expressive role described by Parsons and Bales (1955), by noting that there is some common content in the two. Insofar as problem-solving frequently involves feelings of insecurity and distress, the therapeutic role player may provide some of the needed emotional support, an aspect common to the expressive role. However, problem solving also involves active listening, acting as a "sounding board" for the ideas and reactions of the other, supplying additional information, concepts, or insights, and taking concrete actions in sharing the solution of the problem, the latter being more of an instrumental function. Thus the therapeutic role involves a broader range of activities than the expressive role.

From a review of the sociological and counseling literature, Nye identified four positive responses to a spouse's problem: 1) listens to the problem, 2) sympathizes, 3) gives reassurance and affection, 4) offers help in solving the problem. He also found two proscribed behaviors: 1) reacts with criticism of the person confiding the problem, and 2) discloses confidences to third parties.
For Nye's role analysis to be of optimal use in examining the nuclear family, it must be applied in a developmental framework. Duvall (1971) provides a succinct, eight point summary of the characteristics of a family developmental framework. She notes that this approach:

1) keeps the family in focus throughout its history,
2) sees each family member in interaction with all other members,
3) watches how individuals affect the family unit and the ways the family influences individual development,
4) captures what a given family is going through at a particular time in its life cycle and at a given point in history,
5) highlights critical periods of personal and family growth and development,
6) views both the universals and the differences among families,
7) focuses on the ways in which the culture influences family life, and how families make themselves felt in society,
8) provides a position from which to make predictions concerning the experiences a given family will have at any period in its lifespan.

A major advantage of the family developmental approach is its ability to closely examine the internal dynamics of the family over long periods of time. Rogers (1964) goes so far as to state, "The unique contribution of the family developmental approach to family theory has been its attempt to deal with the dimension of time in the analysis of the family as a small group association" (p. 263). Toward this end, Duvall (1977) presents an eight stage family life cycle model which forms the foundation of the DRA model proposed here.
A Developmental Perspective on Family Roles

Married Couple Stage

The first stage of Duvall's family life cycle is the married couple stage (see Figure 1) and has associated with it three stage critical family developmental tasks. The first is establishing a mutually satisfying marriage. This broad task necessitates execution of a number of the roles discussed above. At the core of this task, the couple will need to work out an allotment of the various roles that each spouse is satisfied with. This will involve the extensive use of the role-making process, unless the couple attempts to settle into a norm-playing pattern and adopt a rigidly prescribed set of traditional role assignments. Even if the latter is the case, the details of role expectations will need to be mutually agreed upon in some way.

Establishing a mutually satisfying marriage will require most couples to enact some form of the provider and housekeeper roles in order to establish and maintain a place of residence. The therapeutic and recreational roles may be important in establishing or strengthening a satisfying relationship. Finally, the sexual role would seem to be quite important at this stage, in that sexual compatibility has been found to be a consistent factor in marital satisfaction (Wallin & Clark, 1958; Mower, 1954; Ellis, 1954).

Duvall lists adjusting to pregnancy and the promise of parenthood as the second stage critical task at the married couple stage. This seems more appropriately assigned to the childbearing stage in that pregnancy can be viewed as part of the childbearing
process. The third task at the first stage is fitting into the kinship network, and directly requires Nye's kinship role.

**Childbearing Stage**

In the second, or childbearing stage, the task of adjusting to pregnancy and the promise of parenthood requires emotional as well as physical support. Thus the therapeutic role may be quite important. The task of having, adjusting to, and encouraging the development of infants will continue to require the roles of provider and housekeeper, as well as adding the new roles of child care and child socialization. The stresses of infant care will require the spouses to be emotionally supportive of each other, so that the therapeutic role will continue to be important. Because infants require constant care which diminishes as the child gets older, the child care role will initially be more important and more vigorously enacted than the socialization role. However, socialization expectations increase with age, while the child's need for constant care diminishes. Thus the child care role will diminish through subsequent stages of the family career, while the socialization role will increase in importance, at least through the teenage stage. The last task in this stage, establishing a satisfying home for all family members, again indicates the need for provider and housekeeper roles.

**Preschool Stage**

The first task under the preschool stage is adapting to the critical needs and interests of preschool children in stimulating, growth-promoting ways. This continues to highlight the importance
of the child care and socialization roles, with socialization
becoming more important than it was previously. The task of coping
with energy depletion and lack of privacy as parents would seem to
involve helping one's spouse, therefore requiring therapeutic role
enactment.

School-Age Stage

The two tasks of school-age families are fitting into the
community in constructive ways and encouraging children's
educational achievement, both of which seem to place a heavy
emphasis on the socialization role. It should be borne in mind,
however, that the roles mentioned in conjunction with previous
stages continue to be important at this point, insofar as they
support the enactment of the highlighted role of socialization at
this stage.

Toward the end of the school age stage and increasing through
the teenage stage, parents become somewhat less important in the
socialization role, while it is enacted to a larger degree by the
school system. Relatedly, Parsons and Bales (1955) note that the
family offers a wide enough range of role participation for the
young child, but that with age the child must learn roles the
family does not offer. It is at this point that participation in
peer group and school activities becomes crucial in the child's
socialization.

Teenage Stage

Although the parents continue to enact the socialization role
in the home, their role begins at this point to become less
salient. This "loosening of the reins" is reflected in Duvall's task of balancing freedom with responsibility as teenagers mature and emancipate themselves. The other task she lists at this stage centers on the marital couple, and involves establishing postparental interests and careers as growing parents. This would seem to require, depending on the couple, some form of the recreational role in establishing or continuing interests, as well as the therapeutic role in supporting each other's exploration of potential interests.

Launching Stage

The tasks of the launching center stage include releasing young adults into work, military service, college, or marriage, and maintaining a supportive home base. This requires, at some point, a transition to the kinship role with the couple's offspring, in that children are now establishing their own lives and families outside the nuclear household. Thus at this point the child care and socialization roles have ceased, the provider and housekeeper roles remain, and the kinship role takes on added emphasis. As before, the sexual, therapeutic and recreation roles continue to be important to varying degrees, depending on the interactional patterns of the particular couple.

Middle Age Parents Stage

In the stage of middle-aged parents, the pattern noted in the previous stage is continued. In order to rebuild the marriage relationship, the therapeutic, sexual and recreation roles are important. Maintaining kin ties with older and younger generations
is again directly manifest in the kinship role.

**Aging Family Stage**

Finally, in the stage of the aging family, the critical tasks may not require different roles so much as shifts in who enacts them. In the case of widowhood, the remaining spouse will somehow have to manage the roles formerly enacted by the deceased. Based on statistical norms, this is most likely to take the pattern of the woman having to adopt a provider role she perhaps has not enacted before, just as the surviving husband would faced with a housekeeper role to which he is unaccustomed. There are additional adjustments necessitated by widowhood and the associated loss of the reciprocal sexual, recreational, and therapeutic roles.

If both spouses survive for some length of time, retirement brings its own set of role adjustments. There is the loss of the provider role by one or both spouses. This could result in financial difficulty and its attendant problems. There may at this stage be an increase in the importance of the recreational and kinship roles in an attempt to compensate for the loss of the provider role.

**Loss of Roles**

In the foregoing framework, illness induced disability or death is viewed as the loss of an individual who has performed crucial roles within the family system. As was illustrated, the roles vacated will depend on the family's role structure and the stage of the life cycle that the family occupies. The family's reorganization will depend largely on the reallocation of roles
formerly enacted by the patient.

Figure 1 presents the major roles parents typically fulfill. The bandwidth for each role varies as the importance of a particular role changes across time. Note that some roles remain constant over the life cycle, while others seem to increase or decrease in significance.

Figure 2 illustrates the different processes of role assignment within position and person oriented families. Since both types of families must engage in the process of role reallocation upon the hospitalization or death of a family member, the following discussion highlights several factors influencing the degree of disruption within the family system and the concommitant stress such factors induce in the course of reorganization.

**Factors Influencing the Degree of System Disruption**

**Trajectory of Illness.** The trajectory of a terminal illness (Glaser and Strauss, 1968) refers to the course a patient follows through periods of decline and ultimately ending in death. Individual trajectories vary greatly in both duration and in the course they follow; it may plunge sharply over a short duration, move slowly but steadily downward, vacilate up and down before declining rapidly, or decline to a long plateau before plunging again. While it should be noted that cancer does not always lead to death, (currently 50% of cancer diagnoses are considered curable [Thomas, 1983]), in most cases there will be some degree of physical decline, either followed by a return to a premorbid level of health, to a stable but lower level of health, or a decline
leading to death.

The course and duration of the cancer patient's trajectory will influence the family system in several ways. Rapid decline may force families to adapt more quickly, whereas the presence of extended plateaus may allow some degree of normative functioning to be reestablished before another period of decline and readjustment is faced. Thus the trajectory will influence whether change within the family is either disjunctive or continuous (Rogers, 1973). Disjunctive change involves a radical and sudden reordering of the role structure of the system, which may be totally unanticipated. A circumstance may arise which the family has never faced before and for which there seem to exist no clearly defined roles, necessitating hasty modifications in the roles of one or more family members. Continuous changes are considerably less disruptive, and occur in a slower, evolutionary manner. This type of change may be more characteristic of families in which the patient experiences a gradual decline across an extended period of time, allowing for a correspondingly gradual modification of family roles.

A patient's trajectory is thus related to the severity of illness, which has been implicated as a factor related to disruption in the family (Weisman & Worden, 1977). One concomitant feature of a serious illness such as cancer is frequent or lengthly hospitalization. Hospitalization is not only stressful at the individual level, but removes the patient from the family system, thus requiring adjustments in the family's role
patterns, and introducing the possibility of family disruption.

**Roles of the patient.** Long term or frequent hospitalization, physical disability due to the illness or its treatment, and the psychological sequelae of the disease may all act to prevent the patient from enacting his or her usual roles in the family. The difficulty of role reallocation will depend in part on the number and nature of roles held by the patient, and the abilities of the other family members (Vollman, et. al., 1971).

In the case of the husband-father, for example, the role of provider may be troublesome to reallocate if another family member does not possess the necessary skills to fill this role. Similarly, if the husband-father's other roles (e.g., child care and socialization, recreational) require characteristics or skills which no other appropriate family members possess, his disability or death will cause a more difficult reorganization.

In the case of the hospitalization or death of the wife-mother, the roles traditionally lost are those of housekeeper and child care. As with the husband-father, if other family members are not capable or not willing to adopt these roles, reorganization and recovery of family functioning will be more difficult.

The roles which family members enact may sometimes affect family dynamics in inconspicuous ways. For example, loss the the husband-father's expressive roles will be especially important to reallocate if the function of this role has been to camouflage or resolve a conflict existing in the family system. If the father's expressive functions within the family served to keep an otherwise
emotionally distant wife-mother involved with other family members in the affection and communication patterns, loss of this function could be most deleterious.

With the hospitalization or death of a spouse there occurs the loss of other roles often associated with these positions. The therapeutic, sexual, and recreational roles can be seen as reciprocal to some degree, in that they require the participation of both spouses (Nye, 1974). Research has indicated that there is an acute sense of loss for the sexual role early in bereavement (Glick, et. al., 1974). It seems likely that the therapeutic and recreational roles will not be so acutely missed in the early stages of bereavement, when family and friends rally to the support of the bereaved. Yet this support soon recedes (Glick, et. al., 1974) leaving the widow or widower facing the absence of the partner with whom he or she had shared their most intimate relationship.

Several authors posit that the roles associated with marriage in this society are more important to women than to men (Pincus, 1974; Nye & Berardo, 1973; Bell, 1963; Mathison, 1970). Females have been traditionally socialized to believe that the greatest achievement in their lives will be to marry, be a beautiful bride, and become a wife and mother (Pincus, 1974). According to this view, a woman's identity is based in large part on her roles as wife and mother. Thus widowhood presents the loss not only of her sexual, therapeutic and recreational roles, but of a fundamental basis of her self-concept as well (Mathison, 1970).
Stage of Family Life Cycle. The DRA model suggests that stage of the family life cycle dictates to a large degree which roles will need to be reallocated when a spouse is hospitalized or dies of cancer. This is because family life cycle stages reflect the particular developmental tasks facing the family and the resources available to meet them. The influence of this factor is illustrated by the following examples: The death of an elderly retired man whose adult children have long established homes in other communities, as compared to the death of a young father whose children are in grade school and whose wife has never worked outside the home. These deaths will cause very different changes in their respective family systems, primarily because of the different life situations and developmental tasks facing their families. Because of the important differences between families in which children are physically present and those in which they are not, the children-present and children-absent stages will be considered separately.

Children Absent Stages. The stages of the family life cycle in which there are not children present may be least difficult for the healthy spouse in terms of role reallocation (the terms healthy spouse and surviving spouse as used in this section are somewhat interchangeable, as the framework is applicable to both chronic and terminal illness). Prior to the arrival of offspring, there are not child-related roles competing for time and energy with the potential provider role of the wife. Since she is not bound by the demands of child-rearing, she has more mobility to pursue a job.
Similarly a widowed husband will not have the child related demands to compound the additional household tasks he may need to assume. Although both the male and female survivor faces the potentially difficult loss of reciprocal roles (e.g. the therapeutic, sexual and recreational roles), it may be somewhat easier at this stage to return to a life style similar to that which the widow(er) led prior to marriage.

A similar type of role reallocation is necessary for the remaining spouse after the offspring have reached adulthood and established their own homes. However, at this point economic problems are common. The economic circumstances of the elderly in this country are generally below average (Nye & Berardo, 1973). Total assets and life insurance payments are often inadequate to support the widow, whose income, if any, is unlikely to provide an adequate supplement (Friedman & Sjogren, 1981). As Nye and Berardo point out,

"...The obstacles to securing employment at this stage of the life cycle are often rather difficult to overcome. Typically, these wives have been absent from the labor market for several years and are, therefore, at a disadvantage with respect to the educational and occupational demands of the labor market. In addition, they frequently are confronted with a pervasive discrimination on the part of employers who are not in favor of hiring older persons, let alone older women. In spite of these handicaps, many older surviving wives do manage to become a part of the labor force. Like their younger counterparts, however, they are heavily concentrated in the low paying jobs." (Nye and Berardo, 1973, p. 619).

Children Present Stages. The most difficult stage for the reallocation of roles is that in which there are preschool
children. At the preschool stage a surviving parent is often hard pressed to assume roles in addition to the child care and socialization, housekeeper and provider roles.

As noted above, various roles are more or less important in various stages of the family career (see Figure 1). Specifically, the child socialization role becomes less a primary function of the parents and more that of the school and peers as the child gets older. The demands of the child socialization and child care roles should decrease with each successive stage of the family life cycle.

Many of the problems of role reallocation, especially in families where the children cannot effectively adopt a portion of the vacated roles, stem from the overloaded role cluster which the healthy spouse attempts to assume. In such situations, this spouse may not be capable of performing all of the role adequately, to the detriment of some aspect of the family system. For example, if the widow is forced to adopt the provider role, she may no longer be able to supervise and control her children as the child care and socialization roles demand.

Previous Patterns of Role Assignment. A factor strongly influencing the family's role reallocation will be the process by which roles had been assigned prior to the illness. Returning to the distinction between position and person oriented families, these two types of families may be expected to engage in different processes of role reallocation. Specifically, person oriented families will have an established process for reallocating roles to
best fit available family resources, while position oriented families do not have an established process, relying instead on cultural norms. Because of the lack of cultural norms for role assignments in the case of chronic or terminal illness, position oriented families may experience significantly more difficulty in role reallocation.

**Affection Patterns.** Another aspect of the family system affecting readjustment is the affection structure. Elliot (1948) notes that if the emotional attachment of the family has been centered on the patient, the absence of this common focus may hinder readjustment and even contribute to the dissolution of the family system. If, on the other hand, the deceased was not an integral part of the affection structure, the role reallocation process may be less stressful. As noted earlier, cancer patients and their spouses often have increased affectional needs. Families with rigid or inadequate affection patterns may be unable to meet these needs and therefore may be subjected to greater system disruption.

**Power Structure.** Another aspect of the family system which affects and is affected by the system's recovery from bereavement is the power structure. In child present stages, the mother often becomes the new head of the power structure in the case of the death of the husband. Many mothers feel that they must firmly establish themselves in this authority role least the children become unruly and unmanageable. This is often a valid concern, for there is a tendency among older children to see themselves as having increased power in the family in their father's absence (Glick, et. al.,
1974). Children, especially boys, may perceive themselves as succeeding the father in the power structure of the family (Pincus, 1974; Silverman & Englander, 1975).

Even if the mother was the actual disciplinarian prior to the father's illness, the threat of his physical intervention may have backed up the mother's directives. Without such support, the widow's authority may be undermined. Further, if wives turn to their children for the affection and emotional support they previously received from their husband, to some degree recreating the reciprocal roles the husband and wife once shared, the widow's ability to demand obedience from her older children may diminish. This often results in widowed families with a weakened basis of authority for the widow but more emotional closeness to the children (Glick, et. al., 1974).

Pincus proposes that while the loss of a spouse rouses the need to regress, the loss of a parent rouses the need to progress, to mature, and to be potent. In fact sons are often expressly told that they are expected to take their father's place, to become "the man of the house"; in cases where the child is capable, this assumption of responsibility may prove helpful. If the child is not capable, such as when the child's age or status in the family are inappropriate to the role, not only will the roles be inadequately performed, but the children themselves may suffer. Emotional withdrawal may become an indication that the child is assuming more responsibility than is appropriate for his/her developmental level (Silverman & Englander, 1975). Gregory (1965)
suggests that the high incidence of high school drop-outs in his sample of children who lost a parent by death may be due to these students being expected to assume the wage-earning and home-making roles of the deceased parent.

