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USE OF FORMAL COMMUNITY SERVICES BY
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THE EFFECTS OF CUES TO ACTION ON THE USE OF FORMAL COMMUNITY SERVICES BY FAMILY CAREGIVERS OF PHYSICALLY DEPENDENT ELDERS

By

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ABSTRACT

THE EFFECTS OF CUES TO ACTION ON THE USE OF FORMAL COMMUNITY SERVICES BY FAMILY CAREGIVERS OF PHYSICALLY DEPENDENT ELDERS

By

Julia Veretta James

A modified version of the Health Belief Model forms the conceptual framework for this study. Four variables derived from this model and explored for their effect on formal community service use were: perceived social support of the caregiver; perceived competence to perform complex health care activities by the caregiver; psychological distress of the caregiver; and, physical distress of the caregiver. The level of functional disability of the care recipient, gender of the caregiver, martial relationship of the dyad, total number residing in the household, and number of children under 18 were control variables.

Implications for advanced nursing practice and primary care include researching cues to action with formal community services that <u>are</u> under the control of the caregiver; evaluating formal services use individually, rather than grouping services together; and, educating other health care professionals in the need to evaluate the entire caregiving family for service needs, not just the care recipient.

This thesis is dedicated to my father
Albert D. Jordan III, who died during its preparation;
my immediate family,
James, Jennifer, Jason and Jeremiah James;
and, my family of origin,
Helen Jordan and her children, and my aunt Jenalice Jordan
without whose support this degree
could not have been completed

ACKNOWLEDGEMENTS

A modified version of the Health Belief Model entitled "Factors Influencing Community Service Use Among Family Caregivers of Physically Dependent Elders" is derived from a model entitled "Factors Influencing Community Service Use Among Family Caregivers of Alzheimers Patients" of Drs. C. Collins, S. King, B. A. Given and C. W. Given, from their studies entitled "Impact of Alzheimer's Disease on Family Caregivers," (Grant #2 RO1 MH41766, Principal Investigator, Clare Collins, Ph.D., R.N.) and "Perceptions of Community Services by Alzheimer's Caregivers," (Grant # PRG-89-098, Principal Investigator, Sharon King, Ph.D., R.N.).

Data for analysis and scales of the four independent variables: "Social Provisions," "Activities of Health Care," "Current Feelings," and "Caregiver Health," were derived from the Michigan State University study, "Caregiver responses to managing elderly at home" (Grant #2 RO1 AGO6584-04, Principal Investigators - C. W. Given, Ph.D. and B. A. Given, Ph.D. R.N.).

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INTRODUCTION

Background of the Problem

Many professionals theorize that the use of formal community services may lessen the physical and psychological distress of caregiving, increase the caregiver's competence in complex care activities, and act as social support to the caregiver (Biegel, Sales, and Schulz, 1991; Maslow, 1990). However, a multitude of studies have found that there is relatively low use of formal community services by caregivers (Caserta, Lund, Wright and Redburn, 1987; Collins & King, 1990; Gwyther, 1988, 1990; Lawton, Brody and Saperstein, 1989; Montgomery and Borgatta, 1989; Stone, Cafferata and Sangl, 1987; Yankelovich, Skelly, White, Clancy, Shulman, Inc., 1986).

There have been many reasons offered for the relatively low use of formal community services, including: a lack of general information about services offered in the community; family opposition to outsiders in the home; lack of health care provider's referral; bureaucratic red tape in eligibility requirements; unavailable, unaffordable, or unacceptable services; fear of poor quality care of the family member; societal attitudes that the woman's role is to be the sole caregiver; and, ethnic and cultural attitudes about the family taking care of its own (Kushman & Freeman, 1986; Collins, Stommel, King, & Given, 1991; Eckert & Smyth, 1988; United States Congress, Office of Technology

Assessment, 1990; Collins, King, Given, & Given, in press; Hendrick & Inui, 1986; Gywther, 1990; Brody, 1981; Holmes, Teresi, & Holmes, 1983). However, another way to approach this problem is to explore the reasons for formal service use among those who do use them.

Statement of the Problem

The purpose of this study is to describe the effects of cues to action, both external and internal, on the use of formal community services by family caregivers. The cues to action are derived from the Health Belief Model and are depicted graphically in Figure 1.

The external cue to action considered in this study is the perceived adequacy of informal social support. The internal cues to action considered in this study are the caregiver's appraisal of perceived competence in health care activities, physical distress and psychological distress.

If these cues to action are predictive of variation in formal community service use, health care providers need to know about it. This knowledge could be used to screen caregivers while the care recipient was hospitalized and find the caregivers who were most likely to use formal community services. Thus, health care dollars could be targeted and services offered to those most likely to use or benefit from the use of the services. If policy makers were aware that formal community service use was not only a function of care recipient characteristics, but also of caregiver cues to action, wiser policies might be formulated.

To understand the importance of these cues to action on the use of formal community services by family caregivers of physically dependent elders, conceptual definitions of the variables under study are presented, following Table 1 which lists the proposed dependent, independent, and control variables of the study and Figure 1, which shows the theorized relationships among these variables.

REVIEW OF LITERATURE

Conceptual Definitions of the Variables as Derived from a Literature Review

Conceptual definitions of the variables of this study will be derived from this review of literature. Variables of the study are: 1) use of formal community services; 2) perceived levels of social support; 3) physical distress of the caregiver; 4) psychological distress of the caregiver; 5) levels of perceived competence to perform complex health care activities for the elder.

Formal community service use has been conceptualized in various ways. Formal community services have been conceived as an intervention to reduce psychological distress or physical distress (Stommel, Collins, Given, King, & Given, 1988; Anthony-Bergstone, Zarit, & Gatz, 1988; Haley, Levine, Brown, & Bartolucci, 1987; Silven, DelMaestro, Gallagher, Lovett, Benedict, Rose, & Kwong, 1986; Whitlatch, Zarit, &

TABLE 1. PROPOSED VARIABLES OF THE STUDY

DEPENDENT VARIABLES - FORMAL COMMUNITY SERVICES

1. Visiting Nurse Services (VNS)
2. Case Management Services
3. Adult Day Care
4. Chore or Housekeeping Services
5. Meals on Wheels or Home Delivered Meals
6. Occupational, Physical, or Speech Therapy (OT/PT/Speech)
7. Family Support Groups
8. Health Professional Assists (HP Assists) with Complex Health Care Activities of:

   a. Urinary Catheter Care; b. Oxygen Administration; c. IV/Hickman/Broviac Catheter Care and Dressing; d. IV Medications/Fluids/Feedings; e. Tube Feedings or IV Feedings; f. Injections; g. Special Exercises or Physical Therapy; h. Bedsores/Ulcers Care; i. Other Skin Problems; j. Colostomy Care; k. Post-Op Incision or Wound Care; l. Oral Medications; m. Nasogastric Tube Care (NG); n. Urine Incontinence; o. Stool Incontinence; p. Tracheostomy Care; q. Respirator Care; r. Suctioning

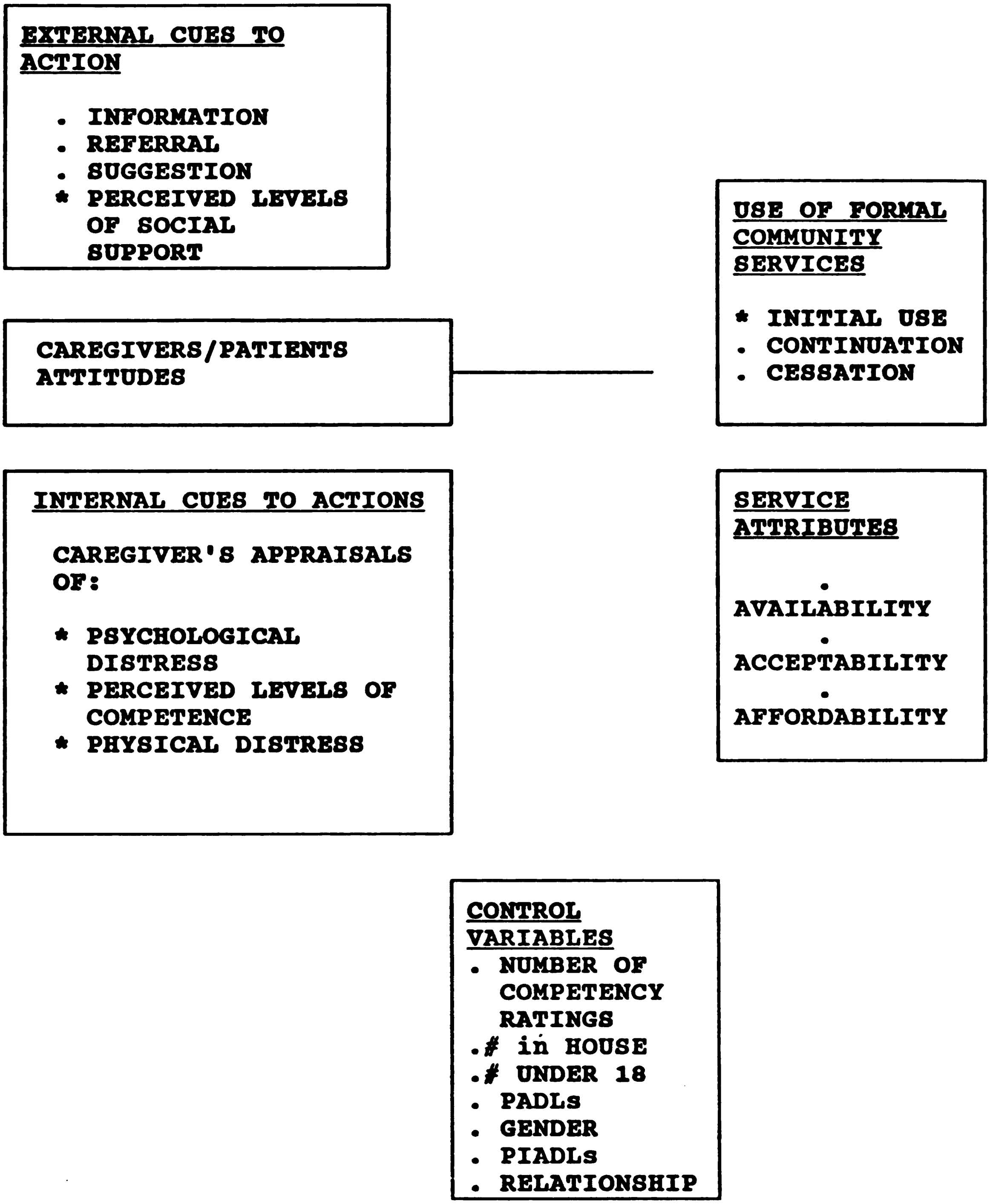
INDEPENDENT VARIABLES - CUES TO ACTION

1. Perceived Levels of Social Support (SocSupp)
2. Perceived Levels of Competence to Perform Complex Health Care Activities (Competnc)
3. Psychological Distress (Depress)
4. Physical Distress (PhysDis)

CONTROL VARIABLES

1. Number of Activities which Caregiver Assisted and Rated his/her Competency (Comprats)
2. Caregiver Gender (Gender)
3. Spouse/Nonspouse Relationship between Caregiver and Care Recipient (Relation)
4. Number of Adult Members of Family in Household (# in House)
5. Number of Children in Household (# under 18)
6. Patient Limitations in Activities of Daily Living (PADLs): a. Dressing; b. Eating; c. Bathing; d. Walking; e. Toileting; f. Transferring
7. Patient Limitations in Instrumental Activities of Daily Living (PIADLs): a. Cooking; b. Housework; c. Shopping; d. Laundry; e. Transportation; f. Money Management

