

OUTREACH PROGRAM FOR CAREGIVERS  
OF THE CONFUSED ELDERLY

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## Chapter I

## INTRODUCTION

Caregiving has become a critical personal health care issue as a greater percentage of the population live to advanced old age. The increase of disabilities associated with the aging process, and a steady rise in the cost of institutional care has pressed a greater number of families to accept responsibility for providing care to the dependent elders (Schneider & Emr, 1985). This burden of providing care to elderly debilitated family members over an extended period of time can create a family crisis of such magnitude that the health and well-being of other family members are severely affected.

Caregiving to the cognitively impaired, such as those with Alzheimer's disease, can place extreme demands on caregivers' psychological, physical, and financial resources. Frequently, the caregivers' health also is adversely affected. Biegel, Shore, and Gordon (1984) assert that the decision to institutionalize an elder family member is more closely related to the level of the burden on the family than to the physical or mental deterioration of the elder person. Other studies also indicate that the adversities and problems expressed by caregivers of Alzheimer's patients point to the need for supports external to the family to assist in meeting this burden. When these supports are available, it is possible to delay institutionalization of the dependent elder, as well as to decrease the potential of the caregiver's declining health status

(Mace & Rabins, 1981; Zarit, 1985; Gwyther & Matteson, 1983). Yet the number of programs to meet these needs are limited and few have been evaluated for their effectiveness.

The purpose of this study is to develop an effective community-based model program of long-term supportive services consisting of education, counseling, and referral services for caregivers of person's with Alzheimer's disease. As a base for program development, a needs assessment was done to learn more about the specific problems this sample of caregivers encounter. The most outstanding need identified in the survey was the importance of long-term support services for the caregiver due to the chronic stress involved in caregiving. This supports Gwyther's & Matteson's (1983) findings that "patient and family caregivers need sustained, long-term comprehensive, appropriate, and acceptable services during specific stages of the illness" (p. 110). Although the assessment did not indicate a single pattern of response to caregiving, it showed that an available family support system played a major role in maintaining the confused elderly in the community.

A second finding of the 55 persons who responded to the survey were requests for education, counseling, and a vast array of community resources. (See Appendix A for detailed results of the assessment.) These findings were similar to those of Pratt, Schmall, Wright, and Cleland (1985). Their study of caregivers in the Mid-Willamette Valley suggested that an effective intervention program

would provide information about Alzheimer's disease and community resources, offer emotional support, and increase caregiver's confidence in problem solving and their ability to redefine problems.

Consequently, the needs survey provided the guidance for developing an Outreach Program for community-based caregivers in the Mt. Angel area, providing long-term supportive services by responding to their requests for assistance through counseling, education, and referral services.



## Chapter 2

## SELECTED LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK

This chapter will present the biopsychosocial aspects of dementia and selected concepts from human systems theory in order to understand the dynamics involved in caregiving and its effect on the entire family system. In addition, House's four-part definition of social support will be presented. This conception of social support provided guidance for the development and evaluation of a community-based program for families of patients with Alzheimer's disease. The program was designed to provide support services in response to the specific needs of caregiving families that are coordinated, acceptable, and as close to their natural environment as possible; in order to assist, support, and preserve family caregivers for the confused elderly.

Dementia

Dementia is not a normal part of the aging process, however, it is among the most feared disorders of later life. It is thought to affect between 5 and 10 percent of the total population over 65 years of age (Mortimer, Schuman & French, 1981). In these people who are affected, approximately 50 percent have Alzheimer's disease (Tomlinson, Blessed & Roth; 1970). With the increase in longevity a significant frequency in the incidence of dementia, or cognitive impairment associated with advanced age has occurred.

Similarly, an emerging definition of aging describes the

interactive aspects of a biopsychosocial view - biological referring to life expectancy, psychological referring to the adaptive behavioral capacities of the individual, and social referring to the social roles of the individual with regard to the expectations of his group and society for someone of that age (Birren & Renner, 1977). It is useful to apply this definition to the confused person with Alzheimer's disease to understand the significance of the increasing size of the elderly population; the inherent problems limiting the demented individual's capacity to adapt to the environment; and the inability to perform appropriate social roles. More specifically, Kahn (1975) describes dementia as a "bio-psycho-social phenomenon", emphasizing that although the biological aspects are not currently treatable, the psychological and social aspects can often be ameliorated through appropriate interventions.

#### Human Systems Theory

A confused, elderly family member is one subsystem in the family system. Thus, the use of human systems theory, connoting interdependency or interaction of components, is helpful to explain the family dynamics involved in providing in-home care for a confused, elderly family member and the effect of caregiving on the entire family system. The human systems model encompasses the flow of an interactive nature of the biological, psychological, and sociological forces that impinge on the confused individual and family (Kast & Rosenzweig, 1979).

With increasing awareness of the forces affecting the confused elder, it becomes evident that the health and dynamics of the family as a whole have a tremendous impact on the demented individual. The human systems model focuses primarily on the confused elderly within the family context and emphasizes the roles of various health disciplines and community groups within the system. Therefore, the human systems model supports the concept of providing health care resources and support services to meet the diverse needs of Alzheimer's families.

#### Family Caregivers

A number of studies have documented the extensive responsibilities that family members assume as caregivers for the elderly (Montgomery, 1982; Shanas, 1979; Brody, 1977; Aronson & Lipkowitz, 1981). Moreover, Brody (1977), and others, have pointed out that despite the challenges and the burden of the caregiving role, the family unit remains the preferred vehicle for care by both the elderly and their families. Family members provide the major component of long-term care for the memory-impaired elderly despite the fact that the biggest share of government expenditure for dementia patients is made for services in institutions.

#### Effects of Caregiving

Few other disorders place as much stress on family members as dementia. The term "caregiver burden" is now widely used in the literature to describe the physical, psychological, emotional,

social and financial problems that are experienced by family members caring for the memory-impaired elderly. The findings of George & Gwyther (1986) suggest that "caregiver burden" is experienced primarily as defined in mental health and social participation by the caregiver. Family members often experience much anxiety and uncertainty over difficulties that arise during the gradual and progressive deterioration of the patient. Substantial proportions of caregivers become clinically depressed (Eisdorfer et al., 1983). Consequently, families of persons with Alzheimer's often experience severe social isolation. Social isolation has been identified as being highly influential in decisions regarding institutionalization (Zarit, Reever & Bach-Peterson, 1980). Recent studies (Fitting, Rabins, Lucas & Eastman, 1986; George & Gwyther, 1986; Zarit, Todd & Zarit, 1986) have confirmed earlier findings that institutional placement of the confused elderly is better predicted by characteristics of caregivers and the caregiving context than by the illness characteristics of the demented adults. Clinically, the Alzheimer's process causes progressive impairment to the patient, and the family system. Therefore, supportive services must be designed to facilitate and strengthen the entire family system if it is to function optimally during this time of extended strain.

In general, descriptive studies report high levels of strain in caregiving families and potential erosion of family supports. This strain is frequently attributed to high levels of stress experienced or the competing commitments of family members (Brody, 1981;

Cantor, 1983; Eggert et al., 1977; Johnson, 1983). Johnson & Catalano (1983) studied family supports to understand what happens when high caregiver needs persist on a long term basis. Their findings suggest that competing family commitments and declining health status, combined with increased social isolation of the patient and caregiver, can place the long-term care of the older person by the family in jeopardy. Findings such as these have led researchers to maintain that if problems could be differentially identified and supplemental supports made readily available, then breakdowns in family supports could be forestalled. Specifically, Brody & Lang (1982) argue that "unless family caregiving efforts are supplemented and strengthened, emotional and physical problems may be perpetrated down through the generations, ultimately affecting all family members and increasing the social and emotional costs to the community" (p. 20). Clearly, Alzheimer's disease is not only a tragic problem for the afflicted person, but poses a serious threat and heavy burden to their families and significant others. Accordingly, the lack of treatment for victims of Alzheimer's disease and the obvious needs of the relatives who provide home care for them has caused greater attention to be focussed upon ways in which family caregivers can be supported and assisted.

Caregiving is not only emotionally expensive but also financially expensive. Families often care for their relatives at home until their emotional and financial resources are exhausted. If and when

institutionalization occurs, the costs may reach well over \$30,000 a year. Since home care is the most cost-effective way of helping persons with Alzheimer's disease, community-based support services may be cost saving in nature by delaying institutionalization. This investment could lead to important savings as well as improved quality of life for the patient and the family. Therefore, the value of support services to the family, as a means of preventing the illness of the caregiver, is an important consideration.