A final consideration concerning the power structure revolves around the relative power shared between the husband and wife, and returns to the discussion of the stage of the family life cycle. Blood and Wolfe (1960) found that the husband's power was greatest in the preschool stage in that the wife was most dependent upon him during this period. Therefore, the wife's transition to the head of the family's power structure may be most difficult at this time because it requires a more dramatic shift from dependence to independence. This presents another factor which may contribute to the difficulties of role reallocation at the preschool stage discussed earlier.

Age, Type of Death, and Subsequent Recovery

The literature suggests that an important factor in terms of subsequent family reorganization is the nature of the death which occurs. A common distinction is between expected and unexpected death. This distinction singles out the function of anticipatory grief in the course of eventual recovery (Lindeman, 1944; Kastenbaum, 1977; Fulton, 1971; Parkes, 1975; Carey, 1979; Ball, 1977; Mathison, 1970; Sander, 1980; Troup & Greene, 1974).

Typically the term refers to the capacity to experience grief and come to terms with loss before it actually occurs. Some authors speculate that a good deal of the grief process can be completed by
the time death occurs, resulting in a much less intense reaction to the death than would ordinarily be expected (Fulton & Fulton, 1971).

Others hold a different view. Kastenbaum (1977) observed that "...the early introduction into the grief process (anticipatory grief) did not seem to reduce the impact of the actual death" (p. 246). Instead, he argued, the difference in expected versus unexpected death became evident following the initial impact:

The women who had lived with an awareness of impending bereavement seemed more able to pull themselves together and regain a relatively normal level of functioning. One could not pay the emotional suffering in advance, then, in return for an easier time at the moment of impact. Yet the opportunity to live with the idea of eventual bereavement seemed to help the widow make quicker and more adequate use of her recuperative resources. (p. 246).

His position argues that anticipatory grief does not actually soften the initial impact of death, but does aid the survivor in drawing upon her recuperative resources, which may in turn make for a less stressful process of family reorganization.

Ball (1977) found at 6 to 9 months after the death of a spouse that age was a significant variable in the measurement of overall grief. Younger widows (46 and under) were more severely affected than older widows, showing a more intense grief reaction. Further, it appears that after the age of 45, anticipation is not a mitigating factor because grief past this age is less severe regardless of the type of death.

A recent study by Sanders (1980) may indicate that the pattern described by Ball is short term in nature, and that from a more
longitudinal perspective the trend may in fact reverse. Sanders found that younger widows manifested a greater intensity of grief initially, but at 18 months a reverse trend was noted, whereby older spouses showed a greater grief reaction.

The importance of the intensity of the widow's grief as a factor in the degree of disruption of the family system lies in the assumption that an extended, intense grief reaction will interfere with the effective reorganization of the family role structure, especially since the surviving spouse will be the key figure in this process. Accepting this assumption, widows of anticipated deaths, if they do in fact show quicker and more adequate personal recovery, will also accomplish more effective family reorganization.

Summary

Several factors have been reviewed with affect the reorganization of the family system following the chronic or terminal illness of a parent. These include the stage of the family life cycle, the roles of the patient, the opportunity for anticipatory grief, and whether the family is position or person oriented. These factors appear to play an important part in the reorganization process and the attainment of optimal role reallocation. Specifically, a person oriented family, with open communication, and experience in the role making process, may more adequately adapt to member loss.
<table>
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<tr>
<th>Stage of the Family Life Cycle</th>
<th>Stage-Critical Family Developmental Tasks</th>
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<td>Married Couple</td>
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<tr>
<td>Childbearing</td>
<td>Having, adjusting to, &amp; encouraging the development of infants Establishing a satisfying home for both parents &amp; infant(s)</td>
<td></td>
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<tr>
<td>Preschool-age</td>
<td>Adapting to the critical needs &amp; interests of preschool children in stimulating, growth-promoting ways Coping with energy depletion &amp; lack of privacy as parents</td>
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<td>Aging Family Members</td>
<td>Coping with bereavement &amp; living alone Closing family home or adapting it to aging Adjusting to retirement</td>
<td></td>
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Figure 1. Developmental Role Analysis of the Nuclear Family System.

*Adapted from works of Nye (1976) and Duvall (1977).

*P = Provider; H = Housekeeper; T = Therapeutic; R = Recreation; S = Sexual; K = Kinship; CC = Child Care; CS = Child Socialization.

Width of band indicates relative importance of the role within a given stage.
Figure 2. Flow Chart of Role Reallocation.
Statement of Hypotheses

The conceptual framework outlined above allows for the formulation of specific hypotheses about family adjustment to cancer in a parent from a longitudinal perspective.

Time One. At the initial data collection point the following hypotheses are tested:

Hypothesis 1. Families at different stages of the family life cycle will engage in different patterns of role reallocation due to differences in family resources.

Hypothesis 2. Because of limitations in nuclear family resources, families in which children are schoolage and younger will be characterized by less adequate role enactment, greater role conflict and role strain, (i.e., the worry or guilt one has regarding role enactment) and a less cohesive, more conflictual family environment.

Hypothesis 3. Higher levels of communication between spouses will result in more adequate role enactment, less role conflict and role strain, and a more cohesive, less conflictual family environment.

Hypothesis 4. Families employing ascribed roles prior to the onset of cancer will report more adequate role enactment, less role conflict and role strain, and a more cohesive, less conflictual family environment.

Hypothesis 5. The pattern of role reallocation a family employs will influence the adequacy of role enactment, the amount of role strain and role conflict, and the overall level of family cohesion and family conflict. Specifically, families which inequitably redistribute roles will report less role competency, greater role strain and role conflict, and a less cohesive, more conflictual family environment.

Time Two. At the first follow-up, five months after the initial assessment, the following hypotheses are tested.
Hypothesis 6. Families in the earliest stage of the family life cycle will show the following changes over time to a greater extent than families with older children:
   a) decreased role competency
   b) decrease family cohesion
   c) increased family conflict
   d) increased role strain
   e) increased role conflict

Hypothesis 7. Families with lower levels of communication at the initial (time one) assessment will report lower cohesion and role competency and higher family conflict, role strain and role conflict at the five month follow-up (time two) than those with higher levels of communication at time one.

Hypothesis 8. Families employing ascribed roles will show the following changes over time to a greater extent than families employing achieved roles:
   a) decreased role competency
   b) decreased family cohesion
   c) increased family conflict
   d) increased role strain
   e) increased role conflict

Hypothesis 9. Families experiencing more frequent and/or more lengthy hospitalization will show the following changes over time than those experiencing fewer, shorter hospitalizations:
   a) decreased role competency
   b) decreased family cohesion
   c) increased family conflict
   d) increased role strain
   e) increased role conflict

Hypothesis 10. Families adopting a role reallocation pattern which overloads the healthy spouse will show the following changes over time to a greater extent than families reallocating roles to others inside or outside the nuclear family:
   a) decreased role competency
   b) decreased family cohesion
   c) increased family conflict
   d) increased role strain
   e) increased role conflict

Time 3. The same set of hypotheses tested at time two will be tested at the second follow-up, one year after the initial
In addition to testing the above hypotheses, an attempt was made to collect data of a qualitative nature about families coping with the effects of cancer in a parent. Thus the present study attempts to gain the advantages of a "convergent" methodology as described by Neimeyer and Resnikoff (1982). Convergent methodology refers to the use of different research methods to approach the same topic. It has been argued that the convergence or agreement of results from different methods enhances the validity of a study's results (Campbell & Fisk, 1959; Bouchard, 1976).

Qualitative data is often useful in its own right, especially in the early stages of investigation in a particular area (see Appendix A). With this in mind, qualitative data are employed in an attempt to characterize the experiences of cancer stricken families. When combined with the use quantitative data, a form of "methodological triangulation" emerges (Neimeyer and Resnikoff, 1982). Besides offering a potentially greater breadth and depth of understanding of the events under consideration, similar findings from dissimilar methods provide a degree of validity unattainable by the use of either method alone (Webb, et. al., 1966). It is hoped that this complex and multifaceted convergent methodology will provide a richer understanding of a complex and multifaceted human experience, the effect of a chronic and terminal illness on the family.
METHOD

Subjects. All patients admitted to the oncology service at the Ohio State University Hospital during the months of December, 1982 through October, 1983 who met the following eligibility requirements were approached as potential subjects:

1) a primary diagnosis of cancer
2) children under the age of 20 living in the parental home
3) a spouse willing to participate in the project
4) permission of the attending physician to include the patient in the study.

A total of 81 patients were initially approached and told that longitudinal research of cancer patients and their families was being conducted. The nature of the study was explained to them, including the necessity of data collection for a period of one year. Of the 81 patients approached, 5 refused, 1 consented but died prior to data collection, and 9 consented but were discharged before data could be collected and did not respond to follow-through contacts. Of the 66 remaining subjects, 12 completed only part of the data collection process before they were either discharged or died. This left a sample of 30 female and 24 male patients in 54 families upon which complete initial (hereafter referred to as time one) data was obtained. All 54 patients had been hospitalized for cancer on at least the current occasion for a
period of at least one week.

Five months after each couple's initial assessment, follow-up instruments were mailed to their homes. Nine patients had died within this five month period. Of the 45 survivors, 29 couples (17 female and 12 male patients) responded, representing a response rate of 64.4% of the available sample, and 54% of the total initial sample.

By June, 1984, one year had elapsed since the initial data collection for 34 couples. Of these, 14 patients had died, one had divorced and one refused to continue at time two. The remaining 18 were sent one year follow-up material. Nine responded, representing 50% of the available sample.

A total of 16 families had patients die during the course of the study. Three months after the patient's death, surviving spouses were sent a letter requesting their participation in post-bereavement data collection. Eight spouses consented to provide post-bereavement data about their experiences, representing 50% of the available sample.

**Instruments.** Each patient and spouse individually completed the following instruments at the initial, 4 month and one year assessments:

A) Washington Family Role Inventory (WFRI).

The WFRI (Nye & Gecas, 1976) is composed of 42 questions regarding the role expectations, role enactment, role competence, role strain, and role conflict within the nuclear family. For most items, the respondent indicates which of a
set of choices best describes their family situation. Subscale scores derived from this instrument and their definition were as follows:

1) **Role competence:** an evaluation of the adequacy of the role performance of each spouse. This factor was calculated in two different ways:

   a) Husband's (hereafter HTRCA) and Wife's (WTRCA) total role competency average—to derive a general measure of the husband's/wife's role competency across all the roles measured by the WRFI, the sum of the husband's/wife's rating by both spouses was divided by the total number of roles available, regardless of the number specifically enacted by the husband.

   b) Husband's (hereafter HERCA) and Wife's (WERCA) enacted role competency average—to derive a measure of the husband's/wife's competency on only those roles which he/she and the spouse indicate that he/she specifically enacts, the sum of the husband's/wife's role competency ratings by both spouses was divided by the number of roles indicated as actually enacted by the husband/wife.

2. **Role conflict:** a measure of the amount of disagreement or conflict between spouses as to how roles
should be enacted.

3. **Role Strain**: a measure of the amount of worry or guilt an individual reports regarding his or her role performance.

B. Marital Communication Inventory (MCI).

The MCI (Bienvenu, 1979) is composed of 36 items describing interactions between spouses using a 4 point rating scale. Husbands and wives individually indicate the degree to which each item characterizes their communication.

C. Family Environment Scale (FES).

The FES (Moos, 1974) is composed of 90 true/false items which assess the social climate of families. It focuses on the measurement and description of the interpersonal relationships among family members, and the basic organizational structure of the family. The FES has a total of 10 subscales. Those of most immediate significance for the current study are those measuring family cohesion (FESC) and family conflict (FESCON).

D. Initial Interview Data.

When circumstances allowed, an audio-taped, semi-structured interview was conducted with both patients and spouses individually to assess:

1. the process of role assignment the family employed
2. the nature of the communication directly related to the illness
3. the reaction of the children
4. major stressors
5. major sources of aid and support.

Demographic information was also gathered. Interviews were
completed with both spouses in 26 families, with one spouse in 23, and were not obtained with either spouse in the remaining 5. Typical interfering circumstances included early discharge, the unavailability of an out-of-town spouse, or physical inability to complete an interview because of disease and/or treatment.

E. Time One Classifications.

The following classifications were made on the basis of interview data obtained at the time of the initial assessment:

1. **Family Life Cycle Stage Classifications.**

   Families were classified into one of three family life cycle stages based on the ages of children. If all children were 12 years of age or younger, the family was included in the Schoolage and Younger stage. Families with children ages 12 to 20 and children under 12 were included in the Adolescent and Younger stage. Finally, if all children were over 12 years of age, the family was included in the Adolescent and Older stage.

2. **Role Reallocation Patterns.**

   a) Nuclear Redistribution—Spouses indicated that role reallocation took place entirely within the nuclear family, with the healthy spouse and children assuming new roles.
b) External Redistribution—Spouses indicated that role reallocation involved others outside the nuclear family, such as a spouse's parents and siblings, neighbors, and hired housekeepers.

c) Overload Redistribution—Spouses indicated that the bulk of role reallocation fell to the healthy spouse with little or no involvement of others either within or outside the nuclear family.

Seven families retained their premorbid role enactment patterns. These families were therefore not included in the following analyses which were intended to test hypotheses concerning role reallocation.

3. Previous Role Assignment Method.

Families were classified into one of two role assignment methods on the basis of their description of the process they used to assign roles within the family.

a) Achieved roles—couples indicated that roles were assigned according to the individual preferences and abilities of family members.

b) Ascribed roles—couples indicated that roles were assigned according to preexisting expectations the couple brought into their marriage, most often in accordance to cultural sex roles.
F. Hospital Records.

Each patient's hospital charts were examined to determine the number and length of hospitalizations occurring between time one, time two and time three assessments.

Post-Death Instruments.

Surviving spouses of patients who died were sent the following instruments:

A. Beck Depression Inventory (BDI)

The BDI is composed of 21 items regarding symptoms associated with depression. Respondents indicated on a four point scale items reflecting their feelings and behavior of the past week. A total score based on the summation of all items provides a measure of the current level of depression.

B. Modified Washington Family Role Inventory (Appendix B)

The Washington Family Role Inventory was modified to eliminate questions pertaining to husband-wife interactions. Use of this instrument provided measures of role strain and role conflict comparable to the measures derived from the original instrument.

C. Family Environment Scale (described above)

Post-Bereavement Interview Data

When circumstances allowed, an audio taped, semi-structured interview was conducted with the spouse following the death of the patient. These interviews attempted to assess:
1) the sequential experience of the family through the illness and bereavement
2) periods of particular difficulty
3) helpful activities by various groups of people
4) unhelpful activities by various groups of people
5) reactions of children.

Interviews were obtained from four of the eight responding spouses.
RESULTS

To determine whether it was valid to assume that families could accurately be characterized by considering the combined responses of husbands and wives, correlations were obtained between husbands' and wives' scores on all variables under consideration. All correlations were statistically significant. To further test this assumption, each hypothesis was tested using husbands' and wives' scores separately. These analyses yielded results that were in every case similar to the combined analyses. Thus it was concluded that the combined scores accurately reflect the characteristics of the families under examination, and it is these which are presented below.

Test of Hypotheses - Time One

Hypothesis 1. Families at different stages of the family life cycle will engage in different patterns of role reallocation.

To test this hypothesis, a chi square test was conducted using stage of family life cycle and time one role enactment pattern as the classificatory variables. The significant (p < .0001) chi square which resulted (see Table 1), suggested that Stage 1 families tend to engage in either external redistribution or overload patterns while Stage 2 and 3 families tend to engage in
Table 1
Comparison of Role Redistribution Patterns Among Family Life Cycle Stages at Time One

<table>
<thead>
<tr>
<th></th>
<th>Number (and Percentage) of Families Within a Particular Stage</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>External Redistribution</td>
</tr>
<tr>
<td>Schoolage children</td>
<td>7 (50%)</td>
</tr>
<tr>
<td>and younger</td>
<td></td>
</tr>
<tr>
<td>Adolescents and</td>
<td>7 (43.8%)</td>
</tr>
<tr>
<td>younger</td>
<td></td>
</tr>
<tr>
<td>Adolescents and</td>
<td>2 (16%)</td>
</tr>
<tr>
<td>older</td>
<td></td>
</tr>
<tr>
<td>Chi Square:</td>
<td>31.27</td>
</tr>
<tr>
<td>Significance:</td>
<td>$p &lt; .0001$</td>
</tr>
</tbody>
</table>
nuclear redistribution. These results indicate that there is a significant relationship between stage of family life cycle and pattern of role reallocation.

Hypothesis 2. Because of limitations in nuclear family resources, it is hypothesized that families in which children are schoolage and younger will be characterized by less adequate role enactment, greater role conflict and role strain, (i.e., the worry or guilt one feels regarding role enactment), and a less cohesive, more conflictual family environment.

Scores on dependent variables were placed into high and low categories, using the overall sample mean as the dividing point. A chi square test was used to assess whether there were differences related to a family's stage in the family life cycle. These results are graphically displayed in Figure 3. It can be seen that the first stage of the family life cycle was somewhat less cohesive and had higher role conflict in relation to the other two stages, and that the second stage had a significantly more conflictual family environment ($X^2 = 13.8, p < .001$). The clearest pattern to emerge from this series of comparisons is that the third stage of the family life cycle, in which all children are in adolescence or older, shows the least disrupted functioning. Families in this stage reported relatively greater family cohesion, less family conflict, less role conflict and role strain than their younger family counterparts. Thus, although the hypothesized pattern of differences among different stages of the family life cycle were not observed, there does seem to be support for the more general hypothesis that stage of family life cycle effects family
Figure 3. Dependent Measures in Low and High Groups Across Family Life Cycle Stages at Time One.
functioning.

**Hypothesis 3.** Higher levels of communication between spouses will result in more adequate role enactment, less role conflict and role strain, and a more cohesive, less conflictual family environment.

