death; spouses' focus also changed according to which task their husbands or wives had to face. Generally, spouses' focus did not differ, according to patient group, as much as the patients' focus did. Spouses described more uncertainty even when their husbands or wives were able to describe the inevitable outcome. Reported in the following section are the results of comparing the types of work of patients and spouses. The comparison includes a review of the objects of their work, and the similarities and differences in work type and resources for both patients and spouses.

Patient and Spouse Work

Patient and spouse work was compared according to the object of the work. The work is directed toward these different objects: self, others, and disease. Secondly, types of work which showed key similarities and differences are reported. Finally, differences in how patients and spouses generally viewed the future are described.

Objects of Work. Patients' work was mostly directed toward self, whereas spouses' work was directed toward others. Patients' work of hoping, daily living, and controlling were concerned with self and a portion of maintaining work was also involved with self through the patients attempting to maintain the support of others. Surviving work was the one type of spouse work which clearly focused only on self, although a portion of other types of work would support self as well as help others. For example, taking stock work helped the spouses prepare themselves for loss. Generally, however, spouse work was directed to others. For example, hoping, helping and preserving work we~~re directed~~ to the patient and family. In contrast, the object of patients' work was on others only in preparing work. The goal of preparing work was to plan ahead to equip the family to manage following the patient's death. As well, a portion of maintaining work was concerned with helping others through the patients purposefully adopting a "positive" or "serene" attitude which they felt served to calm the family.

Patients approached the disease directly and had a specific category of work dealing only with the disease. The goal of fighting work was to do the best they could against the disease. Spouses, however, could only approach the disease indirectly through the provision of emotional and physical help to the patients and through hoping for a desirable outcome.

Work Similarities and Differences. With the exception of one type, work was different for patients and spouses. Hoping work was the only type of work which was the same for both patients and spouses, and it also had the same goal and focus.

The one area of work that predominated for patients and spouses differed for the two groups. For patients, controlling work predominated; for spouses surviving work was discussed the most. Though the types of work differed, there were similarities in what patients and spouses wished to achieve. Patients desired to control "self" in the situation and spouses desired to "hang on" or "carry on" during the situation. Both of these areas of work were directed toward what the individual could do on her/his own behalf to manage or control the emotional reactions experienced as a result of advanced cancer.

Some of the work, although different for patients and spouses, seemed to support each others work. For example, patients' daily living work was supported by spouses' helping work. Spouses, by accommodating a continued role for patients and by being positive, allowed patients to live as normal and meaningful lives as possible. In contrast, some of the patients' and spouses' work resulted in conflict. If spouses, in order to survive, must "not think about it" and patients, in order to prepare the family, must talk about what to expect and how to "take down the sheers for cleaning", then there are difficulties for both patients and spouses. Generally, spouses were aware that they must make the compromises and accommodate to patients' needs, not their own.

Time Perspective. A difference in how time was viewed existed between the patients and spouses. Generally, patients' descriptions of particular types of work were more future oriented than were spouses' work descriptions. Spouses of patients in the uncertain group described more future plans in their work than did spouses of patients in the inevitable group. However, patients, regardless of group, provided more descriptions of what they planned for the future. This was evident in hoping, preparing, maintaining, and fighting work.

Spouses described more efforts to manage the present and to remember the past. Spouses' work of preserving and taking stock are examples of the different time perspective that existed between patients and spouses. Patients did not describe as much involvement in the past except where they described the source of their inner strength, and where they described their childhood and past death related experiences. Overall, the basic difference in the time perspectives of patients and spouses was that patients were more oriented in the present and future, and spouses were more oriented in the present and past.

Patient and Spouse Resources

Both patients and spouses used a variety of resources to help them handle the diagnosis of advanced cancer. However, spouses used resources from a greater variety of sources than the patients did. Patients' main source of help was from within themselves; whereas, spouses relied more on outside support. Patients' main outside help came from their spouses; the main source of outside help for spouses came from family and friends. Generally, it was enough for the patients to be with their spouses, however, spouses expressed more need for contact with others and to be more active socially.

Summary

Patients engaged in six types of work and spouses engaged in five. Each type of work had a goal and a focus, with the focus changing according to patient group. In addition to a goal and focus, patients' and spouses' work was directed toward an object. Three objects were identified: self, others, and disease. Patients' work was predominantly directed toward self and spouses' was predominantly directed toward others. Patients were able to direct one type of work toward the disease; spouses were only able to deal with the disease indirectly by helping the patients.

Only hoping work was the same for both patients and spouses. Some patients and spouses work supported each others efforts and some work types resulted in conflict.

Patients and spouses had different perspectives on time. Spouses concentrated on the present and past, and patients looked more to the present and future.

Resources were vital to both patients and spouses, but spouses used resources from a greater variety of sources than patients did. Patients described more need to rely on spouses than on anyone else.

Couple Responses

A final portion of the last interview was conducted with the couples together. The intent of this interview was to elicit their responses to questions dealing with the effect of the situation on them as a couple, to discover what, from their experiences, they might like to share with health care workers and others facing the same situation and to allow them the opportunity to comment on their reactions to taking part in the interviews. Their responses to each of these aspects are described in the following sections.

Effect of the Disease

Despite the potentially dreadful physical effects of a diagnosis of cancer on individuals, respondents indicated there were also positive effects on their personal life with others and a heightened sense of appreciation for the "small things" which can otherwise be overlooked. Positive comments most often given by both patients (6/7) and spouses (4/7) had to do with their perception that they felt closer to one another since the diagnosis. In addition to feeling closer, there was also a sense of deepened appreciation for their life together and for life in general. Both patients and spouses remarked on their enhanced sense of what was valuable and important in their lives:

> (Spouse)
> Mrs. G.: I could see nothing but bad at first, but I have worked through that I think. It's unfortunate that things like this have to happen to increase awareness so much, but I would say we're more perceptive, and express our love more freely and appreciate time, even though we think we've always done that.
>
> (Patient)
> Mr. G.: It has heightened things. It makes you aware of some of the aura (of life). We take notice of the smaller things.

Participants also reported that the effect of the diagnosis on the family was also positive in that it served to draw the children closer to one another:

> (Patient)
> Mrs. A.: The children have become closer to one another. Without being morbid about it, they're forever laughing and joking.

Telling the children and watching the children's reaction to the situation, however, was reported as being very difficult for three of the four couples who still had children at home. They discussed the trauma that their children experienced initially, but the parents could now see some positive responses in the children as well:

> (Spouse)
> Mrs. G.: I mentioned to you how hard it was to talk to the girls. One had a disastrous year scholastically ... doing a lot of daydreaming. But right now she's just sailing. We're doing a lot of sitting and laughing now.

Two spouses reported negative effects of the situation were that their freedom to interact outside the home was limited and one spouse stated the disease "added a bit of worry". Overall, however, responses indicated that some of the effects of the diagnosis were positive, resulting in an expressed determination to "enjoy life", "make the most of our time together", "be more open to express affection" and to "get our priorities lined up".

Recommendations to Health Care Workers

All couples wanted health care workers to give them information which they called "the truth" or "the facts". In addition, couples appreciated staff who displayed knowledge, patience and sensitivity in their approach to care of the patient or families. Two couples expressed concern that AIDS research not replace attention to or remove money from cancer research. One patient expressed the need to be able to talk to someone "who could face up to it" until such a time when her family and friends "came around to the point that they could talk because they just couldn't in the beginning". Generally, couples looked to the health care worker for skilled care of "machines" and "I.V.s" and to provide answers to their questions. Couples appreciated it if, in addition to meeting the practical care needs, the health care workers met those needs in a friendly, concerned manner.