FIGURE 1. FACTORS INFLUENCING FORMAL COMMUNITY SERVICE USE AMONG FAMILY CAREGIVERS OF PHYSICALLY DEPENDENT ELDERS



<u>EXTERNAL CUES TO ACTION</u>

- . INFORMATION
- . REFERRAL
- . SUGGESTION
- * PERCEIVED LEVELS OF SOCIAL SUPPORT

CAREGIVERS/PATIENTS ATTITUDES

<u>INTERNAL CUES TO ACTIONS</u>

CAREGIVER'S APPRAISALS OF:

- * PSYCHOLOGICAL DISTRESS
- * PERCEIVED LEVELS OF COMPETENCE
- * PHYSICAL DISTRESS

<u>USE OF FORMAL COMMUNITY SERVICES</u>

- * INITIAL USE
- . CONTINUATION
- . CESSATION

<u>SERVICE ATTRIBUTES</u>

- . AVAILABILITY
- . ACCEPTABILITY
- . AFFORDABILITY

<u>CONTROL VARIABLES</u>

- . NUMBER OF COMPETENCY RATINGS
- .# in HOUSE
- .# UNDER 18
- . PADLs
- . GENDER
- . PIADLs
- . RELATIONSHIP

von Eye, 1991); a compliment or a supplement to the services provided by the primary caregiver (Berry, Zarit, and Rabatin, 1991; Lawton, Brody, & Saperstein, 1989; Greene, 1983; Noelker, & Bass, 1989; Stommel, Wang, Given, Given, & Collins, 1992); and, as an outcome in a decision-making model based on the Health Belief Model about the initiation, use, and continuation of formal services (Collins, King, Given, & Given, in press; Collins, Stommel, King, & Given, 1991). The dependent variable in this study is the use of <u>formal community services</u>. It is in the later way that formal services will be used in this study.

Formal community services are defined as services provided by formally organized agencies in the local community of the caregiving dyad which may: supplement the services in which the social support network is unwilling or unable to assist the caregiver; decrease the physical or psychological distress of the caregiver; or, improve the competence of the caregiver by improving the caregiver's skills in providing care in complex health care activities or by supplementing those abilities. Services that may meet these criteria are: Visiting Nurse Services (VNS); case management services; adult day care; chore or housekeeping services; home delivered meals; occupational therapy, physical therapy, and/or speech therapy; family support groups; and, health professional assists with complex health care activities.

Perceived adequacy of social support is the first independent variable of this study and is an external cue to action in this model. Cobb (1976) suggests that social support can be conceived as: information leading a person to believe that he/she is cared for and loved, esteemed and valued, and belongs to a communication network. Kaplan, Cassel, & Gore (1977) conceives social support as: the degree to which a person's needs for affection, approval, belonging, and security are met by significant others. House (1981) conceives of social support as: an interpersonal transaction involving emotional concern, instrumental aid, information, and/or appraisal. Several researchers have stated that social support is a multidimensional concept which includes the amount, types, sources, and structure of support (Dean, Lin, & Ensel, 1980; Thoits, 1978).

Robert Weiss (1974) developed a conceptualization of social provisions which offers a comprehensive view of what people receive from their relations with others. He asserted that, for a person to be adequately adjusted, the person's social relationships must provide six social provisions. These are: attachment, reassurance of worth, reliable alliance, guidance, social integration and opportunity for nurturance. Although Weiss did not conceive of social provisions as a buffer to life stresses such as caregiving, his concepts of social provisions have been used extensively in this way. The conceptual definition of social support for this study is derived from Weiss's Social Provisions model. Adequate social support is defined as: the provision of adequate guidance, attachment, social integration, and at least a reliable alliance through relationships with others which is necessary for adjustment in psychological and physical health and may affect the use of formal community services if social support is perceived by the caregiver to be inadequate.

The second independent variable and the first caregiver internal cue to action in this model is perceived competence. Few studies have used the term perceived competence, but some similar concepts have been studied. Archbold, Stewart, Greenlick and Harvath (1990) described caregiving as a role in which the person providing care learned aspects of the role and evaluated their own abilities to conduct the role. They termed this "preparedness". Haley, Levine, Brown, and Bartolucci (1987) conceptualized self efficacy in caregiving as: the level of confidence the caregiver felt in their ability to manage specific activities of daily living, instrumental activities of daily living, and behavior problems of the care recipient.

Lawton, Kleban, Moss, Rovine and Glicksman (1989) employed the concept of "mastery" as one component of caregiver appraisal and defined mastery as: the positive view of one's ability and ongoing behavior during the caregiving process. Perceived competence may be only one of several internal cues to action to the caregiver in the decision-making process of whether or not to seek and use formal services (Collins, King, Given, & Given, in press).

A refinement of this last conceptual definition, and the definition of perceived competence for this study is: the caregiver's self appraisal of his/her ability to perform complex health care activities for the care recipient with requisite or adequate skills. Thus, lack of <u>perceived competence</u> may be an internal cue to action of the caregiver to seek and use formal services. These services may supplement caregiver abilities, or lead to a gain in the requisite skills needed to give competent care.

The second caregiver internal cue to action in this model is <u>physical distress</u>. Many researchers have found that caregiving may have a negative impact on the caregiver's physical health. This negative impact on health may be called <u>physical distress</u>. Ware and Sherbourne (1992) suggest that health status consists of levels of physical functioning, role functioning, bodily pain, general mental health, emotional effects on role functioning, vitality, and general health perceptions. Given, Given, Stommel, Collins, King, and Franklin (1992) surmised that different levels of dependency in the care recipient and different levels of depression in the caregiver have an impact on the caregiver's physical health.

Biegel, Sales, and Schulz (1991) indicated that caregiving can cause changes in the physical health of the caregiver which may influence the outcomes of caregiving such as institutionalization of the care recipient, and also that deterioration in physical health can be an outcome of caregiving. For this study, physical distress is conceptualized as a multidimensional self appraisal of the caregiver that he or she has limitations in physical functioning, role functioning, social functioning, a negative appraisal of one's own health, and pain which acts as an internal cue to action in the decision-making process about the use of formal services. While mental or psychological health is often included as a factor in physical distress, it will be considered separately in this study.

The final internal cue to action and independent variable of this study is psychological distress. Psychological distress is conceptualized as a measure of caregiver burden in most of the early caregiving studies (George & Gwyther, 1986; Poulshock & Deimling, 1984; Zarit, Todd, & Zarit, 1986). More recently, psychological distress has been viewed as either a temporary reaction to caregiving which may nonetheless effect long term consequences of caregiving such as formal service use or institutionalization of the care recipient (Elliot & Eisdorfer, 1982; Given, Collins, & Given, 1988), or a long term consequence of caregiving (Cohler, Groves, Borden, & Lazarus, 1989) or both (Schulz, Tompkins, Wood, & Decker, 1987; Schulz, Thompkins, & Rau, 1988; Schulz, Biegel, Morycz, & Visintainer, 1989).

Further, psychological distress can be manifested as anxiety or hostility (Anthony-Bergstone, Zarit, & Gatz, 1988); depression (Dura, Stukenberg, & Kiecolt-Glaser, 1990; and Schulz et al., 1987, 1988, 1990; Young & Kahana, 1989); emotional discomfort associated with performing specific tasks of caregiving; negative feelings about caregiving's impact on the caregiver's health, well-being, family relationships, and social life; negative emotions resulting from the decline of a loved one and negative emotions resulting from the time and effort required by caregiving (Thompson & Doll, 1982). For this study, psychological distress is a multidimensional self appraisal of a caregiver's level of negative affective status as expressed in his or her depression and which may affect the caregiver's decision to use formal services.

In addition to the independent and dependent variables of the study, several control variables are included in the study. The control variables of the study are: number of complex health care activities which the caregiver assists the care recipient and rated himself/herself on competency, gender of the caregiver, relationship of the caregiver to the care recipient (spouse/nonspouse), number of adult members in the household, number of children in the household, and the level of functional disabilities of the care recipient as measured by patient limitations in activities of daily living and patient limitations in instrumental activities of daily living. These particular control variables were selected because they were powerful predictors of the use or nonuse of formal community services in previous research (Colerick & George, 1986; National Long-Term Care Channeling Demonstration Project, 1982, 1984, 1986; George & Gwyther, 1986; Montgomery, Gonyea & Hooyman, 1985).

In summary, there is empirical literature to support the conceptual definitions of the independent and the dependent variables of this study.

Finally, the use of a model to relate variables to one another has been found useful in many research studies. The decision to use formal community services by the caregiver is a process that involves input from the environment (external cues to action) as well as appraisal of the individual (internal cues to action). Cues to action is a concept from the Health Belief Model. The Health Belief Model has been used in many studies of the use/nonuse of health services (Baric, 1969; Becker, 1974; Becker, Drachman, Kirst, 1974; Kasl, 1974; Kirst, 1974; Mikhail, 1981; Rosenstock, 1974). The relationships between the cues to action and use of formal services will be discussed next.

Theoretical Basis of the Study

A modification of the model from "Understanding Community Service Use Among Family Caregivers of Alzheimer's Patients" by Collins, King, Given and Given which is explained in the forthcoming book, Future Directions in Alzheimer's Disease and Family Stress is the basis for Figure 1. The original model and this modification are both based on the Health Belief Model.

Referring to the model in Figure 1, the following variables are likely to influence the decision to use formal community services: family caregiver and patient attitudes towards community service use; service availability, affordability, and acceptability; information, referral, and/or suggestion were offered to the family caregiver. If these variables are present and positively affected the caregiver's attitude towards the use of services, then the remaining variables of the model (starred in the model) may be the deciding factors in the decision-making process. These other variables consist of caregiver cues to action which are the focus of this study. Caregiver cues to action are the caregiver's subjective appraisals of: the adequacy or inadequacy of their informal support networks (external cue to action); their perceived competence or incompetence to care for the patient (internal cue to action); their physical distress caused by caring for their physically dependent elder (internal cue to action); their psychological distress related to the care of their physically dependent elder (internal cue to action).

The purpose of this study is to determine whether these cues to action predict variation in the use of formal community services among family caregivers of physically dependent elders. The research questions derived from the model in Figure 1 are:

1) Does the external cue to action, levels of perceived informal social support, predict variation in the use of formal community services?

2) Among families whose elders required complex care, does the internal cue to action, levels of perceived competence to perform complex health care activities for the elder, predict variation in the use of formal community services?

3) Does the internal cue to action, physical distress of the caregiver, predict variation in the use of formal community services?

4) Does the internal cue to action, psychological distress of the caregiver, predict variation in the use of formal community services?

Review and Synthesis of Empirical Evidence in the Literature Concerning the Effects of Cues to Action on the Use of Formal Community Services by Family Caregivers

There is literature to support the notion that caregiver physical and/or psychological distress may cue the caregiver to use formal community services and there is also literature to support the view that physical and/or psychological distress is a barrier to the use of formal community services. There is literature that shows that low levels of perceived social support is a cue to the use of formal community services and there is literature to support the view that high levels of perceived social support is a cue to use formal community services, as more members of the social support network give more information about services. Only one study has previously used perceived competence in complex health care activities as a cue to action for caregivers and that study was of caregivers' of Alzheimer's disease patients, rather than caregivers' of physically dependent elders. A summary of that literature is presented here.