To test this hypothesis, Spearman rank order correlations were conducted between scores on the Marital Communication Inventory and scores on the husband's total role competency average, wife's total role competency average, husband's enacted role competency average, wife's enacted role competency average, role conflict, role strain, family conflict and family cohesion. As Table 2 shows all correlations were significant and in the predicted directions.

**Hypothesis 4.** Families employing achieved as opposed to ascribed roles prior to the onset of cancer will report more adequate role enactment, less role conflict and role strain, and a more cohesive, less conflictual family environment.

The mean of each dependent variable for subjects in the two role assignment method categories are presented in Table 3. To test this hypothesis a Mann-Whitney U test was conducted on the dependent variables. There were statistically significant differences in the predicted direction on family cohesion ($p < .04$), wife's total role competency average ($p < .03$), and husband's enacted role competency average ($p < .02$), while the husband's total role competency average approached significance ($p < .07$). While the remaining differences were not statistically significant, they were all in the predicted direction. These results suggest
Table 2
Spearman Rank Order Correlations of Dependent Measures with Marital Communication Scores at Time One

<table>
<thead>
<tr>
<th>Dependent Variable</th>
<th>r&lt;sup&gt;a&lt;/sup&gt;</th>
<th>p&lt;sup&gt;b&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Cohesion&lt;sup&gt;b&lt;/sup&gt;</td>
<td>0.457</td>
<td>.001</td>
</tr>
<tr>
<td>Family Conflict</td>
<td>-0.517</td>
<td>.001</td>
</tr>
<tr>
<td>Role Conflict</td>
<td>-0.512</td>
<td>.001</td>
</tr>
<tr>
<td>Role Strain</td>
<td>-0.214</td>
<td>.013</td>
</tr>
<tr>
<td>Wife's Total Role Competency Average</td>
<td>0.241</td>
<td>.040</td>
</tr>
<tr>
<td>Husband's Total Role Competency Average</td>
<td>0.481</td>
<td>.001</td>
</tr>
<tr>
<td>Wife's Enacted Role Competency Average</td>
<td>0.293</td>
<td>.016</td>
</tr>
<tr>
<td>Husband's Enacted Role Competency Average</td>
<td>0.376</td>
<td>.003</td>
</tr>
</tbody>
</table>

<sup>a</sup>Higher marital communication score indicates better communication between spouses.

<sup>b</sup>Higher scores indicate a higher degree of the particular characteristic for all variables.
Table 3
Means of Dependent Measures by Role Assignment Method
at Time One

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean of Families in:</th>
<th>Achieved Roles</th>
<th>Ascribed Roles</th>
<th>P Value on Mann-Whitney Analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Cohesion&lt;sup&gt;a&lt;/sup&gt;</td>
<td></td>
<td>7.97</td>
<td>7.23</td>
<td>0.037</td>
</tr>
<tr>
<td>Family Conflict</td>
<td></td>
<td>2.11</td>
<td>2.68</td>
<td>0.192</td>
</tr>
<tr>
<td>Role Conflict</td>
<td></td>
<td>16.60</td>
<td>17.38</td>
<td>0.529</td>
</tr>
<tr>
<td>Role Strain</td>
<td></td>
<td>11.37</td>
<td>11.55</td>
<td>0.853</td>
</tr>
<tr>
<td>Wife's Total Role Competency Average</td>
<td></td>
<td>3.93</td>
<td>3.26</td>
<td>0.027</td>
</tr>
<tr>
<td>Husband's Total Role Competency Average</td>
<td></td>
<td>3.84</td>
<td>3.49</td>
<td>0.069</td>
</tr>
<tr>
<td>Wife's Enacted Role Competency Average</td>
<td></td>
<td>4.18</td>
<td>3.89</td>
<td>0.123</td>
</tr>
<tr>
<td>Husband's Enacted Role Competency Average</td>
<td></td>
<td>4.02</td>
<td>3.73</td>
<td>0.016</td>
</tr>
</tbody>
</table>

<sup>a</sup>Higher scores indicate a higher degree of the particular characteristic for all variables.
that in those families which assigned roles on the basis of competency rather than sex, there appears to be more competently enacted roles and more family cohesion.

In a post hoc comparison to determine whether the method of role assignment influenced the pattern of role reallocation a family employed, a chi square was conducted between method of role assignment and role redistribution enactment pattern. These results are presented in Table 4. As can be seen, there was a tendency among families using ascribed roles to adopt an overloaded pattern (24.0% of ascribed role families vs 14.8% of achieved role families), while achieved role families were more likely to engage in external redistribution (51.9% of achieved role vs 36.0% of ascribed role families).

Hypothesis 5. The pattern of role allocation a family employs will influence the adequacy of role enactment, the amount of role strain and role conflict, and the overall level of family cohesion and family conflict. Specifically, families which inequitably redistribute roles will report less role competency, greater role strain and role conflict, and a less cohesive, more conflictual family environment.

The means of each dependent measure for the three role redistribution patterns are presented in Table 5. To test the hypothesis, a Kruskal-Wallis one-way analysis of variance was conducted on the dependent measures using role redistribution classifications as the independent variable. No significant differences were found.
Table 4

Comparison of Role Redistribution Patterns
Between Role Assignment Methods at Time One

<table>
<thead>
<tr>
<th>Number (and Percentage) of Families Within a Particular Stage</th>
<th>External Redistribution</th>
<th>Nuclear Redistribution</th>
<th>Overload Redistribution</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Achieved Roles</td>
<td>7</td>
<td>5</td>
<td>2</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>(51.9%)</td>
<td>(33.3%)</td>
<td>(14.8%)</td>
<td></td>
</tr>
<tr>
<td>Ascribed Roles</td>
<td>9</td>
<td>10</td>
<td>6</td>
<td>25</td>
</tr>
<tr>
<td></td>
<td>(36%)</td>
<td>(40%)</td>
<td>(24%)</td>
<td></td>
</tr>
<tr>
<td>Chi Square:</td>
<td>1.98</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Significance:</td>
<td>p = .37</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 5
Means of Dependent Measures Within Each Role
Redistribution Pattern at Time One

<table>
<thead>
<tr>
<th></th>
<th>External Role Reallocation</th>
<th>Nuclear Role Reallocation</th>
<th>Overload Role Reallocation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Cohesion*</td>
<td>7.79</td>
<td>7.52</td>
<td>6.77</td>
</tr>
<tr>
<td>Family Conflict</td>
<td>2.36</td>
<td>2.65</td>
<td>3.09</td>
</tr>
<tr>
<td>Role Conflict</td>
<td>16.89</td>
<td>17.55</td>
<td>18.91</td>
</tr>
<tr>
<td>Role Strain</td>
<td>11.46</td>
<td>11.45</td>
<td>13.32</td>
</tr>
<tr>
<td>Wife's Total Role Competency Average</td>
<td>3.71</td>
<td>3.34</td>
<td>3.57</td>
</tr>
<tr>
<td>Husband's Total Role Competency Average</td>
<td>3.78</td>
<td>3.60</td>
<td>3.46</td>
</tr>
<tr>
<td>Wife's Enacted Role Competency Average</td>
<td>4.21</td>
<td>4.04</td>
<td>3.76</td>
</tr>
<tr>
<td>Husband's Enacted Role Competency Average</td>
<td>4.01</td>
<td>3.74</td>
<td>3.71</td>
</tr>
</tbody>
</table>

*Higher scores indicate a higher degree of the particular characteristic for all variables.
Time Two

A major goal at this stage of the research was to assess possible changes in the relative condition of families characterized by differences on certain theoretically important variables. To assess the hypothesized differences among families, comparisons were made among families on data collected at two separate points in time, at the initial assessment and at the five month follow-up. Nonparametric statistical procedures were used because of the value range and the non-interval nature of the dependent measures.

To assess potential differences between the entire time one sample and those responding at time two, a Kruskal-Wallis analysis of variance was conducted on the time one dependent measures using response status at time two as the independent variable. Subjects were divided into those responding at time two, those choosing not to respond and those who had died prior to the time two assessment. Results of this analysis are presented in Table 6. It can be seen that there were a number of significant differences between those responding at time two and those who either died or chose not to respond. Thus the sample of time two respondents is not representative of the entire time one sample, showing instead significantly higher levels of communication and family cohesion and significantly lower family conflict, role strain and role conflict. Subsequent analyses of the following data must be interpreted in light of these differences.
<table>
<thead>
<tr>
<th></th>
<th>Respondents (N=29)</th>
<th>Nonrespondents (N=16)</th>
<th>Deceased (N=9)</th>
<th>X</th>
<th>SD</th>
<th>X</th>
<th>SD</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marital Communication</td>
<td>99.7 (18.0)</td>
<td>96.1 (21.5)</td>
<td>87.2 (21.8)</td>
<td>.10</td>
<td></td>
<td>.009</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family Cohesion*</td>
<td>1.8 (1.1)</td>
<td>3.2 (2.5)</td>
<td>4.1 (1.8)</td>
<td>.000</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family Conflict</td>
<td>10.8 (4.8)</td>
<td>13.9 (4.1)</td>
<td>12.9 (4.8)</td>
<td>.016</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Role Conflict</td>
<td>16.7 (7.4)</td>
<td>20.2 (8.2)</td>
<td>17.8 (9.8)</td>
<td>.07</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Role Competency</td>
<td>28.3 (7.0)</td>
<td>27.9 (7.5)</td>
<td>24.5 (8.0)</td>
<td>.17</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Husband Role Competency</td>
<td>26.8 (9.9)</td>
<td>23.4 (13.9)</td>
<td>24.6 (8.1)</td>
<td>.38</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Higher scores indicate a higher degree of the particular characteristic for all variables.
Test of Hypotheses - Time Two

Hypothesis 6. Families in the earliest stage of the family life cycle will show the following changes over time to a greater extent than families with older children:
   a) decreased role competency
   b) decreased family cohesion
   c) increase family conflict
   d) increased role strain
   e) increased role conflict

To test the hypothesis that families at the earliest stage of the family life cycle would report the most disruption, the scores of subjects in the three classifications were compared separately at times one and two by means of a Kruskal-Wallis analysis of variance. These comparisons are presented in Table 7. At the initial data collection point, there were no differences on these measures between families at different life cycle stages. By time two, however, stage 3 (adolescent and older children) families reported significantly lower conflict than younger families. Other dependent measures show a similar pattern, whereby stage 3 families report less role strain and role conflict across time than families with younger children.

Hypothesis 7. Families with lower levels of communication at the initial (time one) assessment will report lower cohesion and role competency and higher family conflict, role strain and role conflict at the five month follow-up (time two) than those with higher levels of communication at time one.

To test the effect of pre-existing levels of communication on families' subsequent role functioning and psychosocial environment, the time one communication scores were entered into a correlational
Table 7
Means and Kruskal Wallis Analysis of Variance at Time One and Time Two
by Stage of Family Life Cycle

<table>
<thead>
<tr>
<th>Family Life Cycle Stage</th>
<th>1&lt;sup&gt;a&lt;/sup&gt;</th>
<th>2</th>
<th>3</th>
<th>p=</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>p=</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Cohesion&lt;sup&gt;b&lt;/sup&gt;</td>
<td>7.6</td>
<td>8.1</td>
<td>7.8</td>
<td>NS</td>
<td>7.7</td>
<td>7.6</td>
<td>7.4</td>
<td>NS</td>
</tr>
<tr>
<td>Family Conflict</td>
<td>2.3</td>
<td>2.1</td>
<td>1.4</td>
<td>NS</td>
<td>2.5</td>
<td>2.3</td>
<td>0.8</td>
<td>.01</td>
</tr>
<tr>
<td>Role Strain</td>
<td>11.4</td>
<td>10.2</td>
<td>11.3</td>
<td>NS</td>
<td>10.8</td>
<td>10.9</td>
<td>10.3</td>
<td>NS</td>
</tr>
<tr>
<td>Role Conflict</td>
<td>18.4</td>
<td>16.5</td>
<td>15.4</td>
<td>NS</td>
<td>16.7</td>
<td>15.8</td>
<td>15.4</td>
<td>NS</td>
</tr>
<tr>
<td>Husband Role Competency</td>
<td>25.5</td>
<td>29.6</td>
<td>30.7</td>
<td>.07</td>
<td>25.6</td>
<td>27.6</td>
<td>27.8</td>
<td>NS</td>
</tr>
<tr>
<td>Wife Role Competency</td>
<td>27.1</td>
<td>27.3</td>
<td>24.5</td>
<td>NS</td>
<td>30.0</td>
<td>28.1</td>
<td>23.5</td>
<td>NS</td>
</tr>
<tr>
<td>Marital Communication</td>
<td>96.2</td>
<td>103.1</td>
<td>101.2</td>
<td>NS</td>
<td>96.3</td>
<td>100.7</td>
<td>103.1</td>
<td>NS</td>
</tr>
</tbody>
</table>

<sup>a</sup>1 = Schoolage and younger; 2 = Adolescents and younger; 3 = Adolescents and older.

<sup>b</sup>Higher scores indicate a higher degree of the particular characteristic for all variables.
analysis with time two scores on the dependent measures. These correlations are presented in Table 8. With the exception of role strain and wives' role competency, all correlations were significant in the predicted direction.

As a post hoc analysis of the effect of current level of communication on the dependent measures, subjects' communication scores obtained at time two were correlated with the time two dependent measures. These correlations, presented in Table 9, indicate that current level of communication is even more strongly associated with the family's role functioning and psychosocial environment.

Hypothesis 8. Families employing ascribed roles will show the following changes over time to a greater extent than families employing achieved roles:
   a) decreased role competency
   b) decreased family cohesion
   c) increased family conflict
   d) increased role strain
   e) increased role conflict

To test the hypothesis that families who assign roles on the basis of cultural norms will report more disruption, the scores of subjects in the two classifications were compared at time one and then at time two by means of a Kruskal-Wallis analysis of variance. These comparisons are presented in Table 10. Although there were no significant differences in any of the dependent measures at time one, there were a number of effects four months later. Families using achieved roles showed more cohesion and role competency and less family conflict, role strain and role conflict by time two. In contrast to the virtually identical levels of communication
Table 8
Correlations Between Previous (Time One) Communication Scores and Current (Time Two) Dependent Measures

<table>
<thead>
<tr>
<th>Dependent Variable</th>
<th>r</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Cohesion</td>
<td>.25</td>
<td>.01</td>
</tr>
<tr>
<td>Family Conflict</td>
<td>-.32</td>
<td>.01</td>
</tr>
<tr>
<td>Role Strain</td>
<td>.08</td>
<td>NS</td>
</tr>
<tr>
<td>Role Conflict</td>
<td>-.32</td>
<td>.01</td>
</tr>
<tr>
<td>Husband's Role Competency</td>
<td>.34</td>
<td>.01</td>
</tr>
<tr>
<td>Wife's Role Competency</td>
<td>.13</td>
<td>NS</td>
</tr>
</tbody>
</table>
Table 9
Correlations Between Current (Time Two) Communication Scores and Current Dependent Variables

<table>
<thead>
<tr>
<th>Dependent Variable</th>
<th>r</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Cohesion</td>
<td>.55</td>
<td>.001</td>
</tr>
<tr>
<td>Family Conflict</td>
<td>-.49</td>
<td>.001</td>
</tr>
<tr>
<td>Role Strain</td>
<td>-.12</td>
<td>NS</td>
</tr>
<tr>
<td>Role Conflict</td>
<td>-.40</td>
<td>.002</td>
</tr>
<tr>
<td>Husband's Role Competency</td>
<td>.39</td>
<td>.002</td>
</tr>
<tr>
<td>Wife's Role Competency</td>
<td>.32</td>
<td>.01</td>
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</table>
Table 10
Means and Mann-Whitney U Test Results at Time One and Time Two by Role Assessment Method

<table>
<thead>
<tr>
<th></th>
<th>Achieved Roles</th>
<th>Ascribed Roles</th>
<th>p=</th>
<th>Achieved Roles</th>
<th>Ascribed Roles</th>
<th>p=</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Cohesion</td>
<td>8.1</td>
<td>7.5</td>
<td>NS</td>
<td>8.1</td>
<td>7.2</td>
<td>.10</td>
</tr>
<tr>
<td>Family Conflict</td>
<td>1.5</td>
<td>2.1</td>
<td>NS</td>
<td>1.0</td>
<td>2.3</td>
<td>.02</td>
</tr>
<tr>
<td>Role Strain</td>
<td>10.3</td>
<td>11.3</td>
<td>NS</td>
<td>9.6</td>
<td>11.8</td>
<td>.07</td>
</tr>
<tr>
<td>Role Conflict</td>
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<td>17.6</td>
<td>NS</td>
<td>15.0</td>
<td>16.0</td>
<td>NS</td>
</tr>
<tr>
<td>Husband Role Competency</td>
<td>30.1</td>
<td>26.9</td>
<td>NS</td>
<td>29.8</td>
<td>24.1</td>
<td>.02</td>
</tr>
<tr>
<td>Wife Role Competency</td>
<td>27.4</td>
<td>24.9</td>
<td>NS</td>
<td>29.0</td>
<td>25.2</td>
<td>NS</td>
</tr>
<tr>
<td>Marital Communication</td>
<td>100.0</td>
<td>100.1</td>
<td>NS</td>
<td>106.0</td>
<td>95.6</td>
<td>.03</td>
</tr>
</tbody>
</table>

*Higher scores indicate a higher degree of the particular characteristic for all variables.
reported at time one by both types of families, families using achieved roles also reported significantly higher communication at time two.

Hypothesis 9. Families experiencing more frequent and/or more lengthy hospitalization will show the following changes over time than those experiencing fewer, shorter hospitalizations:
   a) decreased role competency
   b) decreased family cohesion
   c) increased family conflict
   d) increased role strain
   e) increased role conflict

To test the hypothesis that families experiencing frequent and/or lengthy hospitalization will report more disruption, two variables representing hospitalization were entered into a correlational analysis with difference scores calculated for each dependent measure from time one to time two. The hospitalization variables were 1) number of hospitalizations between time one and time two, and 2) percent of days between time one and time two spent in the hospital. The first variable ranged from 0 to 12 hospitalizations and the second ranged from 0 to 51% of days spent in the hospital. Neither the correlational analysis nor visual inspection of scatterplots of the data yielded any discernable relationship between hospitalization and changes in the dependent measures.

