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IS THERE A SIGNIFICANT RELATIONSHIP BETWEEN THE IMPACT OF SYMPTOM DISTRESS ON DEPENDENCIES IN ACTIVITIES OF DAILY LIVING, INSTRUMENTAL ACTIVITIES OF DAILY LIVING, SATISFACTION WITH HEALTHCARE PROVIDERS, AND SATISFACTION WITH INFORMATION RECEIVED DURING CANCER TREATMENTS

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By

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ABSTRACT

IS THERE A SIGNIFICANT RELATIONSHIP BETWEEN THE IMPACT OF SYMPTOM DISTRESS ON DEPENDENCIES IN ACTIVITIES OF DAILY LIVING, INSTRUMENTAL ACTIVITIES OF DAILY LIVING, SATISFACTION WITH HEALTHCARE PROVIDERS, AND SATISFACTION WITH INFORMATION RECEIVED DURING CANCER TREATMENTS

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This descriptive study, using secondary data and a convenience sample of 72 clients diagnosed with a solid tumor or lymphoma, symptomatic or having dependency in either self-care or instrumental activities of daily living, and currently under treatment for new or recurrent disease, was undertaken to examine the relationship between the impact of symptom distress on dependencies in activities of daily living, instrumental activities of daily living, caregiver satisfaction with health care providers, and caregiver satisfaction with information received during cancer treatment. Findings included caregiver and patient sociodemographic profiles. The clients were found to have experienced low severity of symptom distress, with caregivers reporting the greatest self-care deficit in instrumental activities of daily living and high degree of provider and informational satisfaction. Limitations of the study, recommendations for future research, and implications for advanced nursing practice are presented.

ACKNOWLEDGEMENTS

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TABLE OF CONTENTS

Table of Contents (Continued)

LIST OF TABLES

LIST OF FIGURES

INTRODUCTION

Improvements in diagnostic and cancer treatment techniques has made it possible for patients diagnosed with cancer to receive treatment in ambulatory care centers while remaining in their homes (Ferrell, Cohen, Rhiner, & Rozek, 1991). Cancer diagnosis and treatment bring about fear and emotional tension creating impaired comprehension and communication (Hiromoto & Dungan, 1991; Northouse, 1984). Individual responses vary widely and are different to predict, but include psychological distress and mood disturbances (Munkres, Oberst, & Hughes, 1992).

Researchers have identified how cancer influences virtually every dimension of life, testing the coping resources of the individual and family as they struggle to normalize life on a daily basis (Ferrell, et al., 1991; Given, Stommel, Given, Osuch, Kurtz, & Kurtz, 1993; Gotay, 1984; Haberman, Woods, & Packard, 1990; Lewis, Stetz, & Primono, 1986). After a diagnosis of cancer, patients require support from health care providers to obtain needed information to prepare for the effects on functional status and management of symptom distress created by cancer treatments. Typically, patients and families have not been adequately prepared to meet the physical and psychological demands associated with a cancer diagnosis (McCorkle & Given, 1989). The patient-caregiver dyads experience powerlessness, ambivalence, interdependence, uncertainty, and role change (Lewis, Ellison, & Woods 1985). The development of a partnership between health care providers and the patient is essential in providing information and anticipatory guidance that will empower the patient while facing the impact of cancer treatments.

This study seeks to address the following research question among patients with cancer who are receiving treatments and their caregivers: Is there a significant relationship between patient reported symptom distress and caregivers perceptions of dependencies in activities of daily living, instrumental activities of daily living, satisfaction with health care providers, and satisfaction with information received during cancer treatments. There may be a difference in how the caregivers and patients ultimately perceive the impact of cancer and its treatment on symptom distress, dependencies in ADL/IADL's, and satisfaction with health care providers, and information received. This study does not address this issue, however, it is a strong indicator for continued research in this patient population, as perceptions of the dyad separately and together need to be used to guide health care interventions in order to achieve optimum treatment outcomes. The identification of treatment impact on cancer patients will enable a primary health care provider to better prepare the patient for multidimensional changes necessitated by both the treatment of the disease and potentially the long term effects of the disease.

The research questions to be explored are: 1) What is the relationship between patient symptom distress, and the impact as perceived by caregivers on activities of daily living, and instrumental activities of daily living for patients with cancer? 2) What is the relationship between patient symptom distress and caregiver satisfaction with health care providers? and 3) What is the relationship between patient symptom distress and caregiver satisfaction with information received during cancer treatment?

The author will review relevant literature in the area of activities of daily living and instrumental activities of daily living, symptom distress, and the demands of illness subconcepts of caregiver satisfaction with health care providers, and caregiver satisfaction with information received during the course of illness. King's theory of goal attainment will be utilized as the theoretical framework to describe the context within which the relationship among study variables can be couched. A descriptive correlational design will be used to address the study hypothesis. Study findings, relevance and practice implications for nurses in advanced practice will be discussed.

LITERATURE REVIEW

A diagnosis of cancer is regarded as a dreaded emotional and life threatening experience, in which the primary burden of care has increasingly become the responsibility of the patient and family due to improvements in diagnostic and cancer treatment techniques shifting treatment centers to ambulatory care centers (Given et al., 1993; Hiromoto & Dungan, 1991; McCorkle & Given, 1989).

As treatment progresses the cancer patient has greater difficulty in maintaining a life pattern of normalcy. Need for assistance with normal activities of daily living increases as physical and psychosocial reserves decrease. Supportive relationships and the communication style within the family is known to affect the adaptation and self care practices of the patient (Lewis et al., 1985).

For the purposes of this study the conceptual definitions are extrapolated from "Family Homecare for Cancer Patients" funded by the

American Cancer Society, with Barbara A. Given and Charles W. Given as principal investigators. The conceptual definitions of functional status, symptom distress, and the demands of illness subconcepts of satisfaction with health care providers, and satisfaction with information received will be discussed within the review of literature.

Activities of Daily Living and Instrumental Activities of Daily Living

Dependency in activities of daily living and instrumental activities of daily living are defined as a person's need for help or assistance from other people in order to perform activities that under ordinary circumstances an adult can perform independently (McCorkle et al., 1989A), and is one of the most relevant indicators of survival time (Rueben, Mor, & Hiris, 1988). Activities of daily living (ADL) are activities that people do habitually and universally and their performance without help is recognized as necessary for independent functioning (Stone & Murtaugh, 1990). ADL's include personal self care functions that require a minimum of physical strength, i.e., eating, bathing, toileting, and movement within ones residence (Given & Given, 1991; Stone & Murtaugh, 1990). Given's (1993) study indicates the patients' symptom distress and number of dependencies in ADL's significantly correlate with reported levels of patient depression. A severely disabled person is defined as having two or more impairments in ADL functioning (Cummings et al., 1990; Stone & Murtaugh, 1990). Two or more deficits in ADL's is the primary disability measure used to determine eligibility for federally reimbursed skilled home care assistance (HCFA, 1990; Stone & Murtaugh, 1990).

Instrumental activities of daily living include those activities of daily living that require greater strength and endurance, i.e., housework, shopping, laundry, and cooking (Given & Given, 1991; Stone & Murtaugh, 1990). Need for IADL assistance is an important indicator of the services chronically ill individuals need to live in the community. Having one or more IADL limitations is associated with subsequent nursing home placement and hospitalization (Branch, Goldberg, & Cheh, 1982; Donaldson & Jagger, 1983). Physical deterioration as a result of both the disease and the effects of treatment affect the ability of patients with cancer to perform everyday activities and may even compromise their ability to comply with prescribed treatment plans (Mor, Allen, Houts, & Siegel, 1992).

Since use of diagnosis alone is a poor indicator of health care needs, cross referencing ADL & IADL deficits with the clients diagnosis, age, comorbid conditions, and severity of illness (Taylor, 1988) significant insight is provided for development of an individualized health care plan. The ability to predict patient outcomes and develop effective health care plans to meet their needs is highly dependent on identification of the disease progression, the treatment side effects and the ADL/IADL deficits. Assessing the impact of cancer treatments and predicting outcomes is focused primarily on a patients' functional performance. Functional performance in adults over the age of 18 years is readily evaluated by using the Karnofsky Performance Scale (Crooks, Waller, Smith, & Hahn, 1991; Milstein, Cohen, & Sinks, 1985; Mor, Laliberte, Morris, & Wiemann, 1984) as a tool to assess the individuals ability to function and work within their community.

The Karnofsky Performance Scale (KPS) has been widely used since its development in 1948 with proven validity and reliability (Mor et al., 1984). Crooks et al. (1991) use the KPS to determine outcomes and risk in the geriatric population. The KPS was highly predictive of hospitalization, survival days, community residence and institutionalization.

Higher risk populations like the elderly and those with serious chronic illnesses such as cancer, require more comprehensive assessments with innovative multidisciplinary plans frequently due to comorbid preexisting conditions and diminished access to social support systems. Mor et al. (1984) evaluated the Karnofsky Performance Status scale as a reliable measure of cancer patients' ADL & IADL status, as well as, a predictor of response to therapy and survival. The KPS scale was shown to be a reliable instrument in measuring the degree of impairment experienced by cancer patients as a result of the disease and/or treatment and should be able to predict the length of survival of terminally ill cancer patients.

Instrumental functioning includes activities requiring the expenditure of strength and endurance. Unmet needs or assistance with transportation to the physician may affect treatment compliance and outcomes (Mor et al., 1992). Support from other outside resources to perform self care activities is a strong indicator of overall severity of illness. The ability to independently perform activities of daily living and instrumental activities of daily living is greatly dependent on the severity of symptom distress caused by the disease and/or treatment (Dodd, 1992; Sarna, 1993).

Symptom Distress

Symptom distress is defined as "the subjective manifestation of discomfort reported by the patient in relation to the perception of the symptom experience" (McCorkle & Young, 1978; McCorkle & Given, 1989).

The presence of symptoms, as well as, the severity of symptoms are assessed to determine the patients' perception of symptom impact. In Given's (1993) study the patients' depression was explained largely by their symptomatology, and to a lesser extent by loss of mobility. This study found that cancer sites and stages of disease progression impacts prognosis, disability and treatment-related symptomatology which influence the patients' psychological adjustment and depressive symptomatology. The patients' immobility, symptom distress and numbers of dependencies in ADL were all moderately to highly correlated with patients' reported levels of depression. This study suggests that a cancer patients' depression was largely explained by the physical discomfort related to symptomatology of the cancer or the associated treatment and, to a lesser extent, by loss of mobility. In Rhodes, Watson, and Hanson (1988) study tiredness and weakness were identified as symptoms that most interfere with self-care activities.

Outpatient chemotherapeutic treatments are becoming intensified in terms of potential toxicity. Increasingly toxic doses of chemotherapeutic agents create greater symptom distress and decreased functional status placing patients at greater risk for developing treatment complications. The side effects of cancer treatments that were reported with the greatest frequency in Dodd's (1982) study were nausea and vomiting, loss of hair, taste and smell changes, and decrease appetite. In that study patients used a five point Likert scale to rate the severity of each side effect with an average score of 3.6. Dodd found that the greater the number of chemotherapeutic drugs a patient received the lower the functional status and greater the impact on self care with increased risks for complications. The severity of treatment side effects (symptom distress) has a greater affect on the patients' overall functional status than the number symptoms experienced (Musci & Dodd, 1990).