Recommendations to Other Couples

Overall, couples indicated that it was important to "appreciate the time", "enjoy each day", "live day to day" and "do the best you can". Two couples felt they really could not recommend anything because they felt everyone was different. One spouse expressed a sense of helplessness in the situation and therefore could not begin to tell anyone else how to manage. Having and sharing the facts and being positive and patient were also included as recommendations to other couples experiencing similar situations.

Effect of the Interview

Of the seven couples, all patients (7/7) and five spouses found the process of participating in the study helpful. The response by Mrs. A. typified patient comments about the effect of the interviews:

> Mrs. A.: If anything, it helps. You talk. You ask a question, you bring out things you maybe hadn't thought about or were thinking about, but not bringing forth.

Some patients (4/7) commented on the importance of creating more understanding with the hope that future patients and their families would benefit. Another effect of the interview was to give patients reassurance that health care workers were interested in how cancer affected them and their families:

> Mr. [redacted] It's nice to know that somebody has interest ... so akes us feel better too -- we are not caught in a grou ause there's nothing worse than feeling like a number and forgotten.

Although the effects of participating were positive for most respondents (12/14), for two patients and one spouse the interviews also had a disturbing, as well as a positive effect. For these patients, it was disturbing to remember the initial diagnosis with all of the events which were a part of that time, such as "telling the children". Facing the future was the other disturbing issue of which patients were reminded during the interviews. The spouse who reported a disturbing effect from the questions because they caused him to think of the future loss of his wife, went on to say the interview was "maybe disturbing at the time but not in the results". Two spouses reported that taking part in the interviews had no effect on them at all; one prefaced this remark with the statement "what can help?". Nearly all patients and spouses found it helpful to have the opportunity to talk and to feel that they were contributing in some way to an improved understanding of the disease.

CHAPTER V

DISCUSSION OF RESULTS AND IMPLICATIONS

The purpose of this study was to identify what resources the spouse/caregiver and the patient used to manage the care of a patient with advanced cancer in the home. In addition to identifying the type of resources used, the sources and usefulness of these resources were also described. Results revealed more information than whether resources were useful or not, which was the researcher's original intent. The results described the purpose that resources served for patients and spouses. Furthermore, the concept of patient and spouse <u>work</u> was developed. Findings also resulted in a different classification system for resources than was originally developed and used as a basis for the semi-structured interview schedule.

This chapter includes discussion on: 1) major resources used by patients and spouses, 2) resource meaning from the concept of work, 3) implications for practice and research; and, 4) limitations and strengths of the study. The first section on major resources used by patients and spouses includes a discussion of the following specific resources: physical, informational, interpersonal, and spiritual. Resource types are discussed first and then sources are elaborated on for both patients and spouses. In the second portion of the chapter, the concept of work, as it is described in this study, is compared to other areas of work identified in literature. Also, other concepts such as coping and anticipatory grief which are related to work are discussed. Third and fourth sections include discussions of the implications of the findings for practice and research, and limitations.

Resource Types: Patients and Spouses

Resources used to manage chronic illness have been classified in a number of ways. Instrumental, emotional and informational classifications were used by Unger and Powell (1980) as a way of conceptualizing individual resources. Lazarus and Folkman (1984) included recognition of what the individual contributes by identifying such things as health and energy, beliefs, and problem solving abilities as potential resources. The classification suggested by Pearlin and Schooler (1978) of social and psychological resources aligned closest with the internal and external classification system identified in this study. Pearlin and Schooler's social resources included interpersonal networks of people who could assist but did not directly identify tangible resources. Further division, in this study, of external resources into physical and interpersonal helps to identify such resources as medications, information, and help with daily living activities so necessary for an individual with advanced cancer.

Internal resources of character, faith, attitude, and self awareness identified in this study have also been alluded to by Pearlin and Schooler (1978). They identified psychological resources as including personal characteristics people draw upon in time of need. Initially, the classification of physical, emotional, informational, and religious resources was used in this study to develop the focussed interview guide. However, when data were analyzed, a different resource classification evolved. This is possibly a moot point; however, it does point out that qualitative research must be approached without preconceived ideas, or at least with the recognition that initial ideas may not reflect the subjects' perceptions of the issue.

Findings indicated that a number of specific resources were important to patients and spouses. The following section provides elaboration on physical, informational, interpersonal, and religious resources used or sought by patients and spouses dealing with advanced cancer at home.

Physical Resources

Resources to manage pain were most important to both patients and spouses. One patient in this study questioned if "life was worth it" when his pain was at its worst. Once pain was managed, at least to a degree, activities of living were once again something to be sought. Medications were the most common resources used to manage pain, although some patients also supplemented with relaxation techniques. For spouses, fear of future pain or watching pain in their loved ones was traumatic. In addition, the presence of pain caused relational difficulties. One spouse reported pain was largely responsible for the patient's display of anger toward the spouse. Resources next in importance for spouses were anything which assisted with eating and nutrition, such as, vitamins and healthy foods. Comments of "make sure she is eating" and "try to fix him special foods" were made by spouses of patients in the inevitable group. Paramount concern for meeting physical needs has been noted before (Rose, 1976; Edstrom and Miller, 1981; Wright and Dyck, 1984; Hinds, 1985). Resources which allow adequate control of physical symptoms are vital to allow patients and spouses to enjoy the time they have with each other.

<u>Informational Resources</u>. Informational resources were important for emotional adjustment in patients and spouses and for effective physical care of patients. Types of information received included information about the disease, how to meet the care and comfort needs of the patient, and stories of positive outcomes of treatment in other. Patients wanted to know "the facts" and "the truth" about their disease and its progression.

For patients in the inevitable group, getting the facts and the truth meant receiving bad news. Not receiving good news meant these patients had to find another way to be positive about the situation. Patients in the inevitable group accomplished this by ing that there were others who were worse off than they were. Two patients who were told that their cancer was terminal, chose to make up their own minds about the outcome. One, when told his cancer was terminal, responded by saying "to hell with you, I'm going to live until I can't stand no more". The second patient stated he did not find being told his cancer was terminal very helpful at all and concentrated instead on "when I will get better".

For patients in the uncertain group, good news was that the treatment was working or that the cancer was under control. These patients were most satisfied with the type of information they received about their disease. The amount of disease patients have may influence their need for and reaction to information. Derdiarian (1986) in her study of 60 recently diagnosed cancer patients' information needs found that patients with local disease tended to need more information than those with disseminated disease. In addition, the seriousness of the disease may also have an influence in how actively patients pursue information. In their study of 74 cancer patients receiving treatment for life-threatening illness and 72 patients with non-life-threatening illnesses, Feifel, Strack, and Nagy (1987) found that patients with life-threatening illnesses used more confrontational and active information seeking behaviors than did patients with a non-life-threatening illness.

In the present study, one patient in the inevitable group was angry about not being informed about the extent of his disease at some point in his experience with physicians involved in his care. He felt his decision making had been severely hampered. Degner and Beaton (1987) also reported this ongoing problem that patients and families have of obtaining information from health care professionals. In their qualitative study which utilized participant observation, interviews and document review in 14 health centers, Degner and Beaton reported that "lack of information sharing with patients and families represent a major problem in the field of health care" (p. 137). They go on to say that the information received by patients and families was what the health care professionals chose to share, not necessarily what was asked by patients and families. Another patient in the present study, who was a member of the inevitable group, indicated "if you don't ask nothing is going to be volunteered". Questions arise as to whether health care professionals consciously or unconsciously share information more openly if it is good news than if it is bad news, and whether patients do not accept bad news and then feel as if they have not been told.