Hypothesis 10. Families adopting a role reallocation pattern which overloads the healthy spouse will show the following changes over time to a greater extent than families reallocating roles to others inside or outside the nuclear family:
   a) decreased role competency
   b) decreased family cohesion
c) increased family conflict
d) increased role strain
e) increased role conflict

To test the hypothesis that the pattern of role reallocation will affect subsequent role functioning and psychosocial environment, the scores of subjects in the three classifications were compared separately at time one and then at time two by means of a Kruskal-Wallis analysis of variance. These comparisons are presented in Table 11. At both time one and time two, families using an overloaded role reallocation pattern had significantly lower levels of family cohesion. Although there were no other significant differences as a function of role reallocation pattern at time one, a significant difference did emerge by time two in family conflict. Inspection of the means suggests that this effect is due to the low level of conflict in families which relied on a nuclear role reallocation pattern. Contrary to prediction, families adopting an external reallocation pattern showed increased conflict while families adopting both other patterns reported decreased conflict. While there was no initial difference regarding communication, a significant difference emerged by time two, whereby families with a nuclear reallocation pattern showed significantly higher communication than other families.

Time 3 Results

Because of the sample size at time three, the initial step in data analysis was to plot the data across time for each of the dependent measures. Data was plotted separately for patients and
Table 11
Means and Kruskal-Wallis Analysis of Variance Results at Time One and Time Two
Categorized by Role Reallocation Pattern

<table>
<thead>
<tr>
<th>Reallocation Pattern</th>
<th>T1</th>
<th></th>
<th></th>
<th>T2</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Ext. $\bar{X}$</td>
<td>Nuc.</td>
<td>Overload</td>
<td>p=</td>
<td>Ext. $\bar{X}$</td>
<td>Nuc.</td>
</tr>
<tr>
<td>Family Cohesion</td>
<td>7.8</td>
<td>8.5</td>
<td>6.8</td>
<td>.04</td>
<td>7.9</td>
<td>8.4</td>
</tr>
<tr>
<td>Family Conflict</td>
<td>2.4</td>
<td>1.2</td>
<td>2.3</td>
<td>NS</td>
<td>2.7</td>
<td>0.9</td>
</tr>
<tr>
<td>Role Strain</td>
<td>10.4</td>
<td>9.7</td>
<td>13.4</td>
<td>NS</td>
<td>11.6</td>
<td>11.2</td>
</tr>
<tr>
<td>Role Conflict</td>
<td>18.0</td>
<td>13.3</td>
<td>19.3</td>
<td>NS</td>
<td>16.4</td>
<td>14.6</td>
</tr>
<tr>
<td>Husband Role Competency</td>
<td>28.4</td>
<td>30.3</td>
<td>26.2</td>
<td>NS</td>
<td>28.9</td>
<td>23.8</td>
</tr>
<tr>
<td>Wife Role Competency</td>
<td>27.9</td>
<td>26.7</td>
<td>21.1</td>
<td>NS</td>
<td>30.6</td>
<td>25.8</td>
</tr>
<tr>
<td>Marital Communication</td>
<td>96.5</td>
<td>105.3</td>
<td>92.0</td>
<td>NS</td>
<td>93.7</td>
<td>112.4</td>
</tr>
</tbody>
</table>

*Ext. $X$ = External role reallocation pattern.
Nuc. = Nuclear role reallocation pattern.
spouses, and is presented in Figures 4 through 10. Visual inspection of these plots revealed few consistent patterns. The most consistent grouping of both patient and spouse data was by role assignment method. To statistically test the effect of this factor, a Mann-Whitney U test was conducted on the dependent measures using method of role assignment as the independent variable. These results are presented in Table 12. Results indicate that families which negotiate roles on the basis of individual preferences and abilities reported significantly higher communication and significantly less family conflict, role strain, and role conflict than those which assigned roles on the basis of cultural sex role norms.

Nonparametric analysis of variance was also conducted on the time three data to assess the effects of role reallocation pattern and stage of family life cycle. These factors did not account for statistically significant differences among the eight families on which time three data were available.

To assess the effect of hospitalization on the time three data, a Spearman rank order correlation was conducted between these measures and two measures of hospitalization, these being the number of hospitalizations between time two and time three data collections and the number of hospitalized days during this period. Correlations reaching significance were those related to role competence. These correlations, presented in Table 13, indicate that a higher number of hospitalizations and days in the hospital are associated with lower role competence for both husbands and wives.
Figure 4. Graph of marital communication scores across one year for patients and spouses using achieved versus ascribed roles.

*Higher scores indicate better communication
**Subject identification numbers representing each married couple.
Figure 5. Graph of role conflict scores across one year for patients and spouses using achieved versus ascribed roles.

*Higher scores indicate more role conflict.
**Subject identification numbers representing each married couple.
Figure 6. Graph of role strain scores across one year for patients and spouses using achieved versus ascribed roles.

*Higher scores indicate more role strain.
**Subject identification numbers representing each married couple.
Figure 7. Graph of family conflict scores across one year for patients and spouses using achieved versus ascribed roles.

*Higher scores indicate more family conflict.

**Subject identification numbers representing each married couple.
Figure 8. Graph of family cohesion scores across one year for patients and spouses using achieved versus ascribed roles.

*Higher scores indicate more family cohesion.
**Subject identification numbers representing each married couple.
Figure 9. Graph of husband role competency scores across one year for patients and spouses using achieved versus ascribed roles.

*Higher scores indicate higher husband role competency.
**Subject identification numbers representing each married couple.
Figure 10. Graph of wife role competency scores across one year for patients and spouses using achieved versus ascribed roles.

*Higher scores indicate higher wife role competency.
**Subject identification numbers representing each married couple.
Table 12
Means and Mann-Whitney U Test Results at Time
Three by Role Assignment Method

<table>
<thead>
<tr>
<th></th>
<th>Achieved Roles</th>
<th>Ascribed Roles</th>
<th>p=</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Cohesion*</td>
<td>8.33</td>
<td>7.91</td>
<td>NS</td>
</tr>
<tr>
<td>Family Conflict</td>
<td>0.33</td>
<td>1.82</td>
<td>.08</td>
</tr>
<tr>
<td>Role Strain</td>
<td>8.16</td>
<td>11.91</td>
<td>.10</td>
</tr>
<tr>
<td>Role Conflict</td>
<td>11.00</td>
<td>18.18</td>
<td>.001</td>
</tr>
<tr>
<td>Husband Role Competency</td>
<td>30.83</td>
<td>26.91</td>
<td>NS</td>
</tr>
<tr>
<td>Wife Role Competency</td>
<td>28.83</td>
<td>28.18</td>
<td>NS</td>
</tr>
<tr>
<td>Marital Communication</td>
<td>117.33</td>
<td>100.09</td>
<td>.02</td>
</tr>
</tbody>
</table>

*Higher scores indicate a higher degree of the particular characteristic for all variables.
Table 13

Spearman Correlations Between Time 3 Role Competency Measures and Hospitalization Variables

<table>
<thead>
<tr>
<th>Dependent Variable</th>
<th>$r^a$</th>
<th>$p \geq$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wife's Role Competency</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of Hospitalizations</td>
<td>-0.42</td>
<td>.047</td>
</tr>
<tr>
<td>Number of Days Hospitalized</td>
<td>-0.53</td>
<td>.014</td>
</tr>
<tr>
<td>Husband's Role Competency</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of Hospitalizations</td>
<td>-0.26</td>
<td>.157</td>
</tr>
<tr>
<td>Number of Days Hospitalized</td>
<td>-0.41</td>
<td>.052</td>
</tr>
</tbody>
</table>
Discussion

Quantitative Results on Surviving Patients

Future researchers should be aware of the difficulty of maintaining a representative sample in a longitudinal study with this population. Efforts were made to achieve the fullest participation possible. Subjects were sent a cover letter requesting their continued participation along with the follow-up instruments, and then were eventually sent two additional reminders before efforts to elicit their response ceased. Of the 16 subjects who did not respond at time two, four died within two months after the date that their follow-up data was due. One way of viewing the time two response rate is as 78% of subjects who survived more than seven months following the initial assessment. Consideration of the longitudinal results should take into account the fact that despite a response rate of 54% of the total time one sample and 65% of the currently surviving subjects, the subset of respondents to the five month follow-up is not representative of the original sample. The differences in time one data between those who responded, did not respond, and died prior to the follow-up are of interest both in their own right and in the effect they had on the testing of hypotheses.
Examination of these sample differences reveals a potentially informative pattern. At time one, families in which the patient would die within four months had significantly lower communication and family cohesion, and higher family conflict than those in which the patient survived. This result is consistent with the observations of Orcutt (1977) that the terminal phase of cancer is particularly disruptive to the family's role functioning and psychosocial environment. This may be because not only does the terminal patient cease to enact roles within the family, but often creates additional role demands on the remaining family members. Such new roles may include unprecedented physical care of the patient, last minute legal and financial arrangements, and the "death watch" often performed by family members (Sherizen & Paul, 1977; Starker & Starker, 1982).

The sample differences also have important implications for the results of the hypothesis testing done on the follow-up data. The pattern of differences between respondents and non-respondents indicates that respondents represent a more highly functional group of families. These families may have had patients who were generally less debilitated by their disease. Thus the range of dependent measures at time two is likely to be severely truncated when compared to the expected range if all families had responded. Because of this selectively restricted range of scores and the sample size, it becomes statistically more difficult to find differences that actually exist in the population. These factors may account for the lack of significant effects of such
hypothesized factors as number and length of hospitalizations. Conversely, however, these conditions make the significant longitudinal differences that were found more noteworthy.

Present results suggest several important characteristics of families experiencing cancer in a parent during the child present stages of the family life cycle. Specifically, the factors of stage of family life cycle, communication between spouses, and the method and pattern of role assignment had significant effects on various aspects of the families' experiences.

**Stage of family life cycle.** The stage of the family life cycle in which cancer occurs appears important in determining the pattern of role reallocation a family will use. Families in which the children are schoolage or younger were evenly divided between external redistribution of roles and role overload for the healthy spouse while none of the families at this stage employed nuclear redistribution. In contrast, the greater the proportion of children in the family who are adolescents, the more likely the family is to use a nuclear reallocation of roles. Such patterns of role reallocation are easily understood in terms of available family resources. Not only are schoolage and younger children generally unable to adopt primary family roles, accounting for the lack of nuclear reallocation in these families, they concomitantly place greater demands on parents in the child care and socialization roles, partly explaining the relative abundance of overload and external role reallocations at this stage.

In addition to employing different patterns of role
reallocation, families in different stages of the family life cycle differ in their psychosocial environment. Those with adolescents and younger children had a significantly more conflictual family environment. This is consistent with Duvall’s (1977) point that families at this stage have a greater number of developmental tasks facing them and relatively fewer available members to adopt necessary roles. In contrast, families with older children have fewer role demands and more role enactment resources. Hence it is understandable that these older families reported relatively more cohesion, less family conflict, role strain and role conflict.

**Method of role assignment.** The method of role assignment a family has employed prior to the onset of cancer affects role enactment and family environment when cancer occurs. Families which have employed achieved roles had higher levels of role enactment in their reallocated role patterns at time one. These families were also less likely to use an overloaded role pattern, and more likely to engage in external redistribution. The use of achieved roles could be particularly important in the adjustment of families with only younger children who, as noted earlier, are more dependent upon external resources.

The fact that families who use achieved roles premorbidly also show a more cohesive family environment may be due to the opportunity for family members to negotiate roles which are comfortable and fit their interests and abilities. Thus the present results support the position that such families have a built-in process which allows for minimal difficulty in role
reallocate (Vollman, et. al., 1971).

The importance of the method of role assignment is attested to by the longitudinal significance this factor demonstrated. For the time two sample, the family's method of role assignment did not significantly influence role functioning or family environment in the earliest assessment. However, significant effects did emerge five months later. Overall, families using achieved roles fared significantly better across time as indicated by these differences at time two: family cohesion and husband's role competency were significantly higher for families using achieved roles; family conflict and role strain were significantly lower for families with achieved roles. Further, although both types of families reported virtually identical communication levels at time one, families with achieved roles showed significantly higher communication at time two than those with ascribed roles.

This pattern continued at the one year follow-up, in that the method of role assignment differentiated between families on a number of measures. Specifically, families who based role assignments on individual preferences and abilities reported significantly higher communication, and lower family conflict, role strain and role conflict at the one year mark than families who assigned roles on the basis of cultural sex and age norms. This may indicate that, from a longitudinal perspective, families who have negotiated roles to fit individual members prior to the onset of cancer are better prepared to reallocate roles as necessitated by a member's illness.
Role Reallocation Pattern. For the time two sample, family cohesion decreased in families which adopted an overloaded role reallocation pattern while not changing in other families. Family conflict, however, decreased in families with overloaded and nuclear patterns, but increased in families using an external reallocation pattern. These results may indicate that when one family member adopts too many of the family's role responsibilities there is a decreased sense of unity, but it is the addition of an outsider which results in the highest level of family conflict. Perhaps this is because the introduction of a new individual in the family system disrupts existing intrafamilial relationships. The other dependent measures, while not showing statistically significant differences, are consistent in suggesting that families with nuclear reallocation patterns experience the least amounts of role strain and role conflict as well as the least conflictual, most cohesive family environment. It is interesting to note that these same families also showed higher levels of communication at time two. Such families would need more extensive communication to effectively reallocate roles within the nuclear family system.

Communication Between Spouses. One of the clearest results of the present investigation is the value of open communication between spouses in dealing with the changes that cancer forces upon families. The data suggest that open communication allows spouses to more effectively negotiate role reallocations, as demonstrated by the correlation between communication and higher role enactment. This, in turn, results in less role strain and role conflict.
These effects, as well as the greater opportunity to discuss feelings and to seek and offer emotional support, seemingly allowed these families to build a more cohesive, less conflictual family environment. Given these findings, the present study provides empirical support for the role of communication in negotiation of roles proposed by previous authors (e.g., Aldous, 1978; Bonnard, 1961; Vollman, et. al., 1971; Silverman & Englander, 1975), and the resultant effects on the family environment (Elliot, 1948).

Results of the one year follow-up reveal a great deal of variability in the experience of cancer families across time. Some families steadily improved in role functioning and family environment across the year, some progressively declined, while others reported both improvement and decline at different points in time. In light of the many factors influencing a family's cancer experience and the unique nature of the progression of disease in many cancer patients, such variability in the current results is not surprising. It has been noted that families facing serious illness may encounter a series of important events, some resulting in conflict and disorganization and others inducing a heightened sense of cohesion, which may be difficult for longitudinal studies to adequately examine (Speedling, 1982). A fitting description of the present results was offered by Hill (1958) when he suggested that the family's course of adjustment to crisis was like the path of a roller coaster. As Speedling summarizes,

"This is all to suggest that the 'typical' reaction of a family under stress may well involve both positive and negative outcomes over time with various impacts for

Clinical Implications. Although families experiencing cancer in a parent are inevitably faced with a variety of difficulties, the present study provides insight into which families may be at greatest risk. Families in which all children are schoolage or younger are most dependent on external resources. In the present sample external resources employed included extended family members, friends and neighbors, and in a few cases hired helpers. The unavailability of such external resources may place parents in a situation where they cannot meet the many family developmental tasks they must undertake. Clinicians aware of this possibility are in a better position to recognize the possibility of role reallocation problems and to assist such families in locating appropriate resources.

A second factor which may place families at greater risk to the stresses of cancer is a premorbid reliance on ascribed roles, which may mean that the famiy does not have an effective pre-existing method of reallocating roles. If there are no clear cultural prescriptions for who should take over a particular role or how it should be enacted, such families may not be able to effectively negotiate role reallocations so as to take full advantage of available resources. Professionals working with these families may be more effective if they are sensitive to such family dynamics, and can provide assistance in the negotiation of roles. Recognizing the greater vulnerability of position oriented families
may allow early intervention which averts subsequent disruption in role functioning and family environment.

Effective negotiation of roles is also influenced by the communication between spouses. The present data suggests that families in which there is a lack of communication may be more vulnerable to inadequate role enactment and a disrupted family environment. At the time of initial assessment, as well as four months later, those families with open communication seem to be functioning more competently and with more positive affective climates. Therefore, marital communication may present the clinician with a direct focus of intervention with families experiencing cancer. Encouraging and assisting open communication will not only allow for clear and explicit reallocation of roles, but may allow family members to deal more effectively with the variety of feelings associated with cancer and its repercussions.

It must be noted that the Marital Communication Inventory measures the degree to which spouses communicate needs and concerns and express feelings openly, and does not directly assess the openness with which families discuss the ramifications of serious illness or the possibility of death of one of its members. In the following section, the analysis of all interviews conducted at time one is presented. This data suggest that those couples who had the requisite communication skills were in fact more likely to openly discuss the patient's condition and possible death, often with beneficial results. Clinicians must be cautioned, however, that facilitating discussions of death in couples not possessing the
prerequisite communication skills may not affect family functioning in a positive direction.

As described earlier, various roles within the family system will be more or less important in different stages of the family life cycle. Clinicians recognizing the relative importance of roles for a family's particular developmental stage will be in a position to help families prioritize their role reallocations.

Clinicians should also be aware that there are a number of patterns by which families reallocate roles which the patient is no longer able to enact, each with its own advantages and disadvantages. Reliance on individuals outside of the nuclear family seems to present a different set of potential problems than overburdening the healthy spouse or allocating roles to the children. Realizing that there is no single optimal pattern of role reallocation, a clinician can recognize when a family may be overburdening or underutilizing family members and/or resources outside the nuclear family. Individual families vary in their role functioning needs, and may benefit from the objectivity a professional may lend to recognizing and addressing these needs.