Mor et al. (1992) identified the four most commonly occurring symptoms seen during cancer treatments as pain, nausea, diarrhea, and shortness of breathe, and higher number of symptoms correlated with greater declines in functional status. Nausea and vomiting, decreased appetite, altered elimination pattern, pain, generalized weakness, loss of hair, and changes in taste and smell were the most frequently occurring symptoms encountered by patients receiving cancer treatments in similar studies (Dodd, 1982; Given & Given, 1991; Rhodes et al., 1988).

Cancer patients experience hardships in response to changes in their functional status, and symptom distress as a result of cancer treatments or disease progression require sensitivity and multidimensional support from health care providers.

Satisfaction with Health Care Providers

The relationships between primary care providers and patients have a significant impact on patient satisfaction and outcomes. Positive provider-patient-caregiver triads ensure more accurate diagnosis and provide effective health education through enhanced communications (Hilton, Butler, & Nice, 1984). Patient trust (the amount of satisfaction the patient associates with confidence in the provider), provider respect (satisfaction associated with the level of courtesy and consideration shown by providers), accessibility of services (satisfaction associated with the variety and availability of service), and the range of services (satisfaction with the variety and availability of service were four categories used in Hilton et al. (1984) study to explore patient satisfaction in family practice verse non-family practice settings). All four patient satisfaction scores were significantly higher among family practice patients. Previous research shows that patients generally report high levels of satisfaction with medical service and care (Kurata, Nogawa, Phillips, Hoffman, & Werblun, 1992) and lower levels of satisfaction with access to care (Hilton et al., 1984; Kurata et al., 1992).

Kurata et al. (1992) study showed that patient satisfaction with advanced practice nursing providers exceeded that of physicians in the same practice setting. Patients were more satisfied with the amount of time spent with the nurse practitioner, as well as, their technical skills, and explanation of condition. Access to care which included waiting time to see a provider while at clinic setting and number of days to get an appointment was the area identified by patients and providers alike as the areas with greatest need for improvement.

Currently there is little literature available to indicate the extent to which cancer patients are satisfied with the quality of care they receive. Wiggers, Donovan, Redman, and Fisher (1990) study dealt with 232 ambulatory cancer patients about the importance of and satisfaction with the physicians technical competence and interpersonal and communication skills, accessibility and continuity of care, hospital and clinic care, non-medical care, family care, and finances. Most of the patients in this study indicated satisfaction with the opportunities provided to discuss their needs with the health care provider, the interpersonal support of the health care provider, and the technical competence of the health care provider. Only a few patients were satisfied with the provision of information concerning their disease, treatment, and symptom control and the provision of care in the home and to family and friends.

Previous research on cancer patient satisfaction with care does not provide a sound basis upon which interventions to improve patient satisfaction can be developed. Past research does not adequately address the total care needs of cancer patients, and it has not allowed cancer patients themselves to indicate the issue they consider to be of particular importance (Wiggers et al., 1990).

Satisfaction with Information

Providing information regarding the rationale for treatment and actions to be taken to lessen the severity of treatment side effects empowers the patient-caregiver dyad by enhancing coping resources which increases knowledge and participation in care, while decreasing overall anxiety (Call & Davis, 1989; Hiromoto & Dungan, 1991; Nail, Greene, Jones, & Flannery, 1989). Individual coping strategies affects information-seeking behaviors.

Hileman and Lackey (1990) identified the demands of illness as psychological, informational, and those related to household responsibilities. Hileman & Lackey (1990) recognized the need for patients and significant others to have information regarding strategies to preserve and maintain the integrity of the patients' physical being, including dietary requirement, activity levels, pain relieving measures, and disease and treatment course.

Informational needs for both the patient and family correlate with the likelihood of threat for the actual need to be realized (Derdiarian, 1987). The patient seeking information is attempting to appraise harms, threats, and resources in relation to each other. Deriarian's (1987) study found that patients' informational needs related to prognosis and treatment were more important than information related to diagnosis or tests. The information about treatments and prognosis are most definitive of the patients' physical survival. This study implies that individual cancer patients' informational needs should be determined by Maslow's hierarchy of needs, as well as the amount, imminence, and likelihood of threat. Patient-caregiver dyads need anticipatory guidance to effectively manage symptom distress and avoid potentially severe complications (Mor et al., 1992). Information adds predictability to treatment side effects and gives the dyad increased control which improves the overall quality of life (Haberman et al., 1990; Lazarus, 1984).

The literature lacks identification of effective patient educational and counseling approaches for cancer patient-caregiver dyads experiencing recurrence or newly diagnosed disease. Self-determined multidimensional needs of cancer patients as perceived by cancer patients is not addressed in the literature.

This study will provide insight into the impact cancer treatments have in terms of patient experienced symptom distress and functional status which will enhance the knowledge health care providers have about the patients' condition to more effectively focus the informational and treatment needs of this patient population.

CONCEPTUAL FRAMEWORK

The concepts of functional status and symptom distress, satisfaction with health care providers, and satisfaction with information related to the demands of illness concept for cancer patients undergoing treatment have been discussed. A conceptual framework for the management of symptom distress to enhance functional status through satisfaction with health care providers and information received to enhance the quality of life for cancer patients will be presented. The purpose of the conceptual framework will be to develop a model which will be used for theory building in the areas of symptom management to enhance functional status through increased patient-caregiver satisfaction with health care providers and information received, which will be useful for advanced practice nurses in planning and implementing nursing interventions for patients undergoing cancer treatments. Having reviewed the literature on functional status, symptom distress, and the demands of illness subconcepts of satisfaction with health care providers, and satisfaction with information, the research concepts will be explored within King's theory of goal attainment (King, 1981). King's (1981) nursing theory of goal attainment is that nurses and patients can interact in such a manner that goals are identified and decisions are made concerning the means to achieve goals. These goal directed interactions are referred to as transactions, which is the underlying framework for the Theory of Goal Attainment.

The environment is conceptualized as an open system with permeable boundaries which allow the exchange of matter, energy and information between human beings. The family is viewed as a social system bound together by a common purpose.

King's (1981) conceptual framework for nursing practice is based on three interacting systems. The personal, interpersonal, and social systems (Fitzpatrick & Whall, 1989; King, 1981). The interpersonal system is the core of King's conceptual framework (King, 1981). Perceptions, communication and transactions within the nursing theory are the primary components of the human interactional process. Perceptions involve the acceptance and organization of information, processing and acting on the information provided, storing information for future use, and providing information to the health care providers. The perception of the family during the interactional process determine the degree of success the interaction will ultimately have on health related behaviors. The interactional process involves both verbal and nonverbal behaviors between the health care provider and the patient and/or family. Providing information to the patient to facilitate positive health behaviors and outcomes is defined as the communication process (Fitzpatrick & Whall, 1989). Communication is the verbal or non-verbal transfer of information between two or more individuals (King, 1981). The effectiveness of the nurse-patient relationship is based on the quality of the interaction. This communication process is a positive, nurturing, reciprocal interaction where trust and intimacy are integral to it's overall quality and success.

The transaction is the process of interaction in which the nurse and patient relate to environmental factors to achieve valued goals (Fitzpatrick & Whall, 1989). Transactions are goal-directed behaviors that reduce stress or tension during transitional periods in the life cycle (King, 1981). The transactions that occur between the nurse and the patient validate beliefs, symptoms or decreased functional status, and affirms self worth to develop or obtain needed resources to promote health. This support assists the patient and/or family in taking on new roles and reducing stress during cancer diagnosis and treatment. The exchange of information is relative to the demands of illness involving social exchange, bargaining, and mutual goal setting.

Role is identified within the interpersonal system because it depicts the interactive relationship between the advance practice nurse and the patient, and the style and manner of communication that takes place (King, 1981) is the level of communication where patient satisfaction with both the health care provider and the information received occurs. The patient negotiates new roles and establishes goals for the immediate future with plans to achieve them for continued growth and development throughout the crisis (Clements & Roberts, 1983). The advanced practice nurse through the nursing process has the expertise to assess patient status, and facilitate appropriate goal setting to accomplish the expected outcomes. The process of altering roles presents the potential for increased stress for the patient within the family environment.

The family and patient in collaboration with the health care team strive to maintain balance for continued growth and development. This team strives to mitigate stressors which would increase symptom distress, and decrease functional status thereby reducing the effectiveness of nursing care and ultimate patient-caregiver satisfaction with treatment outcomes.

The advanced practice nurse in a primary care setting interacts with the family to share information, knowledge, and set goals as a means to successfully meet the needs of the patient and caregiver while promoting interventions for optimal treatment outcomes. Mutual goal accomplishment leads to patient-caregiver satisfaction. Mutual goal setting, and identification of stressors is based on a mutually trusting, and intimate communication process. The transaction that occurs leads to goal attainment, which activates the family and community network outcomes for the cancer patient.

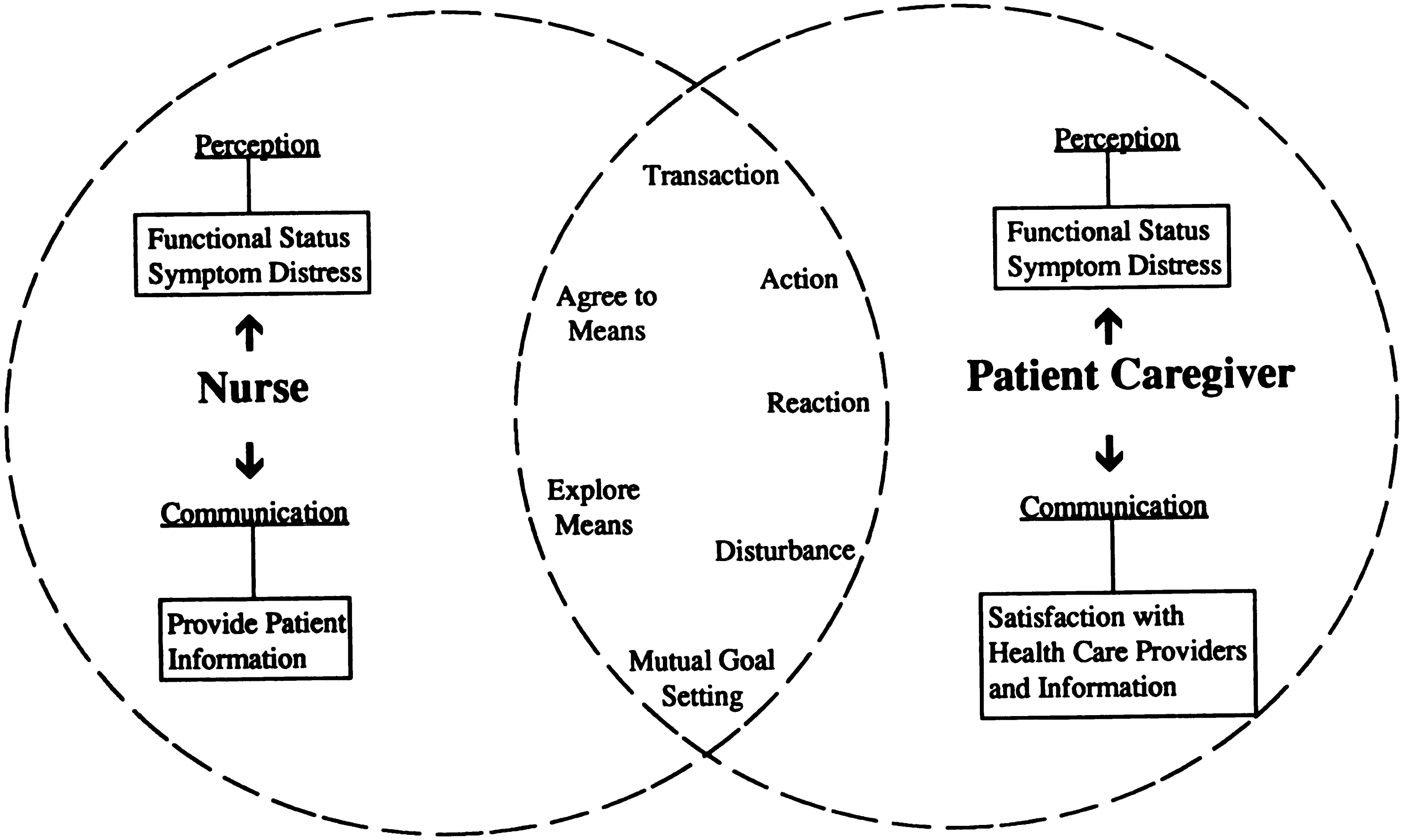
The clinical nurse specialist (CNS) possesses the knowledge that must be conveyed to the patient. The patient acknowledges the CNS as a helping, knowledgeable resource. Decision-making is the action taken based on perceptions of the interactional process. Decisions are focused on ultimate goal attainment, which occurs through the process of mutual goal setting.