### Support

Several definitions of support have been put forth in the literature; many contain similar concepts. House's (1981) four-part definition of the aspects of social support was chosen because it has been empirically tested and because the four concepts are applicable for the development of categories of supportive services for the caregiving family of the confused elderly in the community. Social support as defined by House includes (a) emotional support (affect, concern, listening); (b) appraisal support (affirmation, feedback); (c) informational support (advice, directives, information); and (d) instrumental support (aid, money, labor, time modifying the environment). Social support then, is conceptualized as a dynamic multidimensional process which has significant influence on the caregiving family. Subsequently, the proposed program will be guided by the theoretical perspective that emphasizes social support (emotional, appraisal, information, and instrumental) as vital in

shaping the course and outcome of stressful encounters during the long protracted course of caregiving for the confused elderly.

Interventions targeted for the specific needs of the patient and primary caregiver by professionals were clearly indicated in the needs assessment and in two previous studies. Despite community-based programs, the studies suggest that a professionally oriented, formal program for caregivers should provide three essential components: (a) education, (b) counseling, and (c) referral services. Thus, a long-term care strategy is imperative in response to the growing demand on families to sustain the confused elderly at home in the community. Without these additional supportive services, caregivers will continue to be an at-risk population suffering serious consequences as a result of their caregiving responsibilities.

#### Education

Education is the first essential ingredient for any effective community health program rendering informational support. In the case of a caregiver support program, it provides the necessary information to understand the multifaceted dimensions of the Alzheimer's disease process while focusing on increasing the caregivers' problem solving skills. Caregivers themselves express a strong desire for informational support, which verifies the findings of Wood, Niederehe, & Fruge (1985), "Although professional interventions are certainly useful and needed by many families, it is also true that many families handle the emotional strain of caregiving remarkably well once they

have adequate information about their relative's condition and ways of dealing with it" (p. 22). Karusa, Joss, Nowak & Brice's (1983) study also found that participation in educational programs was associated with increased confidence and comfort in caregiving, a decrease in caregiver stress, an increased tolerance of elderly care recipients, skill in caregiving, improved family relationships, and more effective caregiver interaction with health professionals. Developing an integrated program for caregivers in the community then, begins with a commitment to education, skill building, and sharing practical experience through collaboration; believing that expertise from several disciplines, combined with experiential knowledge, is most helpful when addressing complex problems.

### Counseling

The second essential component of a support program is counseling. Counseling is a means of offering emotional and appraisal support to caregivers throughout the process of coping with this overwhelming illness in the family. Although the research literature on caregiver's counseling is minimal, most of what is known about counseling with the Alzheimer's population is drawn from clinical observation, which suggest that active listening, making suggestions, problem solving, conflict resolution, grief work, and cognitive restructuring are useful. Cutler (1985), an experienced counselor, described the following as the most important elements in providing support for caregivers: (a) allowing caregivers to



air their feelings to someone who understands; (b) modifying the meaning one gives a stressful situation thus reducing the emotional turmoil; and (c) having the security of an on-going relationship with a counselor who provides an emotional anchor. The literature is replete with substantiation that caring for a person with Alzheimer's disease places an enormous emotional burden upon the caregiver. Common responses include denial, anger, guilt and depression; exacerbating the difficulties of caring for the patient as well as constricting the caregiver's ability to develop appropriate coping skills of his/her own life. Thus, therapeutic approaches may be used to decrease guilt and unrealistic expectations that often complicate the coping process. In all cases, therapeutic interventions must be holistic considering the biological, psychological and social variables, and individually prescriptive for the person or family. Furthermore, a family systems perspective is important because of the all-encompassing effect of caregiving on family relationships. Caregiving families face a multitude of stresses. Since there is no clear-cut relationship between the objective nature of caregiving stress and the reported degree of distress and subjective burden (Zarit et al., 1980), counselors working with caregivers must have a broad understanding of the dynamics involved which result in individual responses to the caregiving experience. As a first step, it is important to make an individualized assessment of the patient's behavior and its impact on the caregiver and other family members.

According to Zarit, Orr & Zarit, (1985):

The task for the practitioner, then is to obtain specific information about the problems the patient is having in everyday life, and how the caregiver will react to those problems, in order to identify the areas in which the caregiver may need help. The second proposition is that the burden or stress on family members is determined by several factors, such as the caregiver's skills in coping with difficult or problem behavior and by the social support provided by other family members. Some of the burden might be alleviated. A key to making successful interventions is to identify the specific sources of the burden present in a given case and the extent to which it might be alleviated (p. 70).

Thus, treating the stressed caregiver and family requires clinical skills that an expert clinician can provide in order to help family members cope effectively.

#### Referral Service

The third component of a community-based program is referral resources. They provide instrumental support for caregivers within the community. Instrumental support demands recognition of the complexities inherent in good long-term care -- complexities relating

both to the interdisciplinary nature of such care and to the length of time over which it may have to be sustained (Somers, 1982). Caregivers require a mix of service options and providers must understand the changing needs and demands of caregivers over time.

One example of support that is helpful to families which has recently emerged is the self-help family support lay groups through Alzheimer's Disease and Related Disorders Association. Often referral to these support groups can fill a large gap in service which exists for family caregivers. Although the benefits of family support lay groups have been widely acknowledged, researchers point out that little is known about the potential impact of these lay groups on families needing assistance to coping with the extensive long-term burden (Aronson & Yatzkan, 1984; Clark & Rakowski, 1983; Glosser & Wexler, 1985; Mackey, 1983; Montgomery, 1982; Steur & Clark, 1982). Furthermore, Aronson & Yatzkan (1984) draw this conclusion: "Self-help groups are one part - although a very important part - of the broad spectrum of care that is required for dementia victims and their families, they do not replace other services but rather are complementary to them" (p. 9). Thus, while informal support through lay groups seems important to the caregiver, formal support from professional caregivers and service agencies is also essential.

The true goal of long-term care however, should be for people to receive the right mix of services, at the right time, in the

appropriate place, based on their needs (English, 1981). Few families come to a service agency knowing exactly what they want.

Knowledgeable, skillful professionals are required to match the specific needs of caregivers and their families with the most appropriate community resources available. Jones & Vetter (1984) assert that if families are to continue to care for their increasingly frail relatives, then community services must share the burden with them in reducing strain and psychological morbidity. Thus, the goal of professional advisors to families of the confused elderly should be to provide knowledge of all options available, explore the feasibility of the least restrictive environment for the confused family member, and to support and assist the family in whatever decision they make.

#### Effective Community-Based Program

Planning for evaluation is an integral part of an effective program design in order to determine if the program is fulfilling its purposes. Despite general acceptance of the importance of team care in providing effective community-based programs for the elderly, evaluation to support this notion remains modest. A review of related research provided information on program content and team process, while little attention was given to evaluation of this system of care (Bloom & Soper, 1980; Bottom, 1980; Lefton & Lefton, 1979). Other researchers may disagree about exactly what should be done to provide assistance to community caregivers, but, there is agreement that skilled help and supplemental community supports composed of

multidisciplinary teams of health care professionals are needed (Arling & McAuley, 1983; Bergman et al., 1978; Mackey, 1983; Somers, 1982; Sommers, 1983). In the aggregate, the literature does suggest that a coordinated multidisciplinary approach to the care of the elderly is effective, but evidence and actual evaluation of these programs is not strong.

In conclusion, the literature suggests that comprehensive services for caregiving families of persons with Alzheimer's disease is conceptualized as providing informational support through education; emotional and appraisal support through counseling; and instrumental support through referral services using multidisciplinary professional leadership. Further, although several programs have been developed, adequate evaluation of their effectiveness is lacking. Thus the program developed in this study and described in the next section, included a strong evaluative component.

### Chapter 3

#### METHODS OF PROGRAM DEVELOPMENT AND IMPLEMENTATION

This chapter describes the methods used in the development and implementation of the Outreach Program for family caregivers of the confused elderly. Special emphasis is placed on the development of the program evaluation instrument including the peer review findings and the pilot test.