Finally, the current results indicate that the last months of a patient's life may be particularly disruptive to some aspects of family functioning. During this period families may be especially at risk for role dysfunction and a variety of internal stressors, yet may be least likely to discuss their concerns openly, and may not know how or where to obtain assistance. Recognizing this possibility may allow the health care professional to provide such
assistance through direct consultation or an appropriate referral.

**Suggestions for further research.** One limitation of the present study was the sample size and the resulting necessity to limit the classifications which could be made within the sample. Research with a larger sample would allow the characteristics of families to be more sharply defined. For example, the present use of three family life cycle stages may be too gross a distinction to detect significant differences which may exist among families with children of different ages.

Another limitation was the necessity to group together patients with different types of cancer. Future research focusing on patients having specific types of cancer would allow for a much more refined understanding of the impact of this highly varied disease as well as the impact of the variety of treatments.
Discussion of Post-Bereavement Data

Of the 16 families in which the patient died during the course of the study, 8 surviving spouses consented to provide post-bereavement data about their experiences. Each completed the Beck Depression Inventory, a modified version of the Washington Family Role Inventory, and the Family Environment Scale approximately four months after the death of the patient. Four of these spouses also consented to a post-bereavement interview. It is from this data that the following analyses are drawn. Bearing in mind the limitations to causal inference of this essentially case study approach, the available data can be used to illustrate salient aspects of the DRA model and related issues discussed in the research literature.

Each of the eight surviving spouses represents a unique case in terms of their family situations and the course of their adjustments. However, there were several enlightening similarities and contrasts among the respondents. One such contrast was between the two male survivors. A major difference was that Mr. L was in stage one of the family life cycle, the father of two preschool aged girls, while Mr. N was in the later part of stage two, his 12 year old son being mostly self sufficient around the house. Primarily because of the demands of being the single father of two small children, Mr. L was the only respondent in the post-bereavement sample to report an increase in role strain following the death of his spouse.
This increase in role strain seems to be an interaction between the stage of the family life cycle and the sex of the surviving spouse. Two other respondents were also in the first stage of the family life cycle, but were surviving mothers, not fathers. Both reported lower levels of role strain than did Mr. L, even though both worked in addition to their parental roles, indicating perhaps the more drastic role changes facing surviving fathers in the earliest stages of the family life cycle.

Another important difference between the two surviving fathers was the acknowledgement and acceptance of the eventual deaths of their wives. Although neither spoke openly with their wives about the possibility of death, Mr. N seemed to clearly recognize his wife's terminal condition, and in spite of his wife's reluctance to discuss such topics, spoke openly about his concerns with extended family members. In contrast, Mr. L did not discuss his concerns with anyone, and neither he nor his wife seemed to face the likelihood of her death. Perhaps in part as a result of his difference in recognizing the impending deaths of their wives, Mr. L had the highest Beck Depression Inventory score (29) indicating a moderate level of clinical depression, while Mr. N reported the lowest depression score (4) of the sample.

In this sense Mr. L was similar to Mrs. C, who reported the second highest depression score (18), the only other score in the sample to indicate a clinical level of depression. Like Mr. L, Mrs. C and her husband never accepted the possibility of his death from cancer. In her post-bereavement interview, Mrs. C indicated
that in spite of a number of what in retrospect were undeniable signs of her husband's impending death, he remained convinced of his eventual recovery. She reported that it was much easier for her to "go along with him", and herself never believed, "that we weren't going to win this one". Because of their denial of his approaching death, Mr. and Mrs. C continued to postpone acting on the advice of their attorney to change the ownership of their property to the wife's name. As a result, Mrs. C had been struggling since her husband's death with the legal aspects of settling their estate.

In contrast to Mrs. C and Mr. L, who continued to deny the approaching deaths of their spouses and subsequently reported the two highest depression scores of the sample, Mrs. R readily acknowledged that her husband was dying and tried to prepare herself for it. As she put it, "I was able to start dealing with his [approaching] death. I went through some of the grief before he died, so that when he did die I was as emotionally prepared as you can get, and able to function and do what I had to do. Because I knew that [his dying] was happening. I didn't like it, and I didn't want it, but I accepted it."

Her comments describe the process known as anticipatory grief, whereby significant others experience some of the grief process prior to the patient's actual death. In the present sample, Mrs. R and Mr. N seem to have experienced anticipatory grief, whereas Mr. L and Mrs. C did not, even though they were all exposed to many of the same cues through their spouses' gradual decline. This
highlights the point made by Troup and Greene (1974) that an objectively obvious forewarning of another's death is not sufficient to infer that anticipatory grief will occur. It seems to depend on the willingness or ability of the surviving spouse to acknowledge and accept the possibility of the impending death, not just exposure to cues of such a possibility.

Kastenbaum (1977) argues that anticipatory grief does not lessen the emotional impact of a significant other's death, but does allow the survivor to more effectively draw upon available resources and thus promotes recovery. This seems to have been the case with both Mr. N and Mrs. R. In their post-bereavement interviews, these spouses indicated that they had been able to recognize their own needs as well as those of their children, and to seek out the resources to meet these needs. In contrast, Mr. L and Mrs. C seemed reluctant to pursue the assistance of others, and were the most depressed individuals in the sample.

The willingness of the surviving spouse to reach out to others may modulate the pattern reported by Glick and his associates (1974) in which the influx of support and assistance by others immediately following bereavement soon recedes, leaving the widowed on their own. Mrs. R indicated that she had taken it upon herself to remain actively involved with others, and was continuing to receive the support and assistance of those she called upon. Comparing herself to others in similar circumstances who were more passive in their expectations of support, Mrs. R noted, "They expected everybody to keep calling them, but they need to call [on
others]. Some people don't know what you need, they're afraid to call. You have to get in touch with others". Her assertiveness and willingness to take the initiative in obtaining the assistance and involvement of others seemed to serve Mrs. R well, in that her depression score was second only to Mr. N's as the lowest in the sample.

Although none of the four respondents discussed above communicated with their spouse about the possibility of death, Mr. N and Mrs. R both recognized this possibility and discussed their concerns with others. In contrast, Mrs. K recognized her husband's impending death but had no other family member with whom to discuss her concerns. There was a general lack of communication within the K family, which Mrs. K acknowledged, and a particular avoidance of topics related to her husband's disease. This family seemed to have a great deal of unexpressed hostility prior to the husband-father's death, and the psychosocial environment remained disrupted at the time of the post-bereavement assessment. Mrs. K reported that her two oldest children, ages 16 and 20, "have turned away from me...criticize me and are of no help to me at all now".

The experience of the K family is consistent with the general relationship found between communication and post-bereavement adjustment within the current sample. Scores on the Marital Communication Inventory, representing general communication between spouses at the time of the initial assessment, were significantly correlated with role conflict measured after the patient's death (r = .78, p < .01). This pattern is similar to the findings reported
by Cohen, Dizenhu, and Winget (1977) that families rated as open in communication prior to the patient's death were more flexible in role reallocation and experienced less difficulty in post-death reestablishment.

The nature of communication between spouses focusing specifically on the illness and its prognosis was also related to post-bereavement adjustment. Three of the 8 families reported that there was little or no discussion of these topics prior to the patient's death. Two of these, Mrs. K and Mr. L, have already been described. The third, Mrs. H, reported at the initial assessment that she did not understand that much about her husband's condition, but that she did not want to know more or to discuss it more openly with her husband.

These three low disease oriented communication families were compared to the other five families, who reported at least moderate disease oriented communication with their spouse or another family member. A Mann-Whitney U test was conducted on both pre and post-bereavement dependent measures. The results indicated that there were no differences between these two groups of families prior to the patient's deaths, but that following bereavement the low disease oriented communication families reported significantly higher family conflict (p < .03), significantly lower family cohesion (p < .05), and tended to have higher role strain (p < .09) than those families who had discussed disease related concerns. This may indicate that the benefits of communication regarding the illness and prognosis will be manifest following bereavement. This
is perhaps a function of anticipatory grief, as discussed earlier, whereby surviving spouses can prepare themselves for the impending loss and the subsequent changes that the family will face.

The final trend apparent within the current sample was the consistent decrease in role strain and role conflict between the pre- and post-death measures. All but one spouse reported a lower level of role strain and role conflict following bereavement than at the initial, pre-death assessment. This pattern is also consistent with the findings of Cohen, et. al. (1977), who reported that their sample of bereaved families identified the terminal period as the most difficult for family functioning. It is at this point, when the patient is no longer able to enact roles within the family and may also create new role demands on other family members, that family functioning may be most disrupted. Clinicians should recognize the increased stress and vulnerability of families during the patient's terminal phase. It is this period in which families may be most in need of the assistance of others, both professional and non-professional.
Discussion of Qualitative Data: Recurrent Concerns in Families Facing Cancer

Clinical experience has repeatedly highlighted the importance of family considerations when examining the impact of cancer. This section presents a set of psychosocial issues which consistently recurred throughout the interview segments of the current study. Discussion of these themes, often described in the patients' or spouses' own words, is followed by suggestions of how health care professionals might effectively intervene or in some cases prevent some of the problems experienced by this population.

Communication with Medical Staff: Allaying Uncertainty and the Need to Know

The most commonly mentioned source of stress for both patients and their spouses was uncertainty, which had a variety of causes. A number of patients reported a general uncertainty of what the future held now that they had cancer. They commonly stated that cancer was always "hanging over their heads", determining not only their present situation but influencing their view of the future and their ability to plan ahead as they had in the past. As one patient put it,"You don't know if you have a future or not...whether you've got six months or one year or ten years." Another felt much the same way, "It's inevitable that I'll pass away with it, but you just don't know how soon."

In these cases of general uncertainty of the future, health care professionals usually have little direct control. Much more common, however, were complaints of uncertainty stemming from a
lack of information, information that in many cases was available somewhere within the health care delivery system. Starting with the most specific type of information, many patients and spouses reported that waiting for test results was one of the most stressful aspects of their cancer experience. Having information, whether good or bad, was less anxiety provoking than the uncertainty of not knowing. One patient stated, "Finding out just a little bit at a time is really hard." A spouse indicated that the period spent waiting for lab reports after his wife's mastectomy were "...The two longest days of my life." The strain on both patients and spouse was also illustrated by these excerpts from interviews done on separate days with a male patient and his wife:

Said the patient, "The main thing is to make sure the patient and family get a good understanding of the nature of the illness and treatment and give you all the information they can. I was unhappy yesterday, I was waiting around all day on a biopsy report. I didn't get it until last night. If you could be informed, it would help. The worst thing is not knowing."

His wife concurred, "The hospital should inform us as soon as they know something. He's going nuts waiting on results of tests. You know they're done. It would take a lot of pressure off..."

Some patients were even more disturbed by their association of waiting for test results and the consequent lag time in receiving treatment with the progression of their disease, as in the following: "The main problem was getting my diagnosis, getting a
mammogram done...that was a very stressful time because it took me 19 days to get a mammogram done and get the results read so I could go on to a surgeon. That was very stressful because at that time I could visibly see the tumor mass growing and taking on new dimensions and still was waiting to get the test done. It will always be in my mind whether or not, because of the delay in getting these X-rays done, my lymph nodes would have been positive or negative. Time is very precious and I had two microscopic positive lymph nodes, which now means that I'm in the course of chemotherapy. If I had had no positive lymph nodes I wouldn't have had to do the chemo. That will always be a question in my mind whether or not the time delay caused that metastasis."

Observed another patient, "Waiting to get test results, get appointments, and all that, you think 'Damn it, they may be busy, but I'm hurting.' And cancer doesn't wait on anybody, it keeps right on multiplying whether they can work me in or not. I was getting hostile. I called to get information a number of times. I got aggressive to seek out a solution. When I couldn't get any information, I began to crumble, and finally broke down."

Other patients and spouses also reported difficulty getting information despite actively seeking it. As one spouse put it, "It's difficult here to find things out. Every time I come in I have to go through the process of finding out who his nurse is to get information. We had one doctor who always had his hand on the doorknob, leaning out the door, saying 'Hello—how—are—you—what—can—I—do—for—you—everything—O.K.—today?—good—bye'. I resent that
terribly. I'll ask my husband, 'Did you see the doctor today?' and he'll say 'Yeah, he breezed by.' He's been in that room 24 hours a day for 80 days and the doctor doesn't have two seconds for him? I resent the inconsideration and disrespect to my husband. When I try to talk to him (the doctor) and he acts like I'm taking up his time, I resent that. You've got enough to deal with...that you don't need that. There's been many times that my husband's been very frustrated that the doctor won't spend sufficient time with him."

Many patients and spouses echoed this perception of insufficient availability of the physician for the purpose of information gathering. Comments like, "he's always in such a hurry", or "he's always just in and out" were common, reflecting the hurried nature of most daily patient-physician contact. Similar patterns have been noted by other researchers (Krant, Beiser, Adler & Johnston, 1976) who note that time pressures usually prevent physicians from repeating explanations to multiple family members and precluding checking to ensure that patients and family members understood the information offered.

The need for the doctor to spend sufficient time with a patient or family may be more crucial just before or after certain major events such as surgery. In one case, a spouse described his feelings of anxiety and frustration when, following his wife's surgery, his son, sister-in-law and he each only got a few minutes on the phone to speak with the surgeon, even though they had waited at the hospital throughout the six and a half hour procedure. Each
family member had a different interpretation of the bits of information they had received, and the resulting uncertainty of the patient's actual condition caused great stress for them all. Said the spouse, "All doctors could make it easier on the patient's family if, after a surgery of any kind, they found a little time, even 5-10 minutes, to come and tell them exactly what the situation is." Krant et al (1976) point out that patients and family members are often left to struggle on their own with such fragmented and distorted views of the situation.

Given this desire to be informed, it is fortunate that episodes like the following were rare. A physician other than the surgeon approached a patient several days following surgery and started to describe the necessary arrangements for chemotherapy. Puzzled, the patient asked why he needed chemotherapy now when he had not needed it before. The physician replied that this was standard procedure when the cancer had spread to the lymph nodes. This was the first indication the patient had of the lymph node involvement. His wife arrived later that day to find the patient devastated. It took the wife three days to "track the surgeon down" and confront him about the lack of information. She recalled saying, "Why did you not tell us it was in the lymph nodes? Why do we have to find out second hand?" His reply: "I didn't think you could handle it". Enraged, she responded, "What I can not handle is not knowing, and trying to second guess you...We've always managed to come out on our feet as long as we know. My husband and I both, whatever it is, if we know the details, then we'll adjust
accordingly to whatever needs to be done...Is there anything else we should know?" According to the wife, his next comment was to offhandedly remark, "Yeah, we never beat this game," his way of indicating the patient was terminal. Said the wife, "I thought 'O.K. fella, you're done! I'm not paying this kind of money to be treated like an imbecile.'"

Another factor in the lack of communication between physician and the patient and family involves hospital procedure. Besides the heavy work load of most physicians, especially in a major teaching and research hospital, the procedures followed are often not conducive to effective communication from the family's perspective. Attending physicians usually make rounds once a day and are accompanied by a number of residents, interns, medical students, and nurses. Given the brief presence of this crowd of people, and the fact that the attending physician is often primarily concerned with providing technical information to his charges in jargon that is all but incomprehensible to the average person, it is understandable that the patient and family are left with unanswered questions.

This plight was described by a spouse, "I know this is a teaching hospital, but the doctor would come in with students, and he's talking to the students, not the patient. But she hears something he says and then it doesn't get explained and so we sit there and worry about it until I can corner someone to talk to about it, which is a difficult thing to do. I think people working with cancer patients need to communicate more extensively about
what they're doing and why they're doing it. Better communication is needed. It all becomes routine to the nurses and doctors after a while, but it's not routine to the patients."

Communication difficulties are often compounded by an inability to articulate particular questions, as illustrated by this patient's comments, "Sometimes I think the doctor could explain things better. They work with cancer patients so much and they assume so much. I don't even know the right questions to ask. I don't understand enough about some of the things they do. Any questions I've asked they've always answered, but so much of this stuff is routine to them that I don't think they realize how awesome and overpowering it is to someone who hasn't been through it before. The simplest things to them can be really scary...if you don't understand it or know what's going on. If someone could just explain from step one."

Explanations should be provided prior to the implementation of medical procedures, according to many patients. Assuming that the patient understands or does not desire further information is often erroneous, as illustrated here, "A lot of things weren't explained to me about the surgery. A couple of times he [the physician] even said 'Well we talked about that.' Well if we did, I sure missed it, and I didn't understand. The first time he diagnosed it he made arrangements to put me in the hospital the next day to do a biopsy and a mastectomy...I was still stunned, and he said, 'You agreed to it. I thought everything was settled.' All I could do was sit there and shake my head. I was just bewildered. It all happened
so fast. Later in the hospital they assumed that I understood all the things that would be happening, and I didn't."

Another patient explained, "When a person comes in, they need to explain what they're doing because you can have the hell scared out of you. You can be scared to death and nobody's telling you what they're doing. When I was operated on, it was a damn nightmare. There wasn't any coordination between the doctors. That made it hard on me and on the family." His wife concurred, "He was not prepared for surgery, had no idea what to expect. We should have been better prepared. Then I had to talk to so many people. I had to inform the staff what was going on. We got conflicting information. Finally all the staff consulted and coordinated their efforts. The lack of communication between staff and patient was a big problem." Yet another patient suggests, "Make sure a knowledgeable person explains things and answers questions before they start running tests."