In Figure 1 the research concepts have inserted into King's theory of goal attainment. Functional status and symptom distress are depicted under the perceptions of the patient-caregiver dyad and nurse. Satisfaction with health care providers and satisfaction with information are identified under communication. The theory of mutual goal attainment assumes that transaction, action and reaction take place between the health care provider and the patient. Herein, is the exchange of information that guides the individual health care plan based on the needs of the patient, which is the driving force for the exchange of information/education between the health care provider and the patient.

METHODS

The analysis for this study will be based on data obtained as part of the longitudinal studies supported by grant #1R01NR01915, "Family Home Care for Cancer--A Community Based Model," funded by the National Center for Nursing Research; and grant #PBR-32, "Family Homecare for Cancer Patients," funded by the American Cancer Society. Principal

Figure 1.
Theory Mutual Goal Attainment



Investigator, Barbara Given, PhD, RN, FAAN, A-230 Life Sciences, Michigan State University, East Lansing, MI 48824-1317.

The primary aim of this study is to examine the relationship between the impact of symptom distress, on dependencies in activities of daily living, instrumental activities of daily living, caregiver satisfaction with health care providers, and caregiver satisfaction with information received during cancer treatment.

Sample

This study employed a convenience sample of 196 patient-caregiver dyads recruited through six community based cancer treatment centers. Criteria for inclusion were as follows: adult patients over 20 years of age, diagnosed with a solid tumor or lymphoma, symptomatic or having dependency in either self care or instrumental activities of daily living, and currently under treatment for new or recurrent disease. Each patient was asked to identify his/her primary caregiver. In a subsequent telephone interview, the caregiver was asked to verify that he/she was in fact the primary caregiver for the patient. Dyads interested in participation completed and returned a card to the research center. Over 80 percent of those caregivers who indicated an interest in the project returned cards and were then contacted by the research staff to determine eligibility and to explain conditions for participation in the study.

In Table 1 sociodemographic characteristics of the caregivers and patients, types of cancer, treatment modalities and illness status (primary versus recurrent cancer) of the patients are presented. Approximately two thirds of the caregivers were female, while the patients were almost equally divided according to gender. Eighty

Table 1

Sociodemographic Characteristics of Caregivers and Patients (N=72)

	Caregiver		Patient	
	#	%	#	%
Age (in years)	X=55.7	SD=12.98	X=60.78	SD=12.53
Males	20	28	44	61
Females	52	72	28	39
Caregiver Relationship to Patient				
Spouse	52	72		
Parent	2	3		
Other	18	25		
Caregiver Education				
Less than high school	10	14		
Completed high school	28	39		
Some college and above	34	47		
Illness Status				
Primary			56	78
Recurrent			16	22
Primary Site of Cancer				
Bladder			1	1
Breast			7	10
Colon/Rectal			18	25
Gastrointestinal			2	3
Gynecological			3	4
Lung			30	42
Lymphoma			5	7
Other			6	8
Current Patient Therapy				
Chemotherapy			56	78
Radiation			15	21
Hormonal			1	1
Other			20	28
Household Income	X=$35902	SD=$20542	Range=$1000-$72500	

percent of the caregivers were married to their patients. Just over half of the caregivers and their patients had received some college education. Fifty-three percent of the patients were newly diagnosed and 47 percent were experiencing recurrence at time of entry into the study. The four most prevalent primary sites were breast, lung, colorectal, and lymphoma. Finally, the treatment modality was primarily chemotherapy, with some patients undergoing radiation and hormonal treatments or combination.

Data Collection

The data collection was completed through telephone interview by graduate nursing or medical students specially trained in role playing, using a structural interview guide and self-administered questionnaires.

Three scales were used to measure the identified concepts from patients and their caregivers.

Cancer related symptomatology was measured using the McCorkle Symptom Distress Scale (McCorkle & Young, 1978). This self-report measure was administered to patients via mailed questionnaire. This was a twelve item questionnaire designed to obtain information about symptom occurrence and severity on a 5-point Likert scale.

Content and face validity was established when the initial tool was established in 1978 through pilot study conducted with cancer patients reporting the symptoms measured by the scale. In previous studies the Cronbach coefficient alpha was used to determine the reliability of the scale. The reliability coefficient alpha was .82143 and the standardized item alpha was .8256 indicating the scale has good reliability (Given & Given, 1989).

Measurement of patients' deficits, i.e., ADL, and IADL were accomplished through the use of modified versions of two scales. The first was taken from the OARS Multidimensional Assessment Questionnaire (Filebaum & Snyder, 1981). The second measure of patient functioning, derived from the Medical Outcomes Studies (Steward, Ware & Brook, 1981) focused on mobility and ability to perform identified physical tasks. In validity studies the ADL and IADL were related to patients' status as community residents of residents of institutions (Given & Given, 1989). In a study by Wolinsky et al. the IADL and ADL measures were found to have high reliability with alpha coefficients of .83 and .85 respectively (Given & Given, 1989). This is a fourteen item scale designed to identify the intensity of assistance required from the care provider on behalf of the patient on a 5-point Likert Scale.

The satisfaction with treatment scale is a subscale of the Demands of Illness Inventory developed by Haberman et al., 1990. This scale obtains information about treatment issues measured on a 5-point Likert Scale ranging from 0 "not at all" to 4 "extremely". The subscale administered deal with accommodation to regimen; treatment evaluation; and relationship with providers. For the purpose of this study this subscale was examined in two parts. Question 1-6 examine the caregiver relationship with providers, and questions 7-16 examine caregiver satisfaction with information received regarding cancer treatment.

The Demands of Illness Inventory (DOII) was developed and revised as part of a larger research program focusing on the impact of breast cancer, diabetes, and fibrocystic breast changes. The initial DOII contained 110 items and nine hypothesized dimensions or subscales: physical symptoms, personal meaning of illness, cognitive functioning, family functioning, illness attribution, body image, symptom monitoring, treatment issues, and emotion. The DOII's content validity has been examined and supported by researcher and clinical specialist. The internal consistency reliability were obtained for DOII: coefficient alpha, item subscale, and subscale-subscale correlations. The treatment issues subscale used in this study displayed satisfactory internal consistency reliability. Construct validity has been examined by correlational analysis indicating that the DOII measures a discrete concept (Haberman et al., 1990).

Operational Definitions

Activities of Daily Living. The self care activities as reported from the caregivers perspective include: 1) eating, bathing, dressing, toileting, grooming; 2) mobility--walking, movement inside the house, transferring bed to chair, lift/turn in bed; and 3) incontinence--need cleaned because of incontinence of bowel or bladder (Given & Given, 1991).

Instrumental Activities of Daily Living. The instrumental activities of daily living are operationalized as: housework, limitations on ability to run, lifting heavy objects (25 lbs. or more), participating in sports, difficulty walking several blocks, lifting or stooping; difficulty walking one block or climbing one flight of stairs (Given & Given, 1991).

Symptom Distress is self reported and included symptoms and the severity of symptoms for the following: nausea, appetite, insomnia, pain, fatigue, bowel, concentration, appearance, outlook, and cough. The presence of symptoms, as well as the severity of symptoms, were assessed to determine the patient's perception of symptom impact.

Satisfaction with Health Care Providers/Satisfaction with Information addresses the sensitivity of the health care provider in interpersonal interactions with the patient-caregiver dyad as perceived by the caregiver. Satisfaction with information received addresses the quality of information provided by the health care provider related to the disease and treatment as perceived by the caregiver. As previously discussed, providing information regarding the rationale for treatment and actions to be taken to lessen the severity of treatment side effects empowers the dyad by enhancing coping resources with increases knowledge and participation in care, while decreasing overall anxiety (Call & Davis, 1989; Hileman & Lackey, 1990; 1991; Nail et al., 1989).

Scoring

Activities of Daily Living and Instrumental Activities of Daily Living. This "Involvement" scale is completed by the caregiver. The evaluation of deficits in ADL/IADL's is a fourteen item scale designed to identify the intensity of assistance required from the caregiver on behalf of the patient on a 5-point Likert Scale ranging from 0-4, with 0 indicating independence and 4 indicating maximum amount of dependency. A total score of "0" is indicative of total patient independence with all ADL/IADL's. A total score of "56" is indicative of total patient dependence with ADL/IADL's on the caregiver.

Symptom Distress. The symptom distress scale is completed by the patient. This is a twelve item questionnaire designed to obtain information about symptom occurrence and severity on a 5-point Likert Scale ranging from 1-5, with 1 indicating "no problems exist" and number 5 indicating the "maximum amount of symptom distress exists". An accumulative score of 12 indicates that minimal or no symptom distress is experienced. An accumulative score of 60 is indicative of severe symptom distress.

Satisfaction with Health Care Providers. The Demands of Illness subscale examines the relationship between the patient-caregiver dyad and the careprovider. Questions 1-6 examine the quality of this relationship as perceived by the caregiver. The 5-point Likert Scale ranging from 0-4 with 0 indicating "not at all" and 4 indicating "extremely". A total score of "0" is indicative of high sensitivity of the health care provider as perceived by the caregiver. A total score of "24" is indicative of low sensitivity of the health care provider as perceived by the caregiver.