All spouses of patients in the inevitable group reported frustration in meeting their own informational needs. They were not told by their husbands or wives even though in two cases spouses felt that the patients knew. One spouse found out during the interview that she had not been kept informed by her husband. All spouses in the uncertain group reported going with patients to see the doctor and were satisfied with the type and amount of information received. The factors which may contribute to this lack of information sharing by patients in the inevitable group were not looked at in this study. A longitudinal study would be required to explore whether information sharing behaviors changed as a result of worsening disease or whether personality factors or the patients' desire to protect spouses played a role.

Information supplemental to the medical approach to care included: vitamin therapy, holistic medicine techniques, and referrals to other physicians. One spouse had received a number of book suggestions from friends dealing with how to cope. Not all of these suggestions had positive results. After reading one of the recommended books, the spouse was distressed to read that stress and diet caused cancer and she felt that this indicated she had in some way contributed to her husband's illness by not giving him a healthy environment. This was a direct attack on her attempts to provide a healthy diet and a good environment for her family; as a result she was discouraged rather than helped by the information. On the other hand, positive stories about how other people lived with cancer were an encouragement to two couples. One spouse reported that hearing from an acquaintance about how he managed cancer in his family was helpful. Hinds (1985) noted as well that most of the help with patient care and support to families came from their relatives and friends.

Informational resources used by patients and spouses were related to disease, care and psychological comfort. The amount and type of medical information was not always as the patient would have liked. Two patients in particular were not satisfied with the amount of information provided. However, the rest of the patients felt the information given was adequate and complete. However, being told that his disease was terminal was reported as not being very helpful for one patient leading to the question of how and when to tell people bad news. Spouses were not always kept informed by patients, but it was not clear from this study if this was an established way of relating in those cases or if seriousness of the illness influenced the amount of information given to spouses by patients.

Interpersonal Resources

Relationships between spouses and patients comprised an important interpersonal resource. The supportive influence patients' responses can have on family caregivers has been noted in writings dealing with care of the elderly. The results of Hirschfeld's (1983) study of 30 family caregivers of demented elderly patients, showed that caregivers continued to live with and care for their elderly relative when caregivers found satisfaction in their relationship with the patient. The results of a study of cancer patients also showed that confident and cooperative patients were among the factors which allowed home care for the terminally ill (Parkes, 1978). The results of this present study showed that in situations where patients were depressed or angry, spouses reported difficulty in trying to help them. One spouse went on to say "I have to get away from this illness". Patients acknowledged the role they played in their family's adjustment. Four patients elaborated on the attitude they assumed to help their families be around them and accept the illness. A positive attitude on the part of the spouses toward the situation was also an important interpersonal resource for patients. One patient reported that although she did not know if her husband was really as positive as he portrayed himself to be, it was very supportive to feel he was positive about her disease outcome. Thorne (1985) found in her study of eight families made up of patients, six spouses, three adult children and three other kinfolk, that strategies which support normalcy were valued by families and one aspect of normalcy was a positive attitude.

For spouses, another aspect of interpersonal resources dealt with their need to be able to discuss the situation with someone other than the patient. Talking it out with friends was especially important for four of the spouses. In Hill's (1984) study of 50 family caregivers of elderly relatives, participants also described the need to have someone to talk to who was objective.

Religion

The role of religion, spirituality or faith was not explored in depth in this study, but some information was obtained which warrants further investigation. Spouses volunteered that there had been a change in their approach to religion. One change was to become more philosophical: "I think more about life and death issues". Others reported an increase in religious activities such as praying and going to church. Patients, unlike spouses, did not discuss their use of religious resources as much; however, two patients reported that religious activities were not used, but then stated that "faith was something else". Aspects of "something else" were not investigated in this study. A spiritual sense of connection with the universe was reported by two other patients as supportive because it allowed a way to make sense of the situation. One patient's universe had God in the center; the other patient's universe had nature in that position. One patient felt that she would grow in spiritual depth and understanding as a result of her illness. She reported that she had not as of yet, but she was seeking this growth. She reported she had observed spiritual serenity in a dying North American Indian lady whom she had met prior to her illness and she would like to achieve this serenity herself now that she was dying.

Although, in this study, spouses reported using more religious resources than patients, other researchers report an increase in the uses of religious resources by patients when they are aware of a terminal illness (Reed, 1986; Sodestrom and Martinson, 1987). These researchers, however, did not study family members. Reed (1986) used the Religious Perspective Scale a an Index of Well Being with 57 people who were terminally ill and with 57 healthy adults matched by age, gender, education, and religious affiliation. The results of her study showed that terminally ill patients reported significantly greater religiousness but this increased religiousness did not show the expected positive correlation with well being. Sodestrom and Martinson (1987), in their study of the perspective of nurses and patients on a patient's spiritual coping strategies, reported that patients who knew they were terminally ill used more religious resources such as prayer, reading the bible, and watching or listening to religious programs than did patients who were not aware of their prognosis. The aspects of religion, spirituality, and faith as resources warrant further study.

However, these are not resources which can be "packaged" and given to patients and their families. If they are resources that patients find helpful, then professionals should at least do no harm, by either discrediting the resource or by forcing the spiritual resource onto unwilling patients and spouses. In this present study, for example, one spouse was uncomfortable with questions dealing with religion as a resource and stated a preference not to answer the questions. In contrast, two other spouses stated that their faith in God was a strength for them and allowed them to be hopeful for a cure or spiritual reuniting following death. Even though Bell (1985) notes that spirituality is a mystery and suggests "it is the energy within each person that struggles for meaning and purpose in life", perhaps study of this aspect of life would lead to better understanding of how health care workers can best help patients and families in this personal part of their lives.

Sources: Patients and Spouses

Sources of external resources for both patients and spouses were professionals, family, and friends. The source of internal resources for patients was their character, upbringing and past death related experiences. Degner and Beaton (1987) also noted in their study that the knowledge families took to a cancer situation was what they had obtained from previous health care and life experiences.

Physical Resources

Generally the source of physical resources were health care professionals, such as physicians, nurses, and physiotherapists. These findings have also been reported by others in their review of home care (Zajac, 1985; Gotay, 1984). The source of medications as a physical resource was physicians. Other physical resources, such as canes and bath tub helps, came from the local cancer institute.

Informational Sources

Doctors were the source of information related to the disease, its treatment, and prognosis. Cartwright, Hockey and Anderson (1973) also found that the family doctor or the hospital doctor were the sources of disease related information. Couples, in the current study, reported that nurses were their informational source for specific care techniques, such as infusion devices. Other researchers have indicated that nurses were not seen as a source of information by patients (Dodd, 1984; Mitchell and Glicksman, 1977). Dodd's study however dealt with patients undergoing radiation therapy and possibly nurses were not seen as being responsible for radiotherapy, and therefore, patients would not expect information related to this technologically complex therapy from nurses. On the other hand, the patients in Mitchell and Glicksman's study were outpatients and patients in their study reported seeing the nurse as someone who "ran the examining rooms and helped the physicians". In contrast, results of the present study showed that nurses were looked upon for specific care technique information. In addition, one patient stated that she talked to nurses about her disease and its seriousness until her family could "catch up" to where she was in dealing with the situation.

Supplemental information concerning care approaches other than those given to couples by the hospital personnel came from friends, acquaintances, and family. In this study, friends and acquaintances were reported as contributing nearly all information on paramedical care approaches, for example, information on vitamins, holistic medicine, and positive thinking techniques. A similar finding was also reported by Grobe, Elstrup and Ahmanne (1981) who reported that very few families learned from health care professionals. In this current study, acquaintances were usually people who were experiencing or had experienced cancer in their own families. Their information dealt mostly with stories of how they managed and the positive results of treatment. This type and source of support was also noted by Thorne (1985).