Indeed, there was evidence that providing information even about simple, routine procedures would have avoided unnecessary anxiety in several cases. For example, "The other day they had done a bone scan and they came in and took a blood draw. I thought nothing of it. A half hour later they came back and had to get another one. I thought 'Oh my God' and asked if it could wait. When they said 'no we have to have it tonight', I went bananas. It turned out it was perfectly normal, it was for my potassium levels, but nobody told me. I thought they had seen something right away and I had it in all my bones and I was dead in two weeks. That
night was bad, but when we found out what was going on, we were fine."

One positive outcome of being informed from the patient and family perspective seems to be an enhanced sense of control. Silberfarb and Greer (1982) point out that two important aspects of cancer that set it apart from most other illnesses are uncertainty and a lack of personal control. Providing sufficient information can often alleviate anxiety in both of these areas, as in the following, "I did appreciate that Dr. N was very open. He gave you several options, told you about available therapies. He also told us we could chose to do nothing. It was good that you still had control over what was going to happen to you. They've explained everything and...they talk very freely in front of the family. They know that the family is just as much involved in the disease as the patient. This seems like a unique approach. The other hospitals didn't handle it this way. With this type of disease, the more the family knows and the more open you (staff) are, the less apprehensive we are; the anxiety isn't there, nor is the fear. Keeping us informed made it much easier."

Descriptions of the positive effects of adequate communication between staff and the patient/family not only further attest to the importance of this area, but also point out that some physicians are very effective in their role as an information provider. Typical of the responses elicited by the question of what had been most helpful was, "Having things explained to me," "Knowing what to expect was most helpful," and "It was good to have been told what
to expect. The most helpful thing the doctor did was to take time to explain things to me."

Nurses were also frequently praised for the information they provided to patients and families. The fact that they would make the effort to track down requested information and take time to answer questions was greatly appreciated. When this role was enacted by nurses, it could sometimes relieve the time demand on physicians. This possibility, however, assumes that physicians are willing to allow nurses to provide information freely, which was not always the case.

Ambivalence of the patient. Effective staff-patient communication also depends on the attitudes and behavior of the patient and family. One problem is the ambivalence observed in several patients and spouses about seeking and receiving information. This ambivalence was evident in comments such as, "There are questions that sometimes I think I want to know (the answer to) and yet I'm afraid to know..." Patients sometimes recognize that their reluctance to seek information had negative consequences: "It's strange, you don't want to know but you've got to know. If you don't know your imagination makes it much worse." One patient's strategy for dealing with this ambivalence required an understanding between herself and the staff; "There are a few things I'm not ready for yet, and I haven't been able to ask about. I didn't even ask about myself but very slowly as the months went by. When I got ready I would ask (about) what I felt I could handle and then I wouldn't ask any more, and they understood that.
My doctor that did the first surgery understood...that he could tell me things until he was blue in the face when I didn't want to hear it and I wouldn't hear it, so they waited for me to ask questions."

These last comments introduce a problem that was confirmed in discussions with several of the oncologists involved in the treatment of the present sample of patients—that in fact information was provided to the patient and family of which they subsequently claimed to have no knowledge. One explanation in such situations is that the patient and family were under such stress at the time the information is offered that they were unable to assimilate it. As one patient described it, "I told the doctor to be honest...I knew I needed a hysterectomy. I thought O.K. I can handle that. I got to the hospital and in one day I was told, by different people, that I would need a colostomy, need a radioactive insert, need a private room, couldn't move at all because the insert would move, nobody could come see me, that I had rectal cancer...all within 12 hours...I didn't have enough time to assimilate it or sort through it. I was completely overloaded."

Because the diagnosis and treatment of cancer is new and extremely stressful to most patients and families, health care providers may need to offer information a number of times before it can be assimilated and understood.

Another behavioral characteristic of the patient and family which influenced communication with staff was their degree of assertiveness. Weisman and Worden (1975) have noted that more
assertive patients ask for and receive better attention and services. This seemed to be the case with the present sample, at least in terms of seeking and receiving desired information. As a spouse described it, "Both of us are kind of shy, and we didn't want to make a scene. But we should have asked more questions. We never asked enough to know what was going on. They didn't tell us in advance what was going on. They didn't tell us in advance what was going to happen. Not knowing what they (medical procedures) were for, they scared us pretty bad. If someone had told us it would have been O.K." Another spouse felt that if not for her assertiveness, she would not have been adequately informed, "If I were unassertive or intimidated, I wouldn't know anything at all. We've never had a doctor say 'Have your wife come in so we can talk to both of you.'"

Frustration over a lack of information can lead some patients or spouses to go beyond simple assertiveness. One husband, after failing to obtain information regarding his wife's condition and being unable to contact the attending physician, finally asked his wife's roommate in a voice loud and angry enough to alert most of the nearby nurses station, "Just how the hell do you get to see a doctor around here?" Fortunately the head nurse responded to the man's obvious need for information, and was able to set up an appointment for him. But it was only after the spouse had become sufficiently anxious to provoke such an outburst that the situation was noticed and resolved.

There are clear benefits for the family to be informed and
involved in the patients illness through the removal of some degree of uncertainty, and with it the alleviation of anxiety. Several spouses pointed out that the family's involvement may also be beneficial to the medical treatment of the patient. Having lived with and observed the patient for a number of years, spouses are in an especially good position to notice changes in personality, behavior, and mental status, areas often affected by cancer and its treatment. These changes may not be noticed by medical staff who have limited background information and limited opportunities for observation in these areas (Silberfarb & Greer, 1982; Levine, Silberfarb & Lipowski, 1978).

It is also erroneous to assume that patients themselves will always report or even be aware of changes they are experiencing. As one spouse recalled, her husband would reflexively respond with "fine" to any inquiries about how he was feeling, even at times of acute physical and emotional discomfort. Perhaps as a form of denial, this same patient initially indicated that there were no other incidents of cancer in his family, even though his father and brother had both died of colon cancer. When his wife became aware of this pattern, she began to accompany him to medical appointments and to be present during rounds in an effort to insure that accurate information was available to staff. By keeping notes of her own behavioral observations in such areas as sleeping and eating patterns, mood shifts, and memory, she was able to provide otherwise unavailable information that eventually led to changes in her husband's medication.
Communication within the family. Communication between staff and the patient and family seems related to the nature of communication within the family. Although almost all patients and their spouses wanted to be informed of their conditions, some were reluctant to face the implications of a poor prognosis. Some physicians collude in this avoidance by presenting an overly optimistic picture to the patient, a picture usually welcomed by the patient and not challenged by even a doubting spouse. In the words of one such spouse, "Even though Dr. M keeps saying he's going to cure him, I don't think there is any cure. It's just a matter of time. I don't think the 5 FU (chemotherapy) is doing much good and don't know if we're getting any answers. Of course most of the time I talk to [the doctor] he's around my husband and I don't know whether he just doesn't want to really go into how advanced it is...Sometimes [the doctor] says, 'Well he may just have a few months', but in front of my husband he gives the impression there may be many years and that's contradictory. I think he's going downhill myself..."

Because they could not discuss the true nature of his situation between themselves, this couple could not confront the doctor to get a straightforward account of his condition and the implications for their future. Not being pressed to provide such information, the doctor did not feel compelled to make certain the patient and his wife had an accurate, detailed understanding of the prognosis, which was in fact poor.

A similar situation with another couple seemed to reflect more
of the spouses reluctance to seek information about her husband: "These doctors give you all this hope. Like (my husband's) dad didn't even live a year after the diagnosis and his doctor said '...well you knew he was terminal', but we didn't really. I wonder if its that way with (my husband) or whether there is hope, but I've never inquired. I hardly ever talk to the doctor without (my husband) being there and I'd never ask in front of him. If it was bad, I wouldn't want him to hear."

This wife's last comment represents the most common reason given for a lack of communication between spouses regarding the illness; the desire to protect one another from anxiety induced by sharing their own concerns and fears. This pattern is one of three described by Hinton (1981) by which couples avoid discussing a serious illness. Over 70% of those individuals in the current sample who indicated they would at times like to talk more with their spouse about the illness listed the desire to protect him or her as the major deterrent. In talking to both spouses separately, it became apparent that this was often a mutual effort on the part of both patient and spouse. Each felt that to express fears and concerns would upset the spouse, something to be avoided even at the cost of carrying their own pent up feelings.

Sometimes this fear of upsetting the spouse was based on experience, for others it was mostly on speculation. As one patient put it, "I was afraid, but he was more afraid. I was willing to listen to the good and the bad and then decide what to do, whereas he only wanted to hear good things. I'm reluctant to
discuss it because it upsets him and that causes tension between us." Asked what prevented her from discussing her illness more with her husband, another patient stated, "Well, he doesn't help me...I think he feels so sorry for me that by the time I say how I feel that he feels even worse than I do...so I don't say 'I hurt here...I'm afraid I'm going to die...because he doesn't know what to say to me. I've always felt I never wanted to hurt him and I feel like it does hurt him when I tell him how I feel." Another patient echoes this sense of responsibility to not make others unhappy when she says, "I've held it in. I hate to see people crying and unhappy and I sure don't want to be the cause of it."

This need to protect others often took a toll, especially on patients. While facing a potentially life threatening illness, they felt compelled to keep their negative feeling to themselves, sometimes resulting in additional physical and emotional stress. Some felt obligated to "take care of" everyone else. Several patients reported that their families seemed to have a harder time than they did in dealing with their illness, and instead of being supported, felt that they were the ones supporting their families. Because of their need to protect others, they often attempted to provide this support, if only by keeping their own feelings to themselves.

Some of these patients and spouses had tried to share their feelings and concerns and to elicit those of their spouse only to find that there was an increase in anxiety or a quick change of topic. Others, however, had never actually attempted to
communicate at this level with their spouse. When asked if this type of communication was something she desired, one such patient stated, "Yes, but I don't want to upset him. Maybe it's only me that thinks that. Maybe I just think he'll get upset."

Glaser and Strauss (1966) note that dangerous topics must be avoided if a "mutual pretense" that the prognosis is not poor is to be maintained. Dangerous topics include the patient's death or fears of death and events that will happen afterward. Avoidance of such dangerous topics was clearly indicated in the description several patients and spouses gave of their communication. One example was a wife whose husband would only discuss the technical, medical aspects of his disease, and would not discuss what the illness and its treatment was doing to him. Several patients and spouses reported a reluctance on their partners part to discuss anything related to the possibility of death, including wills, changes in property ownership, and funeral arrangements. One spouse indicated that her husband's reluctance to change mortgage and title arrangements was his way of denying the seriousness of his condition, and that it was easier to "go along" with him than to challenge his denial.

Another pattern encountered was what might be termed "fair weather communication." As long as the news was good and the outlook optimistic, these individuals were open and encouraged discussions with their spouses. But as one patient described the change, "Now he won't talk about it. I think he's afraid. If I bring it up, he won't talk about it. I think I'll talk about it
more when I get home and feel better. Right now I feel so bad. I have enough to handle with just the illness. We talked at first when it was more optimistic. He said if I had any fears, will talk. Now it doesn't look as good. He's more worried, and he won't talk."

One unfortunate aspect of such fair weather communication is that it is often precisely during these difficult periods that the patient is most in need of the spouse as a confidant and supporter. Issues, which if discussed might bring some degree of peace of mind, remain unsettled and unsettling. The patient just quoted continued to say, "I have a lot of fears. I don't confide in anyone because the only person I feel I can confide in is my husband and he's taking this so hard that I don't want to add to his burden. So I hold it inside. I haven't told anyone else this, but I don't think I'm going to live much longer. So I've been thinking, maybe when I go home we'll have a family conference and face these things. It's going to be better if they're prepared, whether they like it or not."

Much of this woman's concern about death focused on the effects it would have on her family. Discussion of the anticipated effects may well have eased some of these concerns. For example she wanted her husband to remarry, feeling that he would need a companion to take her place. She also had certain ideas about how she wanted their children to be raised. At the time of our interview in the midst of a stressful period for her, none of these feelings had been shared with her husband, which seemed to add to
her discomfort. Of more pressing concern, however, was her own immediate future. As she confided, "I wouldn't say this to my family, but if I'm going to die from this, I'd just like to die before I have to go through all that [repeated operations and continual pain] and get it over with!" The treatment implications of such a stance appear to make this information most important to share with the family and those charged with her care. Yet because of her desire not to burden or upset others, she kept these fears to herself.

Several patients and spouses attested to the benefits of open communication. Many had to overcome an initial reluctance to talk about the illness and their feelings, only to find support and relief. Their need to express their feelings finally overcame their need to protect others, usually with positive results. Occasionally they succeeded in not only reducing some of their own anxieties and increasing the emotional closeness to their spouse, but also managed to allay some of the spouse's concerns. One spouse noted that when they were facing a particularly dire situation, her husband explained that he was not afraid to die. This made it much easier for her, having been concerned about her husband's fear and anxiety.

Another spouse, however, reported that although her husband seemed to benefit from it, he was seldom willing to share his feelings. As she said, "When [my husband] does talk about it he seems to feel a lot better, because you can really build things up in your imagination. It can be ridiculous. If you get it out in
the open it releases pressure...and takes some of the emotionalism out of it. I used to cry every time I thought about it. Now I think I can deal with it better, now that I've talked about it."

Similar advantages to open communication were echoed by several patients and spouses, but most reported that such discussion was difficult to initiate, citing both their own and their spouses' emotional reactions. Several had to find cognitive behavioral strategies to allow them to broach emotionally difficult topics. One self instruction technique was described by this spouse, "I was very reluctant to mention things at first...but I didn't want him to bottle things up inside so I figured the best thing to do was to go ahead and talk about it as an every day occurrence if it came up. I had to teach myself to discuss it without getting upset. I would concentrate on what I wanted to say and collect my thoughts...if I started to get upset I would stop for awhile and think about something else until I settled down, then I would bring it up again. I have to settle myself down before I discuss it." This woman recognized the importance of open communication and devised a means of allowing herself to engage in it. Unfortunately, few patients or spouses exhibited this ability, and instead continued to keep their fears and concerns to themselves or to discuss only safe topics.

Time Limits. The relationship between communication with staff and communication within the family is illustrated by one of Glaser and Strauss' (1966) unsafe topics, the issue of providing a time limit on the patient's life expectancy. Acceptance or utilization of
this information depends on who it is presented to and the nature of communication within the family. If the family is denying the gravity of the situation the issue may never come up, although family members may sometimes wonder to themselves about medical expectations. One wife admitted, "We don't deal with it realistically, we avoid it. We continue to make future plans. We have to to get through it. I have to talk to my husband optimistically. I can't really tell him my real fear. I've never been able to ask the doctor, 'How long do you predict he'll live?' I've often thought of asking, but I've never had the nerve to. I don't know if it would help."

While this wife was ambivalent about her own desire to know, she indicated that she would not want her husband to be informed of a time limit on his life expectancy. There was a striking consensus in our sample on this issue: every spouse who had been given such a time limit refused to allow the patient to be so informed. Even in families that had otherwise open communication regarding the illness and their feelings, there was a refusal by spouses to share this type of information. Typical of their reasoning was this wife's: "We had a family conference after the second surgery, the children and I sat down and had a family conference. My son said, 'Mom, it's his body, and his life and he's to know everything'. I put my foot down there. If they set a time limit on his life, he will not know that. My son said 'Mom that's not fair' I said yes it is...if they tell him he's got six months to live and he lives that six months then every day from there on
in he's going to wonder if this is his last day. Then my son agreed. I still feel that way."

When asked how she would handle being given a time limit, this spouse responded, "Well, none of this gets back to him? They have told me...it looks like one to two years, at the rate of growth of the tumors...I'm dealing with it one day at a time, and still believe he should not be told. Because each day brings us all closer to death, but you look at your life as if you're going to live for a long time...and I wouldn't want them to tell me 'You've got three months to live.' I would want them to tell me I was ill, I would want to know what was wrong with me and what could or couldn't be done about it. But I would not want them to set a time limit on my life because I don't believe they can do it...He should know how serious it is, but no time limits!"

Much of the same reaction is evident here, with the added dimension of the effect such knowledge had on the spouse: "There's been nothing I've kept from him except that in the beginning they said three to six months. I felt that's something he didn't need to know, and by keeping it from him it helped. He's known everything but the time limit. I don't like the idea of a time limit. They'll never put a time limit on my family ever again! He's lived longer than any pancreatic cancer patient across the country. He doesn't know that, all the doctor will say is 'you're doing very well.' [My husband] just smiles. We're not keeping a secrets, if he had known, he might be gone. This way I've had four years with him. I've lived with him for 18 years--I didn't think
he could cope with it. I've never regretted not telling him. Look at what he's done. There's no advantages to telling someone a time range. Tell the patient and family what's found and how to treat it. Don't keep the truth from them. I've lived four years with the idea that we only had three months."

According to these spouses, being given a time limit had no advantage and presented several difficulties for them and potential difficulties for the patient. In contrast, the one patient who acknowledged that he had been informed of a maximum life expectancy of one year had a much different reaction. Asked how he felt about being told of such a time limit, he responded,"I think they were trying to be honest with me. I appreciate that. I think it shouldn't be hidden from a person. In my case, with three small children and a wife with no other means of support, I appreciate being told so I can make some plans and arrangements for them. I'm thankful even for the twelve months so I can have time to make these plans and arrangements. I haven't given up, I have hopes of being cured, but I have to face reality too, along the way."

It must be noted that this patient's openness and willingness to view his rather dire situation realistically was somewhat unusual. Relatively few patients facing a similar prognosis seemed willing to pragmatically approach the tasks that lay ahead. Several patients did attend to updating wills and property titles and even discussed funeral preferences, but these were usually patients with somewhat brighter prospects. Others seemed unwilling to acknowledge that these were realistically impending concerns,
and refused to discuss them even if they were brought up by a concerned spouse. The need of these patients to avoid such anxiety-producing reminders of their vulnerable condition precluded their taking part in preparations associated with the possibility of their death.