##### Program Development

##### Needs Assessment

The Benedictine Nursing Center (BNC) is a non-profit long-term care facility located in Mt. Angel, Oregon. The Center has been involved in providing comprehensive health and social services for the community since 1955. The pressing needs of the confused elderly and their caregivers in the community were identified in a needs assessment survey conducted in the BNC service area in conjunction with Oregon Health Science University (OHSU) School of Nursing and the Teaching Nursing Home Program (TNH). An open-ended, self-administered questionnaire was mailed to 180 persons involved in caregiving for a confused elder. The assessment sample consisted of 37 caregivers, comprising 20.5% of the total available.

The purposes of the questionnaire were (1) to assess the impact on the caregiver of caring for a memory-impaired elder, and (2) to find out which resources might be helpful to persons in this role. Previous studies conducted in the Mt. Angel area have focussed primarily on the level of burden for caregivers. This questionnaire

assumed that the caregiver's task was difficult and burdensome, and attempted to explore the reasons for the burden as well as what additional supportive services could be helpful.

#### Outcome of Needs Assessment

The needs assessment sample consisted of 37 caregivers, comprising 20.5% of the total number to whom questionnaires were mailed. The most overriding concern expressed by caregivers was their need for support services which was supportive to the need to develop an outreach program for caregivers. Thus the specific information obtained from the needs survey was used to develop the outreach program. It provided data which guided the team in determining opportunities for services.

#### Program Design and Implementation

Based on the outstanding need expressed by caregivers for long-term supportive services in the community, a multidisciplinary Outreach Program was developed. The goal of the program was to provide supportive services for caregivers of the confused elderly consisting of education, counseling, and referral services. Members of the Outreach team included a mental health nurse specialist, a home health nurse, a clinical nurse specialist in rehabilitation, a chaplain in long-term care, and a lay caregiver from the community who was experienced in providing home care for a confused family member. Team members were committed to provide services with flexibility and creativity, giving people what they needed when, how and where they needed it (Eyde & Rich, 1983) to help caregivers and their families cope more effectively with the

stress and burden of caring for a confused elder. As a result, a partnership between caregivers, health professionals and lay persons in the community evolved.

The Outreach Program was based at the Benedictine Nursing Center in Mt. Angel, Oregon. Initially, notices about the program were sent to Alzheimer's Disease & Related Disorders Association (ADRDA) support groups in the Mid-Willamette Valley. In addition, a short article was published in the BNC newsletter and in local newspapers. A letter was also written explaining the services in detail and sent to caregivers and service providers in the BNC service area (Appendix B).

Prior to meeting with the Outreach Team, an assessment form was completed by the primary caregiver. The purpose of the assessment was to provide essential background information about the caregiver, the family, and the confused elder person. For example, the Memory and Behavior Problems Checklist (Appendix C) was used to identify the occurrence and frequency of everyday problems associated with senile dementia. It was also important to assess how much social support the caregiver was receiving in the form of informational, emotional, appraisal, and instrumental support. This shared assessment process between caregivers and multidisciplinary team members attempted to focus on the family as the true case managers of care with the team members working on their behalf to identify and provide supportive services which might be helpful.

The Outreach Team was available to meet with in-home caregivers on a weekly basis. Caregivers were encouraged to meet with the team,



although telephone consultation was adequate in some situations. If needed, a volunteer was available at the BNC to provide respite care during the time that the family was meeting with the team. After each team meeting a staff conference was held to collaborate on findings, develop further recommendations, and delegate specific responsibilities regarding follow-up calls, referral services, and other strategies identified to assist caregivers. Following each meeting, caregivers were contacted by phone within seven (7) days by a team member to monitor their situation.

The Outreach Team was responsible for tracking the use of the telephone consultation services, involvement in team meetings, referrals to community resources, and participation in educational seminars. Progress notes were made following all contacts with caregivers and were used as a part of process and outcome evaluation. On-going evaluation of the program occurred on a weekly basis to insure that the program remained responsive to the needs of individual caregivers. A \$25 consultation fee was charged although no one was refused services based on inability to pay.

Three distinct phases of program development were conceptualized. The focus of phase one was to establish the multidisciplinary team to provide education, counseling, and referral services. During this phase of the program, formal caregiver education seminars, identification of appropriate referral services available in the community, and training for the team were undertaken. Precise components of phase two were to depend on assessments during phase one, however, it was conceived that

phase two would include in-home evaluations, recruitment and training of in-home volunteers, and exploring avenues to enhance local ADRDA support groups. Contingent upon evaluation of phase one & phase two services, plans for phase three included the expansion of Outreach Team services at the BNC and providing in-home respite services for caregivers. It is postulated that future services to be offered may include architectural and nutritional consultation, and other health related expertise required to help caregivers cope with the multiple problems encountered while struggling to maintain the confused elder in the home. Expansion of the program, both in terms of additional services and additional staff (e.g. geropsychiatrist), will be contingent on the needs expressed by caregivers and available funds. It is recognized that time, resources, energy, and money are the enabling factors guiding the growth and development of the program.

#### Program Evaluation Plan

Once the designed course of action was implemented, process evaluation, such as team conferences and feedback from caregivers, was sought to identify and monitor the various elements of program operations. Evaluation of the outcome to determine the effectiveness of the program was conducted based on data obtained from the program evaluation questionnaire completed by participants. Outcome data were measured, interpreted and related to program objectives, as well as to the information gathered during the other phases of planning and evaluation. Every attempt was made to be responsive to the changing needs of caregivers for the confused elderly, based on the belief that

formal support services should be coordinated, acceptable and available as close to the natural environments as possible (Myers & Drayer, 1979).

### INSTRUMENTS

#### Caregivers Assessment Form

The four-part Caregiver Assessment Form (Appendix C) was adapted from tools previously developed by Pratt, Schmall, Wright & Cleland (1985), the Intermountain West Long Term Care Gerontology Center (1984), and a study by J. Zarit (1982). Part I of the form was utilized to gather descriptive information about caregivers and their family system. Some of the caregiver variables assessed were: relationship to patient; level of education; utilization of community resources; and relationship of family members to care-recipient. Two open-ended questions were also asked: "Describe briefly what effect caregiving has had on your family?" and "Identify your most important needs/problems related to your caring for the impaired person." Part II was used to obtain a profile of the confused person. Some of the variables assessed about the confused person were place of residence; previous occupation; disease onset; and emotional and physical health status. Open-ended questions dealing with changes in the confused elder were also asked: "What were the first signs of impairment?" and "How long ago did you first notice changes in your family member?"

Most importantly, Part III was utilized to assess the problems currently experienced by caregivers, recognizing that "From its insidious beginning throughout its variable, unpredictable course, Alzheimer's disease forces families to constantly adapt and adjust to

new problems" (Chenoweth & Spencer, 1986, p. 272). The Memory and Behavior Problems Checklist (Zarit, 1982) was developed to determine the frequency of behavior problems and how caregivers react to them. Caregivers were asked to read through a list of common problems, such as "wandering or getting lost" and "doing things that embarrass you," and then to indicate how often this behavior occurred during the past month. Total memory and behavior problem scores were generated for the number of difficult problems occurring and their frequency (Zarit, Reeve & Bach-Peterson, 1980). Finally, in Part IV, questions aimed at the helpfulness of support groups and individuals were asked to gain understanding of the caregiver's support system. Caregivers were asked to identify both positive and negative aspects of support groups, as well as satisfaction with support given by close friends.

Content validity of the Adapted Caregiver Assessment Form was established with feedback from a panel of experts (eleven persons) consisting of professional health care providers, care managers, experienced caregivers, and members of the Outreach Team.

Health care professionals agreed that the form was primarily to be used as a clinical tool, in addition to gathering important background information and demographic data for planning services and health policy changes. As an assessment tool this instrument was found to have adequate validity. Because families of patients with Alzheimer's Disease do not have access to the health care they need, the panel of experts agreed that collecting data to be used in the future for policy makers would be valuable if the length was not prohibitive for caregivers

completing the assessment form.

Families from the community involved in the caregiving experience and the development of the Outreach Program were also asked to critique the form. Generally, these caregivers responded by stating that the forms were too lengthy. Although the information may be useful to professionals and policy makers, caregivers disliked having to complete the forms. Given the inherent problems/needs of this specific population, it was decided that most of the information could be acquired indirectly through the caregiver's involvement with the team members and recorded at a later time. Based on limited experience, it was found that caregivers were willing to report current problems spontaneously during team meetings. Since pre- and post-intervention assessment measures are necessary for care planning and program evaluation, Zarit (1982) recommends that the Memory and Behavior Problems Checklist should be used with other methods of evaluation, such as structured interview, after rapport has been developed.