Satisfaction with Information. Satisfaction with information received regarding treatment scale examined the caregivers level of satisfaction with information received during the cancer treatment process. Questions 7-16 examine the quality of information received. The 5-point Likert Scale ranging from 0-4 with 0 indicating "not at all" and 4 indicating "extremely". A total score of "0" is indicative of complete satisfaction by the careprovider with information received from the health care provider. A total score of "40" is indicative of complete dissatisfaction with information received from the health care provider.

Analysis

The descriptive analysis will include: 1) frequencies, means, and standard deviations for each ADL, IADL, and symptom distress identified; 2) Pearson r correlations between items in ADL, IADL, and symptom distress; 3) Pearson r correlations between ADL, IADL, symptom distress, and the DOII subscales of satisfaction with health care providers, and satisfaction with information received. The correlational studies will be used to identify the relationship between the coefficients.

Question #1: What is the relationship between symptom distress, activities of daily living, and instrumental activities of daily living for patients with cancer?

Descriptive statistics will be used to determine: 1) frequencies, means, and standard deviations for each ADL, IADL, and symptom group; and 2) correlations between ADL, IADL, and symptom group.

Question #2: What is the relationship between patient symptom distress and caregiver satisfaction with health care providers?

Descriptive statistics will be used to determine: 1) frequencies, means, and standard deviation for each symptom group, and caregiver satisfaction scores; and 2) correlations between each symptom group and caregiver satisfaction with health care provider scores.

Question #3: What is the relationship between patient symptom distress and caregiver satisfaction with information received during cancer treatment?

Descriptive statistics will be used to determine: 1) frequencies, means, and standard deviations for each symptom group, and caregiver satisfaction with information scores; and 2) correlations between each symptom group and caregiver satisfaction with information scores.

The SPSS-X computer program will be used for data analysis. Tables will include patient characteristics such as age, sex, caregiver relationship to patient, caregiver education, illness status, primary site of cancer, and current patient therapy with descriptive statistics frequencies, means, standard deviation, and percents, if relevant.

If the researcher's hypotheses are true, that symptom distress experts a greater impact on the demands of illness subconcepts identified, than does functional status, then the descriptive statistics shall provide a more detailed view of the needs of recurrent and newly diagnosed cancer patients receiving treatment. This information will assist primary care providers in providing education, implementing clinical interventions, and development and utilization of appropriate community resources to better meet the needs of this client population.

Protection of Human Rights

As previously discussed, study participants were identified through clinics and private practice sites. A card back system was used to assure confidentiality. Consents were obtained from patients who chose to participate in the study. Subjects identified were kept confidential. All findings were compiled in aggregate form and coded numerically for data analysis. The "Family Homecare for Cancer--A Community Based Model" grant received Human Subjects approval in accordance with research criteria. Approval from Michigan State University's Committee on Research Involving Human Subjects will be obtained for data analysis under the expedited review process.

ANALYSIS

Sample Characteristics

This study used a convenience sample of 72 patient-caregiver dyads recruited through six community based cancer treatment centers. Criteria for inclusion were as follows: adult patients over 20 years of age, diagnosed with a solid tumor or lymphoma currently under treatment for new or recurrent disease. Each patient was asked to identify his/her primary caregiver. In a subsequent telephone interview, the caregiver was asked to verify that he/she was in fact the primary caregiver for the patient. Dyads interested in participation completed and returned a card to the research center and were followed by trained graduate nursing and medical students every three months through telephone contact and self-administered questionnaires. Over 80 percent of those caregivers who indicated an interest in the project returned cards and were then contacted by the research staff to determine eligibility and to explain conditions for participation in the study. This data was collected six months after the patient initiated cancer treatments.

In Table 1 sociodemographic characteristics of the caregivers and patients, type of cancer, treatment modalities and illness status (primary versus recurrent cancer) of the patients are presented. There were 72 patient-caregiver dyads participating in this wave of the study. Approximately two thirds of the patients were male (N=44) while 72 percent (N=52) of the caregivers were females. Seventy-two percent of the caregivers (N=52) were married to their patients. Forty-seven percent of the caregivers (N=34) had received some college education. Seventy-eight percent of the patients were newly diagnosed (N=56) and 22 percent (N=16) were experiencing recurrence at the time of entry into the study. The three most prevalent cancer sites were lung (N=30), breast (N=7), and colorectal (N=18). Finally, the treatment modality was primarily chemotherapy, with 21 percent (N=15) of the patients undergoing radiation and 28 percent (N=20) undergoing combination treatments.

<u>Research Question #1</u>. Descriptive statistics were employed to provide background information regarding symptom distress, ADL's, and

IADL's for the sample. Frequencies, means, and standard deviations of ADL, IADL both individually and as a group, as well as, symptom distress are summarized in Table 2.

The caregiver perceived that patients they were caring for required the greatest assistance in dressing (X=.26), and bathing (X=.29) with few ADL deficits. The caregivers reported the greatest deficits in IADLs as compared to ADLs with housework (X=2.21), laundry (X=1.39), and cooking (X=1.12) being the three greatest areas of patient self-care deficit. This finding would seem to correlate with the findings of other researchers, as instrumental activities of daily living are those activities requiring greater strengths and endurance (Given & Given, 1991; Stone & Murtaugh, 1990). Patients in this study present as having minimal ADL deficits. Two or more deficits in ADL's is the primary disability measure used to determine eligibility for federally reimbursed skilled home care (HCFA, 1990; Stone & Murtaugh, 1990). With 28 percent (N=20) of the caregivers being male, it would be of interest to identify if these individuals regularly performed housework, laundry, and cooking before their loved one became ill. If not it would seem that the gender of the caregiver may affect the perception of IADL deficit.

Symptom distress as measured by the McCorkle Symptom Distress scale in this study was self-reported by fewer patients. It is unknown whether 29 fewer patients experienced symptom distress as these questionnaires were not returned by the participating patients. The 43 patients reporting symptom distress (X=1.78) identified their discomfort as relatively mild.

Table 2

Descriptive Statistics for Symptom Distress, ADL's, and IADL's

	Mean	SD	Range	Freq	Alpha
Caregiver Reported					
ADL	.22	.51	0-3	72	.46
eating	.10	.45		72	
dressing	.26	.45		72	
bathing	.29	.80		72	
walking	.10	.42		72	
toileting	.19	.68		72	
bed	.19	.66		72	
combing hair	.07	.42		72	
Caregiver Reported					
IADL	.97	.90	0-3	71	.54
cooking	1.12	1.23		72	
housework	2.21	1.13		72	
shopping	.90	1.09		72	
laundry	1.39	1.28		72	
transportation	.72	.91		72	
money handling	.61	1.09		72	
Symptom Distress	1.78	.49	1-3	43	.52

Correlational studies were completed to answer the first research question regarding the relationship between symptom distress, ADL's, and IADL's. When correlating ADL's and IADL's to symptom distress there was a high correlation at the .01 significance level (r=.4074) with IADL's as reported by the caregiver which is illustrated in Table 3. The two IADL's that correlated the highest were housework (r=.4022) at the .01 significance level, and cooking (r=.3151) at the .05 significance level. Symptom distress did not correlate significantly with ADL's.

Since patients in this study required assistance with housework and cooking it was not surprising to find that the caregivers reported the patients requiring assistance with transportation out into the community.

Research Question #2. Frequencies, means, and standard deviations of symptom distress and caregiver satisfaction with health care providers are summarized in Table 4.

The caregivers that responded to the satisfaction with health care providers questionnaire indicated a high degree of satisfaction with the patients health care provider during the preceding three months. Twenty-eight percent (N=20) of the caregivers did not respond to this component of the study. It is unknown whether the caregivers not responding were satisfied with the health care provider or if they did not respond due to dissatisfaction with the health care provider, and feared retribution to their loved one if the health care provider was criticized. Questions 1-6 deal with the health care providers sensitivity toward the dyad. The questions explore the health care providers sensitivity to the caregivers preferences, opinions,

Table 3

Correlations Between Symptom Distress and ADL's and IADL's Correlation Coefficients

	Symptom Distress
ADL	.0793
Dressing	-.0132
Eating	.0697
Bathing	-.0034
Walking	----
Toileting	-.0285
Getting in Bed	-.0618
Combing Hair	----
IADL	.4142**
Cooking	.3170*
Housework	.3838*
Shopping	.2064
Laundry	.2442
Transportation	.3071*
Money Handling	.1872

*=Significant LE .05
**=Significant LE .01
-----=Printed if coefficient cannot be computed

Table 4

Descriptive Statistics for Patient Symptom Distress and Caregiver Satisfaction with Health Care Providers

	Mean	SD	Range	Freq	Alpha
Symptom Distress	1.78	.49	1-3	43	.52
Satisfaction with Health Care Providers	.33	.55	0-2	52	.48

decisions, and as an individual within the context of the caregiver role.

Correlational studies were completed to answer the second research question regarding the relationship between patient symptom distress and caregiver satisfaction with health care providers. When correlating symptom distress, as reported by the patient, and satisfaction with health care providers, as reported by the caregiver, there is correlation ($r=.1147$), however, this did reach a statistically significant level. Since the correlation is so small, the subscale used may have been to global to adequately capture the specific concerns, symptoms, and daily needs of the cancer population. As indicated previously, past research does not adequately address the total care needs of cancer patients, and has not allowed cancer patients themselves to indicate the issues they consider to be of particular importance (Wiggers et al., 1990). This is consistent with the findings in this study.

Research Question #3. Descriptive statistics were employed to provide background information regarding the sample. Frequencies, means, and standard deviations of patient reported symptom distress and caregiver reported satisfaction with information received are reported in Table 5.

The caregivers that responded to the satisfaction with information from health care providers questionnaire during cancer treatments indicated a high degree of satisfaction with information received during the preceding three month period. Twenty-eight percent ($N=20$) of the caregivers did not respond to this portion of the study. As with the satisfaction with health care providers, it is unknown whether the

Table 5

Descriptive Statistics for Patient Symptom Distress and Caregiver Satisfaction with Information

	Mean	SD	Range	Freq	Alpha
Symptom Distress	1.78	.49	1-3	43	.52
Satisfaction with Information	.69	.74	0-3	52	.55

Table 6

Frequency and Reliability Alphas of Original Study

	Frequencies	Alpha
Caregiver Reported		
ADL	303	.85
IADL	303	.75
Patient Reported		
Symptom Distress	198	.83

caregivers not responding were satisfied with the information provided or if they did not respond due to dissatisfaction with the information received from the health care provider, and feared the patient would suffer if criticisms were made.

To answer the third research question as to the relationship between patient reported symptom distress and caregiver reported satisfaction with information received during cancer treatments correlational analysis were completed. When correlating symptom distress, as reported by the patient, and satisfaction with information received, as reported by the caregiver, the correlation was ($r=.0524$) not at a statistically significant level. As indicated previously, individual cancer patient-caregiver dyads need anticipatory guidance to effectively manage symptom distress and avoid potentially severe complications (Mor et al., 1992). The responding participants in this study indicate their general informational needs were met which added a sense of increased control in dealing with treatment side effects and provided the dyad with a sense of increased satisfaction improving overall quality of life (Haberman et al., 1990; Lazarus, 1984).