**Informing Children.** Another issue concerning family communication is the amount of information provided to children. The basic dilemma faced by parents was a conflict between the desire not to hide things from children and thereby risk a traumatic shock if the patient's condition suddenly deteriorated, versus the desire not to upset them unnecessarily. Almost all parents favored informing children of at least some aspects of the patient's condition.

There was a strikingly common reasoning behind the decision to inform: even young children would usually realize that something was wrong, given their parent's absence while hospitalized, changed appearance, or altered physical or emotional state. If they were not informed, according to most parents, their assumptions about the situation were usually much more upsetting than reality.

Providing accurate information, in terms the child could understand, was felt to ease anxiety by checking the effect of run-away imagination. Said one patient, "My kids knew something was wrong before the diagnosis. Rachel (age 3) thought they were going to cut my tongue off. I told her they were only going to take the 'ouchie' part out and prepared them for what to expect. It made it a lot easier for them knowing exactly what's going on, because when they're little they get pretty goofy ideas sometimes about what's
going to happen."

In addition to limiting children's conjured up fears regarding the illness and its treatment, open communication may avoid misunderstandings in the home regarding a parent's altered behavior. As one patient put it, "I told them right away. I was crying a lot and didn't want them to think all these horrible things that kids can think was possibly wrong, or think I was mad at them or something." Another continued in this vein, "It's easier to be honest. For example, there are times I can't go to school functions, but she (daughter) understands what treatments do to me. She's disappointed, but she understands. It would be hard to live in a home where the child did not know about treatments, did not know why you were ill. They could interpret things differently. Treatments really bring me down, but she understands that. Otherwise she might have much more fear that it was something much worse."

While almost all parents agreed that children should be informed, most emphasized that information should be couched in terms they understand, and that unnecessarily stressful details should be omitted. Most patients, for example, did not describe particularly painful procedures or the possibility of death with their children, especially those school-age and younger. Illustrative comments included, "Kids, when they don't know, are much more scared than when they do. I don't tell them about all the painful procedures...but...kids are like anybody else. Once you understand what's going on, it's not so scary." Or more
bluntly, "The little one doesn't know. He knows I have cancer, but he doesn't know I'm going to die."

On a less threatening level, some patients altered the facts sufficiently to acknowledge physical problems but avoided detailed discussion of the situation. For example, one mastectomy patient explained to her preschool son that she had to wear a sling for her broken arm. This satisfied the boy's curiosity without requiring an explanation of breast cancer and surgery.

Hospitalization caused concern in several mothers of young children over maintaining the child's daily routine. While the mother was in the hospital, these young children tended to test the limits with those put in charge of their care, and often found that they were not as tightly disciplined as usual. This sometimes led to a period of readjustment when the mother returned home. Said one such mother, "When I get home it takes a few days to readjust to the rules and get them back in line. I don't let them get away with as much." This pattern was of special concern of mothers who faced repeated hospitalizations, such as those on monthly chemotherapy regimes. One of these mothers explained, "I'm not home long enough to establish a pattern. Things are disrupted constantly which makes it hard for them to understand when I try to discipline them. They don't listen to me like they used to. Kids need norms or patterns to know the rules. They're no longer certain of the limits with me and are no longer as obedient."

Another mother's attempt to solve this problem was to write down explicit instructions for those taking care of her children in
order to maintain as normal an environment as possible. The key as she saw it was to maintain their daily routine and introduce as few changes as her condition would allow.

Most parents, however, did report behavioral changes in their children related to their illness. Many perceived their older children as more affectionate and more considerate. Others reported a variety of different reactions. One patient's 7 year old daughter became quite angry with her mother when informed that she must go in for surgery. Other children showed fear not only of what might happen to their parent but of "catching" the disease themselves. They avoided physical contact with the patient and even of articles the patient had touched. It took open discussion of the nature of the disease and the passage of time to dispel the myth of contagion in these families.

It was difficult to determine whether some of the behavioral changes in children were due to their parent's illness or to normal developmental changes. One mother reported that her five year old son became "preoccupied with death" as evidenced by a rash of questions about cemeteries and the statement, "I think daddy's going to die." Although such moments were difficult for her, the mother managed to acknowledge her son's fears and reassure him that they were doing everything they could to help his father.

A more indirect behavioral change which may have been related to the father's cancer was the extreme perfectionism displayed by an adolescent male. He became obsessive in his own standard of performance in almost all areas, and was extremely critical of
others who did not so strive for perfection. Considering his father's deteriorating condition and a conflictual family environment, neither of which could he escape or change, it seemed that this boy was exerting maximum effort in those areas of his life which he could control. Realizing this fact might have made it easier for those around him to accept his constant striving and tolerate his frequent criticism.

In sum, children showed a variety of reactions to their parent's cancer, both positive and negative. The consensus among parents was that children, like adults, adjusted better when provided sufficient information. In the words of Fiefel (1976), "Seemingly, the unknown can be feared more, at times, than the most dreaded known reality." (p. 7)

Work, Productivity, and Physical Decline. A major concern for patients and spouses of both sexes centered on work and productivity in the face of physical decline. The most obvious result of an inability to work was the loss of an ongoing income, and many patients and spouses expressed concern about financial affairs, especially medical expenses not fully covered by insurance. Yet even more common were comments reflecting job related concerns which were not directly monetary. Especially for male patients, these concerns most commonly involved the pride and self-esteem which had been associated with their work, and which they now sorely missed. These concerns were sometimes associated with an unsavory sense of dependence, as in, "It gets to the point where you get disgusted. You can't do your work like you used to. 
I used to work hard, and I hate to have to depend on others to do my work for me." Such comments reflect the loss of status, satisfaction and self esteem associated with the provider role described by Lambert (1974).

Both male and female patients viewed work as an opportunity to get out of the sick role or to take their mind off of their disease. As one woman put it, "I was glad I was able to go back to work...That helps me a lot because when I'm at work I don't think about being sick. I don't feel like a sick person." Another woman emphasized, "I feel better on the go, instead of sitting around brooding. When I went back to work, many times I'd forget about this, I'd be so busy. That's why I wanted to go back to work, to keep my mind occupied."

Work also provided benefits to several female spouses during stressful periods. Besides an often much needed income, work offered stability, self esteem, and sometimes a brief escape from the stress of family life with a cancer patient. These points are illustrated in this wife's comments, "He recently said, 'When I come home, you won't be able to go back to work.' (But then I thought) I have to go back to work. I have to have my job. It's only part time, but it's a stability I have to have in my life. It provides me with more than just an income. It's my only outlet. Its the only time I'm out of my house. If I stayed in the house with [my husband] every day...I'm afraid that at some point I might grow bitter towards him because he leans on me so heavily, and I don't want that. Work is the only thing I can find that is
excusable. Everything else I feel guilty about."

Physical decline caused concern over a lack of productivity in other areas besides work. Not being able to fulfill one's former duties in the home also led to frustration and anxiety. Husbands and wives both lamented the loss of domestic roles. Sometimes their roles were obviously missed by the family, which resulted in general family distress. However, some families seemed to adjust almost too well to the loss of the patient's role enactments, which itself induced anxiety in the patient. It was as if during their absence the family had closed ranks on the patient, reallocating roles to the point where there was no longer a needed position for the patient. This was more common in families with older children who were capable of taking over some of the patient's roles. In one such family, the teenage daughters turned out to be quite capable of enacting their ill mother's domestic roles, and the family routine proceeded almost undisturbed. Yet this pattern had a disturbing effect on the patient, causing her to question whether she was actually needed in the family system. As the patient noted, "Because just like I said yesterday, the one daughter was making chili at the kitchen stove and the other daughter was doing the laundry. And there I sat reading the Sunday paper. Well it made me wonder why I even went home."

This particular patient more or less resigned herself to her closed out position in the family. She did not have the physical capability to reclaim any of her former roles. Other patients, however, made an ongoing effort to keep from being overly limited
by their families and to reestablish themselves in the family role system. After being repeatedly told by her daughters the many things she must no longer do around the home, one patient finally asserted herself and made explicit her range of abilities and intention to pursue her former roles.

**Existential Concerns.** Occasionally work and productivity concerns were embedded in more existential issues. One man stated that he missed work in terms of the opportunities for accomplishments it provided, then added, "Look at what I could have accomplished if it hadn't happened to me." This existential concern for accomplishment was not limited to the breadwinner role, as illustrated by this woman's concerns:

"I have a lot of time to think and I ask myself 'what have I done with my life?' I've been busy. I've spent 20 years raising children and enjoyed it. but they're grown, and now I could be doing something else. But now I can't. I think, 'maybe I should have done more good.'...I can't do the volunteer work I used to do...so I'm not doing anybody any good. I'm going to leave this life and what did I ever do? What have I accomplished?...I haven't done anything good. I enjoyed my children and my home, but it went by so fast, and then after it ended, here I am on my back, worrying my family to death. I can't stand being a burden and I can't stand people feeling sorry for me. I feel like I should do my part. I think over and over, what have I done. Maybe I'll have some more time and get to do some of these things."

The most common existential concern centered on the question,
"Why me?" Although most patients and spouses seemed to realize on an intellectual level that neither they nor anyone else deserved cancer, at an emotional level the apparent unfairness of the situation was difficult to accept. Said one patient, "I feel cheated. I know it's wrong, but I think, 'what have I done to deserve it?' when I know deep down that this is really not true, because nobody does anything to deserve it." Added another, "I don't think it's fair. I don't understand why. There's so many things I'm going to miss..." Spouses reflected this feeling as well, as in, "It doesn't seem fair or right. My wife has so much to offer, why her? She tries so hard to help others." This sense of unfairness usually resulted from a contrast of the patient's virtues with less virtuous yet healthy others. The apparent randomness with which the disease struck seemed to heighten anxieties about lack of control. "How can you be so healthy and then, wham, you're in the hospital with what you think is a ruptured appendix and you find out you've got something nobody can cure?" was one woman's question.

Others felt that they had done what they could to prevent the disease and were struck anyway, resulting in a painful sense of helplessness, as illustrated here: "I have feelings of anger about this disease. I know that there are no rules in life, but I feel like I've done things to protect myself against cancer. Although I have my own genetic theories on the disease, so I know I don't have control along those lines, but whatever control I do have, I've made efforts to insure that I don't get it. I go through the 'why
me' syndrome. There's no answer to that but I'm still angry."

This sense of helplessness and impotence were especially evident at the time of a recurrence. This may be the most stressful event for many patients (Silberfarb, Maurer, & Crouthamel, 1980), especially those who had actively striven to ward off the disease. A patient described such an event: "This time was different. Since the first time I was sick, I have completely changed my lifestyle in that I have become very athletic and changed my diet, for example off salt, sugar, fried foods, more fiber, and so on, with the idea of bringing my body to peak condition. When I first got sick I was a fast food junkie, didn't understand nutrition, didn't exercise. I decided that in life there are some things you can control and some things you can't, but one of the things that was within my power to control was my fitness, and I felt that this would help. I'm at such a high level of fitness given my medical problems that everybody, including my doctor, could not believe that I was having another episode. My first reaction was, 'What do I have to do to stop it?' (tears) If you get your body in peak condition and you're vigilant as hell and you still get it...its a bigger blow."

In the face of such helplessness, some patients were angry and bitter. One such patient thought of a cardiac patient who was neglecting to follow the orders of his doctor. Her bitterness and despair were evident as she said, "If he dies it's because he didn't follow the rules they gave him. I have no rules. I don't have any control over anything!"
In contrast to the anger, frustration and helplessness felt by many patients and spouses, some actually felt that they had benefitted in an existential sense. These were typically patients with relatively little physical suffering and for whom the prognosis was somewhat more optimistic. Most common were incidents of a reexamination of values and life styles, with a new emphasis on what seemed more truly important in their lives. Said one such patient, "Before, we were into a lot of things that didn't mean too much. But you have to have your priorities in life. Now we only do things that are really important to us. We rule our lives instead of letting our lives rule us. You can get really wrapped up in the world, but when you stand back after something like this and think 'are those things really important?', often they're not."

Religion.

A framework for some patients' and spouses' existential questions was sought through religion, with varying degrees of success. In the face of overwhelming helplessness, some patients seemed to find comfort in abdicating all control to God, believing He would provide for and protect them. Many clung tenaciously to their beliefs, apparently in great need of the certainty and structure they provided. But upon closer examination, some revealed unanswered questions and deep-seated doubts. Their religious beliefs failed to offer solace for what appeared to be undeserved suffering. One spouse's suffering was apparent as he stated, "She's too good a person to be wasted. [My wife] is not that much of a God-fearing person, but that's never been any
problem between us. But [she] never sinned and knew it, she's that
good a person. She's perplexed when people want to pray for
her...I believe in prayer. I believe that you get your own
punishment on earth, and I've believed that for so many years, but
this is beginning to defy my religion. It's beginning to let me
down because that's not happening; somebody's getting punished when
she didn't earn this. That's on my mind and I feel guilty about
it. It defies everything I've always believed in religion. She
does not deserve such punishment...I'm just as religious as I've
always been, but I feel let down. It's not materializing. I don't
believe in asking for things in prayer, but I haven't prayed as
much as I should. Is there a chapel here?"

Not only did religious beliefs sometimes fail to comfort and
support patients and their families, but they were occasionally
manipulated so as to provide a scapegoat for what would otherwise
be unexplained suffering. Such was the case with one spouse who
said, "His parents blame me, partly out of religious differences.
Because I am not of the exact same religious beliefs, the disease
is my fault. I'm not as religious as he is. I'm not a discusser
of my faith. They have made an issue out of it. They were looking
for a target, and I'm the easiest one."

Thus organized religion had a mixed impact within the present
sample. Some patients and spouses seemed to find genuine comfort
and support in religion during the stressful periods they faced.
Others found their beliefs of little comfort because they failed to
justify or explain the suffering they faced. Still others, few in
number, found themselves to be victims of a form of religious persecution, adding to an already stressful situation.

Guilt. Religious uncertainty was one of several sources of guilt reported by patients and spouses. One of the spouses quoted above after doubting his religion began experiencing guilt over his doubts. He also seemed to feel guilty over not praying sufficiently, as if his wife's suffering was somehow the result of his negligence in prayer. He and other spouses also reported guilt over concern for their own well being at a time when the patient was ill. One such guilt inducing concern was the presence of physical symptoms in the spouse. A husband reported, "I can't believe how guilty I felt thinking about my own pain rather than her situation, which was much worse. I mean, she's going to die."

Other spouses were quick to label any ponderance of their own stress as self pity, and experienced guilt for not being wholly focused on their spouse's condition. Even when it was suggested that they could not completely ignore their own needs and expect to continue to support the patient, such spouses stoically maintained that they shouldn't think of themselves in such a situation.

In contrast to this self-generated guilt, one spouse described her husband's attempts to induce guilt and manipulate her and their children. He insisted on her constant presence and claimed that he would sleep much better if she was there, implying that her absence was a prime cause of his sleeping difficulty. She felt that if she did not firmly set limits, his helplessness would continue to spread into other areas until he was completely dependent on her.
Thus unlike the stoically self denying spouses just described, this woman was stoically resistant to her husband's manipulations, partly for his own good and partly for her well being. As she observed, "But if I get sick, there's nobody left to run this show."

The major source of guilt reported by patients stemmed from perceiving themselves as burdens who were impeding the lives of their family. In contrast to the patient just described who attempted to induce guilt and thereby manipulate his family to succumb to his dependency needs, another patient took the opposite tack because of her own guilt. As she described it, "I made my family go on vacation this morning. They need to get away. My husband said 'I really don't want to go...' but he needs to get away. I said 'don't make me feel like I've ruined everybody's vacation on top of all the other things I've done'...like causing all this worry and stress. It's not guilt, because I know I didn't do it deliberately. It's just there, it's changed how we all are...well, I guess I do feel that way (guilty)."

Recognizing that they had not intentionally contracted cancer and were powerless to alter it did little to assage the guilt these patients felt, as in one woman's comments: "I don't want my illness to hold up their lives. They have long lives to live way past when I go. What I've felt all along is this guilt that I'm disrupting their lives. It's stupid because there's nothing I can do about it. I do everything I can to keep my health, it's not as if I neglected my health. But I feel like they depend on me psychologically as a supportive person...so they've always counted
on me. I think that's a role a mother should play."

This woman saw herself as the strength of the family in many ways, and thus felt not only as if she were holding up her children's lives but was letting them down as a source of support. Even in her weakened condition, she expected herself to support her family, and had difficulty being the supported one.

**Body Image and Sexuality.** Several types of cancer and cancer treatment were the cause of problems with body image and sexuality. These problems ranged from anxiety over hair loss and attractiveness to concerns about sexual capabilities.

Loss of hair was common among several patients on certain chemotherapy regimes, and elicited a variety of responses. Some male patients mentioned that they were mildly annoyed about the hair loss and change of appearance but claimed that this was the result of vanity and tried to discount its importance. Others were openly anxious over their baldness, to the extreme of one woman who stated that this had been the most stressful aspect of her entire cancer experience. As she put it, "Even going through surgery and knowing that I might die with my cancer didn't bother me as bad as when I walked past the mirror and saw my bald head. I would cry every time."

A common permanent body image change took place for mastectomy patients, who also showed a variety of reactions. Several women directly or indirectly admitted to difficulties in coping with this change. One such patient stated she had always enjoyed having an nice figure, and through working with the public in her job,
enjoyed having men flirt with her. She admitted that it would
"hurt her ego" not to receive this attention. Another indirectly
indicated that she had concerns about body image and the reaction
of others by describing the effort she expended to keep her
mastectomy a secret.

Other mastectomy patients seemed to be greatly assisted in
their adjustment by the reactions of their husbands. One such
patient described her acquaintance with four other mastectomy
patients at the time of her operation, all of whom had since been
left by their husbands. She, however, was very secure both in her
marriage and in her body image because of her husband's direct
verbal assurances that her loved her and had married her for that
reason, not because of her body. Another spouse described his
reaction to his wife's urostomy and appliance. His wife felt at
first that she would be repulsive to him sexually, but he verbally
reassured her otherwise, then added, "...my actions speak louder
than anything I could say...When she recovered enough that we
could have sex, we just continued in the same way as much as possible."