Evaluation Form to Determine Helpfulness of Outreach Team for  
Caregivers of the Confused Elderly

The evaluation of this program can be viewed as having two different but interrelated components. The first is a process evaluation, which is based on the extent to which the program meets its defined objectives. In the end, the primary thrust of any health care program is concerned with the accomplishment of positive patient outcomes. Thus, the final step in program evaluation involves a measure of these outcomes. Therefore, in order to ascertain the effectiveness of the

Outreach Program and make ongoing decisions to improve the efficiency of the project, a program evaluation tool was developed. The "Evaluation Form to Determine Helpfulness of Outreach Team for Caregivers of the Confused Elderly" (Appendix D) was adapted from a published document with the addition of five investigator designed questions. The original evaluation instrument (Glosser & Wexler, 1985) consisted of 17 items regarding the helpfulness of various aspects of educational/supportive groups for relatives of patients with Alzheimer's disease. This tool was used because of its pertinence to House's definition of social support and to the overall goal of the Outreach Team to provide supportive services to caregivers through education, counseling, and referral services. For instance, Item #11, "Feeling less isolated and alone suggests emotional support; Item #12, "Information about social and community services" suggests informational support; and Item #4, "Getting support from other caregivers" suggests instrumental support. One additional item was added by the investigator; "Learning that resources exist in the community to help with emergencies"; due to the reported value of knowing that help is available for caregivers in the community setting. Each item was rated on a five-point Likert Scale from one (not very helpful) to five (very helpful). The total helpfulness score is the sum of all responses and may range from 17 to 85 points.

Five open-ended, investigator designed questions were added to the evaluation form in order to gain qualitative information about specific aspects of the program. These items asked what caregivers found most and least helpful; whether or not they received the specific help they

needed; residence of the confused person at the time they sought assistance; and requested specific suggestions to improve the program. The investigator designed questions yielded further information about the various aspects of social support provided through the Outreach Team meeting. This tool was primarily instrumental in determining the efficacy of the program for caregivers.

The "Evaluation Form to Determine Helpfulness of Outreach Team for Caregivers of the Confused Elderly" was subjected to peer review by seven professionals and one lay caregiver for content validity. The objective was to determine how well the items matched the program dimensions. Reviewers were knowledgeable about the Outreach Program and in addition were given literature outlining House's (1981) four-part definition of social support. Analysis showed that the tool was heavily weighted toward informational support questions. There was general agreement (greater than 50% of the total in each category) that the items measured the four aspects of social support as follows: (a) informational support in 14 items, (b) emotional support in 5 items, (c) appraisal support in 2 items, and (d) instrumental support in 2 items. Generally, the tool appeared to be useful for determining the helpfulness of informational support for caregivers. However, it may have not adequately addressed the helpfulness of the emotional, appraisal, and instrumental aspects of social support. In summary, the peer review process indicated that content validity was very modest because it did not adequately address the appraisal, emotional and instrumental dimensions of social support and pointed to the need for further instrument development to strengthen

the evaluations of this program. Furthermore, since the tool was analyzed by a limited number of reviewers, it should be subjected to further scrutiny for balance, unidimensionality, objectivity, and other criteria. As indicated earlier, Glosser and Wexler (1985) have pointed out that "there have been few, if any published systematic evaluations of these programs" (p. 233). However, the adaptation of this tool is the best available at this time.



## Chapter 4

## PROGRAM EVALUATION: FINDINGS AND DISCUSSION

Analysis and Interpretation of the Program Data

The evaluation tool was pilot tested by four caregivers following their meeting with the Outreach Team. The data from the questionnaires are shown in Table 1. To facilitate analysis and interpretation of the preliminary data, the individual categories have been consolidated in Table 1 into (a) mean rating of items, and (b) proportion of participants' rating as "very helpful".

Table 1

Participants' Ratings of the "Helpfulness" of Seventeen Factors in Outreach Team Meetings (n=4).

Factor	Mean Rating <sup>a</sup>	Proportion of Participants Rating as "Very Helpful"
Finding out how others deal with their problems	3.75	.25
Sharing feelings with Outreach Team Members	3.00	.25
Information about medical aspects of dementia	4.00	.25
Getting support from other caregivers	4.50	.25
Learning practical solutions to everyday problems	3.33	--
Learning how to handle the person with dementia	3.00	--
Learning about problems with family members of dementia persons	1.50	--

<sup>a</sup>Possible range of scores is 1-5; a higher score indicates greater perceived "helpfulness" of team meetings.

Table 1 (Cont'd)

Participants' Ratings of the "Helpfulness" of Seventeen Factors in Outreach Team Meetings (n=4).

Factor	Mean Rating <sup>a</sup>	Proportion of Participants Rating as "Very Helpful"
Information about medical services for persons with dementia	3.75	.50
Learning things to do to feel better yourself	3.33	.25
Information about different dementias	2.67	--
Feeling less isolated and alone	3.33	.25
Information about social and community services	3.33	.25
Information about nursing homes	4.25	.50
Learning where to get more help when you need it	4.00	--
Information about legal/financial concerns	4.00	.25
Learning how to get along with other members of your family	1.50	--

<sup>a</sup>Possible range of scores is 1-5; a higher score indicates greater perceived "Helpfulness" of team meetings.

Table 1 (Cont'd)

Participants' Ratings of the "Helpfulness" of Seventeen Factors in Outreach Team Meetings (n=4).

Factor	Mean Rating <sup>a</sup>	Proportion of Participants Rating as "Very Helpful"
Learning that resources exist in the community to help with emergencies	4.00	.50

<sup>a</sup>Possible range of scores is 1-5; a higher score indicates greater perceived "Helpfulness" of team meetings.

Respondents listed the following six items "most helpful" (rank ordered with the item receiving the highest rating on the scale listed first):

- Getting support from other caregivers;
- Information about nursing homes;
- Learning that resources exist in the community to help with emergencies;
- Information about medical aspects of dementia;
- Information about legal/financial concerns; and
- Learning where to get more help when you need it.

Participants responses to the five open-ended questions were diverse. The responses reflected personal caregiver situations and the myriad of problems caregivers face. The participants' comments indicated that they found information about diagnostic evaluation of the confused person, nursing homes, dementia, medications, and alternative placement options most beneficial, suggesting that imparting information to the family is the single most important initial step. These responses verify the findings of the needs assessment that caregivers need a variety of supplemental services to maintain a confused elder in the home and the importance of having knowledgeable professionals available to assist them in obtaining assistance and solving problems.

Another theme that emerged from the responses to the five open-ended questions was the importance of knowing there was a place to turn in which there was the opportunity to share feelings

and exchange information with professional, caring people and with other caregivers. These comments reflect the multidimensional aspects of support required by caregivers and suggest the value of a partnership between caregivers, health professionals, and lay persons. (Bergmann et al, 1978; Clark & Rakowski, 1983; Kahan, Kemp, Staples & Brummel-Smith, 1985).

Team meetings were not universally helpful. One caregiver indicated that he/she was not comfortable with sharing feelings with others and did not benefit by suggestions related to getting along with other family members. It appeared that the time-limited team/group process format was not optimal for resolving family conflicts and discussing sensitive issues in this situation. It would seem that, in addition to participation in formal team meetings, primary caregivers in some situations may best be served by interventions that also involve other members of the extended family, such as family therapy.

Overall, the respondents indicated that they received the help they needed and made the following suggestions for improving the program: (a) keeping foster home-care list updated, and (b) 24 hour hot-line for patient, caregiver, and the family. Finally, one caregiver summarized the value of the Outreach Program by stating that she would be "eternally grateful" for the "caring response" she received when "help was very much needed".