Interpersonal Resources

Patients looked mainly to their spouses as their source of support. Others have also reported that spouses play a pivotal role for patients with cancer (Northhouse, 1984; Wethingtra and Kessler, 1986). The patients in the present study, especially those in the inevitable group, wished to be with their spouses and immediate families more than with anyone else. In contrast, spouses of patients in the inevitable group reported need for greater numbers of people interactions and elaborated on the role friends and family played in their support. Both patients and spouses reported that the illness caused them to change their priorities for how and with whom they would spend their time. This was especially true for the patients and spouses who were members of the uncertain group. The result was that they took more time for vacations together and as one spouse put it, "cut out any extracurricular activity", which would take him away from his wife. Reports in the literature of isolation and lack of help from friends and family when someone is terminally ill (Giacquinta, 1977; Parkes, 1980) may have been a pattern established prior to the time when the illness became debilitating. Friends may have felt left out earlier in the illness trajectory and did not know how to assist when the illness worsened. Withdrawal of family members was not reported by the subjects of this study. If anything, the immediate family (children) were closer since the illness, that is they visited more often and were reported as being more considerate to the patient. Others have also written that families report feeling closer (Slaby and Glicksman, 1985).

In the present study, only two examples of friends' withdrawal were discussed by patients. One patient felt that some of his friends no longer visited as often due to their concern for his fatigue level and for the fact that any noise they may make would cause him more pain. A second patient discussed an interaction which she had with two friends shortly after she had been diagnosed with cancer. She reported that her friends attempted to avoid her when they met in a shopping center. The friends were visibly uncomfortable and were relieved when she terminated the interaction. Subjects of the present study indicated that, there was some withdrawal of friends, but acquaintances with past cancer experiences either personally or in their families sought out patients and spouses to see if what they had learned from their experiences could be of help. Couples in the uncertain group changed their activities in order to spend more time together and this factor may lead to isolation later as the disease progresses. A second explanation for isolation later in the disease process may have to do with the lack of ability to get out of the home due to increased debility of the patient. An element of social restriction was noted by three spouses, two in the inevitable group and one in the uncertain group. This was due to patients' lack of mobility and reluctance to be left alone. Getting out was an important issue for all spouses and patients in those situations where the disease had progressed to a point where it was limiting mobility.

Religious Resources

Sources of religious resources reported were clergy, priest, friends, religious icons in the home, and an internal belief system. Sodestrom and Martinson (1987) reported that the majority of 25 cancer patients identified family members as their spiritual source. Patients and spouses in this current study did not report that family members were a source of religious help; however, this aspect was not investigated in depth.

FIRM Results

An interesting finding from the results of FIRM was the fact that only one couple scored low on mastery and health scale, even though four patients were troubled with pain, weight loss, and decreased mobility. However, of these four patients, all were able to be up and about to some degree. It has been noted in a previous study that mobility may play a major role in patient's sense of well being. Reed (1986) found in her study of religiousness in terminally ill and healthy adults, that reported well being was related less to the medical model of health and more to being able to get around. The importance of being able to be up, get out, move about, and be useful was repeatedly commented on by the most debilitated patients in the present study. The results of FIRM's mastery and health scale, and results of Reed's study support the view that mobility is used by patients as a judge of their well being more than the medical diagnosis.

Resource Meaning: The Concept of Work

One of the most important findings of this study is the notion that patients and spouses engage in several types of work in order to manage the major task they are facing, and that they utilize energy and resources in order to accomplish their work goals. The concept of work evolved as a result of the realization that patients and spouses were expending energy to manage their situation. Also, they used words and phrases such as, "it's hard", "it's difficul ", "do as well as you can", which are usually associated with work, to describe their reactions. In addition, they identified resources which they used to help them manage. Energy expenditure, descriptive words, and resource use completed the requirements necessary to permit the view that patients and spouses were working.

The overall concept of work is presented first with reference to how patient and spouse work relates to existing ideas of work in society. Work is also discussed as a way of providing a context for coping and coping behaviors. Secondly, other types of patient and spouse work identified in the literature are described with discussion on how this current investigation contributes to this body of knowledge. Finally, the fit between patient and spouse work, as previously described in chapter four, is discussed with regard to the object of their work, similarities and differences in their work and the perspective of time.

The Concept of Work

The idea of work is not foreign to North Americans. The phrase "protestant work ethic" describes a belief that being busy at a worthwhile endeavor for most of the day is to be valued. Work is usually thought about in relation to an occupation with financial or other types of return. However, in addition to being used to describe an occupation, work is also used to explain efforts required to build interpersonal relationships; children's play is often called work. Work is considered an appropriate way to describe what a person does to deal with grief. The notion that patients and spouses work on their own behalf to deal with advanced cancer is an expansion of the concept of work. Previously, work has been narrowly defined and used to describe behaviors dealing with a limited part of the human experience. The results of this study support a broader view that includes a variety of types of work applied toward dealing with a diagnosis of advanced cancer in the family. Work, as it is described in this investigation, provides the context for behaviors used by patients and spouses as they deal with advanced cancer. There is perhaps less tendency to view people as passive recipients of professional care when their activities are viewed as work.

It seems to be helpful to view behaviors such as "keeping busy" and "not dwelling on it" as attempts to control oneself within a bad situation, survive a situation, or get on with daily living, than to have these behaviors as part of a list labelled as denial or distraction techniques. Although it is true that at times people use denial or distraction, this study points out that these techniques are helpful in confronting the disease and in order to continue to live as normal a life as possible. The concept of coping and coping strategies also benefit when viewed within a concept of work.

Coping, as a general concept, can be applied to both patient and spouse responses to advanced cancer. Lazarus and Folkman (1984) noted that the process of coping must be examined in a specific context. They state that to be able to study and evaluate coping, one must understand what the person is coping with, and that the more narrowly defined the context is the easier it is to link a particular coping thought or action to the contextual demand (p. 142). Viewing actions and thoughts of patients and spouses dealing with advanced cancer in the home as contributing to the accomplishment of specific types of work provides that contextual view. Coping functions defined within specific contexts are less general and more situation specific (Lazarus and Folkman, p. 149).

Viewing patient and spouse behavior in the context of work to be done shows that although some of their behaviors are the same, what they hope to accomplish is different. Some of the early work which identified that patients go through stages as they face death (Kubler-Ross, 1972) has been taken to mean that each person moves in a set sequence through set stages, and that ideally each person should go through to a stage of acceptance. Clinical discussions have been overheard that include the family in these stages as well, even though Kubler-Ross identified stages from talking with dying patients not families. Nor was it her intent to have sequencing occur as a result of these stages. Utilizing the view that patients and families work and that they have different work to do helps to prevent this tendency to sequence patients through stages (Gullo, Cherico and Shadick, 1974). The concept of work also provides some additional information about the coping strategies suggested by Weisman

(1979). Weisman looked at newly diagnosed cancer patients and listed 15 strategies he observed in patients trying to manage this situation. Viewing these strategies from the point of view of resources used in order to accomplish certain work provides additional information about what is happening to patients and spouses in a cancer situation. For example, understanding that the distraction technique of "doing things" helps patients carry on with daily living and assists them to keep their spirits up, which in turn supports their families, allows a more complete view of not just a coping strategy, but what patients hope to accomplish by using a particular strategy.