In summary, the results of this study indicate that the participants were independent, as there was minimal symptom distress reported by the patients themselves, and minimal ADL deficits as reported by the caregivers. The caregivers report a high degree of satisfaction with both the health care providers and information received during cancer treatments. There was significant correlations between the symptom distress and IADL deficits in housework, cooking, and transportation. It is unknown whether this correlation was impacted by the gender of the caregivers. Symptom distress did not correlate significantly with ADL's or satisfaction with health care providers of satisfaction with information. The findings in this study correlate with those of other researchers. The ability to independently perform instrumental activities of daily living is greatly dependent on the severity of symptom distress caused by the disease and/or treatment (Dodd, 1992; Given et al., 1993; Mor et al., 1992; Musci & Dodd, 1990; Sarna, 1993). The patients' dependencies in IADL's are expected to be directly related to the impact of caring on the family members' daily schedules or previous socialization in performing the needed IADL.

The conceptual framework as previously discussed deals with King's theory of goal attainment. The core of this model assumes there is a transaction between the advanced practice health care professional and the patient-caregiver dyad. This transaction occurs to identify self-care deficits and symptom distress. The informational component provided by the health care professional is essential to mitigate stress during the cancer treatment process. The results of this study indicate that patients in the first six months of cancer treatment were not severely distressed. The health care professionals need more information as to the patients' and caregivers' perceptions of symptom distress, ADL/IADL deficits, and satisfaction with health care providers, and information received. If congruency is found between patient and caregiver perceptions then the caregiver surveys will provide adequate insight into the needs of the dyad.

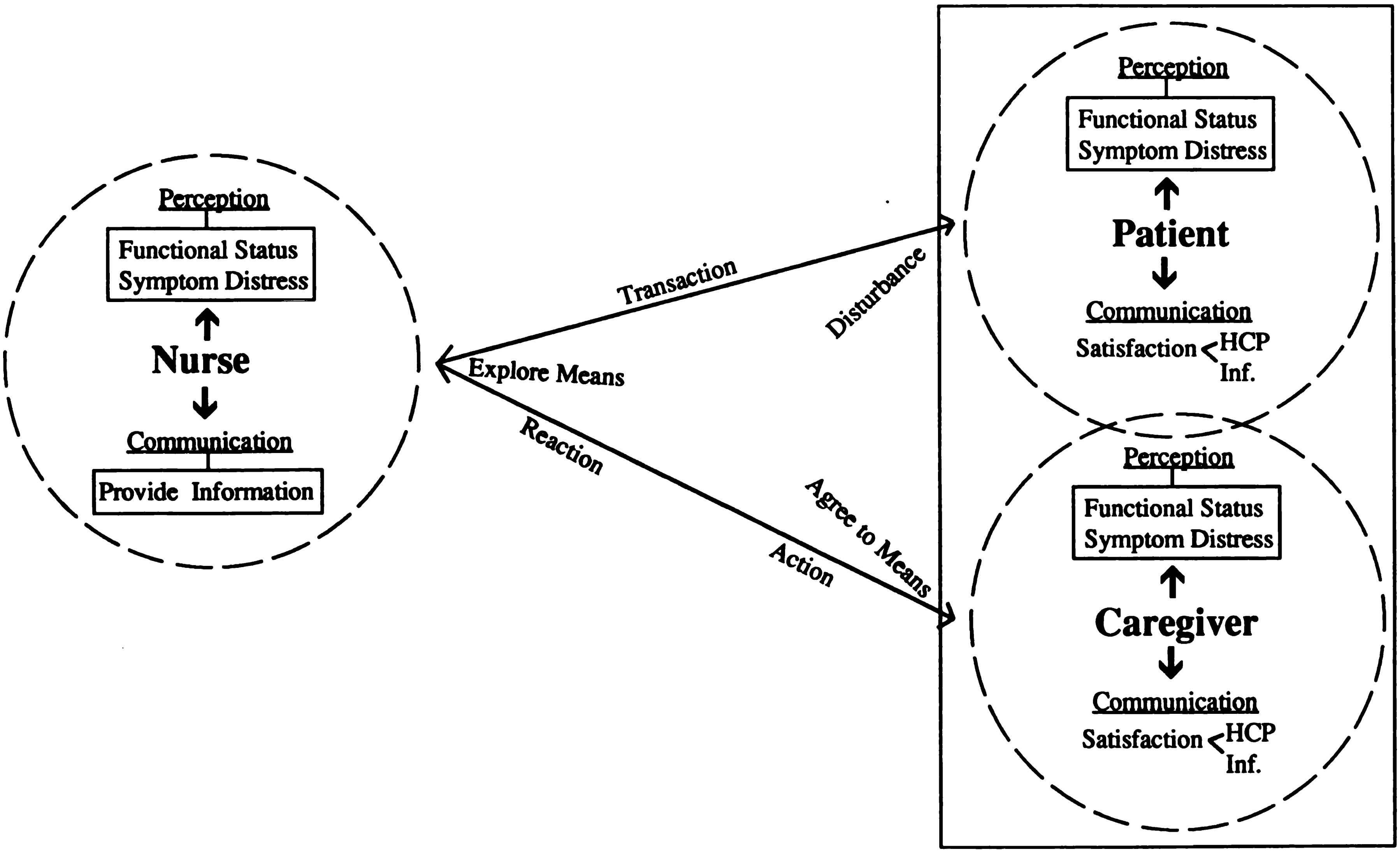
As a result of the study findings, this researcher would retrospectively alter the conceptual framework to better fit the needs of the study population and facilitate the research and clinical processes. As previously recommended, the advance practice nurse functioning in the role of researcher or clinician must assess the client's and caregivers' perceptions of all study variables both individually and together as a dyad in order to adequately identify potential self-care deficits or ineffective coping. Assessment must include those areas not traditionally addressed by the health care system which include; caregivers knowledge and ability in the operation of household appliances, automobiles, financial management, and home maintenance. The model in Figure 2 would seem to more adequately guide this process.

STUDY LIMITATIONS

This study was completed on secondary data. The sample size (N=72) for this study was significantly smaller than the original study (N=302). The clients participating in the study during Wave III, may have had a more homogenous sociodemographic profile. The smaller sample size may have created a smaller distribution among the population still participating in the study. In reducing the size of the sample a degree of variability in responses is lost as evidenced by the alphas obtained in the original studies. These are depicted in Table 6.

Since 28 percent (N=20) of the care providers did not respond to the self-administered satisfaction questionnaires, it seems reasonable to conclude that phone interview of both patients and care providers would provide stronger insight into the impact of cancer and its treatment. The results are based on self-reports of the respondents, and so are affected by pressures of self-presentation and social desirability. Patient-caregiver dyads may need reassurance that the treating health care provider will not receive feedback on individual responses. The data collection may need to be conducted on a bimonthly

Figure 2.
Modified Mutual Goal Attainment



basis to obtain more current information from the dyad. A time period of three months may allow the dyad to forget or minimized both negative and positive experiences. The satisfaction tool is global and does not seem to lend itself well to the specific needs and concerns of the cancer patient-caregiver dyad. This study was conducted only on Wave III of a much larger individual study. Examination of patient-caregiver profiles of previous study waves may provide insight into the 28 percent (N=20) of caregivers who did not respond to the satisfaction surveys in the third wave of the study. The patients (N=29) not responding to the Wave III symptom distress survey may have dropped out of the study for numerous reasons including death. Examination of patient profiles in previous studies may provide valuable insight into the findings in this study.

The caregiver involvement tool does not provide the researcher with knowledge of which IADL activities the care provider performed prior to the patient's cancer diagnosis and treatment, or if there had been a change in caregiver involvement since cancer diagnosis. Knowing the caregivers involvement with running the household prior to the patients cancer diagnosis will provide insight into their perception of caregiver burden, as well as, the type of amount of support/services they will require to meet the challenges of caregiving. As previously mentioned, the gender and historical involvement in running and household of the caregiver may skew the data results.

IMPLICATIONS FOR NURSING PRACTICE

The results of this study provided insight into the ADL, IADL, symptom distress, satisfaction with health care providers, and satisfaction with information received for patient-caregiver dyads during cancer treatments. Some of the research methodology could be altered to determine the perceptions of both the patient and caregiver (see Implications for Further Research). Patient limitations during this phase of cancer treatment, as described, will assist the health care provider in identifying needs of the dyad when evaluation for coordination of resources within the family unit and community at large.

In the clinical setting the clinical nurse specialist (CNS) utilizes collaboration and consultation with other members of the health care team, technical skills and nursing knowledge to assess and formulate nursing diagnosis while providing direct primary nursing care. The formal educational process enables the advanced practice nurse to base assessments, and nursing diagnosis on nursing theory to promote the clients ability for self-care, maintenance of health, promotion of rehabilitation in relation to disabilities, and effectively cope with chronic health problems like cancer (MSU Faculty, 1991). Identifying the clients readiness to learn becomes a primary factor in the education and health promotion process. During assessment and educational processes, the clinician utilizes counseling skills to facilitate problem-solving within the family structure to enhance the individuals coping behaviors. The CNS must assess the patient-caregivers perceptions of functional status and symptom distress to adequately provide information needed to the dyad to successfully help the dyad mitigate potentially stressful events and side effects of the disease and its treatment. A comprehensive assessment is completed through the development of a trusting relationship between the dyad and primary caregiver.

The assessment for this population must include the traditional health related items during functional assessment, i.e., bathing, dressing, eating, toileting. However, the assessment must also be expanded to include those items not directly related to the physical well being of the patient, which include, i.e., laundry, transportation, housekeeping, shopping, and functional management. The functional assessment then becomes a comprehensive assessment of the dyad and their roles within the family unit.

Health care providers must also assess the patient and caregivers perception of symptom distress at each contact. As previously indicated, this study supports the findings of other researchers (Dodd, 1992; Given et al., 1993; Mor et al., 1992; Musci & Dodd, 1990; Sarna, 1993) in that the inability to perform instrumental activities of daily living are highly correlated to the severity of symptom distress. The perceptions of symptom distress of both patient and caregiver must be assessed to identify potential incongruencies in patient and caregiver perceptions to adequately provide the dyad with stress mitigating strategies. Ultimately the patient-caregiver will be equipped with the needed knowledge and skills to implement appropriate self-care behaviors and effectively cope with the chronic illness. Consequently, the dyad will experience a high sense of satisfaction with the information received and the health care provider.

Patient and caregiver satisfaction with health care providers and information received during cancer treatments must be part of the evaluation process at each contact. Allowing the dyad to individually provide feedback into the health care system will provide immediate insight into the human interactional process. Early identification of problems with the interpersonal process will be identified and can then be dealt with within a time frame that will more adequately meet the needs of the population served. Ineffective provider styles and interventions will be more readily identified. The providers and interventions that are determined effective will be identified and can then be expanded on and taught to other members of the health care team.

During the assessment process the advanced practice nurse should be watchful for caregiver stress and ineffective coping, knowing when to provide stabilizing support, and when to utilize the referral process to obtain care needed for the dyad. The clinical nurse specialist (CNS) must provide ongoing assessments of the needs of the cancer patient-caregiver dyad. The ADL/IADL deficits of the patient will change over the course of the disease as treatments change and the disease progresses or recurs. Patient dependencies in ADL/IADL's impact the degree of involvement the caregiver will have in meeting the daily self-care needs of the patient.