Caserta, Lund, Wright and Redburn (1987) found that caregivers who had begun to use formal services had lower levels of perceived social support than caregivers who were not using formal services. Noelker and Bass (1989) found that families move through the use of assistance in stages. Families begin using services provided by their informal support network but move to using formal services when the level of expertise required to give care or quantity of care exceeds that which can be provided by the primary caregiver and their informal social support network. On the other hand, families and other members of the social support network may facilitate the use of formal services by informing the caregiver about services available in their community (Bass and Noelker, 1987). Thus while social support seems to affect the use of formal services, the direction of this effect remains uncertain.

Caregivers who perceive themselves to be competent in managing the care of their care recipient may not perceive a need to use formal services (Lawton, Brody, and Saperstein, 1989). Also, caregivers who perceive themselves to be highly competent report lower levels of physical distress and depression than caregivers who report less competence (Haley, Levine, Brown, & Bartolucci, 1987). Therefore, formal community service use may be affected by the caregiver's perceived competence level in two ways: a direct influence on the use or nonuse of formal services and an indirect influence through its effects on the caregiver's appraisal of their physical and psychological distress.

Caregivers may become physically and psychologically distressed before they decide to find and use formal services (Bass & Noelker, 1987). Although caregiver physical and psychological distress was predictive of formal service use, distress accounted for very little of the variation in formal service use studied by Noelker and Bass (1989). But again there is evidence to the contrary. In studies of Alzheimer's patients' caregivers, it was found that physical or psychological distress may <u>prevent</u> the caregiver seeking formal services (United States Congress, Office of Technology Assessment, 1990). In this case, physical or psychological distress may act as a barrier to the use of formal services rather than act as a cue to action. While the literature provides evidence that physical and psychological distress affect the use of formal services, it is not yet settled in what way it affects use.

Rationale for the Present Study

This study continues the exploration of a decision-making process model, the Health Belief Model, which has been widely used in health care research and has been effective in discovering relationships between the environment, the individual's appraisal of the environment and the use of health care services. This study examines four caregiver cues to action in the decision-making process. Their effect on the use of formal services within the health belief model is presented graphically in Figure 1. This particular model was developed and used in the study of the effect of caregiver cues to action, attitudes and values on the use of formal community services among Alzheimer's patients (Collins, King, Given, & Given, 1992). It has not been previously employed to study caregivers of physically dependent elders.

Therefore, the present study offers both a continuation of the caregiving studies that have explored the relationship between caregiver cues to action and the use of formal services and a new approach in applying this model to caregivers of physically dependent elders.

Most previous studies of the use of formal community services are cross-sectional and have looked at service use among long-term caregivers. This study, in contrast, assesses the caregiver cues to action (predictor variables) of psychological distress, physical distress, levels of social support, and levels of competency to give care in complex health care activities during the intake interview (Wave I) which was conducted within six weeks of discharge from the hospital and then assesses the use of services (outcome variable) during Wave II which was conducted three months after hospital discharge. Therefore, not only is service use examined early in the caregiving process, but also assessment of use of services is at a later point in time than the predictor variables. This allows the researcher to, at least, establish the temporal sequence of the predictor variables and the outcome variables which has not been done in most previous studies.

In summary, this study uses a model which has been previously tested with caregivers of Alzheimer's patients, in a sample of caregivers of physically dependent elders; examines new caregivers use of formal community services; and, examines caregivers' service use at two points in time-prediction of service use based on cues to action, and result, variation in the use of formal community services.

The results of this study will add to the knowledge base of advanced practice nurses and primary care providers, and be a basis of policy making and program formulation, by discovering if these caregiver cues to action effect variation in the use of formal services.

METHODS

The Sample

To address the research questions, the following analyses are based on data from a sample of patients recently discharged from Midwestern hospitals with a variety of physical illnesses. The cases in this panel study were screened for eligibility requirements of:

1) Care recipient age 55 or older.
2) A primary caregiver at home to assist the care recipient.
3) New functional losses of the care recipient following discharge from the hospital.

In addition to these eligibility criteria, the data for this secondary analysis is further restricted to those caregivers in Wave II, who completed Wave I and Wave II phone interviews, and the Wave II self administered booklet (SAB), N=250. This subsample was selected because only cases who completed both the Wave I and Wave II telephone interviews and the Wave II SAB answered all the questions that relate to this study's research questions. Information on the original study's human subjects' protection and approval of UCRIHS is included in Appendix F.

Operational Definitions,Instrumentation,and Analysis Plan

Table 1 presents a list of all possible dependent, independent and control variables to be used in this study. The dependent variables of this study measure use or nonuse of various formal community services. They are coded as dichotomous categorical variables. Caregivers and their care recipients are grouped into one of two categories: They use or do not use any of a number of particular formal community services. Twelve services were addressed in the original study:

1) Doctor's office visits.
2) Emergency Room or Urgent Care Clinic visits.
3) Overnight hospitalization.
4) Nursing home or rehabilitation center stay.
5) Visiting Nurse Services, (VNS).
6) Case management services.
7) Adult day care.
8) Chore or housekeeping services.
9) Meals on wheels or home delivered meals.
10) Occupational, physical or speech therapy.
11) Family support groups.
12) Paid assistance of a family member or friend.

For the present study, the above list of formal services will be divided into three categories: 1) medical services which are the first four services listed, they are not included in this analysis because, conceptually, they are not formal community services which help maintain a physically dependent elder in the community; 2) VNS; and, 3) formal community services which make up the rest of the list except paid assistance by a family member or friend. Conceptually, paid assistance by a family member or friend should be considered part of informal social support, and therefore will not be included among the formal community services. In sum, the formal community services included in the following analyses are: case management services, adult day care, chore/housekeeping services, meals on wheels/home delivered meals, and occupational therapy/physical therapy/speech therapy, and family support groups.

Visiting Nurse Services are used most often by patients and their families upon discharge from the hospital. Conceptually, VNS is a medical service at that time as it is often ordered by the doctor to facilitate early discharge from the hospital. However, Visiting Nurse Services, beyond the initial discharge period, may or may not be used by patients and their families, and may represent a formal community service rather than a medical service. Therefore, if VNS use is found to occur in Wave II (three months after hospital discharge), it will be included as a formal community service.

One additional formal community service considered here is assistance by health professionals with complex health care activities. In the Health Activities Questionnaire (Appendix B) caregivers are asked whether the person(s) who assists them in the complex health care activities are health professionals. If the caregiver indicates that he or she receives assistance in complex health care tasks by a professional, then this will be considered formal service use by this caregiver and is part of the dependent variables. The complex health care activities for which assistance by a health professional is considered are: urinary catheter care, oxygen use, IV/Hickman site care, IV medication administration, tube feedings, injections, exercises, care of bedsores, care of other skin problems, colostomy care, post-op incision care, oral medication administration, care of urinary incontinence, care of stool incontinence, nasogastric tube care, tracheostomy site care, home respirator care, and suctioning. The health professionals are: registered nurse, licensed practical nurse, and/or home health care aide. If a patient receives assistance from any of these health professionals in any of the aforementioned activities, then the outcome is scored as 1 for "assistance by health professional" and 0 for no assistance in any of these activities.

Because most studies have found that formal community service use is low among family caregivers and many statistical tests will yield insignificant results when groups are too small, only those formal services used by 25 or more subjects will be examined as outcome variables.

Before considering the effects of the independent variables on the service use outcome variables, the outcome variables will be crosstabulated and correlated with each other using phi to see if there are pattern(s) of joint usage of several of these formal community services. For example, if it is found that most caregivers who used meals on wheels also used chore/housekeeping services, then those services would be combined into a single variable. Services which do not group themselves will be analyzed separately. If it is found that the use of any given service does not consistently predict the use of any other, then each of the services with 25 or more users will have to be analyzed separately.

The independent variables of the study are derived from the research questions. The first independent variable of the study is <u>perceived level of social support</u>. A self report scale of perceived social support that has been used in many caregiving studies is the "Social Provisions Scale" which was developed by Russell and Cutrona in 1984. It was based on Weiss's theory about social support which provides a multitude of benefits its recipients (1974). Psychometrics of the scale have been very good in a variety of samples over the past ten years. Reliability and validity of the original twenty-four question scale was reported by Russell and Cutrona at the American

Psychological Association Convention, Toronto (1984). A modified 9-item version of this scale was used to measure perceived levels of adequacy of social support in the Caregiver Studies and this study. Results from the reliability analysis for this version of the scale is presented below in Table 3.

The revised version of the "Social Provisions Scale," can be found in the Wave II Self-Administered Booklet and in Appendix A. This scale uses a Likert response scale with 4 possible responses: 1=strongly disagree; 2=disagree; 3=agree; 4=strongly agree. Questions 2, 4, 7, and 8 are stated negatively so they are reverse scored to provide a unidirectional scale. Summation of item responses results in a highest possible score of 36, and a lowest possible score of 9.

The second independent variable is <u>perceived level of competence to perform complex health care activities</u>. In the Wave I Telephone Instrument, eighteen questions were asked (questions 13 through 30 of the telephone interview) about complex health care activities or treatments, such as urinary catheter care, IV medication administration, and tracheostomy care, etc. (Appendix B). Each question contains five parts:

1) Does your relative have or require help with...;
2) If yes, how frequently do you help your relative with..;
3) If caregiver assists with the treatment, how competent do you feel in helping your friend or relative with...;

4) If your relative has/requires help with..., how often do others help your friend/relative with ...;

5) If others help, are they family or friends or health professionals or both?

The competence portion of the questions uses a four point Likert Scale from 0=not at all competent, to 3= extremely competent. In order to construct a competency scale from this questionnaire, which adjusts the competency ratings for both the difficulty and the number of care tasks a patient needs assistance with, the following procedures are adopted. For each complex health care activity in which the caregiver is involved, his or her competency score is standardized. Since caregivers are unlikely to find all care activities equally difficult, their average raw competency ratings will also reflect the overall difficulty of the care activities they happen to perform. On the other hand, a standardized competency rating will capture how individual caregivers rate their competency relative to the average caregiver who performs that particular activity. Since standardized individual competency scores represent deviations from the norm, they can be summed and averaged across individual activities. The relative competency score (COMPETNC) of an individual thus represents his or her average competency rating relative to all the caregivers involved in the same assistance activities. Since the number of assistance activities can vary among caregivers, an additional control variable is computed representing a count of all activities a caregiver is involved in

(COMPRATS). Table 2 presents a summary of the Health Care Activities questionnaire results which will be used to construct the competency scale.

The third independent variable is <u>physical distress of the caregiver</u> and will be measured with the Medical Outcomes Study 20 item Short Form health survey (MOS SF-20). The MOS SF-20 was developed at Duke University to measure health in terms of functioning and well-being as part of the Medical Outcomes Study (Ware, 1987; Stewart, Hayes & Ware, 1988; Stewart and Ware (editors, in press). The SF-20 has been in use for over eight years and has been found to be reliable, with a variety of age groups, races and diagnoses, in rating a broad array of health concepts in a short five to ten minute survey.

The MOS SF-20 is found in the Wave II Self-Administered Booklet. The MOS SF-20 consists of six sub-scales:

1) A 6 item physical functioning scale;
2) A 5 item mental health scale;
3) A 5 item current health perceptions scale;
4) A 2 item role functioning scale;
5) A single item pain scale;
6) A single item social functioning scale.