Other patients and spouses did report changes in sexuality.
One male patient stated that he had completely lost his sex drive.
He thought, "Maybe its because I'm weak, you kind of lose your
momentum for it...and its a psychological thing too, whether you
want it or not. Because there's days I feel good but still don't
want to have it. It's all related to having cancer. It sticks in
the back of your mind, 'I'm a cancer patient, so I can't have
sex.'"
The wife of another patient also reported a decrease in her husband's sex drive, but also described an accompanying decrease of physical affection, which she found even more frustrating. She to some degree associated affection with an expression of gratitude for her efforts to support her husband, and felt unappreciated by his lack of such expressions.

Female patients also reported a loss of sex drive in their husband's, a change which both perplexed and troubled them. These women also distinguished between sex and affection. One woman, who indicated that she was receiving neither, made it clear that it was the affection she missed most. Another woman indicated that her husband was still physically affectionate, often holding and hugging her, but had virtually no sexual desire. She felt that he perceived her as very fragile when she was ill, and was afraid of hurting her. Although she thought that the fragility was "more in his mind than real", his sexual interest and aggressiveness had completely died. Such responses are consistent with the findings of Leiber, Plumb, Gerstenzang and Holland (1976) who reported that cancer patients of both sexes and their spouses reported an increased desire for physical affection along with a decreased desire for sexual intercourse.

Other women were concerned about changes in their own sexual capacities. Some faced the prospect of bearing no more children. Those with cancer of the pelvic region were concerned about sexual responsiveness and ability to engage in intercourse. Some indicated that there was little medical advice available about
these topics, and that some of their questions remained unanswered. **Summary and suggestions.** The preceding has highlighted some of the common themes running through the interviews of a variety of cancer patients and their spouses. Whereas the preceding portions of this dissertation have focused primarily on the internal dynamics of the family system, this section has also addressed the important interface between the family and the health care delivery system. It is from this perspective that the following suggestions are offered.

The most common and strongly stated theme throughout the interviews was the patients' and families' need to know, and the variety of stresses which accompanies the uncertainties of cancer. Providing accurate, understandable information at the time it is requested appears extremely useful in allaying the anxiety associated with many of the causes of this uncertainty. Patients often cited being informed as much as possible about what to expect in the way of prognosis, tests, routine hospital and medical procedures, treatment effects and side effects and other aspects of life as a cancer patient as among the most helpful and appreciated activities medical staff could engage in. One patient commented that those responsible for her transportation, the aides who wheeled her to various tests and procedures, were perhaps the most helpful staff she had encountered because of the information they could provide about upcoming medical events. Patients could be more thoroughly and uniformly informed if primary care personnel routinely took responsibility to provide such information.
Whoever provides this information will need to realize that for a variety of reasons, patients and family may not be able to comprehend or assimilate all that they are told in a single briefing. Patients may be overwhelmed with too much information at once, may not have the vocabulary or knowledge base to understand the disease or treatment, or may engage in denial as a defense against the threat of what they are faced with. Whatever the reason, information may need to be offered a number of times before understanding and assimilation occur. Health care personnel should also avoid equating a lack of specific questions with a lack of desire to know or as possession of sufficient information. Many patients and spouses either do not know enough about the topic at hand to ask a reasonable question or are too unassertive to ask questions they do have. Rather than appear foolish or risk a negative response from staff, these individuals remain uncomfortably uninformed in silence. Initiating discussions which offer opportunities to ask questions may be achieved by asking if they understand as much as they want or if they are uncertain about any aspect of the disease or treatment.

These small promptings seem more appropriate than forceful presentations of information which the patient or family did not request and is reluctant to pursue once initiated. To do the latter runs the risk of stripping away what may be a necessary period of denial. Although denial has gained a generally negative connotation, especially in the popular literature (Kubler-Ross, 1969), it is sometimes the only effective defense an individual has.
against an otherwise overwhelming situation. To take away this defense without replacing it with another effective coping strategy is to put the individual, and the family, at greater risk for trauma.

The foregoing suggestions are based on the premise of open communication throughout the interacting systems of medical staff and family. Experience suggests that this is not always the case. Glaser and Strauss (1968) describe degrees of communication from open awareness through closed awareness, where different components of the staff-family-patient triangle either share or withhold their awareness of the true situation. The various forms of closed awareness provide distinct problems for the individuals in different parts of the systems. Physicians who forbid patients or family members to be informed place nurses and others responsible for care in a potentially stressful bind. Nurses must be mindful of what or how much each patient can be told, if family can be told more than the patient, or vice versa, and so on. This can add greatly to an already stressful work load, especially when patients or families ask direct questions about forbidden topics, or suspect that they have not been "leveled" with and attempt to gain support for their suspicions. Similar difficulties are experienced by spouses who face the formidable, if not impossible, task of controlling a number of verbal and nonverbal cues if they are to hide the truth from a patient who is suspicious of the prognosis (Glaser & Strauss, 1966). Tension may result in the staff and family systems, ultimately disrupting the functioning of both.
Even if communication is essentially open in both the staff and family systems, lack of coordinated efforts by the health care team can result in misleading and conflicting information being presented to the family, resulting in confusion and anxiety. Krant et al (1976) suggest group conferences between staff and family, allowing for an exchange of questions and information. Whenever possible, a continuity of care by the same staff members would help eliminate conflicting or confusing communication, in that those who are personally familiar with the case could orchestrate the flow of information among staff and between staff and family.

Another useful suggestion by Krant et al (1976) is the rehearsal by other family members of roles which the patient can no longer enact. While open communication is necessary for such activity, effective role rehearsal may be slow and difficult to achieve because of the nature of "limited linkage" (Magrabi and Marshall, 1965). This concept refers to the fact that long established patterns within human relationships enhance or impede the attainment of other patterns at a subsequent time. A long dependent, ineffectual wife whose dominant, overprotective husband can no longer fill his former roles, may have great difficulty in assuming the instrumental tasks now abandoned. Conversely, The authoritarian, aloof father whose wife can no longer provide for the affectional needs of the family may have a difficult time fulfilling the expressive roles now lacking. In contrast, families which have had greater role flexibility in the past may respond more quickly to role rehearsal in that their prior experience has
enhanced their attainment of a reallocated role pattern.

Existential concerns maybe one of the most difficult areas for health care professionals to address. One reason for this is that there are no real answers to the variations of the question "Why me?" After a patient or family member has explained all the reasons he should not have gotten cancer, and reflected on the number of people more deserving of such a fate, how is one to respond? One must agree that it is not fair, that the patient did not deserve such suffering and loss. Acknowledging that there are no easy and universal instructions for dealing with these questions, there are some guidelines provided by the interview data which might prove helpful.

First, health care personnel should avoid inadvertently implying that the patient may actually deserve cancer or be responsible for its occurrence. References to too much smoking or delay in seeking treatment are of no comfort to someone facing existential depression. Instead one can emphasize the control the patient does presently have. He or she can seek treatment, can control diet, can reduce smoking, or can refuse further treatment. An emphasis on present control can be made concrete by allowing the patient to determine as much as possible the course of his or her day. Such things as the time of bathing or other non-critical procedures which can be approached with some flexibility may give the patient a sense of self control he or she has in few other areas.

Another tactic to avoid is blunt confrontation that "things
could be worse". It seems of little comfort to someone in a dire situation to have pointed out that someone else is suffering even more. What can be done effectively is to help the patient refocus on the positive aspects of life still available. The presence of family or friends, the ability to experience an important event like the marriage of a child or the birth of a grandchild, or even the ability to control pain, may be discussed in an attempt to interrupt ruminations over depressing subjects.

Sometimes all that can be done is to acknowledge the patient's or family's existential plight. Allowing the ventilation of feelings to a noncritical listener who does not quickly change the topic or flee the scene to protect their own vulnerability may provide what little relief is available to some of the more frightening aspects of cancer.

Finally, the current structure of our hospital based health care delivery system is in many ways inadequate to meet the psychosocial needs of cancer patients or their families. As Krant et al (1976) point out,

The enormous growth in medical technology has tended to accentuate disease oriented care as opposed to person oriented care. Hospitals are remarkable efficient places for the management of disease states, but often times do not consider family members as essential primary targets for concern and intervention when a fatal illness, and especially when a terminal period, envelops a group. The nature of the hospital system is such that family members play an entirely secondary role to that of the patient, but even so, suffer a sharp discontinuity in their relationship with the institution when the particular family member, as patient, dies.

The physician is essential to a family-centered effort of this type. It is essentially for his services that the patient and the family have come. His guidance and advice in the matter of interventive help during this period of losing and bereaving can be
crucial. In their training, many physicians feel that they have inadequate skills, and inadequate time, to deal with the many psychological and social issues in patients and their families. A trained staff dealing mainly in these areas, especially with family members, can be of significant assistance when the physician emphatically grasps what they are trying to do. It is our hope that physicians will come to appreciate the deep 'pain' associated with fatal and terminal illness for family members, as well as the patient, and will harness resources to help such individuals" (p 303-304).

Suggestions for sweeping revisions of the modern hospital system are beyond the scope of this work. However, greater sensitivity to the psychosocial needs of the patient and family on the part of hospital staff functioning within the current system may reduce the level of suffering until such revisions can be ascertained and implemented.
References


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Appendix A

The Utility of Qualitative Data
Qualitative data is often useful in its own right, especially in the early stages of investigation in a particular area. Neimeyer and Resnikoff argue that the bias against qualitative research methods rests on at least two misconceptions. One is the issue of representative sampling. It has been claimed that analysis based on qualitative data are insufficient for scientific generalization (Lindberg, 1926). Yet inferences derived from any sampling procedure must be carefully restricted. Qualitative and quantitative approaches handle the inferential process in different ways: Quantitative methods rely on statistical sampling, while qualitative techniques rely upon theoretical sampling. Lindberg states,

"Theoretical sampling, in which the researcher studies individuals with certain characteristics and generalizes only to that population, can provide as much external validity as statistical sampling. Therefore, the wholesale dismissal of qualitative methods on the basis of the nonrepresentativeness of their sampling is unwarranted. Moreover, it obscures the fact that the informed and judicious application of theoretical sampling can provide a rich source of data for both heuristic and scientific purposes, even when the sample size is very small." (p. 78)

The second common criticism of qualitative techniques is that they do not permit causal interpretation. Experimental studies attempt to establish causality by direct comparisons. Typically, the researcher constructs two or more similar groups, deliberately exposes one to the hypothesized causal agent(s) or independent variables, and looks for resulting differences or effects. If the effects are present only in those groups so exposed, and competing
causal agents can be ruled out, then causality can be inferred. In contrast, many qualitative techniques employ analytical induction to establish causality. Essentially the researcher compares groups exposed to the hypothesized causal agents with those not so exposed, much the same as in experimental designs. In this case, however, the researcher does not actively control the variables under consideration. Rather, he or she looks for cases that resemble those at hand in all respects but the suspected causal agents, and then determines whether the effects exist in the absence of this agent. Thus one is searching for empirical instances which negate the causal hypothesis.

This type of research method is appropriate to the present topic, where the hypothesized causal agents of cancer and its repercussions could never be deliberately imposed in a "controlled" manner. Given that qualitative techniques will provide useful data that would be neglected by an exclusive reliance on quantitative methods, it must be recognized that much of this data cannot be approached in terms of a prior hypotheses. Far from being a deficiency in methodology, this fact actually presents certain advantages.

"Based primarily on a deductive approach, more traditional methodologies necessarily limit their investigations to a set of preconceived hypotheses concerning the relationships among events. These hypotheses can provide clarity to the study, but by eliminating other, perhaps more viable options, this approach may occasionally contribute to the study of trivial variables. In contrast, qualitative research methods allow meaningful research hypotheses and tests to emerge from the data itself. Thus they entail, 'a continuous movement between emerging conceptualizations of reality and
empirical observations' (Denzin, 1970, p. 186). This closely parallels the revision and recasting of experimental hypotheses which characterize more deductive approaches. Qualitative-inductive methods differ though by not establishing a prior restrictions on the hypotheses to be tested, by permitting subjective, non-quantifiable data, and by preserving the continuity of the ongoing behavior under study." (Neimeyer & Resnikoff, 1982, p. 77).
Appendix B

Modified Washington Family Role Inventory
1. Who in your family currently does the following tasks?

<table>
<thead>
<tr>
<th>Task Description</th>
<th>One of my Children</th>
<th>Another Relative (Sister, brother, Aunt, Uncle, etc.)</th>
<th>Friend or Neighbor</th>
<th>Community Service</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Earning the family income.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Housekeeping</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Keeping in touch with relatives.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. Organizing family recreation.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. Taking care of preschool children</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. Teaching, helping and disciplining GIRLS, age 6-12</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>BOYS, age 6-12</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

2. To whom, if anyone, do you talk to about your own problems?

<table>
<thead>
<tr>
<th>Person</th>
<th>Frequently</th>
<th>Occasionally</th>
<th>Seldom</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Son or daughter.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Other family member.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Friend</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. Counselor or others.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
3. How well are the following things done in your household now?

4. Organizing and helping with family recreation.

<table>
<thead>
<tr>
<th>Rating</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never gets done</td>
<td>1</td>
</tr>
<tr>
<td>Much below average</td>
<td>2</td>
</tr>
<tr>
<td>A little below average</td>
<td>3</td>
</tr>
<tr>
<td>About average</td>
<td>4</td>
</tr>
<tr>
<td>Above average</td>
<td>5</td>
</tr>
<tr>
<td>Unusually good</td>
<td>6</td>
</tr>
</tbody>
</table>

5. Earning a living.

<table>
<thead>
<tr>
<th>Rating</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not employed outside home</td>
<td>1</td>
</tr>
<tr>
<td>Much below average</td>
<td>2</td>
</tr>
<tr>
<td>A little below average</td>
<td>3</td>
</tr>
<tr>
<td>About average</td>
<td>4</td>
</tr>
<tr>
<td>Above average</td>
<td>5</td>
</tr>
<tr>
<td>Unusually good</td>
<td>6</td>
</tr>
</tbody>
</table>

6. Keeping in touch with relatives

<table>
<thead>
<tr>
<th>Rating</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Never gets done</td>
<td>1</td>
</tr>
<tr>
<td>Much below average</td>
<td>2</td>
</tr>
<tr>
<td>A little below average</td>
<td>3</td>
</tr>
<tr>
<td>About average</td>
<td>4</td>
</tr>
<tr>
<td>Above average</td>
<td>5</td>
</tr>
<tr>
<td>Unusually good</td>
<td>6</td>
</tr>
</tbody>
</table>

7. Taking care (or took care) of small children

<table>
<thead>
<tr>
<th>Rating</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Much below average</td>
<td>1</td>
</tr>
<tr>
<td>A little below average</td>
<td>2</td>
</tr>
<tr>
<td>About average</td>
<td>3</td>
</tr>
<tr>
<td>Above average</td>
<td>4</td>
</tr>
<tr>
<td>Unusually good</td>
<td>5</td>
</tr>
<tr>
<td>No small children now</td>
<td>6</td>
</tr>
</tbody>
</table>

8. Teaching, helping and disciplining children, age 6-12.

<table>
<thead>
<tr>
<th>Rating</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Much below average</td>
<td>1</td>
</tr>
<tr>
<td>A little below average</td>
<td>2</td>
</tr>
<tr>
<td>About average</td>
<td>3</td>
</tr>
<tr>
<td>Above average</td>
<td>4</td>
</tr>
<tr>
<td>Unusually good</td>
<td>5</td>
</tr>
<tr>
<td>No children this age</td>
<td>6</td>
</tr>
</tbody>
</table>
9. Do you ever worry or feel guilty about how you do each of the following activities?

<table>
<thead>
<tr>
<th>Activity</th>
<th>I Worry Frequently</th>
<th>I Worry Sometimes</th>
<th>I Never Worry</th>
<th>I Have Never Done This</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Housekeeping.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Keeping in touch with relatives</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Helping with family recreation</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. Earning money for the family</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. Caring for small children</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. Teaching, helping and disciplining children</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

10. How often if there is disagreement in your family about each of the following activities?

<table>
<thead>
<tr>
<th>Activity</th>
<th>Never</th>
<th>Seldom</th>
<th>Sometimes</th>
<th>Frequently</th>
<th>Very Frequently</th>
<th>Never Had Children That Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Housekeeping.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>2. Earning money</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>3. Visiting or writing relatives</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>4. Recreation.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>5. Sharing problems with each other</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>6. Care of preschool children</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>7. Teaching and disciplining GIRLS, age 6-12</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>Boys, age 6-12</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
</tbody>
</table>
11. We would like to know how you feel about taking part in each of these roles (activities). Assume that if you didn't do the task, someone else would do the task for you. Please circle the answer which best describes how important or unimportant it is to you that you take part in the activity. If you have no children now, please think of how you would feel if you had children.

<table>
<thead>
<tr>
<th></th>
<th>Very Important To Me</th>
<th>Quite Important To Me</th>
<th>Some Importance To Me</th>
<th>Little Importance To Me</th>
<th>Prefer Not to Do It</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Housekeeping</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>2. Earning an income</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>3. Visiting and</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>writing relatives</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Getting family</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>recreation started</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Taking care of</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>your preschool</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>children</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Teaching, helping</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>and disciplining</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>your children 6-12</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

12. If you work for pay (or usually do), what is your job? (Check here ______ if you do not work. And go on to #14)

   JOB _____________________________________________________________________________

13. How many hours per week do you work? HOURS: ____________

14. What is your current level of income?
   $______ per ________

15. What are your current sources of income?
   _____________________________________________________________________________
   _____________________________________________________________________________
   _____________________________________________________________________________
   _____________________________________________________________________________