When male caregivers are involved the health care provider needs to determine the degree of previous involvement in household maintenance, as additional outside resources may need to be accessed. Informal support systems from other family members and/or friends may be available and should be explored. The baby boomer generation in combination with the "age wave" may change the type of resources the health care community will ultimately require to meet the needs of chronically ill patients. Increasing numbers of women are leaving the home to seek outside employment opportunities to help meet the financial needs of their families. The multigenerational families living in one household are returning form the past bringing with it new challenges to the family unit (Dychtwald & Flower, 1989), as well as, to governing social policy. Exploring the needs of the dyad with both the patient and caregiver will facilitate the development of a comprehensive treatment plan that will ultimately function as a road map for success for the family.

Recurrent disease and end stage disease present different challenges for the patient-caregivers and primary health care providers. Patients with recurrent disease need information from the primary care physician on other treatment options (Adams, 1991), and the possibility of dying from recurrent disease. Additional community resources for transportation and skilled home nursing services may be needed to support the physical demands that more potentially toxic treatments may impose. Patients that have caregivers that are highly educated, or have mean incomes at opposite ends of the scale, or are not family members will require vastly different health care and community resources to meet their ADL/IADL needs. It is clear that the needs of cancer patient-caregiver dyads are individualized and require specialized assessments, planning, implementation, and evaluation to adequately meet their needs.

Counseling and guidance for the patient-caregiver dyad through values clarification enables the CNS to provide anticipatory guidance throughout the treatment process. The educational process regarding the disease, treatment, and available community resources is continuous as the needs of the dyad are in a constant state of flux. The primary care provider must develop goal oriented strategies in a collaborative effort with the dyad to foster maintenance and achievement of health-oriented goals will enhance the patient's ability to overcome barriers of powerlessness, and improve the understanding of actions and compliance required to achieve positive outcomes. In assisting the client in this manner, the CNS must continually assess the dyad's personal, social, spiritual, and psychological resources.

Networking within the community for access to both formal and informal support systems is a key factor in mitigating the impact of cancer and its treatments. The CNS with specialized knowledge possesses the clinical judgement skills to assess the ADL/IADL deficits and symptom distress to plan for and coordinate access to community resources when added assistance from formal or informal systems are warranted. The health care delivery system must continually be evaluated to assess appropriateness and effectiveness, based on the presenting needs of the cancer patient served.

Evaluation of health care interventions through satisfaction surveys with both patients and caregivers will provide information regarding the effectiveness of the individual health care providers, as well as, the information provided during the course of treatment. The caregivers in this study indicated a high degree of satisfaction with both the health care providers and the information received during treatments. The satisfaction instrument used was global in nature. The CNS must assess the communication process with the patient-caregiver dyad at each contact using nursing theory to guide his/her practice. The research model used in this study was adapted from King's theory of goal attainment, and is readily adaptable to clinical practice from which it is intended. The evaluation of nursing process by both the client and the nurse takes place within the core of the goal attainment model. The process of action, reaction and transaction are vital for the establishment and ultimate achievement of health directed goals. Figure 2 depicts the clinical adaptation for mutual goal attainment in the clinical setting. The perceptions, communication and transactions within this nursing theory are the primary components of the human interactional process. This process provides the advance practice nurse with needed insight for effective patient care interventions.

Client advocacy within the health care system and in the community at large will assure that needed consumer resources are available to promote health within the entire community. Identifying needs within the health care delivery system, and the community guides practice and facilitates a pro-active approach to institute necessary change in the delivery of health care and related social policy for this patient population.

The clinical nurse specialist continually evaluates patient population needs and provides needed community education for early detection of cancers, risks associated with various types of cancer, and encourages consumers to choose a lifestyle that minimizes their cancer risk.

RECOMMENDATIONS FOR FURTHER RESEARCH

As a result of this study, some suggestions for future research can be made.

First, researchers should explore not only caregivers responses to assistance needs but also patients' perceptions of their own limitations and compare them to determine if caregivers' responses accurately reflect patient needs in ADL, IADL, satisfaction with health care providers, and satisfaction with information provided during cancer treatments. If the caregiver and patient responses significantly correlate, then caregiver responses may be adequate for future research. The IADL questionnaire needs to include gender specific information, so as to better determine if the caregiver performed the household chore prior to the disease diagnosis and treatment. The gender specific items, i.e., cooking, laundry, housework could include qualifiers that would determine the caregivers historical involvement in those activities.

Further research is needed to explore the increased costs associated with cancer diagnosis and treatment for families during various cancer types and stages. The financial impact of breast, colorectal, lymphoma, and lung cancer would provide insight to help health care providers impact social policy to support those patients whose health care costs are the highest. Costs for families would include equipment and supplies, medication, chore/housekeeping services, transportation costs, skilled care costs, expenditures not reimbursed by health insurance, and lost earnings.

Additional research is needed in the area of symptom distress as perceived by cancer patients and their caregivers. The development of symptom distress tools designed specifically for cancer patients and their caregivers in various stages of disease need to be explored. This information will provide valuable insight into the degree of symptom distress and severity perceived by cancer patients and their caregivers experience across the stages. The impact of patient symptom distress on the caregiver will be readily apparent. Effective interventions can be developed based on the specific symptom needs of each dyad and incongruent perceptions addressed.

It would be beneficial to replicate this study on more severely ill patients across the stages of cancer. This information would provide insight for clinicians, educators, and policy makers in the development of clinical and social support systems that would more effectively provide needed resources to cancer patients and their families.

The intent of this research study was: 1) to explore the relationship between patient reported symptom distress and the impact, as perceived by the caregiver, on ADLs and IADLs; 2) identify the relationship between patient reported symptom distress and caregiver satisfaction with health care providers; and 3) determine the relationship between patient reported symptom distress and caregiver satisfaction with information provided during cancer treatments.

Caregiver involvement in areas of ADLs and IADLs have been described for patients receiving cancer treatments. The impact of symptom distress in the first six months of cancer diagnosis and treatment has been described. Finally, caregiver satisfaction with health care providers, and information received during cancer treatments has been presented. The findings in this study are similar to other researchers (Cummings et al., 1990; Given & Given, 1991; and Stone & Murtaugh, 1990). The study participants reported minimal ADL deficits and were not severely disabled, although had experienced IADL deficits that correlated significantly with experienced symptom distress. The satisfaction information presented herein like with other research does not adequately address the total care needs of cancer patients, and has not allowed cancer patients themselves to indicate the issues they consider to be of particular importance (Wiggers et al., 1990).

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APPENDICES

MICHIGAN STATE
UNIVERSITY

OFFICE OF
**RESEARCH
AND
GRADUATE
STUDIES**
**University Committee on
Research Involving
Human Subjects
(UCRIHS)**
Michigan State University
225 Administration Building
East Lansing, Michigan
48824-1046
517/355-2180
FAX: 517/336-1171

August 6, 1993

TO: Nancy J. Winters
538 Boone Rd.
Quincy, MI 49082

RE: IRB #: 93-355
TITLE: IS THERE A SIGNIFICANT RELATIONSHIP BETWEEN THE IMPACT OF SYMPTOM DISTRESS ON DEPENDENCIES IN ACTIVITIES OF DAILY LIVING, INSTRUMENTAL ACTIVITIES OF DAILY LIVING, SATISFACTION WITH HEALTHCARE PROVIDERS, AND SATISFACTION WITH INFORMATION RECEIVED DURING CANCER TREATMENTS
REVISION REQUESTED: N/A
CATEGORY: 1-E
APPROVAL DATE: August 6, 1993

The University Committee on Research Involving Human Subjects' (UCRIHS) review of this project is complete. I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and methods to obtain informed consent are appropriate. Therefore, the UCRIHS approved this project including any revision listed above.

Renewal: **UCRIHS approval is valid for one calendar year, beginning with the approval date shown above. Investigators planning to continue a project beyond one year must use the enclosed form to seek updated certification. There is a maximum of four such expedited renewals possible. Investigators wishing to continue a project beyond that time need to submit it again for complete review.**

Revisions: UCRIHS must review any changes in procedures involving human subjects, prior to initiation of the change. If this is done at the time of renewal, please use the enclosed form. To revise an approved protocol at any other time during the year, send your written request to the UCRIHS Chair, requesting revised approval and referencing the project's IRB # and title. Include in your request a description of the change and any revised instruments, consent forms or advertisements that are applicable. the year, please outline the proposed revisions in a letter to the Committee.

Problems/ Changes: Should either of the following arise during the course of the work, investigators must notify UCRIHS promptly: (1) problems (unexpected side effects, complaints, etc) involving human subjects or (2) changes in the research environment or new information indicating greater risk to the human subjects than existed when the protocol was previously reviewed and approved.

If we can be of any future help, please do not hesitate to contact us at (517) 355-2180 or FAX (517) 336-1171.

Sincerely,

DE. Wright

David E. Wright, Ph.D.
UCRIHS Chair

DEW:pjm

cc: Dr. Barbara Given

MSU is an affirmative-action equal-opportunity institution

ID _ _ _ 2
CARD 0 5 2

34. During the past month, how many days have you been so sick that you were unable to carry out your usual daily activities (like going to work, working around the house, etc.). Write in number of days.

___ Number of days

Bqpsick

42 43

Symptoms

For each of the following symptoms there are 5 different numbered statements. Think about what each statement says, then place a circle around the one statement for each symptom that most closely indicates how you have been feeling lately. The statements on each are ranked from 1 to 5, where number one indicates no problems and number five indicates the maximum amount of problems. Numbers two through four indicate you feel somewhere in between these two extremes. PLEASE CIRCLE ONE NUMBER FOR EACH SYMPTOM.

NAUSEA (1)

Bsymp1

44

35.

1	2	3	4	5
I seldom feel any nausea at all	I am nauseous once in a while	I am often nauseous	I am usually nauseous	I suffer from nausea almost continuously

NAUSEA (2)

Bsymp2

45

36.

1	2	3	4	5
When I do have nausea, it is very mild	When I do have nausea, it is mildly distressing	When I have nausea, I feel pretty sick	When I have nausea I feel very sick	When I have nausea, I am as sick as I could possibly be

APPETITE

Bsymp3

46

37.

1	2	3	4	5
I have my normal appetite	My appetite is usually, but not always, pretty good	I don't really enjoy my food like I used to	I have to force myself to eat my food	I cannot stand the thought of food

INSOMNIA

Bsymp4

47

38.