Each item of the MOS SF-20 uses the Likert response method for scoring, but the various sub-scales have different numbers of response categories. Stewart, Hayes and Ware (1988) report the reliability and validity of the MOS SF-20 and its sub-scales.

For this study, all of the sub-scales <u>except</u> the mental health sub-scale (SAB questions 33, 34, 35, 36 and 37) will be used to determine physical distress of caregivers. Due to the similarity of the questions in the mental health sub-scale and the CES-D, which will be used to measure psychological distress, the mental health scale of the MOS SF-20 is omitted, resulting in a fifteen item scale. The MOS SF-20 is <u>usually</u> scored so that high scores mean better health in all scales <u>except</u> the pain scale and items # 22, 39, and 40 are reverse scored. <u>However</u>, this author will use higher scores to mean greater caregiver physical distress so items #29, 30, 32, 38, and 41 will be reverse scored; and items #22, 39, and 40 will be scored without reversing. This gives a unidirectional scale with lower scores indicating less caregiver physical distress and higher scores indicating greater caregiver physical distress. Reliability analysis will be done and reported on this <u>15 item revision</u> and if the scale can be improved by item deletion, this will be done and reported in Table 3. The questions that form this 15 item scale are presented in Appendix C.

The last independent variable is <u>psychological</u> <u>distress</u> <u>of</u> <u>the</u> <u>caregiver</u>. Psychological distress will be measured using the twenty question, Center of Epidemiologic Studies - Depression Scale (CES-D). The CES-D was developed as part of the Community Mental Health Assessment Program of the Center for Epidemiologic Studies. The CES-D was developed for use with the general population to identify the presence of depressive symptomatology and its severity. The CES-D

TABLE 2. RELIABILITIES AND DESCRIPTIVE STATISTICS FOR CONTROL AND INDEPENDENT VARIABLES

SCALES ()=# OF ITEMS	CRONBACH'S ALPHA	MEAN INTER-ITEM CORRELATION	SCALE MEAN	SCALE STANDARD DEVIATION	VARIANCE
PADL(6)	.931	.689	11.108	6.185	38.250
PIADL(4)	.817	.528	10.886	3.022	9.134
SOCIAL(9) SUPPORT	.875	.438	28.763	4.630	21.440
MOS-SF (14)	.916	.635	26.721	9.068	88.755
CES-D(20)	.929	.405	14.309	9.623	92.602

TABLE 3. ABSOLUTE COMPETENCY RATINGS OF CAREGIVERS ASSISTING IN COMPLEX CARE ACTIVITIES (N=205)

VALUE	FREQUENCY	VALUE	FREQUENCY
1.00	2	2.50	16
1.50	2	2.67	10
1.60	1	2.71	1
1.67	1	2.75	2
2.00	22	2.80	1
2.25	2	2.83	1
2.33	8	2.86	1
2.40	1	3.00	134

MEAN 2.747 STANDARD ERROR 0.029
MEDIAN 3.0 MODE 3.0
VARIANCE 0.174

uses a Likert response scale with 0 = rarely or none of the time; 1= some of the time; 2 = most of the time; and 3 = almost all of the time. Questions 4, 8, 12, and 16 are stated positively so they will be reverse scored to provide a unidirectional scale. The possible range of scores is zero to 60 in this summated scale. In field tests in two communities the average scores ranged from 7.80 to 9.92 with standard deviations of 7.50 to 9.31. A national survey found a mean CES-D score of 8.7 with a standard deviation of 8.4 (Sayetta & Johnson, 1980). Radloff (1977) reported the psychometric properties of CES-D. The CES-D has been found to have high alpha coefficients and split halves correlations in measures of its internal consistency and has correlated well with other mental health measures in terms of discriminant validity.

This scale is found in the Wave II Self-Administered Booklet in a section entitled "Current Feelings," (Appendix D). The CES-D will be scored as discussed by Radloff and Locke (1986), with a score of above 17 indicating possible depression and above 23 probable depression. Reliability analysis will be done and reported on this scale and if item deletion can improve the reliability this will be done and reported in Table 3.

SPSS/PC+ software will be used in this analysis (Norusis, 1991). Since the dependent variables, use of various formal community services, are dichotomous categorical variables, logistic regression is the method with which the data will be analyzed (Edens, 1987). A logistic regression model will be used to discover how well the independent variables of the study: physical distress of the caregiver; psychological distress of the caregiver; perceived incompetence to perform complex health care activities; and, perceived inadequate social support; predict the probability of formal community service use when gender of the caregiver, relationship to the care recipient (spouse, nonspouse), number of members of the household, number of children in the household, number of complex care activities that the caregiver assists the care recipient with, and the level of functional limitations of the care recipient are used as the control variables.

The control variables measuring levels of functional limitations in the patient or care recipient, consists of the limitations in patient's activities of daily living (ADLs) and patient's instrumental activities of daily living (IADLs). They are measured as a count of the relevant activities in which the care recipient needs supervision, or assistance to perform. ADLs considered in the study will be: dressing, eating, bathing, walking, toileting, and transferring. IADL's considered in the study will be: cooking, housework, shopping, laundry, transportation, and money management. Reliability analysis will be done and reported on both scales and if the scales can be improved with item deletion this will be done and reported in Table 3.

Only independent variables which have responses from 25 or more subjects will be used in the logistic regression models. As shown below in Table 2, there are cases in which caregivers do not perform any complex health care activities or refused to answer questions concerning activities in which they are not involved, thus resulting in missing values for those cases. This has led to further reductions in sample size.

RESULTS AND FINDINGS

The Sample

The variables for this study were taken from four interview tools of the Wave II SAB and Wave I and II Telephone Interviews. As noted in the "Final Report Executive Summary of Caregiver Responses to Managing Elderly Patients at Home", of the 628 cases who completed the Wave I interview, subsequently 65 died, 15 were institutionalized, 5 were hospitalized, 8 gained a new caregiver, 48 refused to participate further, 20 could no longer be contacted, 6 were lost to the study for other reasons, and 150 no longer required care. This resulted in 249 caregivers who completed these four measures and are thus available for analysis. The mean age of the patients was approximately 73 years old and their caregivers were approximately 59 years old. Numbers of nonspouse and spouse caregivers were almost equal, spouse - 148, non-spouse - 102. However, women caregivers outnumbered men caregivers nearly two to one, women - 105, men - 43.

Among the formal community services considered for analysis, family support groups, adult day care, and home delivered meals each had less than 25 subjects using them. Given these small numbers of service users, they were not included in the logistic regression models. Formal community services with 25 or more users were: VNS - 119 users; case management services - 27 users; chore/housekeeping services - 37 users; and occupational therapy/physical therapy/speech therapy - 55 users.

The Health Care Activities Questionnaire included a question on assistance by a health care professional in all 18 complex care tasks listed. One hundred and forty-six caregivers did not use health care professionals to assist them in any of the health care activities, mainly because the care-recipients did not have a need for assistance in these activities. Most of the other caregivers (N=76) had assistance from a health professional in at least one health care activity. Seventeen had assistance in two activities, and ten had assistance in three to eight activities. However, in three care activities (Nasogastric tube care, Tracheostomy care, and Respirator care), caregivers used no health professional assistance, these three activities were dropped from further analysis.

Three more activities, (namely IV/Hickman care, Tube Feedings, and Suctioning), were dropped from analysis because every caregiver who performed those activities responded that they were extremely competent resulting in <u>no</u>

variation. This leaves the following activities: urinary catheter care, oxygen, IV meds, injections, exercises, bedsore care, other skin problems care, colostomy care, post-op incision care, oral meds, urinary incontinence, and stool incontinence.

Crosstabulations were performed on all of the possible two way combinations of services, and it was found that in only two combinations did 25 or more subjects use two services. In those combinations (VNS with OT/PT/Speech therapy and Exercises with OT/PT/Speech Therapy) the phi statistics were not significant. In summary, the use or non-use of the first four formal community services appear to be almost independent of each other.

Since no service groups emerged that were used together and the use of health professionals in individual complex health care activities was generally low, the following procedure was adopted for further analysis: all of the complex health care activities were combined as a single variable to be known as Health Professional Assistance; in further analyses the resulting five community services or service groups (VNS, Case Management Services, Chore/Housekeeping Services, OT/PT/Speech Therapy, and Health Professional Assistance), were examined separately.

The data in Table 2 summarize the reliability analysis and descriptive statistics for all the scale variables used as control variables (PADLs and PIADLs) or independent variables (Social Support, MOS-15, CES-D). The reliability analysis led to two other changes in the final scales employed. From the PIADL scale, two items were deleted (transportation and money management), because their inclusion would have reduced alpha to 0.78. Further, one ADL item was deleted from the new MOS-15, both on statistical and conceptual grounds. Conceptually, this item asked if the caregiver was limited in his/her ability to eat, dress, bath, or toilet his or herself, and caregivers who are limited themselves in these ADLs are unlikely to continue caregiving. Statistically, this item would have reduced alpha slightly to 0.9132. As the data in Table 3 reveal, after these small modifications, all scales display excellent reliability.

Relative competency rating scales have not been used in previous caregiving studies, therefore, there are no reliability statistics for them. The competency scale was constructed from a health care activities questionnaire (Appendix B). Possible Competency Self-Rating Scores were: 0 = not competent at all; 1 = not very competent; 2 = somewhat competent; and, 3 = very competent. Forty-three caregivers did not assist the recipient in any of the 18 listed complex health care activities, and thus were not asked to rate their competence.

Although the possible raw competency scores ranged from 0 to 3, ratings by all of the caregivers in each activity ranged from 2.20 to 3.00. As can be seen from these figures, caregivers rated themselves somewhat to very competent in each of the activities.

An absolute competency scale was constructed for all of the activities in which the caregiver assisted and rated their competence (ABSCOMPR). Two hundred and five caregivers rated their competence in all 18 activities. This scale took the raw competence scores and divided it by the number of activities the caregiver assisted (COMPRATS). The values of the absolute competency scale ranged from 1 to 3, this meant no caregivers rated themselves as not competent at all in _any_ of the activities in which they gave complex care. The values, frequency of each value, mean and its standard error, median, mode and variance are presented below as Table 3.

As can be noted from this table, sixty-five percent of the caregivers rated themselves as extremely competent in the activities in which the provided complex health care. There was very little variance in the absolute competency ratings. The relative competency ratings (COMPETNC) were used as the independent variable in the logistic regression because it adjusts for differences in the difficulty of the tasks.

The relative competency rating was computed based on the standardized ratings by health care activity (ZSCORE). The descriptive statistics of the ZSCORES are reported in Appendix E. A ZSCORE of 0.000 means that a caregiver rates him or herself as competent as the average among all

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caregivers who assisted in that complex health care activity. A negative ZSCORE means that a caregiver rated her or himself less competent than the average caregiver who assisted in that complex care activity. A ZSCORE greater than 0.000 means that a caregiver rated himself or herself more competent than the average caregiver who assisted in that activity. As can be noted from the ZSCORES, most caregivers rated themselves the same as the average caregiver in each of the activities.

Overall, Relative Competency Scale Scores (ZSCORES) for individual caregivers, adjusted for the number of activities in which the caregiver assisted, ranged from -0.85 (N=1) to +0.32 (N=1), with a mean of 4.3277 E -16, a median of 0.026, and a mode of 0.026. Approximately twenty-five percent of the caregivers (N=50) rated themselves below the average caregiver score in the scale (-0.85 to -0.04), one hundred and two caregivers (~50%) rated themselves very near the average caregiver (-0.03 to +0.07) and 54 caregivers (~25%) rated themselves higher than the average caregiver score (+0.08 to +0.32). Again, the scores indicate little variation in caregivers' competency ratings.