#### Limitations of the Program

Although it is not within the scope of this study to present an extensive evaluation of the Outreach Team, some comments regarding

the importance of evaluating this system of care are warranted. Because family management is of primary concern in the treatment of Alzheimer's disease, it is important to assess the essential components of a comprehensive community-based family intervention program. First of all, despite general acceptance of the value of team care in geriatrics, supportive scientific evidence to substantiate this belief remains modest (Wood-Dauphinee & Clarfield, 1985). As was the case with this study, a consistent difficulty in evaluating care programs is the lack of comparison groups. The overall conclusion that the multidisciplinary team approach to providing support and assistance is efficacious for community caregivers for the confused elderly is difficult to interpret as no information is provided about similar caregivers treated by other modes of intervention, or not "treated" at all. Secondly, it is becoming increasingly important as economic constraints increase for those requiring long-term health care that health professionals provide convincing evidence as to the effects of various approaches to care. Specifically, the determination of cost-benefit ratios for interventions, such as the outreach team could provide useful evidence. Thirdly, any comprehensive evaluation model should first include an examination related to the decision to create the program, followed by devising a system to monitor the execution of the program and to assess program impact (Rossi & Freeman, 1983). Vigorous evaluation of the efficacy of this intervention would provide professionals with a wider range of services which could be utilized to enhance the coping abilities of families

of the confused elderly. Thus, as the program is operationalized and caregivers participate, there must be on-going interplay between process and outcome information.

Although evaluation of participants may serve to highlight the possible strengths and weaknesses of this particular intervention, several factors may limit the generalizability of these findings which are similar to those reported by Glosser and Wexler (1985). They are: (a) no direct evaluation of individual family members coping skills; (b) lack of sensitivity for discriminating among various factors; (c) no knowledge of relative efficacy of program for different family members; and (d) lack of comparison with alternative interventions. Despite these limitations, it is hoped that a detailed analysis will be extended in other interventions and outreach programs so that multiple strategies can be more effectively combined for the management of one of our most serious and costly medical and social problems.

#### Discussion and Recommendations

It is too soon to draw conclusions about the effectiveness of the Outreach Program since only a limited number of participants have used the program's services at this time and a larger sample is needed to truly evaluate its effectiveness. Some preliminary comments can be offered. First, supplemental supports were helpful to caregivers and there was unanimous agreement that those who participated received the help they needed from the program. Based on caregivers' feedback, it appeared that referral resources were the most important;



with education ranking a close second. Counseling may have been so differentially defined by caregivers that its perceived value was difficult to pinpoint or explain on this form.

Second, due to the lower helpfulness values scored on Item #7 and #16 dealing with family issues, it may be necessary to change the wording on those items. The literature, as well as reported experiences of caregivers, all attest to the effects of caregiving on the entire family system; however, it is possible that the items, as posed, are interpreted by caregivers as threatening or demeaning in nature. Furthermore, it may not be acceptable for caregivers to discuss personal or family problems given the values and cultural norms of this particular population. Another explanation is that issues dealing with family problems are very sensitive and might be best dealt with in a one-to-one counseling relationship, or in some instances, family therapy, as opposed to the group process. Thus alternative methods for facilitating family adjustment need to be considered and tested for efficacy. However, the point remains that it is difficult to address the diverse needs of caregivers via one programmatic approach and the form must be completed by a greater number of respondents before suggestions or trends should cause significant changes in program design.

Third, it may be worthwhile to consider another evaluation tool that provides greater systematic, quantifiable measures of change resulting from the program. In examining the limited number of studies which have attempted to test the efficacy of family intervention,

McCann (1986) points out the importance of assessing the specific expected changes in attitudes, care patterns, and other family dynamics that are targeted for change. Also, it would be helpful to devise an evaluation tool that measures the components of the program in a more balanced fashion. Finally, the feedback obtained from this form is only one part of the total evaluation methodology. Outcome evaluation must be carefully combined with other mechanisms, such as process evaluation information, to provide a complete picture of the effectiveness of the Outreach Team for family caregivers.

The importance of integrating theory, research and service approaches is sensed by all in the field of aging; however, the implementation and evaluation of an Outreach Program for caregivers of the memory-impaired elderly is not easy. The Outreach Program described in this study provided one model where points of view from several disciplines and lay persons were woven together to develop intervention strategies to provide supportive services for family caregivers within the community.

Based on the findings of this program, areas for development and study are needed to demonstrate how programs can yield more long term benefits for caregiving families in addition to systematically measuring the effectiveness of family interventions in Alzheimer's care. There are several major areas that need to be improved:

1. Develop a mix of service options, such as in-home evaluations, when resources become available.

2. Revise the Caregiver Assessment Form to a structured interview format to enhance data collection.
3. Revise the evaluation tool to:
  - a. differentiate the aspects of social support, and
  - b. improve systematic evaluation of the program.
4. Further research to determine how multiple strategies can be more effectively combined to assist caregivers.

In summary, family caregivers for the confused elderly best respond to a multifaceted approach to address their complex needs. The design and implementation of the Outreach Program provides a model program for one of our most serious health and social problems by establishing a collaborative effort combining the skills and knowledge of health care professionals and experienced caregivers. Under nursing leadership, the program offers a creative approach to bridging the gap between institutional services and in-home care, focussing on providing services for Alzheimer's caregivers and their families. Through combined disciplines and service components, the Outreach Program provides an integrated continuum of long-term care. Clinical experience indicates an especially important role for nursing through a bio-psychosocial approach to understanding the potential human responses to caregiving for the confused elderly and the provision of appropriate services to address the specific needs of this population. In this light, the study presents strategies in which an intervention program consisting of education, counseling and referral services were developed to address the problems faced by family caregivers within the community.

REFERENCES

- Arling, G. & McAuley, W.J. (1983). The feasibility of public payment for family caregivers. The Gerontologist, 23(3), 300-306.
- Aronson, M.K. & Lipkowitz, R. (1981). Senile dementia, Alzheimer's type: The family and the health care delivery system. Journal of the American Geriatrics Society, 19(12), 568-571.
- Aronson, M.K. & Yatzkan, E.S. (1984). Coping with Alzheimer's disease through support groups. Aging, 347:3-9.
- Bergman, K., Foster, E.M., Justice, A.W. & Matthews, V. (1978). Management of the demented elderly patient in the community. American Journal of Psychiatry, 132, 441-449.
- Biegel, D.E., Shore, B.K. & Gordon, E. (1984). Building support networks for the elderly: Theory and application. Beverly Hills: Sage Publications.
- Birren, J.E. & Renner, V.J. (1977). Research on the psychology of aging: Principles and experimentation. In J.E. Birren & K.W. Schaie (Eds.). Handbook of aging and the individual. New York: Van Nostrand Reinhold.
- Bloom, B.S. & Soper, K.A. (1980). Health and medical care for the elderly and aged population: The state of the evidence. Journal of the American Geriatrics Society, 28: 451-455.
- Bottom, W.D. (1980). Teaming up in geriatrics. Geriatrics, 35: 106-110.
- Brody, E.M. (1977). Long-term care of older people: A practical guide. New York: Human Services Press.
- Brody, E.M. (1981). Women in the middle and family help to older people. The Gerontologist, 21, 471-482.
- Brody, E.M. & Lang, A. (1982). They can't do it all: Aging daughters with aging mothers. Generations, 7(2), 18-20,37.
- Cantor, M. (1983). Strain among caregivers: A study of experience in the United States. The Gerontologist, 23(6), 597-604.
- Chenoweth, B. & Spencer, B. (1986). Dementia: The experience of family caregivers. Gerontologist, 26(3), 267-272.

- Clark, N.M. & Rakowski, W. (1983). Family caregivers of older adults: Improving helping skills. The Gerontologist, 23(5), 637-642.
- Cutler, L. (1985). Counseling caregivers. Generations, 10(1), 53-57.
- Eggert, G.M., Granger, C.V., Morris, R. & Pendleton, S.F. (1977). Caring for the patient with a long term disability. Geriatrics, 32, 102-114.
- Eisdorfer C. & Cohen, D. (1981). Management of the family and patient coping with dementing illness. Journal of Family Practice, 12: 831-837.
- Eisdorfer, C., Kennedy, G., Wisnieski, W., & Cohen, D. (1983). Depression and attributional style in families coping with stress of caring for a relative with Alzheimer's Disease. The Gerontologist, 23. 115-116.
- English, N. (1981). Long-term care in the community. In G. Sorenson (Ed.). Older persons and service providers: An instructor's training guide. New York: Human Services Press.
- Eyde, D.R. & Rich, J.A. (1983). Psychological distress in aging: A family management model. Rockville, Maryland: An Aspen Publication.
- Fitting, M., Rabins, P., Lucas, M.J. & Eastman, J. (1986). Caregivers for dementia patients: A comparison of husbands and wives. Gerontologist, 26,(3), 248-252.
- George, L.K. & Gwyther, L.P. (1986). Caregivers well-being: A multidimensional examination of family caregivers of demented adults. Gerontologist, 26,(3), 253-259.
- Glosser, D. & Wexler, G. (1985). Participants evaluation of educational/ support groups for families of patients of Alzheimer's disease and other dementias. The Gerontologist 25(3), 232-236.
- Gwyther, L.P. & George L.K. (1986). Caregivers of dementia patients: Complex determinants of well-being and burden. Gerontologist 26(3), 245-247.
- Gwyther, L.P. & Matteson, M.A. (1983). Care of the caregivers. Journal of Gerontological Nursing, 9(2), 92-116.