1	2	3	4	5
I sleep as well as I always have	I have occasional spells of sleeplessness	I frequently have trouble getting to sleep and staying asleep	I have difficulty sleeping almost every night	It is almost impossible for me to get a decent night's sleep

PAIN (1)

Bsymp5 48

39. 1	2	3	4	5
I almost never have pain	I have pain once in a while	I frequently have pain -- several times a week	I am usually in some degree of pain	I am in some degree of pain almost constantly

PAIN (2)

Bsymp6 49

40. 1	2	3	4	5
When I do have pain, it is very mild	When I do have pain, it is mildly distressing	The pain I do have is usually fairly intense	The pain I have is usually very intense	The pain I have is almost unbearable

FATIGUE

Bsymp7 50

41. 1	2	3	4	5
I am usually not tired at all	I am occasionally rather tired	There are frequently periods where I am quite tired	I am usually very tired	Most of the time I feel exhausted

BOWEL

Bsymp8 51

42. 1	2	3	4	5
I have my normal bowel pattern	My bowel pattern occasionally causes me some concern and discomfort	I frequently have discomfort from my present bowel pattern	I am usually in discomfort because of my present bowel pattern	My present bowel pattern has changed drastically from what was normal for me

CONCENTRATION

Bsymp9 52

43. 1	2	3	4	5
I have my normal ability to concentrate	I occasionally have trouble concentrating	I often have trouble concentrating	I usually have at least some difficulty concentrating	I just can't seem to concentrate at all

ID _ _ _ 2
CARD 0 5 2

APPEARANCE

Bsymp 10 53

44. 1	2	3	4	5
My appearance has basically not changed	My appearance has gotten a little worse	My appearance is definitely worse than it used to be, but I am not greatly concerned about it	My appearance is definitely worse than it used to be, and I am concerned about it	My appearance has changed drastically from what it was

OUTLOOK

Bsymp 11 54

45. 1	2	3	4	5
I am not fearful or worried	I am a little worried about things	I am quite worried, but unafraid	I am worried and a little frightened about things	I am worried and scared about things

COUGH

Bsymp12 55

46. 1	2	3	4	5
I seldom cough	I have an occasional cough	I often cough	I often cough and occasionally have severe coughing spells	I often have persistent and severe coughing spells

/jh
11/09/90
113:2

ID _ _ _ 1 1-4
Card 0 5 8 5-7.
Date _ _/_ _/_ _ 8-13
INT _ _ 14-15
INT Code 3 16
Study 6 17

DEMANDS OF ILLNESS INVENTORY

Below is a list of events and thoughts that some individuals experience when someone in their family faces a health problem like cancer. Please read each item carefully and indicate the extent to which you have experienced the following problem in relation to your relative's cancer or treatment experience <u>during the past three months.</u>

0 = NOT AT ALL
1 = A LITTLE
2 = MODERATELY
3 = QUITE A BIT
4 = EXTREMELY

At times, some of my spouse's/loved one's health care providers have:

1. been insensitive to my preferences for treatment. Bdillc1 0 1 2 3 4 __ 18
2. acted as if my opinions are unimportant. Bdillc2 0 1 2 3 4 __ 19
3. made decisions without my best interests in mind. Bdillc3 0 1 2 3 4 __ 20
4. not told me the truth about changes in his/her health. Bdillc4 0 1 2 3 4 __ 21
5. not shown concern for me as a person. Bdillc5 0 1 2 3 4 __ 22
6. not thoroughly explained my spouse's/loved one's health status to me. Bdillc6 0 1 2 3 4 __ 23

As I've experienced my partner's/loved one's illness situations, I've:

7. wanted more facts about the treatments. Bdillc7 0 1 2 3 4 __ 24
8. had questions that I wanted to ask but just couldn't. Bdillc8 0 1 2 3 4 __ 25
9. felt rushed to make a hasty treatment decision. Bdillc9 0 1 2 3 4 __ 26
10. wanted to be more assertive about the direction his/her treatment should take. Bdillc10 0 1 2 3 4 __ 27
11. wanted to be told the reason why, when asked to do something for treatment Bdillc11 0 1 2 3 4 __ 28
12. realized I was initially unclear about the treatment he/she would receive. Bdillc12 0 1 2 3 4 __ 29
13. been dissatisfied with the progress of his/her treatment. Bdillc13 0 1 2 3 4 __ 30
14. been dissatisfied with his/her medical care. Bdillc14 0 1 2 3 4 __ 31
15. felt his/her illness was incorrectly managed. Bdillc15 0 1 2 3 4 __ 32

ID _ _ 1
CARD 0 5 8

16. worried his/her illness may be incorrectly managed in the future. Bdillc 16 0 1 2 3 4 33

(Care Provider: Selected from <u>Demands of Illness Inventory</u>. Woods, Haberman, & Packard, 1987.)

/jh
11/8/90

CA III, WAVE III
Health Service Utilization
Page 15

	ID __ __ __ 1	1-4
	CARD 0 4 6	5-7
DATE	__ __/__ __/__ __	8-13
	INT __ __	14-15
	INT CODE 3	16
	Study 6	17

INVOLVEMENT

The next set of questions addresses the PRESENT level of performance of the person you care for on a number of activities and the way YOU AND OTHER PEOPLE help him/her. For each item, please choose the response that most closely describes the patient's PRESENT condition and how you assist him or her.

INTERVIEWER: <u>OTHER PEOPLE</u> category may include assistance from agencies, paid helpers, and family and friends. The purpose of these questions is to assess <u>current</u> involvement. CLARIFICATION -- "Generally speaking over the past month..."

---

1. DRESSING

(INTERVIEWER: Category definitions are meant for purposes of clarification)

This category includes the entire process of dressing or being clothes, including change from bed clothing into the set of clothing worn during the day, and change to bed clothing at night. This category DOES NOT include management of clothing during toileting. <u>If your relative always wears bed clothing during the day, answer "NEVER DRESSED"</u>. Select the category that best describes your relative's level of functioning for DRESSING.

1a. With regard to dressing, would you say (______________) ... (CHECK ONE)

Bkdress1 __ 18

_____ <u>IS INDEPENDENT</u>--(does not need help of another person in any part of this activity) (GO TO ITEM #2). (1) 0

_____ **NEEDS SUPERVISION ONLY--(requires another person present during the activity to instruct or watch for problems, but does not need the physical help of another person.) (2) (Go to 1b)** 1

_____ **NEEDS SOME PHYSICAL HELP--(requires physical help and the presence of another during all or part of this activity.) CARE RECIPIENT PARTICIPANT. (3)** 2

_____ **NEEDS TOTAL PHYSICAL HELP--(Needs another person to carry out this activity.) CARE RECIPIENT DOES NOT PARTICIPATE. (4)** 3

_____ **IS NEVER DRESSED (5)**

(The next set of questions is about how frequently you and other people help your relative/friend with dressing.)

ID _ _ _ 1
CARD 0 4 6

Bkdress.3

1b. How frequently do YOU help the patient with dressing? (CIRCLE ONE) __ 19

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

INTERVIEWER: "Help" includes any combination of supervision, some physical help, and total physical help.

INTERVIEWER: Even if caregiver "never helps", GO TO PART C. OF QUESTION (others help).

Bkdress 4

1c. How often do OTHER PEOPLE help the patient with dressing? (CIRCLE ONE) __ 20

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

ID _ _ _ 1
CARD 0 4 6

EATING

This category includes all types of food and liquid taken by mouth.

INTERVIEWER: Includes all types of presentation used--tray, finger foods, etc.; client does not need to use utensils.) Does not include selection or preparation of food.

2a. With regard to eating, would you say (______________) ... (CHECK ONE)

Bkeat1 ___ 21

_____ **IS INDEPENDENT--**(Does not need help of another person in any part of this activity) (GO TO ITEM #3). (1)

_____ **NEEDS SUPERVISION ONLY--**(requires another person present during the activity to instruct or watch for problems, but does not need the physical help of another person.) (2)

_____ **NEEDS SOME PHYSICAL HELP--**(requires physical help and the presence of another during all or part of this activity.) CARE RECIPIENT PARTICIPATES. (3)

_____ **NEEDS TOTAL PHYSICAL HELP--**(needs another person to carry out this activity.) CARE RECIPIENT DOES NOT PARTICIPATE. (4)

_____ **NOT APPLICABLE** (needs tube feedings, IV's ONLY--go to item #3)

(The next set of questions is about how frequently you and other people help your relative with eating.)

Bkeat3

2b. How frequently do YOU help the patient with eating? (CIRCLE ONE) ___ 22

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

ID _ _ _ 1
CARD 0 4 6

INTERVIEWER: "Help includes any combination of supervision, some physical help, and total physical help.

INTERVIEWER: Even if caregiver "never helps", GO TO PART C. OF QUESTION (Others Help).

Bkeat4

2c. How often do OTHER PEOPLE help the patient with eating? (CIRCLE ONE) __ 23

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

3. BATHING

This category includes all activities of bathing, whether tub or shower or bed bath: entry into tub or shower, wetting, soaping, rinsing, exit, drying body. Does not include washing of head or drying hair. Does not include dressing or undressing. Select the response that best describes your relative's level of functioning for bathing.

3a. With regard to bathing, would you say (____________) ... (CHECK ONE)

Bkbath1 __ 24

_____ **IS INDEPENDENT**--(Does not need help of another person in any part of this activity) (GO TO ITEM #4). (1)

_____ **NEEDS SUPERVISION ONLY**--(requires another person present during the activity to instruct or watch for problems, but does not need the physical help of another person.) (2)

_____ **NEEDS SOME PHYSICAL HELP**--(requires physical help and the presence of another during all or part of this activity.) CARE RECIPIENT PARTICIPATES. (3)

_____ **NEEDS TOTAL PHYSICAL HELP**--(needs another person to carry out this activity.) CARE RECIPIENT DOES NOT PARTICIPATE. (4)

ID _ _ _ 1
CARD 0 4 6

(The next set of questions is about how frequently you and other people help your relative with bathing.) Bkbath3

3b. How frequently do YOU help the patient with bathing? (CIRCLE ONE) __ 25

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

INTERVIEWER: Even if caregiver "never helps", <u>GO TO PART C. OF QUESTION</u> (others help).

3c. How often do **OTHER PEOPLE** help the patient with bathing? (CIRCLE ONE)

Bkbath4 __ 26

NEVER	**ONCE A WEEK OR LESS**	**SEVERAL TIMES A WEEK (2-6)**	**ONCE A DAY**	**SEVERAL TIMES A DAY**

4. **WALKING INSIDE THE HOUSE**

This category includes all upright movement on foot over the floor inside the house. MUST MOVE AT LEAST FIVE FEET. May use cane, walker, crutches, or handrail. Select the response that best describes your relative's level of functioning for walking.

4a. With regard to walking inside the house, would you say (____________)... (CHECK ONE) Bkwalk1a __ 27

_____ **IS INDEPENDENT**--(Does not need help of another person in any part of this activity) (GO TO ITEM #5). (1)

_____ **NEEDS SUPERVISION ONLY**--(requires another person present during the activity to instruct or watch for problems, but does not need the physical help of another person.) (2)

_____ **NEEDS SOME PHYSICAL HELP**--(requires physical help and the presence of another during all or part of this activity.) CARE RECIPIENT PARTICIPATES. (3)

_____ **NEEDS TOTAL PHYSICAL HELP**--(needs another person to carry out this activity.) CARE RECIPIENT DOES NOT PARTICIPATE. (4)

_____ **UNABLE TO WALK**--(will not bear weight.) (GO TO ITEM 5)

ID _ _ _ 1
CARD 0 4 6

INTERVIEWER: Even if caregiver "never helps", GO TO PART C. OF QUESTION (Others help).