To test the hypotheses, dependent (service use) variables were dichotomously coded, use versus non-use, and logistic regression was performed on each of the each of the possible services used by 25 or more caregivers. Five identified dependent variables were employed: VNS, Case Management Services (Case), Chore/Housekeeping Services

(Chore), OT/PT/Speech Therapy (OT/PT), and Health Professional Assists with Complex Care Tasks (HP Assists). Four independent variables tested were employed, consistent with the research questions. They were: Social Support (Socsupp), Physical Distress (Physdis), Psychological Distress (Depress), and Relative Competence in Complex Health Care Activities (COMPETNC). The independent variables were entered simultaneously into the regression with the following control variables: number of complex health care activities with which the caregiver assisted the care recipient and rated their competency (Comprats), gender of caregiver (gender), caregiver's relationship to care recipient (Relation), number of persons residing in the household (# in House), number of children under 18 years old residing in household (# under 18), patient's ADL limitations (PADL), patient's IADL limitations (PIADL), and a constant. Table 4 displays the results of entering all the variables on one step.

The results in Table 4 reveal only four significant coefficients for the independent variables and none of the independent variables seem to be related to the use of physical, occupational, or speech therapists or to the use of health professional assistance in complex health care tasks. Social support affects the use of VNS (b=1.212, p=0.015), social support and psychological distress affect the use of case management (b=1.232, p=0.049; b=0.076, p=0.021), and physical distress appears to influence the use

Table 4. Logistic Regression Results to Predict Use or Non-Use of Five Formal Community Services

	Dependent Variables					
	VNS		Case		Chore	
Independent Variables	B	Sig.	B	Sig.	B	Sig.
Social Support	1.212	.015*	1.232	.049*	.711	.317
Physical Distress	.040	.088	.029	.311	.096	.004*
Psych. Distress	.017	.548	.076	.021*	.006	.884
Competnc	-.941	.467	.332	.827	4.839	.101
Control Variables						
Comprats	.343	.026*	.435	.026*	.043	.861
Gender	-.148	.778	-.585	.399	-1.266	.103
Relation	-1.631	.001*	-.065	.923	-2.053	.007*
# in House	-.449	.098	.174	.697	-0.825	.185
# under 18	.406	.483	-7.346	.797	-6.272	.833
PADL	.136	.531	-.157	.608	-0.484	.148
PIADL	.763	.010*	-.048	.904	0.840	.088
Constant	-5.924	.003	-8.321	.004*	-4.750	.169

	Dependent Variables		
	VNS	Case	Chore
% Predicted	69.14%	88.96%	87.73%
Sensitivity	72.09%	14.29%	11.11%
Specificity	65.79%	100%	97.24%

VNS Likelihood Results

	Chi-Square	df	Significance
-2LL with Constant	125.238		
-2LL with variables	104.601	151	.999
Model Chi-Square	20.636	11	.037*
Improvement	20.636	11	.037*
Goodness of Fit	145.187	151	.618

CASE MANAGEMENT Likelihood Results

	Chi-Square	df	Significance
-2LL with Constant	223.962		
-2 LL with variables	181.555	150	.041*
Model Chi-Square	42.407	11	.000*
Improvement	42.407	11	.000*
Goodness of Fit	157.604	150	.319

CHORE Likelihood Results

	Chi-Square	df	Significance
-2LL with Constant	113.256		
-2LL with variables	85.480	151	1.000
Model Chi-Square	27.776	11	.0035*
Improvement	27.776	11	.0035*
Goodness of Fit	224.883	151	.0001*

Table 4 (cont.)

	Dependent Variables			
	OT/PT		HP Assists	
Independent Variables	B	Sig.	B	Sig.
Social Support	-.187	.716	.456	.290
Physical Distress	-.007	.760	-.002	.943
Psych. Distress	-.008	.794	.003	.895
Competnc	-1.712	.160	-1.003	.387
Control Variables				
Comprats	.078	.630	.350	.017*
Gender	.718	.163	-1.584	.003*
Relation	1.200	.044*	-.313	.478
# in House	-0.258	.446	.217	.404
# under 18	.771	.251	-.559	.316
PADL	.111	.633	-.165	.412
PIADL	.443	.157	.714	.011*
Constant	-1.732	.393	-3.030	.086

	Dependent Variables	
	OT/PT	HP Assists
% Predicted	76.07%	63.80%
Sensitivity	10.26%	56.41%
Specificity	96.77%	70.59%

OT/PT/SPEECH Likelihood Results

	Chi-Square	df	Significance
-2LL with Constant	179.375		
-2LL with variables	161.621	151	.263
Model Chi-Square	17.754	11	.0875
Improvement	17.754	11	.0875
Goodness of Fit	160.797	151	.2775

HP ASSISTS Likelihood Results

	Chi-Square	df	Significance
-2LL with Constant	225.665		
-2LL with variables	202.504	151	.003*
Model Chi-Square	23.162	11	.017*
Improvement	23.162	11	.017*
Goodness of Fit	162.361	151	.2495

of chore services (b=0.096, p=0.004). Concerning the first research question, levels of perceived informal social support do predict variation in the use of two of the five formal community services studied - VNS and Case Management. With respect to the second research question, levels of perceived competence to perform complex health care activities for the elder does not predict variation in the use of any of the five services studied. Regarding the third research question, physical distress of the caregiver does predict variation in the use of chore services. In response to the fourth research question, psychological distress of the caregiver does predict variation in the use of case management services. These few significant coefficients are all positive which does not fit with the Health Belief Model in all cases.

For example, the findings show that: (1) more physical distress of the caregiver raises the odds of using chore services, and (2) more psychological distress raises the odds of using case management. The signs of these two coefficients are consistent with the expectations based on the theoretical model. However, the positive effect of greater social support on the likelihood of having VNS and Case Management services, at first, seems counterintuitive.

One possible explanation for the positive effect of greater social support on the likelihood of using VNS and Case Management services is reverse causation. Caregivers may actually see VNS and Case Management as part of their social support. Since the use of services began at hospital discharge and prior to the Wave I interview, it is not possible to disentangle the effect of using these two formal services from the caregivers' perceptions of social support.

Table 4 also shows that the competency rating of the caregiver does not seem to affect any of the five formal services. However, two technical problems may account for this finding. As noted earlier, there was little variation in these competency ratings among the caregivers. Thus, their variation cannot have a strong effect on variation in the use of services.

The other problem with the competency ratings appears to be multicollinearity. When regression coefficients are of medium to large size, but remain insignificant, this often indicates that the variable in question correlates highly with other variables in the equation. The net effect is, its individual contribution can not be disentangled. Whatever the reason for the non-significant findings, on the whole it can be concluded that the four independent variables representing cues to action could not be shown to affect the likelihood of use of formal community services.

On the other hand, many of the control variables affect the likelihood of using at least some of the five formal community services. However, the patterns are not consistent. For example, spouse caregivers (relation=1) are less likely that nonspouse caregivers (relation=0) to make use of VNS or chore services but are more likely to have

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physical, occupational, or speech therapy services for their care recipient. Three of the control variables, number of people in the household, number of children under 18 years old in the household, and patient's limitations in activities of daily living did not influence the odds of using any of the formal community services in this study. In addition, the sets of control variables that have significant effects on the five service use variables <u>differ</u> depending on the service in question.

A further way of looking at these logistic regressions is to examine how well the independent variables <u>combined</u> affect and predict the outcome in question. In particular, the analysis will focus on goodness of fit tests and indicators of the ability to predict service use. Both the log likelihood test (-2LL) and the Pearson Goodness of Fit tests compare observed sample values of the outcome variable (use or nonuse) to the predicted outcomes. These predicted outcomes are probabilities of use associated with each case's constellation of independent variables. Thus, a well fitting model is one where the deviations of observed from predicted outcomes are <u>NOT</u> statistically significant. By that criterion, only the Chore service model does not do well.

Another way of looking at the predictive capacity of the models is to compare these simple indices: (1) the percent of cases whose usage pattern (use or nonuse) has been correctly predicted by the model; (2) the percent of users who have been correctly predicted (sensitivity); and, (3) the percentage of non-users who have been correctly predicted (specificity). Since all of the models predicted correctly more than 50% of the cases, they did better than chance for overall predictability. However, sensitivity (the ability to predict users) was poor for three services (case management, chore services, and physical/occupational/speech therapy) and not great for the assistance by health professional. By contrast, the models did much better in predicting non-users of services with specificity readings of 97% for the Chore Services and Physical/Occupational/Speech Therapy models and 100% for the Case Management model.

In sum, the logistic regression models show their best results in predicting who will <u>NOT</u> use a particular service, but not who will. In addition, among the individual predictor variables, the control variables seemed to have greater predictive power than the independent variables which are the focus of the theoretical model. In this study, cues to action as operationalized here, do not seem to contribute to our ability to predict the use of formal community services.

Limitations of the Study

In assessing why the cues to action did not contribute to our ability to predict the use of formal community services, it was found that the order of the questions in the health activities questionnaire may have contributed to the technical problem of small variation of perceived competence among the caregivers. The questionnaire asked the caregivers if they assisted in the care of their family member or friend and, only if they answered 'yes', were they then asked to rate their competence. It is therefore possible that caregivers who did not perceive themselves to be competent to perform complex health care tasks for the care recipient had decided not to assist the care recipient and only the caregivers who perceived themselves as competent to perform these tasks were questioned about their levels of competence. If the questionnaire had first asked the caregivers about their competence to perform complex health care tasks, then asked about their own assistance, and finally asked if they used health professionals to assist the care recipient in tasks for which they did not feel competent, then there may have been much more variation in the responses to the competency portion of the questionnaire and the tool may have been a better predictor of formal community service use. Another problem with the health activities questionnaire is that it does not ask if the health professional who assists is part of VNS services. This may account for the multicollinearity encountered in the Health Professional Assists model and the VNS model.

The timing of asking the questions about social support in relation to the VNS and Case Management Services models may have been a problem. If the caregivers had been asked during the hospitalization of their care recipients about their perceptions of their levels of social support, this may have improved the ability of perceived levels of social support to predict the use of formal community services rather than when VNS and Case Management may have become part of their social support network.

The social support questionnaire used does not ask caregivers about assistance received from family or friends in terms of physical labor, or in terms of monetary contributions that could pay for assistance to the care recipient or the caregiver, nor does it ask the health care expertise levels of members in their social support network. The Social Provisions Scale does ask caregivers about sources of guidance, social integration, emotional attachment(s) and reliable alliance(s) in their lives. It is possible that some of the caregivers had members in their social support network who were competent to assist the patient in complex health care activities, or in other ways which could have reduced the physical, and/or the psychological distress that may be a result of caregiving. Because these questions were not asked, it is not possible to rule out that some of the lack of ability to predict the use of formal services is due to not asking the right kinds of questions about social support.

The health care activities questionnaire does ask about the assistance of family or friends in complex care activities. In retrospect, this could have been used as part of the social support predictor and may have improved the ability of social support to predict variation in the use of formal community services.

There are many other independent variables that may predict the use of formal services besides the four cues to action which were selected for this study. Several variables within the model which may predict the use of formal community services and which were not studied include: referral; information; suggestion; caregiver attitudes and patient attitudes; and availability, affordability, and acceptability of formal services. Other independent variables that might be related to the use of formal services that were not included in this study and were not in the model were derived from a review of caregiving literature.