- House, J.S. (1981). Work stress and social support. Reading, MA: Addison-Wesley Publishing Co.
- Johnson, L.C. (1983). Dyadic family relations and social support. The Gerontologist, 23(6), 377-383.
- Johnson, C.L. & Catalano, D.J. (1983). A longitudinal study of family supports to impaired elderly. The Gerontologist, 23(6), 612-618.
- Jones, D.A. & Veher, N.J. (1984). A survey of those who care for the elderly at home: Their problems and their needs. Social Science and Medicine, 19(5), 511-514.
- Kahan, J., Kemp, B., Staples, F. & Brummel-Smith, K. (1985). Decreasing the burden in families caring for a relative with dementing illness. Journal of the American Geriatric Society, 33(10), 664-670.
- Kahn, R.L. (1975). The mental health system and the future aged. Gerontologist, 15(1), 24-31.
- Karusa, J., Joss, D., Novak, C. & Brice, G. (1983, November). Evaluation of a community training program for families of the elderly. Paper presented at annual meeting of the Gerontological Society of America, San Francisco, CA.
- Kast, F.E. & Rosenzweig, J.E. (1979). Organization and management: A systems approach (3rd ed.). New York: McGraw Hill.
- Lefton, E. & Lefton, M. (1979). Health care and treatment for the chronically ill: Toward a conceptual framework. Journal of Chronic Diseases, 32, 339-344.
- Mace, N.L. & Rabins, P.V. (1981) The 36-hour day. Baltimore: John Hopkins University Press.
- Mackey, A.M. (1983). OBS and nursing care. Journal of Gerontological Nursing, 9(2), 74-85.
- McCann, J.J. (1986). Family oriented interventions in Alzheimer's care. The American Journal of Alzheimer's Care and Related Disorders, 1(3), 16-21.
- Montgomery, R.J. (1982). Impact of institutional care policies on family integration. The Gerontologist, 22(1), 54-58.

- Mortimer, J.A., Schuman, L.M. & French, L.R. (1981). Epidemiology of dementing illness. In J.A. Mortimer & L.M. Schuman (Eds.) The epidemiology of dementia (pp. 3-23). New York: Oxford University Press.
- Myers, J.M. & Drayer, C.S. (1979). Support systems and mental illness in the elderly. Community Mental Health Journal, 15(4), 277-286.
- Pratt, C., Schmall, V., Wright, S. & Cleland, M. (1985). Burden and coping strategies of caregivers to Alzheimer's patients. Family Relations, 34, 27-30.
- Rossi, P.H. & Freeman, H.E. (1983). Evaluation: A systematic approach. Beverly Hills: Sage Publications.
- Schneider, L.E. & Emr, M. (1985). Alzheimer's disease: Research highlights. Geriatric Nursing, 6(3), 136-138.
- Shanas, E. (1979). Social myth as hypothesis: The case of the family relations of old people. The Gerontologist, 19(11).
- Somers, A.R. (1982). Long-term care for the elderly and disabled: A new health priority. The New England Journal of Medicine, 307(4), 221-226.
- Sommers, P.R. (1983). Life cycle nursing: Health care planning for the future. Journal of Gerontological Nursing, 9(2), 103-107.
- Steuer, J.L. & Clark, E.O. (1982). Family support groups with a research project on dementia. Clinical Gerontologist, 1(11), 87-95.
- Tomlinson, B.E., Blessed, G. & Roth, M. (1970). Observations on the brains of demented old people. Journal of Neurological Science, 11: 205-242.
- Wood-Dauphine, S. & Clarfield, A.M. (1985). Evaluating geriatric team care programs: Why and How. Clinical Gerontologist, 3(3), 23-34.
- Woods, A.M., Niederehe, G. & Fruge, E. (1985). Dementia: A family systems perspective. Generations, 10(1), 19-22.
- Zarit, J.M. (1982). Predictors of burden and distress for caregivers of dementia patients. Unpublished doctoral dissertation, University of Southern California.

- Zarit, S.H., Orr, N.K. & Zarit, J.M. (1985). The hidden victims of Alzheimer's disease: Families under stress. New York: New York University Press.
- Zarit, S.H., Reever, K.E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. The Gerontologist, 20(6), 649-655.
- Zarit, S.H., Todd, P.A. & Zarit, J.M. (1986). Subjective burden of husbands and wives as caregivers: A longitudinal study. Gerontologist, 26(3), 260-266.



OUTREACH PROGRAM FOR CAREGIVERS  
OF THE CONFUSED ELDERLY

By  
Linda Kruse, BSN, RN

Approved: \_\_\_\_\_

*Joyce Collins*  
Advisor

This study focussed on the development and implementation of an Outreach Program for family caregivers of the confused elderly. The research design was exploratory and descriptive. The results from a needs assessment survey was used to design and implement a multidisciplinary Outreach Program to provide long-term supportive services for caregivers of Alzheimer's patients. The program had three parts: education, counseling and referral services. The "Evaluation Form to Determine Helpfulness of Outreach Team for Caregivers of the Confused Elderly" was adapted from a published document with the addition of five investigator-designed questions and used to determine the effectiveness of the program. Responses from the program participants listed the following six items from the evaluation instrument as "most important"; (a) getting support from other caregivers, (b) information about nursing homes, (c) learning that resources exist in the community to help with emergencies, (d) information about medical aspects of dementia, (e) information about legal/financial concerns, and (f) learning where to get more help when you need it. Responses to the five open-ended questions indicate that imparting information to the family is the single most important initial step. These findings support the work of Pratt, Schmall, Wright, and Cleland, (1985), and are important for nursing because through combined disciplines and service components, the Outreach Program provides an integrated continuum of long-term nursing care. The results of this study are encouraging but the model needs more extensive testing to determine any long-term benefits of such a program.

Appendix A: Needs Assessment Data

Needs Assessment Data

Because there was not one specific standard that could be utilized as a basis of comparison for analyzing the data collected, the writer elected to use the findings of previous studies identified through a review of the literature for a basis of comparison. The first report from the Alzheimer's Caregiver Research Project conducted by Oregon State University and ADRDA, Columbia Mid-Willamette Valley Chapter (Pratt, Schmall, & Wright, 1983) was most useful in providing comparable information.

<u>Personal Data</u>	<u>Questionnaire Results</u>	<u>Alzheimer's Caregiver Research Project (ARCP)</u>
County of Residence		
Marion Co.	26 or 70.3%	Combined Mid-Willamette Valley
Polk Co.	6 or 16.2%	
Clackamas Co.	2 or 5.4%	
Linn Co.	1 or 2.7%	
Washington Co.	2 or 5.4%	
Mean caregiver age	61 years	61.3 years
Mean length of caregiving	60.1 months	49.1 months
Mean age of care-recipient	79 years	74.9 years
Caregiver sex	84% female	86% female
	16% male	14% male
Relationship of recipient	45.9% spouse	58% spouse
to caregiver	35.1% parents	30% parents
	13.5% family member	12% family member
	5.5% friend	-----

Appendix B: Caregivers' Letter

BENEDICTINE NURSING CENTER  
540 SOUTH MAIN ST. MT. ANGEL, OREGON 97362  
PHONE (503) 845-6841

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**John H. Hogan**  
ADMINISTRATOR



Outreach Program

47

Dear Caregiver:

This is to inform you of a new service being offered through the Benedictine Nursing Center for Caregivers of the confused/memory impaired elderly.

Starting October 24, we will be offering an Outreach Program consisting of referral, counseling and information service on Thursday afternoons from 1:00 - 3:00 p.m. There will be a team composed of a mental health nurse, chaplain, home health nurse and volunteer caregiver who will be available to assist you with problems you may be encountering in caring for the memory impaired person in your home.