Patient Work

The fact that patients have work to do was first noted by Janis (1958) who described certain behaviors he had observed in surgical patients as they anticipated surgery. He called this anticipation process "worry work" and stated that patients used mental activities to prepare themselves for the crisis of surgery (p. 375). Janis felt that this worry work enabled individuals to adjust better to a painful situation and if the work was not done individuals were at a disadvantage post surgery. Janis did not provide elaboration on what these mental activities were or how they helped patients to prepare. However, he did note that information from the physician was essential if patients were to complete their worry work. A similar type of work was noted from the results of the current study. Preparing work in this study included behaviors patients engaged in to prepare their families, as well as themselves, for an inevitable or uncertain outcome. The mental and physical activities which were a part of preparing work differed for the two groups of patients. Patients who were members of the uncertain group, like Janis' (1958) patients, worried about preparing their families. On the other hand, patients who were members of the inevitable group gave specifics about how they were preparing their families and themselves. One patient, who was a member of the inevitable group, described his funeral plans; two other patients, who were also members of the inevitable group, outlined how they were to be looked after once they were not able to be up and about. The stage of illness had an impact on the degree patients had progressed from worry to action. For patients in the current investigation, like Janis' patients, information was essential in order to make specific plans. The importance of information for family and patient decision making has also been noted by others (Hine, 1980; Derdiarian, 1986; Degner and Beaton, 1987).

Portions of other patient work, identified in this present study, could be a part of what Janis (1958) identified as mental activities that the patients utilized prior to surgery. Patients in this study described the use of mental relaxation techniques and other mental activities, such as purposefully not dwelling on the situation by thinking or doing something else in order to control themselves. Fighting work, which involved doing the best they could against the disease, may also have been a part of what Janis observed in patients presurgery. The notion of patients working was not picked up by other writers until recently.

Specific work patients engage in while hospitalized has been noted in three publications (Stepter, 1981; Strauss, Fagerhaugh, Suczek, and Wiener, 1981; Fagerhaugh, Strauss, Suczek and Wiener, 1987). Strauss et al. (1981) discuss a number types of work engaged in by hospitalized patients. Although the setting was different and the authors do not provide information on patient diagnosis, some of the work described by Strauss et al. is the same as patient work found in the current study. For example, Strauss et al. described patients' "body work" as expenditure of energy and time along with courage and will to maintain composure, control their bodies for tests, and look to their own comfort needs. In this present study, the efforts of daily living work for patients also involves using energy to attempt to live as normal a life as possible. Hospitalized patients would not have had the same demands for normal living as patients at home. Therefore, certain work and goals may be different for patients at home vis a vis patients in the hospital.

Fagerhaugh et al. (1987) describe patient safety work in a technologicalized hospital. The authors identify such behaviors as monitoring IV's and selecting which staff they would prefer do certain procedures as examples of patient safety work in a hospital. They allude to the fact that families are also involved but do not give any details of family work which may be different than patients' work Their findings are based on two years of field work and interviews in six hospitals with over 100 staff and patients. Details about diagnosis, stage of disease or treatment are not provided. Work focus, as noted in the current investigation, changes by disease stage and spouses engage in different types of work than do patients.

Spouse Work

Although very little has been written about patient work, even less has been published about the possibility that spouses engage in work when their husbands or wives are seriously ill. Fagerhaugh et al. (1987) mentioned that families have safety work to do when a loved one is hospitalized; they imply however that the work is the same for both patients and families. The results of this current study show that although some of patient and spouse work requires similar behaviors only one area of work is the same for both patients and spouses. An element of safety work as described by Fagerhaugh et al. was reported by spouses in the current study and categorized under helping work. One spouse outlined her concern while her husband was hospitalized that the nursing staff were not caring for his Port-A-Cath the way in which she and her husband had been taught to care for it at home and she was worried that the staff would plug it. The same spouse described her efforts to have her husband moved when he was admitted to the same room as a smoker. Helping work activities, which involved concern for patients' safety at home, were such things as "watching that he doesn't get dizzy and fall" and "ensuring that she is not left alone".

Although references to the fact that families have work to do during a loved one's illness have not been included in published reports, the idea that families work post death has been reported in the grief literature. Lindemann (1944) in his class description of grief responses, used the term "grief work" to encompass all behaviors individuals display in order to become separated from the deceased and readjusted to life without their loved one. If it is appropriate to think of an individual as engaging in work after the death of a loved one, then it would also seem to be appropriate to think of an individual engaging in work prior to the loss as well. The goal, focus and object of the work would be different. For example, part of grief work for an individual is to separate from the deceased. Results of this current study show that spouses are mainly concerned with doing all they can for their husbands and wives and consciously try to spend as much time as possible with them. This finding was also reported by Silverman (1974) in her study of 39 women whose husbands had suffered long term illness. Silverman's study involved doing follow up interviews with the widows three weeks after their husbands' death. Although there is lack of agreement in the literature concerning the labelling of some predeath reactions in survivors as anticipatory grief, some parallels exist between what writers have identified as anticipatory grief reactions and what has been identified as spouse work in the present study. These parallels will be discussed later in the chapter.

Fit Between Patient and Spouse Work

Findings from the present study, in which patient and spouse behaviors were identified as work they do in order to deal with advanced cancer in the home, are similar to behaviors described by others in related research. Mages and Mendelsohn (1979) describe a variety of tasks patient have to do depending on stage of disease. The concept of anticipatory grief, as outlined by Rando (1986) also contains elements of patient and family behaviors similar to those noted in the present study. This section presents discussion of the relation of these concepts to the findings of patient and spouse work as outlined in the present study. The object of patient and spouse work is discussed first, followed by a review of work similarities and differences, and lastly the perspective of time as viewed by patients and spouses is discussed.

Object of Work

The image of patients and spouses working to manage a diagnosis of cancer has not been directly discussed in any published information. Research on patients in different disease stages by Mages and Mendelsohn (1979) however, has provided information on patient behaviors and tasks which agree with the findings of the current study. Mages and Mendelsohn carried out semi-structured interviews with two retrospective samples; one sample (N21) was 6 to 12 months post treatment and the second (N35) was 3 to 6 years post treatment. They also interviewed a third group of patients (N31) who were receiving or had just received treatment. From their study, Mages and Mendelsohn identified seven issues that patients must deal with depending on disease stage. These issues include managing the discovery of cancer and its primary treatment, dealing with recurrent disease, and managing terminal illness. Each issue required an adaptive task. For example, the adaptive task for terminal illness was to prepare to leave family and friends, provide for loved ones, learn to use medical assistance and internal resources to minimize pain, and so on (p. 265). Although, Mages and

Mendelsohn call this one task, it would seem to be a number of tasks of which many agree with the findings of the present study. The work of preparing families, as identified in the present study, parallels well with the adaptive task related to terminal illness. However, patients in this current study engaged in much more work than preparing to leave their families or providing for their families. They also used energy and resources to maintain the support of others, carry on with daily living, fight the disease and so on. In fact, patients in the current study had work to do which was similar to tasks identified by Mages and Mendelsohn as occurring in patients who were experiencing the possibility of recurrence. The tasks identified by Mages and Mendelsohn were listed as being specific to a particular disease stage without overlap. In the present study, patients in both groups had the same work but the focus of the work was more specific for patients in the inevitable group. The stage of disease did have an influence on patient work but not to the point of the work being different as noted by Mages and Mendelsohn.