Given, Given, Barry and Lin (1993) found that patients _referred_ for formal services had more functional limitations, were older, and needed more medical treatments, than patients who were not referred for formal services. The caregivers of patients _referred_ for formal services were more likely to be female, non-spouse and to live separately from the care recipient. Actual _users_ of formal services were found to be patients who had greater functional limitations than non-users of formal community services and patients who had employed caregivers. Gender of the caregiver, spouse/nonspouse relationship, number of complex health care activities in which the caregiver assisted and level of functional limitations were used as control variables in this study because of these findings and here again proved to be significant.

Several other studies also report that the strongest predictors of use of formal service are the age of the care recipient and the extent of the patient's impairments (Hess & Soldo, 1985; Noelker & Wallace, 1985; Given, Stommel, Collins, King & Given, 1990). Bass and Noelker (1987) found that higher levels of caregiver strain were predictive of formal service use. Other variables that may be related to formal service use include:

1) Payer of services, as there is anecdotal evidence that caregivers do not use formal services if they must pay for them out of pocket (National Long-Term Care Channeling Demonstration, 1982, 1984, 1986).

2) Number of household members, as these may assist the primary caregiver with the elder (Stommel, Wang, Given, Given, & Collins, 1992). This was used as a control variable in this study.

3) Number of children of the primary caregiver, as the caregiver may need more services to care for more than one dependent (Stommel, Wang, Given, Given, and Collins, 1992). This also was used as a control variable in this study.

4) Socioeconomic status of the caregiver.

5) Educational background of the caregiver.

It has been found in several research studies that better educated caregivers and caregivers of higher socioeconomic status use more services for onerous tasks than caregivers who are less educated or of lower socioeconomic status. Also, caregivers who are better educated and of higher socioeconomic status are more likely to participate in research studies than caregivers who refuse to participate (National Long-Term Care Channeling Demonstration, 1982, 1984, 1986; Rosenthal & Rosnow, 1975).

Other difficulties in this study, besides the predictive values of the independent variables chosen and those not chosen is the fact that the sample is not random and the caregivers who agreed to participate may not be representative of the population of caregivers in the United States. So even if the results of this study of cues to action in the use of formal community services by family caregivers had been more satisfactory, the results could not be easily generalized to other populations of caregivers. This is called sample bias (Hochbaum, 1958).

Sample bias in caregiving research has been reported by Dura and Kiecolt-Glaser (1990), in mental health research by Bebbington, Harry, Tennant, Sturt and Wing (1981), and in general survey research by Rosenthal and Rosnow (1975). Rosenthal and Rosnow also reported that research participants were more likely to be women, better educated, and of higher socioeconomic class than non-participants.

The sample from the MSU family caregivers studies, "Caregiver Responses to Managing Elderly Patients at Home", have some of these same characteristics. Most caregivers were women who were better educated and of higher socioeconomic class than caregivers who refused to participate and than the general population of the United States. Another characteristic of the MSU sample that makes it problematic to generalize to the larger population in general is the high percentage of whites who participated. Little can be discovered about the differences between caregivers of different ethnic backgrounds or races from this sample because few minority caregivers participated.

The dependent variables chosen for analysis were limited to those which had 25 or more users of formal community services among the caregivers and care recipients, but these selected services may not be services for which cues to action have any bearing. Instead, use of these services, especially VNS, Case Management Services, Occupational/Physical/Speech Therapy, and Health Professional Assistance, may be affected by the decisions of discharge planners about characteristics of the patient or availability of the service in the community or even eligibility of the dyad for third party payment for those services. The only service used in this study which may have been under the control of the caregivers' ability to decide to use the service and therefore influenced by caregiver cues to action is Chore Services.

Therefore, finally, the model chosen may not have been appropriate for the services chosen in this study. More appropriate models for this study's dependent variables (formal community services) may be either a model which focuses on the environment of health care delivery such as the "access to medical care" model developed by Aday, Andersen, and Fleming originally in 1980, and revised and depicted graphically by Urrutia-Rojas and Aday (1991), or a model of "transitions" as when there are role changes and identity changes in course of family life such as from family member or friend to caregiver and from family member to family patient or care recipient. Such a model was developed by N. K. Schlossberg (1981) and recently expanded and depicted graphically by Schumacher and Meleis (1994). Both models acknowledge that not all decisions are under the control of the caregiver, but rather may be influenced by the services available in the community, eligibility of the caregiving dyad for third party payment, or care recipient functional limitations in activities of daily living or instrumental activities of daily living.

In summary, cues to action did not work well with the five formal services in this study because the use of at least four of these services may not be influenced by caregiver decisions. The only service that may have been influenced by caregivers' cues to action was Chore/Housekeeping services. More important influences on the use of formal community services in this study were the control variables which are not cues to action.

Non-spouse caregivers were more likely to use VNS and Chore/Housekeeping services. Care recipients who had more limitations in Instrumental Activities of Daily Living (PIADLs) were more likely to use VNS and/or Health Professional Assistance in complex health care activities. Male caregivers were more likely to use Health Professional Assistance in complex health care activities. Caregivers who assisted in a greater number of complex health care activities were more likely to use Health Professional Assistance in those activities, VNS, and Case Management services. These findings agree with previous studies of caregiving. A surprising finding was that spouse caregivers were more likely to use OT/PT/Speech Therapy services than non-spouse caregivers. It is doubtful that being a spouse has any influence on the use of this formal service. A much more likely explanation is that this is just a statistical anomaly.

Implications for Existing Literature and Recommendations for Future Research

For the formal community services selected for study, the caregiver cues to action from the theoretical model did not predict service users well. More of the control variables were important in the predictive power of the models than the independent variables. These were: Number of complex health care activities in which the caregiver assisted the care recipient, gender of the caregiver, relationship of the caregiver to the care recipient (spouse/non-spouse), and patient's limitations in instrumental activities of daily living. Of these control variables, only the number of complex care activities in which the caregiver assisted the patient, is amenable to change and could be another cue to action. In this study, the number of complex health care activities was predictive of use of VNS, Case Management Services, and Health

Professional Assistance. Future studies of the use of these formal services should consider the number of complex health care activities in which the caregiver will be involved upon discharge of the patient from the hospital as a cue to action.

No previous study has created and used a Relative Competency Rating Scale of caregivers involved in complex health care activities for care recipients. This scale allowed the researcher to see how caregiver's perceive their competency in relation to the average caregiver performing those same activities. In this study, the scale's construction produced a fairly symmetric distribution. In future studies, relative competency ratings should be taken while the care recipient is hospitalized to see if the caregiver perceives him/herself to be competent in the complex health care tasks required by the care recipient upon discharge and what level of competency predicts service use and/or need. Various nursing interventions should be tried to increase or supplement the caregiver's competency, such as education in the skills needed, identification of members in the caregiver's informal support network who have the competency to assist the caregiver and care recipient in complex health care tasks, and identification of and referral to community services when there is a need. By changing the order in which the questions are asked in the Complex Health Care Activities Scale, a much more useful tool of research in use of formal community services may be developed.

Several formal services were deleted from further analysis due to their small number of users. Future studies examining how caregiver cues to action of physical distress, psychological distress, perceived social support and perceived competence affect services should be conducted on services not included in this study - support groups, adult day care, and home delivered meals. Conceptually, these are services that may reduce the burden of the caregiver and the decision to use these services may be under the control of family caregivers. Therefore, results from such studies could have wide implications for both programs and policies.

Another approach may be to match some of these caregiver cues to action to services on which they may have a more direct effect. For example: using social support levels and psychological distress levels to predict use of support groups; or physical distress to predict use of chore/housekeeping services, home delivered meals, and/or adult day care; or perceived competence in complex health care tasks and inadequate social support (as caregivers may rely on members of their social support network to do care in which they do not feel competent) to predict the use of VNS and health professional assistance prior to hospital discharge may be a more valid study than entering all of the independent and control variables simultaneously into the service models.

A very important insight gained form this study was that use of one service did NOT predict the use of any other service. In all of the articles that were reviewed for this study, the use or nonuse of formal community services was grouped as a single outcome variable. Future studies should examine the use of formal community services individually and see if prediction of service use may be improved.

Finally, use of physical/occupational/speech therapists, case management services, VNS, and health professional assistance may be unrelated to the caregiver cues to action selected for this study. These services may be influenced by third party payment eligibility, and/or decisions of a hospital discharge planner who only considers the care recipient's characteristics and physical needs, and the services available in the caregiving dyads' home community. An ecological model such as the Medical Access model or a change model such as the Transitions Model may be more appropriate for the prediction of the use or nonuse of these four services.

Implications for Advanced Nursing Practice and Primary Care

For the most part few caregivers used formal services. Surprising was the number of care recipients who used Visiting Nurses Services (45%) during the second wave of the caregiver studies as this was three months post hospital discharge. However, upon reading the final report of the original study, it was noted that approximately 65% of the patients had been readmitted to the hospital between Waves I and II. The caregivers who had VNS may have become accustomed to the use of health professionals to assist in care or, VNS could have been ordered by medical staff after the second admission in an attempt to prevent another readmission to the hospital, either one or both of these may account for some of the VNS use at Wave II.

VNS use and use of health professional assistance in complex health care activities were predicted fairly well by the logistic regression models. Both of these services are high cost items and require highly trained personnel. As such, being able to predict users of these services would be important to hospital discharge planners and caregiver characteristics should be considered in discharge planning as well as care recipient needs. All of the caregiver cues to action in this study could be assessed prior to discharge, so that the hospital discharge planner is aware of the caregiver's need status and decisions for services include this input. The role of the Nurse in Advanced Practice (ANP) in this situation is to be an advocate for his or her client. Often discharge planners are overburdened with multiple cases and little time for individual attention to caregiver needs. The ANP has a knowledge of their clients and the clients' needs that has developed over the years and by informing the discharge planner about unique needs and situations, thus the ANP can be an advocate for the caregiver and the care recipient. The ANP works with families and as such knows the needs of not only the patient but also the rest of the family. As the 'expert', the ANP should educate other health care providers with whom the family has contact about family needs and how families can be assisted in their caregiving roles and tasks.

The physical status of the caregiver should be considered in hospital discharge planning as physical distress was significant in the chore services model. Housekeeping in addition to caregiving can be stressful to the caregiver. This is especially true if the caregiver does not live with the care recipient as would be the case when the relationship between the caregiver and the care recipient is nonspouse, which was a significant control variable in this model. The ANP again is the most likely person to be aware of these situations and should collaborate with the primary care nurse, social worker or discharge planner to assist the family caregiver and patient in making the transition from hospital to home as easy as possible for the family including dealing with such instrumental activities of daily living as housekeeping, shopping, and transportation which may be difficult for the newly discharged client and for the caregiver, and may not be factors generally considered by hospital personnel.

Psychological distress and social support should be assessed in caregivers prior to the care recipients discharge from the hospital, and if social support is not perceived as adequate by the caregiver, then services to mobilize his or her support system or to provide a support system should be implemented. The social support may help the caregiver to maintain their sense of being cared for as they give care and prevent or ameliorate some of the distress caused by caregiving. A baseline of the psychological status of the caregiver taken prior to the patient's discharge or even during a routine visit to the primary care provider prior to the beginning of the caregiving experience could then be followed over the course of the caregiving experience and if there is an increase in psychological distress during the experience, appropriate interventions could be implemented.