Examples of problems/information that may be addressed include:

- dealing with problem behaviors
- when to seek legal, medical advice
- how to deal with your own feelings
- what resources are available to help you
- making the decision to place in nursing home or foster care

This is just a partial list of some of the common concerns that could be discussed.

If you wish to utilize this service, you should contact Joanne Rader, Mental Health Nurse at the BNC to make an appointment. There is a fee of \$25.00 for the initial consultation. If this fee presents a problem to you, please discuss this with the nurse. Our intention is to make this service available to all. Following the consultation someone will be calling you to see how things are going and to offer further help as needed.

If you need to bring the memory impaired person with you to BNC, please let us know ahead so we can arrange for a volunteer to spend time with them while you talk with the team. If you are unable to come to BNC, we could try to arrange a conference call. Our purpose is to provide education,

information and support to you as the caregiver in the most cost-effective, convenient way possible.

Please try to call between the hours of 9:00 a.m. - 5:00 p.m., Monday - Friday. Leave a message with your name and number if the Mental Health Nurse is not available, and your call will be returned.

Sincerely,  
Joanne Rader, R.N., M.N.  
Mental Health Nurse

Appendix C: Assessment Form &  
Memory & Behavior Problems Checklist

CAREGIVER ASSESSMENT FORM

I. Caregiver Family Profile

1. Name \_\_\_\_\_ Date \_\_\_\_\_

2. Age \_\_\_\_\_ 3. Sex:  Male  Female 4. Zip Code \_\_\_\_\_

5. What is your present marital status?

(1) Never Married  (2) Married  (3) Divorced

(4) Separated  (5) Widowed

6. Are you presently: (check one)

(1) Employed Full-Time  (2) Employed Part-Time

(3) Unemployed  (4) Retired  (5) Full-Time Homemaker

7. Religious Affiliation: (optional)

Protestant  Catholic  Jewish  Other  None

8. Level of Education: Please circle the highest grade of school that you completed.

Grade School	High School	College	Grad School
1 2 3 4 5 6 7 8	9 10 11 12	1 2 3 4	1 2 3 4

9. What is your relationship to your impaired family member or friend?

(1)  Son

(4)  Daughter-In-Law

(2)  Daughter

(5)  Brother (or in-law)

(3)  Son-In-Law

(6)  Sister (or in-law)

(Cont'd)



- (7) \_\_\_ Grandson                      (10) \_\_\_ Friend  
 (8) \_\_\_ Granddaughter              (11) \_\_\_ Other  
 (9) \_\_\_ Spouse                              Specify \_\_\_\_\_

10. How close would you describe your relationship to be with your impaired family member or friend according to the scale below? (circle a number)

1	2	3	4	5	6	7
Distant			Average		Very Close	

11. Circle the number of hours per day that you, as the caregiver, need to be with or use in preparing to provide care to the patient?

Less than 2 hours	2-6 hours	7-11 hours	12-16 hours	17-21 hours	22-24 hours
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12. How long have you been providing care to the person with dementia?

\_\_\_ Less than 6 mos.    \_\_\_ 6-12 mos.    \_\_\_ 1-2 years  
 \_\_\_ 3-5 years        \_\_\_ 5 years or longer

13. It is important for us to know more about those who live in the household with you. Circle the total number of persons living in the household:

1 2 3 4 5 6 7 8 9 10

Please complete the following chart and include only those who live in the same home as you.

(Cont'd)

Relationship to confused person (daughter, son, spouse, grandchild, friend, etc, and age):

	Age		Age
1.	_____	6.	_____
2.	_____	7.	_____
3.	_____	8.	_____
4.	_____	9.	_____
5.	_____	10.	_____

14. Describe briefly what impact caregiving has had on your family (i.e. source of conflict and strain).

15. Before the start of your caregiving role, would you say your physical health was:

5	4	3	2	1
Excellent	Good	Don't know	Fair	Poor

16. How would you rate your health at the present time?

5	4	3	2	1
Excellent	Good	Don't know	Fair	Poor

17. If your health status has changed, do you feel caregiving has affected that change?

5	4	3	2	1
A great deal	Some	Not Sure	A little	Not at all

18. Do your family or friends help (support) you?  Yes  No

(Cont'd)

If yes, in what ways? Please check appropriate response(s)  
(May be more than one):

- Emotional support such as concern, listening.
- Appraisal support such as affirmation, feedback.
- Information support such as advice, direction, information.
- Instrumental support such as aid, money, labor, time.
- Other: please explain:

19. If you family member is living with you, what do you believe is the probability that this person will be living in a nursing home one year from now? Use the scale below to indicate this possibility. (Circle a number below.)

1	2	3	4	5	6	7
Definitely Not			Don't Know			Definitely Yes

Any Comments:

20. What if any, community resources have been most helpful to you in your current situation?

- Educational programs for caregivers
- Meals-on-Wheels
- Respite care
- Personal aide
- Paid household help
- Paid nursing or other care for the patient
- Other. Please specify:

(Cont'd)

21. How have your feelings toward this person changed (if at all) as a result of his/her having developed the impairment?

Yes  No If yes, could you describe how?

22. Use the space below to identify your most important needs/problems related to your caring for the impaired person.

Thank you.

**PART I - "Other"**

The following questions are optional - although the information would be useful, it is entirely up to you if you want to respond.

23. What was your approximate net family income from all sources, before taxes in 1984? (check one)

- |   |   |
|---|---|
| <input type="checkbox"/> less than \$10,000 | <input type="checkbox"/> 20,001 - 25,000  |
| <input type="checkbox"/> 10,001 - 15,000    | <input type="checkbox"/> 25,001 - 30,000  |
| <input type="checkbox"/> 15,001 - 20,000    | <input type="checkbox"/> 30,001 and above |

24. Has caregiving affected your financial situation?

Yes     No    If Yes, please indicate the impact:

- |                                     |                          |                          |                          |                          |
|-------------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| <input checked="" type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| A great deal                        |                          | Some                     |                          | Very little              |

25. How do you feel about the adequacy of your financial resources?

- |                                     |                          |                          |                          |                          |
|-------------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| <input checked="" type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Confident                           | Some Concern             | Unsure                   | Able to Make "ends meet" | Very Worried             |

26. What are the sources of financial support that the impaired person receives? (Check all that apply)

- |                             |                         |
|-----------------------------|-------------------------|
| 1) Welfare _____            | 6) Savings _____        |
| 2) Medicare _____           | 7) Stocks/Bonds _____   |
| 3) Medicaid _____           | 8) Family Support _____ |
| 4) Social Security _____    | 9) Other _____          |
| 5) Retirement Pension _____ |                         |

Thank you

**PART II - Confused Person's Profile**

Please answer the following questions about the impaired person.

1. Name \_\_\_\_\_ 2. Age \_\_\_\_\_
3. Sex: \_\_\_\_Male \_\_\_\_Female 4. Zip Code of Residence \_\_\_\_\_
5. What is her/his marital status?
  - 1) Married \_\_\_\_\_
  - 2) Widowed \_\_\_\_\_
  - 3) Separated \_\_\_\_\_
  - 4) Divorced \_\_\_\_\_
  - 5) Never Married \_\_\_\_\_
6. What were the major occupation (s) of the impaired person?
7. Is there a church group that s/he is associated with? \_\_\_\_Yes \_\_\_\_No  
Please indicate which one (optional):
8. What is the highest level of education that s/he completed?
 

Grade School	High School	College	Grad School
1 2 3 4 5 6 7 8	9 10 11 12	1 2 3 4	1 2 3 4
9. Where does the dementia patient live?
  - 1) In the same household as you \_\_\_\_\_
  - 2) In a home separate from you \_\_\_\_\_
  - 3) In a nursing home or adult residential care facility \_\_\_\_\_
  - 4) Other: Please specify.
10. How long has s/he resided at the above location?
 

\_\_\_\_ Years      \_\_\_\_ Months
11. How long ago did you first notice changes in your family member or

friend?

\_\_\_\_\_ Years      \_\_\_\_\_ Months

12. What were the first signs of the impairment?

13. Would you describe the onset as gradual or sudden?

Gradual     
  Uncertain     
  Sudden

14. When was the impairment first diagnosed by a doctor?

Number of months or years ago \_\_\_\_\_

15. Name, address and telephone number of her/his physician:

16. What was the diagnosis?

17. How would you rate the patient's emotional health status?

5                  4                  3                  2                  1  
 Excellent      Good      Average      Fair      Poor

18. How would you rate the patient's physical health status?

5                  4                  3                  2                  1  
 Excellent      Good      Average      Fair      Poor

Thank you.