The main object of spouse work in the current study was the patient. Spouses were more concerned about patients than they were about themselves as was evident by the fact that out of five categories of work only one was directed toward spouses themselves. Others have also noted that spouses are more concerned about patients than themselves (Wright and Dyck, 1984; Howell, 1986). However, spouses in the current study were also aware that patients' well being depended on them remaining healthy and in good spirits; therefore, a large amount of their energy and resources were used to survive. The results of Howell's (1986) descriptive study of 30 spouses of cancer patients also showed that spouses had to manage unpleasant thoughts, find someone to share their feelings with, and deal with the effect the disease was having on the children. Spouses in Howell's study also had as their object of concern others, including patients and children, and lastly themselves, without discussion of possible efforts on their part towards the disease. As in the current study, patients were the only ones who could directly work on the disease.

Work Similarities and Differences

Only one type of work, hoping work, was the same for both patients and spouses. The extent that patient and spouse work differs may contribute to the isolation and communication difficulties in families often reported in the literature (Giacquinta, 1977; Krant and Johnston, 1978; Reilly and Patten, 1981). If there are times when patients, in order to fight the disease, use their anger as an energy source, spouses may experience discomfort in their relationship. There will also be times when the work of one group compliments the work of the other. This can be seen in the area of daily living work for patients and helping work for spouses. Patients wish to go on with life as normal and do normal things and spouses work to maintain a role for the patients and give them something to do. Others have also noted the importance of maintaining normal life activities for patients (Chalmers, 1984; Thorne, 1985). In her study of eight families, Thorne reported the importance of living normally in spite of the disruptions caused by cancer. To her subjects, normal meant being able to "go fishing" and "do things". Chalmers discusses similar findings in patients with chronic airflow obstruction. She noted that patients attempt to place their illness into a framework of normality.

Another area of difference for patients and spouses was in the degree of uncertainty displayed by individuals, especially among patients and spouses in the inevitable group. Patients in the inevitable group were able to acknowledge the fact of their impending death. Spouses, on the other hand, had difficulty with the fact that their husbands and wives were going to die. They reacted by "not thinking about it" and determining to "cross that bridge later". Perhaps only patients can view their own death as inevitable, leaving spouses to perceive patients' death as uncertain regardless of whether patients themselves view it as inevitable or uncertain. Spouses, at the time of the interviews, may not have been able to acknowledge that the patient's death was inevitable. Doing so would have communicated a sense of giving up and in the spouses' view it was important for the well being of the patient to be positive. Silvermann (1974) noted a similar reaction in the wives of terminally ill husbands in her study on anticipatory grief. In the present study, the strain of this ambiguity showed in the interviews. Generally, the spouses' reactions were more emotionally intense, that is, they displayed more sadness than patients did during the interviews. Four of the seven spouses cried at some time during the interviews: only one of the seven patients cried.

The concept of anticipatory grief, as presented by Rando (1976) shows similarities to some of the types of patient and spouse work found in the present study. In her work, Rando identified certain tasks of a dying patient as examples of anticipatory grief. For example, these tasks included arranging wills, coping with loss, planning the future through allocation of time and energy, dealing with numerous psychosocial problems, and so on. Many of these tasks parallel the findings of the present study and are merely given different terms and placed within the context of work rather than grief. Anticipatory grief, as a way of looking at patient reactions, does not allow as broad a view of other patient tasks which involve such things as hoping, maintaining support, getting on with daily living, and fighting the disease.

Better agreement exists between anticipatory grief and some spousal work. This is especially notable in the work of taking stock and preserving. In these areas of work, spouses review the patients' character and their life together and create or review memories. Rando (1986) describes these same features as examples of a family's anticipatory grief reaction through striving to take in the loved one and putting images into the mind so that these pictures will remain after the patient's death. Better agreement seems to exist between the findings of this study and what has been labelled by others as anticipatory grief. However, the results of the present study show that although the dying patient is the most important individual to spouses, they also are very much involved with their own survival and that of their children.

Time Perspective

Spouses were not as involved with the future as were patients. Rando (1986) also reported many of the patient tasks were future oriented. However, she noted that families were also involved in making plans for the future which did not involve the dying person. The results of the present study do not support that spouses are involved in removing their husbands and wives from their future plans. In fact, spouses were not looking at the future at this point. They were more concerned with enjoying each day and making the best of the time they had left as a couple. It may be that because patients in this study were up and about and involved with the family, in spite of their pain and debility, spouses were not forced to look at the future without their husbands and wives. Rando (1986) does not indicate degree of debility of the patients in her work and it may be that as patients become increasingly bedridden, spouses are forced to view the future as it will be without their loved one.

Implications for Practice and Research

The purpose of this study was to identify what resources patients and spouses used to manage care of someone with advanced cancer in the home. The concept of work that evolved from the conceptual analysis requires additional investigation with more individuals in different life stages and settings to ensure its validity before it can be assumed as a guide for nursing practice with patients and families experiencing advanced cancer. However, even prior to further validation of the concept, t idea that patients and spouses are actively working on their own behalf does have implications for the practice of nursing in caring for these individuals.

Implications for Nursing Practice

The notion of patients and spouses as workers removes any sense that they are passive recipients of professional care. This fact alone may change previous reluctance on the part of health care professionals to share information with patients and families. The difficulty patients and families have in acquiring information is repeatedly noted in studies (Wright and Dyck, 1984; Degner and Beaton, 1987). Patients and spouses, in this study, wanted information on the disease, its prognosis, and treatment, and they wanted this information given in understandable terms with a compassionate manner. An information role for nurses was identified by patients and spouses to allow them to deal with physical care needs for specialized infusion devices and equipment.

Methods of providing emotional support to patients and families have always been a challenge for nurses in oncology. Nurses are consistently referred to as providers of emotional support; however, what that means is rarely addressed. The notion that patients and spouses work and that at times their work may be different, leading to conflicts within relationships, can assist nurses in their support role by allowing them to interpret reasons for possible conflicts to patients and spouses thus helping them to understand interpersonal dynamics which may be occurring within the family. In addition, the knowledge that spouses need to review their lives with patients and to discuss their husbands and wives' character, can assist nurses to identify a method of providing further emotional support through listening to these life reviews. It was also clear from this study that patients need to discuss the seriousness of the disease with outsiders and that nurses can fulfill this role as well.

The realization that spouses have helping work, which involves maintaining a role for the patient and protecting the patient, can help nurses understand protective behaviors which are often noted when patients are hospitalized and may assist in preventing misunderstanding on the part of hospital staff and families.

Community nurses may be able to communicate the needs of families, in which a member has a serious illness, for their friends to provide short frequent visits rather than long infrequent ones. Spouses may need assistance to realize that they require diversion from the illness, especially as the disease progresses. The realization that spouses play a very important role in supporting the patient and carry most of the concern for patients and any children, make them a vulnerable group which nurses must observe for signs of fatigue. Spouses' devotion to their husbands and wives may not allow them to take time for their own health and nurses may need to reinforce that spouses care for themselves, as well as the patient, without feeling guilty about needing to be away from the situation occasionally.

Nurses must recognize the painful experience of telling children, as was noted in the study, and assist families to transmit information in a hopeful manner.

Further Research Needs

From the results of this study, work has been identified as an important concept by which to understand the behaviors and mental reactions of patients with advanced cancer and their spouse/caregivers. Further investigation with larger numbers of individuals in different settings and at different stages of disease and the life cycle is required in order to validate and further develop the concept of work. Questions which remain to be answered are:

1) Do different categories of work occur in families which are at different points in the life cycle?
2) What work do other family members become involved in?
3) What specific types of work are children involved in?
4) How does work differ for hospitalized patients and families?
5) How does professional health care work and patient spouse work differ?
6) How are work categories influenced by type and stage of disease?

No attempts were made to delve into the unconscious through drawings or dream reports; it may be important to identify possible unconscious work of patients and spouses.