(The next set of questions is about how frequently you and other people help your relative with walking.)

Bkwalk3a

4b. How frequently do YOU help the patient with walking? (CIRCLE ONE) __ 28

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

INTERVIEWER: Even if caregiver "never helps", GO TO PART C. OF QUESTION (others help).

4c. How often do OTHER PEOPLE help the patient with walking? (CIRCLE ONE)

BKwalk4a __ 29

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

ID _ _ _ 1
CARD 0 4 6

/5. TOILETING

This category includes all those behaviors associated with bowel/bladder emptying: getting to and from toilet (or use of toileting equipment such as bedpan), removal/adjustment of clothing, positioning on toilet, cleaning of body parts, replacement of clothing. Select the response that best describes your relative's level of functioning for toileting.

5a. With regard to toileting, would you say (______________)... (CHECK ONE)

Bktoil1 __
30

_____ **IS INDEPENDENT**--(Does not need help of another person in any part of this activity) (GO TO ITEM #6). (1)

_____ **NEEDS SUPERVISION ONLY**--(requires another person present during the activity to instruct or watch for problems, but does not need the physical help of another person.) (2)

_____ **NEEDS SOME PHYSICAL HELP**--(requires physical help and the presence of another during all or part of this activity.) CARE RECIPIENT PARTICIPATES. (3)

_____ **NEEDS TOTAL PHYSICAL HELP**--(needs another person to carry out this activity.) CARE RECIPIENT DOES NOT PARTICIPATE. (4)

_____ **NOT APPLICABLE** (has catheter, colostomy--Go to item #6)

(The next set of questions ia bout how frequently you and other people help your relative with toileting.)

Bktoil3

5b. How frequently do YOU help the patient with toileting? (CIRCLE ONE) __
31

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

INTERVIEWER: Even if caregiver "never helps", GO TO PART C. OF QUESTION (others help).

5c. How often do OTHER PEOPLE help the patient with toileting? (CIRCLE ONE)

Bktoil4 __
32

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

ID _ _ _ 1
CARD 0 4 6

6. TRANSFERRING--IN/OUT OF BED

This category includes movement to and from bed, to chair or wheelchair, or set on toilet or commode. Devices, bars, and other mechanical aids may be used. Select the response that best describes the relative's level of independence.

6a. With regard to transferring, in/out of bed, would you say (__________)... (CHECK ONE) Bkbed1 $\overline{33}$

_____ **IS INDEPENDENT--(Does not need help of another person in any part of this activity) (GO TO ITEM #6). (1)**

_____ **NEEDS SUPERVISION ONLY--(requires another person present during the activity to instruct or watch for problems, but does not need the physical help of another person.) (2)**

_____ **NEEDS SOME PHYSICAL HELP--(requires physical help and the presence of another during all or part of this activity.) CARE RECIPIENT PARTICIPATES. (3)**

_____ **NEEDS TOTAL PHYSICAL HELP--(needs another person to carry out this activity.) CARE RECIPIENT DOES NOT PARTICIPATE. (4)**

_____ **REMAINS BEDFAST--(Go to item 7)**

INTERVIEWER: If relative REMAINS BEDFAST, go to item #7.

(The next set of questions is about how frequently you and other people help your relative with transferring.)

6b. **How frequently do YOU help the patient with transferring? (CIRCLE ONE)** Bkbed3 $\overline{34}$

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

ID _ _ _ 1
CARD 0 4 6

INTERVIEWER: Even if caregiver "never helps", GO TO PART C. OF QUESTION (others help).

6c. How often do OTHER PEOPLE help the patient with transferring? (CIRCLE ONE)

Bkbed4 __ 35

NEVER — ONCE A WEEK OR LESS — SEVERAL TIMES A WEEK (2-6) — ONCE A DAY — SEVERAL TIMES A DAY

The next list includes additional activities with which your relative may require assistance. For each activity, please tell me how much help your relative needs and how frequently you and others help with this activity.

7. COOKING/PREPARING MEALS

Bkcook1

7a. How much help does (______________) presently need with cooking? Does he/she need: (CHECK ONE)

__ 36

_____ **NO HELP?** (Patient is independent.) (Go to item #8)

_____ **SOME HELP?** (Patient requires some assistance; relative participates in this activity.)

_____ **TOTAL HELP?** (Patient does not participate in this activity but has done in the past.)

_____ **TOTAL HELP?** (Patient does not participate in this activity and never has. Not family role.)

_____ **NOT APPLICABLE?** (Patient has tube feedings, IV's ONLY--go to item #8)

7b. How frequently do YOU help the patient with cooking or cook for them? (CIRCLE ONE)

Bkcook3 __ 37

NEVER — ONCE A WEEK OR LESS — SEVERAL TIMES A WEEK (2-6) — ONCE A DAY — SEVERAL TIMES A DAY

INTERVIEWER: Even if caregiver "never helps", GO TO PART C. OF QUESTION (others help).

ID _ _ _ 1
CARD 0 4 6

c. How frequently do OTHERS help the patient with cooking or cook for them? (CIRCLE ONE)

Bkcook4 __ 38

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

8. HOUSEWORK--(PICKING UP, DUSTING, LIGHT CLEANING, VACUUMING, DOING DISHES)

8a. How much help does (__________________) presently need with housework? Does he/she need: (CHECK ONE)

Bklhwrk1 __ 39

_____ **NO HELP?** (Patient is independent.) (Go to item #9)

_____ **SOME HELP?** (Patient requires some assistance; relative participates in this activity.)

_____ **TOTAL HELP?** (Patient does not participate in this activity but has done in the past.)

_____ **TOTAL HELP?** (Patient does not participate in this activity and never has. Not family role.)

8b. How frequently do YOU help the patient with housework or do housework for them? (CIRCLE ONE)

Bklhwrk3 __ 40

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

INTERVIEWER: Even if caregiver "never helps", GO TO PART C. OF QUESTION (others help).

8c. How frequently do OTHERS help the patient with housework or do housework for them? (CIRCLE ONE)

Bklhwrk4 __ 41

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

ID _ _ _ 1
CARD 0 4 6

9. SHOPPING (Includes all types of purchases).

9a. How much help does (__________) presently need with shopping? (Does he/she need: (CHECK ONE) Bkshop1 __ 42

_____ **NO HELP?** (Patient is independent.) (Go to item #10)

_____ **SOME HELP?** (Patient requires some assistance; relative participates in this activity.)

_____ **TOTAL HELP?** (Patient does not participate in this activity but has done in the past.)

_____ **TOTAL HELP?** (Patient does not participate in this activity and never has. Not family role.)

9b. How frequently do YOU help the patient with shopping for them? (CIRCLE ONE) Bkshop3 __ 43

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

INTERVIEWER: Even if caregiver "never helps", <u>GO TO PART C. OF QUESTION</u> (others help).

9c. How frequently do OTHERS help the patient with shopping or shop for them? (CIRCLE ONE) Bkshop4 __ 44

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

10. LAUNDRY

10a. How much help does (__________) presently need with laundry? Does he/she need: (CHECK ONE) Bklaund1 __ 45

_____ **NO HELP?** (Patient is independent.) (Go to item #11)

_____ **SOME HELP?** (Patient requires some assistance; relative participates in this activity.)

_____ **TOTAL HELP?** (Patient does not participate in this activity but has done in the past.)

_____ **TOTAL HELP?** (Patient does not participate in this activity and never has. Not family role.)

ID _ _ _ 1
CARD 0 4 6

10b. How frequently do YOU help the patient with laundry or do laundry for them? (CIRCLE ONE)>

Bklaund 3 __ 46

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

INTERVIEWER: Even if caregiver "never helps", GO TO PART C. OF QUESTION (others help).

10c. How frequently do OTHERS help the patient with laundry or do laundry for them? (CIRCLE ONE)

Bklaund 4 __ 47

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

11. TRANSPORTATION

11a. How much help does (__________) presently need with transportation? Does he/she need: (CHECK ONE)

Bktrans 1 __ 48

_____ **NO HELP?** (Patient is independent.) (Go to item #12)

_____ **SOME HELP?** (Patient requires some assistance; relative participates in this activity.)

_____ **TOTAL HELP?** (Patient does not participate in this activity but has done in the past.)

_____ **TOTAL HELP?** (Patient does not participate in this activity and never has. Not family role.)

11b. How frequently do YOU help the patient with transportation? (CIRCLE ONE).

Bktrans 3 __ 49

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

INTERVIEWER: Even if caregiver "never helps", GO TO PART C. OF QUESTION (others help).

11c. How frequently do OTHERS help the patient with transportation? (CIRCLE ONE)

Bktrans4 ___ 50

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

12. MONEY MANAGEMENT--(PAYING BILLS, MAINTAINING ACCOUNTS)

12a. How much help does (______________) presently need with money management? Does he/she need: (CHECK ONE)

Bkmony1 ___ 51

_____ **NO HELP?** (Patient is independent.) (Go to item #13)

_____ **SOME HELP?** (Patient requires some assistance; relative participates in this activity.)

_____ **TOTAL HELP?** (Patient does not participate in this activity but has done in the past.)

_____ **TOTAL HELP?** (Patient does not participate in this activity and never has. Not family role.)

12b. How frequently do YOU help the patient with money management or do money management for them? (CIRCLE ONE).

Bkmony3 ___ 52

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

INTERVIEWER: Even if caregiver "never helps", GO TO PART C. OF QUESTION (others help).

12c. How frequently do OTHERS help the patient with money management or do money management for them? (CIRCLE ONE)

Bkmony4 ___ 53

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

ID _ _ _ 1
CARD 0 4 6

13. COMBING HAIR OR SHAVING

13a. With regard to combing hair or shaving would you say (__________)... (CHECK ONE)

Bkcomb1 _ 54

_____ **IS INDEPENDENT**--(Does not need help of another person in any part of this activity) (GO TO ITEM #14). (1)

_____ **NEEDS SUPERVISION ONLY**--(requires another person present during the activity to instruct or watch for problems, but does not need the physical help of another person.) (2)

_____ **NEEDS SOME PHYSICAL HELP**--(requires physical help and the presence of another during all or part of this activity.) CARE RECIPIENT PARTICIPATES. (3)

_____ **NEEDS TOTAL PHYSICAL HELP**--(needs another person to carry out this activity.) CARE RECIPIENT DOES NOT PARTICIPATE. (4)

_____ **NOT APPLICABLE**--(No hair at this time--GO TO ITEM #14)

13b. How often do YOU help the patient with combing hair or shaving? (CIRCLE ONE)

Bkcomb3 _ 55

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

INTERVIEWER: Even if caregiver "never helps", <u>GO TO PART C. OF QUESTION</u> (others help).

13c. How frequently do OTHERS help the patient with combing hair or shaving? (CIRCLE ONE)

Bkcomb4 _ 56

NEVER	ONCE A WEEK OR LESS	SEVERAL TIMES A WEEK (2-6)	ONCE A DAY	SEVERAL TIMES A DAY

14. Do you pay anyone to help you care for your relative? (CHECK ONE) _ 57

_____ YES (1) _____ NO (2)

Bpayany