**PART IV - Support Questions**

1. Are you now a member of a support group for caregivers of patients with Alzheimer's disease or other disorders?

Yes (if so, please answer the following questions.)

No (if no, were you before? \_\_\_\_Yes \_\_\_\_No)

a. How long have you been a member of this group?

\_\_\_\_\_months and/or years

b. How helpful has this group been to you in providing KNOWLEDGE/INFORMATION?

<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Not at all helpful	Not very helpful	Helpful	Very Helpful	Too soon to tell	Don't know

c. How helpful has this group been to you in providing EMOTIONAL SUPPORT?

<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Not at all helpful	Not very helpful	Helpful	Very Helpful	Too soon to tell	Don't know

d. Do these support groups meet your expectations?

<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Most of the time	Some of the time	Very little of the time	None of the time	

e. What do you like the most about the support groups?

f. What do you dislike about the support group?



2. Do you receive any of the following kinds of support in caregiving?  
(check all that apply).

- 1. paid household help in the name of the patient
- 2. paid nursing or other care for the patient in the home
- 3. household help from other family members or friends
- 4. caregiving help for the patient from other family members or friends
- 5. visits to the patient by family or friends
- 6. visits to you
- 7. others, please specify

THINKING OF THE PEOPLE YOU FEEL CLOSEST TO, PLEASE ANSWER THE FOLLOWING QUESTIONS:

3. How easy is it for you to contact these people? (circle one choice)

- |              |      |                               |           |                   |
|--------------|------|-------------------------------|-----------|-------------------|
| X            | X    | X                             | X         | X                 |
| Very<br>Easy | Easy | Neither Easy<br>Nor Difficult | Difficult | Very<br>Difficult |

4. As a group, how often do they help you?

- |       |                |           |             |            |
|-------|----------------|-----------|-------------|------------|
| X     | X              | X         | X           | X          |
| Never | Not very often | Sometimes | Quite often | Very often |

5. How satisfied are you with the support that you receive from these people?

- |                         |                       |                       |                    |                   |
|-------------------------|-----------------------|-----------------------|--------------------|-------------------|
| X                       | X                     | X                     | X                  | X                 |
| Not at all<br>satisfied | Satisfied a<br>little | Somewhat<br>Satisfied | Quite<br>Satisfied | Very<br>Satisfied |

6. Of all these people, is there one specific person that you can share your most personal thoughts and feelings with?  Yes  No

(If yes, is this person readily available?  Yes  No

**Memory and Behavior Problems Checklist**

**Instructions:**

Say to caregiver: "I am going to read you a list of common problems. Tell me if any of these problems have occurred during the past week. If so, how often have they occurred? If not, has this problem ever occurred?" (Probe for response that matches one of the frequency choices.)

**FREQUENCY RATINGS:**

**0 = never occurred**

**1 = has occurred, but not in past week**

**2 = has occurred 1 Or 2 times in past week**

**3 = has occurred 3 to 6 times in past week**

**4 = occurs daily or more often**

**7 = would occur if not supervised by caregiver (e.g. wandering except door is locked)**

**8 = patient never performed task**

**BEHAVIORS:**

**FREQUENCY:**

<b>1. Wandering or getting lost</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>7</b>	<b>8</b>
<b>2. Asking repetitive questions</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>7</b>	<b>8</b>
<b>3. Hiding things (e.g. money, jewelry)</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>7</b>	<b>8</b>
<b>4. Being suspicious or accusative</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>7</b>	<b>8</b>
<b>5. Losing or misplacing things</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>7</b>	<b>8</b>
<b>6. Not recognizing familiar people</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>7</b>	<b>8</b>
<b>7. Forgetting what day it is</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>7</b>	<b>8</b>
<b>8. Not completing tasks</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>7</b>	<b>8</b>
<b>9. Destroying property</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>7</b>	<b>8</b>
<b>10. Doing things that embarrass you</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>7</b>	<b>8</b>
<b>11. Waking you up at night</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>7</b>	<b>8</b>
<b>12. Being constantly restless</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>7</b>	<b>8</b>
<b>13. Being constantly talkative</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>7</b>	<b>8</b>
<b>*14. Engaging in behavior potentially dangerous to others (describe)</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>7</b>	<b>8</b>
<b>*15. Engaging in behavior potentially dangerous to self (describe)</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>7</b>	<b>8</b>

<b>16. Reliving situations from the past</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>7</b>	<b>8</b>
<b>17. Seeing or hearing things that are not there (Hallucinations or illusions)</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>7</b>	<b>8</b>
<b>18. Unable to dress self (either partly or totally)</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>7</b>	<b>8</b>
<b>19. Unable to feed self</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>7</b>	<b>8</b>
<b>20. Unable to bathe or shower by self</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>7</b>	<b>8</b>
<b>21. Unable to put on make-up or shave by self</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>7</b>	<b>8</b>
<b>22. Incontinent of bowel or bladder</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>7</b>	<b>8</b>
<b>23. Unable to prepare meals</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>7</b>	<b>8</b>
<b>24. Unable to clean house</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>7</b>	<b>8</b>
<b>25. Unable to use the phone</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>7</b>	<b>8</b>
<b>26. Unable to handle money</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>7</b>	<b>8</b>
<b>27. Unable to shop</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>7</b>	<b>8</b>
<b>28. Unable to do other simple tasks (e.g. put groceries away, simple repairs)</b>	<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>7</b>	<b>8</b>
<b>29. Other: _____</b>							

**\*Rater judges whether behavior is dangerous or merely troublesome.**

Appendix D: Evaluation Form

BENEDICTINE NURSING CENTER  
540 SOUTH MAIN ST. MT. ANGEL, OREGON 97362  
PHONE (503) 845-6841

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**John H. Hogan**  
ADMINISTRATOR



Outreach Program

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We hope this letter sees you managing without too many difficulties since your appointment with the Outreach Team. Caring for a confused elderly loved-one can certainly be a difficult time for all concerned. We hope your visit with the team was helpful in your circumstances.

We are concerned that the Outreach Program is actually meeting the needs of families and friends caring for confused elderly persons. In order to provide the most effective program possible, we would appreciate your evaluation and suggestions. Your assistance in candidly completing the enclosed form would be very helpful to us. All the information gathered will be kept confidential. It will be used to improve our current program, and to provide assistance in request for program-expanding funds from various foundations.

We're very interested in how things have gone for you. Please feel free to call us or write any updates or comments on the back of the evaluation form.

Thank you for your assistance in this evaluation, and for contacting the Outreach Team.

Sincerely,

BNC Outreach Team

**Evaluation Form to Determine Helpfulness of Outreach Team for  
Caregivers of the Confused Elderly**

On a Scale of 1 to 5 (1 indicating not very helpful to 5 indicating very helpful)  
Write in N/A (not applicable) if item wasn't a problem or wasn't covered.  
Please rate the helpfulness of the Outreach Team.

	1	2	3	4	5
1. Finding out how others deal with their problems.					
2. Sharing feelings with Outreach Team Members .					
3. Information about medical aspects of dementia.					
4. Getting support from other caregivers.					
5. Learning practical solutions to everyday problems.					
6. Learning how to handle the person with dementia.					
7. Learning about problems with family members of dementia persons.					
8. Information about medical services for persons with dementia.					
9. Learning things to do to feel better <u>yourself</u> .					
10. Information about different dementias.					
11. Feeling less isolated and alone.					
12. Information about social and community services.					
13. Information about nursing homes.					
14. Learning where to get more help when you need it.					

Outreach Program

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- 15. Information about legal/financial concerns.
- 16. Learning how to get along with other members of your family.
- 17. Learning that resources exist in the community to help with emergencies.

18. Please list the three things that you found most helpful or useful to you.

- 1. \_\_\_\_\_
- 2. \_\_\_\_\_
- 3. \_\_\_\_\_

19. List the three things that were least helpful of useful to you.,

- 1. \_\_\_\_\_
- 2. \_\_\_\_\_
- 3. \_\_\_\_\_

20. Did you get the help you needed?  Yes  No If not, please specify:

\_\_\_\_\_

21. Where was the confused person living at the time you sought help from the Outreach Team? Where are they living now?

\_\_\_\_\_

22. Any suggestions that would add to or improve the Outreach Program, thus making it more effective:

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