Certain resources identified in this study as important require additional investigation. The role of religion, spirituality, and faith was not investigated in depth, but appeared to play an important role for some patients and spouses. What is meant by faith, religion, and spirituality and how these resources can or cannot be supported by health care professionals requires further study by qualitative methods in order to identify the components of spirituality and faith and their differences or similarities to religion.

It was noted by couples who had children still at home that this was a very difficult time for everyone. What effect a parent's diagnosis of cancer has on children needs exploration, not just from the point of view of work but also with a view to identify the concerns, problems, and impact of the disease, as well as what children do to manage the situation.

Results of this study showed that some difficulties were encountered by spouses of patients in the inevitable group when they attempted to get information from their husbands and wives. These same difficulties were not reported by spouses whose husbands and wives were in the uncertain group. A longitudinal study would be needed to investigate where and to what degree information sharing changed as the disease progressed. An article published in 1966 is still being quoted as a source for the fact that patient communication is minimal in areas dealing with death and dying (Abrams, 1966). A more recent publication reported that patients and caregivers (family and friends) did not speak openly about terminal illness (Reilly and Patten, 1981). In contrast, all couples in this study spoke openly about the disease and its prognosis during the interview involving both of them. Some patients in the uncertain group, in speaking about the emotional aspects of the disease, indicated that talking to their spouses constantly about their feelings would not be helpful, but that they did talk about the disease and its treatment. A specific study dealing with the patterns of communication such as what types of communication help, what hinders, and who talks to who about what requires further investigation. The agony of patients who feel they have been deceived or have had information withheld is something families carry with them into every ensuing relationship with health care personnel. Just what it is that prevents patients and spouses from obtaining the information they need clearly requires further study.

Limitations and Strengths

This was a descriptive study meant to investigate what resources patients and spouses used to manage advanced cancer at home. The intent of the study was to identify concepts and themes of resource use in the home by the patient with advanced cancer and the spouse caregiver. The descriptive in-depth nature of the study, and the financial and time restraints of the researcher prevented a study with large numbers of individuals. Therefore, the small sample size precludes any generalizable results. However, as indicated, the intent of the study was not to provide quantitative information which could be applied to similar populations, but to identify information which could be used to further develop theory dealing with patients and spouse/caregivers resource use in the home. Further studies are required in order to investigate the concept of work with other subjects in different age groups and dealing with other diseases.

The study could have been strengthened if the same subjects were followed through the disease stages to discover such things as changing communication pattern and information sharing behaviors. Different work categories may also have evolved as patients and spouses encountered different disease stages. Time was limited however and a longitudinal study was not possible.

It was decided not to include patients who had unresolved physical or emotional problems and this decision may have eliminated a population which could have contributed important information. In addition, 13 couples were approached in order to recruit 7 couples. Therefore, it would be important to know the differences between couples who agreed and those who did not. Reasons volunteered for not participating were as follows: one male patient did not wish to discuss his cancer; another male patient felt it would be of no help to him; three female patients agreed but their spouses refused; and one couple agreed but a mutually acceptable time could not be agreed upon. It is interesting to note that most of the refusals were male initiated and even in the seven couples who participated, one male spouse was only participating "because my wife wants to do this". The apparent difficulty in getting men to participate in this type of research warrants further thought on the part of researchers. Perhaps the interview methodology is not comfortable for men or it may be that they are not comfortable with female interviewers. Whatever the case, one must question how representative the men who participated in this study are of the larger male population who are spouses of cancer patients or cancer patients themselves.

The question of helpfulness of each resource was not explored in depth as initially intended. As the interviews progressed and subjects were given the freedom to expand on their answers, many times the question of helpfulness of a particular resource was not appropriate or sensitive of the milieu of the interaction.

A strength of the study was that it looked at both patients and spouses at the same time for the same reason. The resulting information allowed a comparison of what was happening for each member of the couple. A serendipitous strength resulted when patients were obtained at slightly different stages of their disease, resulting in the identification of two groups of patients and the findings of different tasks and work focuses for the two groups.

Although study limitations must be taken into consideration, the findings of this study resulted in identification of important resources for patients and spouses and showed how active these couples are in dealing with the disease. These are important issues for nurses to understand who work with patients with advanced cancer and their families. The study also identified further questions for research and revealed that information obtaining and sharing continues to be a problem. Conceptual analysis of the interview data revealed that patients and spouses "work" to manage advanced cancer in the home. Patients and spouses described several types of work, each with a different goal and focus. The concept of work adds to the understanding of other concepts; such as coping. Work provides the context in which coping occurs. Viewing patients and spouses as workers helps to prevent viewing individuals with cancer and their families as passive recipients of the work of health care professionals.

The fact that there are different types of work for patients and spouses is information that is useful for practitioners as they support families during this very difficult time. The understanding that at times patients and spouses may be engaged in work which conflicts will be helpful for practitioners as they attempt to assist patients and spouses to understand the events which are unfolding in their lives.

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APPENDIX A

FIRM

FAMILY INVENTORY OF RESOURCES FOR MANAGEMENT

APPENDIX A

FIRM

FAMILY INVENTORY OF RESOURCES FOR MANAGEMENT

Pages 145 to 147 inclusive have been removed due to copyright restrictions. These pages contained the resource measurement instrument FIRM - Family Inventory of Resources for Management by Hamilton I. McCubbin, Joan K. Comeau, and Jo A. Harkins. Information concerning FIRM may be obtained from the

Family Stress, Coping and Health Project
School of Family Resources and Consumer Sciences
University of Wisconsin Madison
1300 Linden Drive
Madison, Wisconsin 53706
Phone: 608-262-5712

APPENDIX B

FOCUSED INTERVIEW SCHEDULE

APPENDIX B

FOCUSED INTERVIEW SCHEDULE

INTRODUCTION

I am interested in learning what resources are being used by people with cancer and their spouses in the home situation. By resource, I mean both the tangible and the intangible things which you have used or are using to manage care at home. An example of tangible items might be things like medical devices, such as canes, dressings and so on, or having someone give you help with your care or housework, An example of intangible resources might be talking to someone about your feelings, or thinking positive thoughts.

PART I

Initial Questions to Aid in Establishing Rapport and to Obtain General Information Regarding the Participant's Interpretation of the Term "Resources"

To be completed with each individual.

1. What has it been like for you managing the care of __________ at home?

   What has it been like for you being cared for at home?

2. What does the word "resource" mean to you?

3. What kinds of resources are you using to manage this situation?

   a) How did you learn of the resource?

   b) Where have you obtained these resources (what has been the source of the resources noted above)?

   c) How helpful/not helpful have the resources been?

PART II

Specific questions will be used if probing is required due to an unclear understanding of resources or a failure on the part of the participants to recall what exact resources are being used.

A. Physical Resources

1. What kind of medical equipment are you using?

   a) How did you obtain it/hear about it?

   b) How helpful/not helpful has this equipment been?

2. What physical help have you had to give care at home/what physical help have you had in order to stay at home?

   a) Who provides this help?

   b) How helpful or not helpful has it been?

3. What community resources have you used (examples if required are such things as meals on wheels, support groups, yard work help, homemakers, transportation help)?

   a) How did you hear about these resources?

   b) How helpful/not helpful have they been?

4. What financial resources have you used?

   a) What was the source of the help?

   b) How helpful/not helpful has it been?

5. What health care resources have you used in the home (examples are physiotherapy, nurses, orderlies)?

   a) How did you hear about these resources?

   b) How helpful/not helpful have they been?

B. Emotional Resources

1. What resources do you use for recreation (example if required: fun time such as games, T.V. watching, reading, social evenings, or going out)?

   a) If appropriate, the source will be explored with the participants?

   b) How helpful/not helpful have these things been?