The more complex the tasks that the caregiver must perform and the more the number of these tasks that the caregiver must perform for the care recipient, the more likely the caregiver is to use formal services. Every caregiver should be fully assessed prior to the patient's discharge for their knowledge of the tasks, for their ability to cope with these tasks both physically and emotionally, and for the extent and level of expertise within their social support network. Those caregivers who can not handle these complex tasks should be helped with appropriate services to support them.

Family caregivers are an 'at-risk' group. They are often forgotten by hospital health care professionals when dealing with patients. Caregiving can be a burden that results in physical health deterioration, psychological distress, feelings of guilt about being incompetent to perform complex health care tasks, and feelings of isolation from their social network due to the time needed to care for their loved one. Therefore, the ANP as a clinician should make an effort to be aware of the clients needs and situations and intervene with appropriate actions to assist caregivers before the at-risk caregiver becomes the patient. This requires not only a knowledge of the caregivers within the practice, but also a knowledge of the resources in the community, a willingness to refer his or her clients to services, an organizational ability to develop new resources as needed, and the persistence to continue seeking resources in the face of budget restraints that are narrowing the eligibility requirements and reducing the programs available to assist caregivers.

Caring for ones clients after the crisis of hospitalization of their loved one is just the beginning. The ANP or other primary care provider must frequently evaluate the formal services offered to their clients and together plan how the family will continue caring for the patient after the service is discontinued. The family and the ANP should also evaluate the services for quality and appropriateness of the service. If the service is not meeting the needs of the family or if the needs of the family have changed since discharge, then the ANP and the family should seek more appropriate services. They should discontinue services when they are no longer needed, not just continue services until the client's eligibility runs out.

Many cultures and subcultures within our society believe that the family should care for its own or the woman should be the sole caretaker of the family. These caregivers may be at higher than average risk for physical distress or psychological distress from the isolation of caregiving, or other potential adverse outcomes of caregiving which may include abuse of the care recipient. The ANP may need to give caregivers permission to use services to avoid such adverse outcomes.

Advanced Nursing Practitioners interact with both families and service organizations within their communities. This provides an opportunity to conduct research into the effects of services upon families and to see the results of interventions that come out of the research first hand. Publication and dissemination of the knowledge gained from this research should be a priority for the ANP. Quality of care and cost effectiveness can not be shown without evaluative research. Other practitioners need to have a sound basis for both their interventions, and their research in their own practices. Published research findings can be that basis.

In the near future, health care reform regulations may require that practices prove both the quality and cost effectiveness of their care before the practice is paid for their services, and therefore, jobs in health care may depend on this research.

In summary, the Nurse in Advanced Practice has many important supporting roles to play in his or her interactions with family caregivers, other health care providers, and with service organizations. The ANP may need to be at various times a collaborator, an educator, an advocate, a researcher, an evaluator, a referral source, as well as a clinician in support of the family caregiver who is doing a job that most feel is one of the most important in their lives - Caregiving!

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APPENDIX A

THE SOCIAL PROVISIONS SCALE

APPENDIX A

THE SOCIAL PROVISIONS SCALE

In answering this set of questions think about your current relationships with friends, family, family members and community members. PLEASE IDENTIFY HOW MUCH YOU AGREE WITH EACH STATEMENT. For example, if you feel a statement is very true of your current relationships, you should circle STRONGLY AGREE. If you feel a statement clearly does not describe your relationships, you should circle STRONGLY DISAGREE. Circle one response for each statement.

1. There are people I can depend on to help me if I really need it.

STRONGLY DISAGREE	DISAGREE	AGREE	STRONGLY AGREE

2. There is no one I can turn to for guidance in times of stress.

STRONGLY DISAGREE	DISAGREE	AGREE	STRONGLY AGREE

3. There are people who enjoy the same social activities I do.

STRONGLY DISAGREE	DISAGREE	AGREE	STRONGLY AGREE

4. If something went strong, no one would come to my assistance.

STRONGLY DISAGREE	DISAGREE	AGREE	STRONGLY AGREE

5. I have close relationships that provide me with a sense of emotional security and well-being.

STRONGLY DISAGREE	DISAGREE	AGREE	STRONGLY AGREE

6. There is someone I could talk to about important decisions in my life.

STRONGLY DISAGREE	DISAGREE	AGREE	STRONGLY AGREE

7. There is no one whom I can depend for aid if I really need it.

STRONGLY DISAGREE	DISAGREE	AGREE	STRONGLY AGREE

8. There is no one with whom I feel comfortable talking about my problems.

STRONGLY DISAGREE	DISAGREE	AGREE	STRONGLY AGREE

9. I feel strong emotional bond with at least one other person.

STRONGLY DISAGREE	DISAGREE	AGREE	STRONGLY AGREE

APPENDIX B

ACTIVITIES OF HEALTH CARE

APPENDIX B

ACTIVITIES OF HEALTH CARE

The next set of questions include health care activities or treatments that (___) may or may not require. First, I will ask if (____) requires this kind of help, and then I will have additional questions about how you and others help.

INTERVIEWER: The following questions have four sections: A, B, C, & D.
Ask Section A — each item for all caregivers.
If answer in section A is NO - go to next item.
If answer in section A is YES - go to section B.
If answer in section B is NEVER or 0 - go to section D.
If answer in section B is 1, 2, 3, or 4 - go to section C then to section D.
If answer in section D is 1, 2, 3, or 4 - go to section E.

(MARK THE APPROPRIATE ANSWERS FOR EACH)

A. Does your relative have or require help with ...	YES NO (CIRCLE ONE)	B. If YES, how frequently do you help your relative with __? 0 = never 1 = once a week or less 2= several times a week (2-6) 3 = once a day 4 = several times a day (CIRCLE ONE)	C. If answer 1-4 to Part B, how competent do you feel in helping your relative/friend with ____? 3 = extremely competent 2 = somewhat competent 1 = not very competent 0 = not at all competent (CIRCLE ONE)	D. If YES to A. how frequently do OTHERS help your friend/relative with ____? 0 = never 1 = once a week or less 2 = several times a week (2-6) 3 = once a day 4 = several times a day	E. If others help, are they family or friends or health professionals or both. CHECK ALL THAT APPLY
	1 2	O 1 2 3 4 Go to Sec. D Go to Sec. C	3 2 1 0 Go to Sec. D.	0 1 2 3 4	Family or Friends Health Prof.
13. Urinary catheters catheter care.	1 2	0 1 2 3 4	3 2 1 0	0 1 2 3 4	____ ____
14. Oxygen Administration.	1 2	0 1 2 3 4	3 2 1 0	0 1 2 3 4	____ ____
15. IV. Hickman or Broviac Catheter care/dressing.	1 2	0 1 2 3 4	3 2 1 0	0 1 2 3 4	____ ____
16. IV. medications/fluids feedings	1 2	0 1 2 3 4	3 2 1 0	0 1 2 3 4	____ ____
17. Tube feedings or IV feedings	1 2	0 1 2 3 4	3 2 1 0	0 1 2 3 4	____ ____

A. Does your relative have or require help with ...	YES NO (CIRCLE ONE)	B. If YES, how frequently do you help your relative with ___? 0 = never 1 = once a week or less 2 = several times a week (2-6) 3 = once a day 4 = several times a day (CIRCLE ONE)	C. If answer 1-4 to Part B, how competent do you feel in helping your relative/friend with ___? 3 = extremely competent 2 = somewhat competent 1 = not very competent 0 = not at all competent (CIRCLE ONE)	D. If YES to A, how frequently do OTHERS help your friend/relative with ___? 0 = never 1 = once a week or less 2 = several times a week (2-6) 3 = once a day 4 = several times a day	E. If others help, are they family or friends or health professionals or both. CHECK ALL THAT APPLY
	1 2	0 1 2 3 4 Go to Sec. D Go to Sec. C	3 2 1 0 Go to Sec. D	0 1 2 3 4	Family or Friends Health Prof.
18. Injections (i.e. pain meds/insulin).	1 2	0 1 2 3 4	3 2 1 0	0 1 2 3 4	___ ___
19. Special exercises/phys therapy.	1 2	0 1 2 3 4	3 2 1 0	0 1 2 3 4	___ ___
20. Care of ulcers/ bedsores.	1 2	0 1 2 3 4	3 2 1 0	0 1 2 3 4	___ ___
21. Skin care (special cleansing/lotions).	1 2	0 1 2 3 4	3 2 1 0	0 1 2 3 4	___ ___
22. Colostomy/ colostomy care.	1 2	0 1 2 3 4	3 2 1 0	0 1 2 3 4	___ ___
23. Care of Post Op. Incision/wound.	1 2	0 1 2 3 4	3 2 1 0	0 1 2 3 4	___ ___
24. Oral medications.	1 2	0 1 2 3 4	3 2 1 0	0 1 2 3 4	___ ___
25. Nasogastric tube and care.	1 2	0 1 2 3 4	3 2 1 0	0 1 2 3 4	___ ___
26. Incontinence of urine.	1 2	0 1 2 3 4	3 2 1 0	0 1 2 3 4	___ ___
27. Incontinence of stool.	1 2	0 1 2 3 4	3 2 1 0	0 1 2 3 4	___ ___
28. Tracheostomy/ tracheostomy care.	1 2	0 1 2 3 4	3 2 1 0	0 1 2 3 4	___ ___
29. Respirator/ care of respirator	1 2	0 1 2 3 4	3 2 1 0	0 1 2 3 4	___ ___
30. Suctioning	1 2	0 1 2 3 4	3 2 1 0	0 1 2 3 4	___ ___

APPENDIX C

MEDICAL OUTCOMES STUDY SHORT FORM - 20 (MOS SF-20)

APPENDIX C

MEDICAL OUTCOME STUDY SHORT FORM - 15 (MOS SF-15)

22. In general, would you say your health is: (CIRCLE ONE)

EXCELLENT VERY GOOD FAIR POOR

For how long (if at all) has your health limited you in each of the following (CIRCLE ONE FOR EACH)

23. The kinds or amounts of vigorous activities you can do, like lifting heavy objects, running, or participating in strenuous sports. (CIRCLE ONE).