2. What resources do you use to manage your feelings about this situation of caring for your spouse/of being cared for by your spouse (example, talk to someone, read, get out and keep busy)?

   a) What or who has been the source of this help?

   b) How helpful/not helpful have these things been?

3. What people/person do you want to be with during this time (who is closest to you)?

   a) What do they provide for you?

   b) How helpful/not helpful has this help been?

4. What helps you when you feel afraid, worried, angry, guilty, sad?

   a) What is the source of that help?

   b) How helpful/not helpful has it been?

5. What helps you feel hopeful, happy, peaceful?

C. Spiritual Resources

1. What inner resources are you using to manage this situation?

2. What mental activities have you used (example: meditation, prayer, yoga)?

3. What formal religious resources do you use (for example, attend church/synagogue or see your clergy)?

D. Informational Resources

1. What have you read or been told which you have used to manage care at home/to manage being cared for at home (probing questions which will be used to seek out exact type of information, will include such things as disease related information, prognosis information, what can be expected, care approaches, use of equipment or drug information)?

   a) What has been the source of that information?

   b) How helpful has this information been?

   c) Have you received any information which you consider to be not helpful?

2. What information have you used to help you make your decisions in this situation (probing if necessary to investigate coordinating efforts like legal issues, treatments and arranging care)?

   a) What has been the source of this information?

   b) How helpful/not helpful has this information been?

PART III

Final general questions to be asked at the end of the final interview with each individual and each couple at the closing interview.

1. Situations like this one have some effect on all who are involved - though some experience greater effects than others. How has this situation affected you as a couple, your family?

2. What recommendations would you have for other couples in this situation?

3. What recommendations would you have for nurses and others who may be responsible for making resources available to you?

4. What effect, if any, do you feel taking part in these interviews has had on you?

APPENDIX C

GUIDE FOR REVIEW OF INTERVIEW SCHEDULE

APPENDIX C

GUIDE FOR REVIEW OF FOCUSED INTERVIEW SCHEDULE

As you review the Interview Schedule, please apply the questions outlined below to each interview question. Each time you answer "no", please provide me with your reasons for answering that way. You may make your comments directly on the Interview Schedule.

1. Is the question appropriate given the research?

2. Is the wording clear and understandable?

3. Have the questions included sufficient kinds of resources to cover the scope of resources you have encountered/used in the community?

4. What additional questions would you suggest be included?

Thank you for your assistance in this research. I hope it will lead to better understanding of how patients and families manage care at home.

APPENDIX D

LETTER OF EXPLANATION

APPENDIX D

LETTER OF EXPLANATION

Dear ________________:

I am a graduate student in the Masters of Nursing program at the University of Alberta and I am also the Education Coordinator, Department of Nursing, Cross Cancer Institute, on Educational Leave. I am presently doing a study on the resources which people use to care for someone with cancer at home. It is often much better for people to be cared for at home rather than in a hospital setting, but providing care at home can be demanding for both the people with cancer as well as for their spouses. I feel we, as health care providers, could be much more helpful to people in similar situations, if we knew more about what people do on their own behalf to manage care at home. For that reason, I would like to set up an appointment with you and your spouse to discuss my study with you and to invite you both to participate in the study. If you agree, I will be asking for three additional meetings. The first meeting would be with both you and your spouse to explain the study and obtain your consent. I would then ask for 2 one-hour interviews separately with each of you. If you have any questions, please call me at 439-5445.

I hope that this study will provide important information for further understanding of home care for people with cancer and I look forward to discussing this project with you.

Sincerely,

Nola Williams, R.N., B.Sc.N.
Graduate Student
Masters Program
Faculty of Nursing
University of Alberta

Education Coordinator
(On Leave)
Cross Cancer Institute

APPENDIX E

CONSENT TO STUDY FORM

APPENDIX E

CONSENT TO STUDY FORM

RESOURCE USE IN THE HOME BY THE PATIENT WITH ADVANCED CANCER AND THE SPOUSE CAREGIVER

Principal Investigator: Nola Williams, R.N., B.Sc.N.
Graduate Student, Masters Program
Faculty of Nursing,
University of Alberta
439-5445

Faculty Advisor: Dr. E. Davies
Associate Professor
Faculty of Nursing
University of Alberta
432-6253

The intent of this study is to discover what resources the spouse/caregiver and the patient use to manage the cancer situation in the home. Through two one-hour interviews held separately with each of you, I hope to be able to seek out patterns of resource use, sources of help and helpfulness of the resources used. Also, you will each be asked to complete a pencil and paper check list inventory of family (meaning the two of you) resources developed for use with families who are caring for a chronically ill member. You will be given an opportunity to look at the interview questions and the inventory prior to agreeing to participate.

I, ______________________, have had the above study explained to me and I understand that the purpose of the study is to identify the resources patients and spouses use to manage care at home. I understand that:

- there may be no benefit to me personally;
- some of the questions may be of a disturbing nature;
- I may withdraw at any time without negative effect on my care;
- I may refuse to comment or answer any question at any time without withdrawing totally from the study;

- I will be able to stop the interview at any time;
- it is not the researcher's intent to provide health care; however, in the event of a serious concern, referral will be made to a nurse in the Cross Pain and Symptom Control Clinic/

I expect that:

- I will be interviewed in my home two times for one hour each time over a period of 10-14 days;
- the researcher will be observing me during the interviews;
- the interviews will be taped and transcribed, but any identifying information will be removed and only the researcher will be aware of my identity;
- the tapes will be listened to and analyzed by the researcher and her faculty advisor;
- upon completion of the study, the tapes will be erased;
- confidentiality will be maintained throughout;
- publications resulting from this investigation will not contain any identifying information or names.

I have been given the opportunity to ask questions and realize that I can ask for additional information at any time. I will be given an opportunity to see a summary of the final report.

I understand what is required of me and I freely consent to be a part of this study.

PATIENT	WITNESS
SPOUSE	DATE

I agree to participate in this study.

ATTENDING PHYSICIAN	DATE

APPENDIX F

DEMOGRAPHIC DATA FORM

APPENDIX F

DEMOGRAPHIC DATA FOR THE MARITAL DYAD

Date ____________________

Dyad Code ____________________

Patient Code ____________________

Spouse Code ____________________

Patient DOB ____________________

Diagnosis ____________________

Spouse DOB ____________________

Stage ____________________

Patient's Gender M F

Date of Diagnosis __________

Length of Time of Spouse in Caretaking Role ____________________

Number and Age of Children (M)__________ (F)__________

Number of People in the Household __________

Length of Marriage __________

Education: Number of years of school completed

Patient:	Grade School	1	2	3	4	5	6		
	Junior High	1	2	3					
	High School	1	2	3	4				
	College	1	2	3	4				
	University	1	2	3	4	5	6	7	8
Spouse:	Grade School	1	2	3	4	5	6		
	Junior High	1	2	3					
	High School	1	2	3	4				
	College	1	2	3	4				
	University	1	2	3	4	5	6	7	8

Ethnic Background:
Patient ____________________
Spouse ____________________

Religion:

Patient:	Protestant	Catholic	Jewish	Muslim	Other
Spouse:	Protestant	Catholic	Jewish	Muslim	Other

APPENDIX G

FILE CARD INFORMATION

APPENDIX G

FILE CARD INFORMATION

Name: Dyad Code ____________________

Patient ______________________ Patient Code ________________

Spouse _______________________ Spouse Code _________________

Address ____________________________________ ________________________

____

Phone Number ________________

Number and Length of Visits:

____

____