LIMITED FOR MORE THAN 3 MONTHS	LIMITED FOR 3 MONTHS OR LESS	NOT LIMITED AT ALL

24. The kinds or amounts of moderate activities you can do, like moving a table, carrying groceries or bowling. (CIRCLE ONE)

LIMITED FOR MORE THAN 3 MONTHS	LIMITED FOR 3 MONTHS OR LESS	NOT LIMITED AT ALL

25. Walking uphill or climbing a few flights of stairs. (CIRCLE ONE)

LIMITED FOR MORE THAN 3 MONTHS	LIMITED FOR 3 MONTHS OR LESS	NOT LIMITED AT ALL

26. Bending, lifting or stooping (CIRCLE ONE)

LIMITED FOR MORE THAN 3 MONTHS	LIMITED FOR 3 MONTHS OR LESS	NOT LIMITED AT ALL

27. Walking one block. (CIRCLE ONE)

LIMITED FOR MORE THAN 3 MONTHS	LIMITED FOR 3 MONTHS OR LESS	NOT LIMITED AT ALL

28. Eating, dressing, bathing, or using the toilet. (CIRCLE ONE)

LIMITED FOR MORE THAN 3 MONTHS	LIMITED FOR 3 MONTHS OR LESS	NOT LIMITED AT ALL

29. Does your health keep you from working at a job, doing work around the house, or going to school? (CHECK ONE)

_____ Yes, for more than 3 months (1)
_____ Yes, for 3 months or less (2)
_____ No (3)

30. Have you been unable to do certain kinds of work, housework, or school work because of your health? (CHECK ONE)

_____ Yes, for more than 3 months (1)
_____ Yes, for 3 months or less (2)
_____ No (3)

31. How much bodily pain have you had during the past 4 weeks? (CIRCLE ONE)

NONE VERY MILD MILD MODERATE SEVERE

32. How much of the time, during the past 3 months, has your health limited your social activities (like visiting friends or close relatives)? (CIRCLE ONE)

ALL OF THE TIME	SOME OF THE TIME	A GOOD BIT OF THE TIME	A LITTLE OF THE TIME	MOST OF THE TIME

38. I am somewhat ill. (CIRCLE ONE)

DEFINITELY TRUE	MOSTLY TRUE	NOT SURE	MOSTLY FALSE	DEFINITELY FALSE

39. I am as healthy as anybody I know. (CIRCLE ONE)

DEFINITELY TRUE	MOSTLY TRUE	NOT SURE	MOSTLY FALSE	DEFINITELY FALSE

40. My health is excellent. (CIRCLE ONE)

DEFINITELY TRUE	MOSTLY TRUE	NOT SURE	MOSTLY FALSE	DEFINITELY FALSE

41. I have been feeling bad lately. (CIRCLE ONE)

DEFINITELY TRUE	MOSTLY TRUE	NOT SURE	MOSTLY FALSE	DEFINITELY FALSE

APPENDIX D

CENTER OF EPIDEMIOLOGIC STUDIES - DEPRESSION SCALE (CES-D)

APPENDIX D

CENTER OF EPIDEMIOLOGIC STUDIES - DEPRESSION SCALE (CES-D)

These next questions are about how you feel, and how things have been with you within the past month.

For each question, read the statement then check the one answer that comes closest to the way you have been feeling during the past month.

DURING THE PAST TIME, HOW MUCH OF THE TIME . . .	ALMOST ALL OF THE TIME	MOST OF THE TIME	SOME OF THE TIME	RARELY OR NONE OF THE TIME
1. were you bothered by things that usually don't bother you?				
2. have you not felt like eating; had a poor appetite?				
3. have you felt that you could not shake off the blues, even with the help from family or friends?				
4. have you felt that you were just as good as other people?				
5. have you had trouble keeping your mind on what you were doing?				
6. have you felt depressed?				
7. have you that everything you did was an effort?				
8. have you felt hopeful about the future?				
9. have you thought your life has been a failure?				
10. have you felt tearful?				

DURING THE PAST TIME, HOW MUCH OF THE TIME . . .	**ALMOST ALL OF THE TIME**	**MOST OF THE TIME**	**SOME OF THE TIME**	**RARELY OR NONE OF THE TIME**
11. has your sleep been restless?				
12. were you happy?				
13. have you talked less than usual?				
14. have you felt lonely?				
15. were people unfriendly?				
16. have you enjoyed life?				
17. have you had crying spells?				
18. have you felt sad?				
19. have felt that people disliked you?				
20. could you not get "going?"				

APPENDIX E

RELATIVE COMPETENCY RATINGS BY ACTIVITY (ZSCORE)

APPENDIX E

RELATIVE COMPETENCY RATINGS BY ACTIVITY (ZSCORE)

```
ZE3 ZSCORE:  HOW CONFIDENT FEEL-CATHETER?
                   Valid   Cum
Value  Frequency  Percent  Percent
-1.05409     4      1.6      1.6
.00000     240     96.4     96.4
.84327       5      2.0      2.0
           -------  -------  -----
Total      249    100.0    100.0
Valid cases   249   Missing cases  0
```

```
ZE9 ZSCORE:  HOW CONFIDENT FEEL-OXYGEN?
                              Valid    Cum
   Value  Frequency  Percent  Percent  Percent
-1.59545         6      2.4      2.4      2.4
  .00000       227     91.2     91.2     93.6
  .59829        16      6.4      6.4    100.0
              -------  -------  -------
   Total       249    100.0    100.0
   Valid cases    249       Missing cases  0
```

```
ZE21 ZSCORE:  HOW CONFIDENT FEEL-IV MEDS?
                               Valid    Cum
    Value  Frequency  Percent  Percent  Percent
-2.04124        1        .4       .4       .4
0.00000       243     97.6     97.6     98.0
0.40825         5      2.0      2.0    100.0
            -------  -------  -------
  Total       249    100.0    100.0
  Valid cases    249     Missing cases     0
```

```
ZE33 ZSCORE:  HOW CONFIDENT FEEL-INJECT?
                              Valid     Cum
   Value  Frequency  Percent  Percent  Percent
-2.29967         4      1.6      1.6      1.6
 0.00000       223     89.6     89.6     91.2
 0.41812        22      8.8      8.8    100.0
             -------  -------  -------
Total          249    100.0    100.0
Valid cases       249     Missing cases     0
```

```
ZE39 ZSCORE:  HOW CONFIDENT FEEL-EXERCISES?
                              Valid     Cum
   Value  Frequency  Percent  Percent  Percent
-3.62820        1       .4       .4       .4
-2.12687        4      1.6      1.6      2.0
-.62555        31     12.4     12.4     14.5
 .00000       177     71.1     71.1     85.5
 .87577        36     14.5     14.5    100.0
           -------  -------  -------

Total         249    100.0    100.0
Valid cases      249     Missing cases      0


ZE45 ZSCORE:  HOW CONFIDENT FEEL-BEDSORES?
                           Valid     Cum
Value  Frequency  Percent  Percent  Percent
-1.78655    2       .8       .8       .8
-.52546     3      1.2      1.2      2.0
 .00000   237     95.2     95.2     97.2
 .73564     7      2.8      2.8    100.0
        -------  -------  -------

Total     249    100.0    100.0
Valid cases  249     Missing cases     0


ZE51 ZSCORE:  HOW CONFIDENT YOU FEEL-SKIN PRO
                           Valid     Cum
Value  Frequency  Percent  Percent  Percent
-5.04454     1       .4       .4       .4
-1.40950     8      3.2      3.2      3.6
  .00000   200     80.3     80.3     83.9
  .40801    40     16.1     16.1    100.0
        -------  -------  -------

Total      249    100.0    100.0
Valid cases   249     Missing cases     0


ZE57 ZSCORE:  HOW CONFIDENT FEEL-COLOSTOMY?
                           Valid    Cum
Value  Frequency  Percent  Percent  Percent
-1.43427    1       .4       .4       .4
-.23905     2       .8       .8      1.2
 .00000   244     98.0     98.0     99.2
 .95618     2       .8       .8    100.0
       -------  -------  -------

Total     249    100.0    100.0
Valid cases  249     Missing cases     0
```

```
ZE63 ZSCORE:  HOW CONFIDENT FEEL-POST OP INCI
                                   Valid     Cum
Value    Frequency  Percent  Percent  Percent
-3.44825    1         .4        .4       .4
-1.46975    7        2.8       2.8      3.2
  .00000  214       85.9      85.9     89.2
  .50876   27       10.8      10.8    100.0
        -------  -------  -------
Total      249    100.0    100.0
Valid cases   249    Missing cases     0


ZE69 ZSCORE:  HOW CONFIDENT FEEL-ORAL MEDS?
                                 Valid     Cum
Value  Frequency  Percent  Percent  Percent
 -7.78131     1       .4        .4       .4
 -2.38928    16      6.4       6.4      6.8
   .00000    82     32.9      32.9     39.8
   .30673   150     60.2      60.2    100.0
         -------  -------  -------
Total       249    100.0    100.0
Valid cases   249     Missing cases     0


ZE81 ZSCORE:  HOW CONFIDENT FEEL-INCONT-URINE
                                 Valid     Cum
Value  Frequency  Percent  Percent  Percent
-3.23347      1       .4        .4       .4
-1.34220      7      2.8       2.8      3.2
  .00000    218     87.6      87.6     90.8
  .54908     23      9.2       9.2    100.0
         -------  -------  -------
Total       249    100.0    100.0
Valid cases   249     Missing cases     0


ZE87 ZSCORE:  HOW CONFIDENT FEEL/INCONT/STOOL
                                  Valid     Cum
Value  Frequency  Percent  Percent  Percent
-3.60000      1       .4        .4       .4
-1.60000      3      1.2       1.2      1.6
  .00000    224     90.0      90.0     91.6
  .40000     21      8.4       8.4    100.0
        -------  -------  -------
Total       249    100.0    100.0
Valid cases   249     Missing cases     0
```

APPENDIX F

UCRIHS APPROVAL

MICHIGAN STATE
UNIVERSITY

April 8, 1994

TO: Julia V. James
A117 Life Sciences

RE: IRB #: 94-152
TITLE: THE EFFECTS OF CUES TO ACTION ON THE USE OF FORMAL COMMUNITY SERVICES BY FAMILY CAREGIVERS OF PHYSICALLY DEPENDENT ELDERS
REVISION REQUESTED: N/A
CATEGORY: 2-H,I
APPROVAL DATE: April 5, 1994

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 green renewal form (enclosed with the original approval letter or when a project is renewed) 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 green renewal 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.**

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.

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

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,

David E. Wright, Ph.D.
UCRIHS Chair

DEW:pjm

cc: Dr. Manfred Stommel

APPENDIX G

CONSENT FORMS

(patient)

MSU FAMILY CARE STUDY
CONSENT FORM

The study in which we are asking you to participate is designed to learn more about the ways in which caring for an elderly family member affects the person providing the care.

Over the next 18 months, 650 caregivers will be interviewed five (5) times over the telephone by a member of the MSU Family Caregiver Study research staff. They will be asked questions regarding changes in your health and issues on your insurance coverage and your health status. If you are willing to participate in this study please read and sign the following statement.

1. I have freely consented to take part in a study of family caregivers conducted by the College of Nursing and the Department of Family Practice, College of Human Medicine, at Michigan State University.

2. The study has been described and explained to me and I understand what my participation will involve.

3. I understand my participation in this study is voluntary, will involve no cost to me, and that my decision will in no way affect my current or future health care.

4. I understand that I may withdraw from participation at any time without penalty to me by calling 1-800-654-8219. My withdrawal would not preclude continued participation by my caregiver.

5. I understand that the results of this study will be treated in strict confidence and, should they be published, my name will remain anonymous. I understand that within these restrictions, results can, upon request, be made available to me.

6. I understand that no immediate benefits will result from my taking part in this study, but am aware that my responses may add to the understanding of health care professionals and may influence future family care.

7. I understand that I have the right to seek further information about this study, and my right relating to it, by calling the research office (517)355-1851 or toll free, 1-800-654-8219.

8. I understand that a member of the research staff may need to review part of my current medical record to obtain a list of my current medical diagnoses/problems. I consent to allow access to the hospital discharge planning documents for information about my home care needs and services, and understand that this information will remain strictly confidential.

9. I understand that a member of the research staff may wish to inquire about my group health insurance policy benefits to understand what benefits are available to me and compare these to what I am presently using. I give my consent for the hospital discharge coordinator to provide my group insurance(s) policy numbers so the research staff may identify what insurance benefits I have, with the understanding that they will remain strictly confidential.

I, ________________________, state that I understand what is required of me as a participant and agree to take part in this study.

Patient signature__________________________________Date_______________

OR

Guardian/Family member__________________________Witness____________________