

**Evaluation of Utilization, Costs, and Outcomes in the PREP
Home-Health Nursing Intervention: A Feasibility Study**

by

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ABSTRACT

TITLE: Evaluation of Utilization, Costs, and Outcomes in the PREP
Home-Health Nursing Intervention: A Feasibility Study

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This quasi-experimental pilot study developed method to evaluate economic issues and outcomes of PREP, an innovative home-health nursing intervention designed to support older disabled persons and their family/friend caregivers over an extended period of time. The intervention focused on caregivers' preparedness to meet the older person's needs and handle the stress of caregiving, predictability of caregiving routines, and enrichment in caregiving.

Twenty-two HMO enrollees and their family/friend caregivers participated in the study. Caregiver/care receiver dyads in the intervention group (N=11) received standard home health plus the services of PREP. Dyads in the control group (N=11) received only standard home health. Cost and service utilization measures were developed and refined, a protocol for a cost analysis of PREP

and standard home was developed, and the costs and outcomes of PREP were compared with the costs and outcomes of standard home health.

Because it was hypothesized that PREP would offset the utilization and thus the cost of some health and social services and induce demand for other services, a comprehensive service utilization profile was developed for each dyad for the study period and served as the basis for determining costs. Utilization and cost data were collected from HMO computer files, HMO member charts and from study participants. The outcome of PREP was measured using the PREP Effectiveness Scale, which measured the degree to which the intervention increased caregivers' perception of preparedness, predictability, and enrichment in caregiving.

Average monthly costs for home health services, which included the additional cost of PREP, were significantly higher in the intervention group. Average monthly costs in each of four other service classes--institutional, outpatient, community social services, and pharmacy, durable medical equipment and medical supplies--were lower in the intervention group, although not significantly lower. Average total monthly costs were also lower, but not significantly lower, in the intervention group. Scores on the PREP Effectiveness Scale were significantly higher in the intervention group ($M=4.1$) than in the control group ($M=3.1$), demonstrating that PREP was more effective than standard home health in increasing caregiver's perceptions of preparedness, predictability, and enrichment.

These findings suggest that PREP has promise as a cost-effective intervention for providing long-term management of health problems to older people and their families. Based on these findings, the full clinical trial of PREP was recommended.

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CHAPTER 1

INTRODUCTION

Background

An estimated 6.2 to 6.5 million (22-23%) of the 28.6 million older persons in the United States in 1985 had some form of long-term care need, ranging from a need for help with ordinary household tasks, such as preparing meals and using the telephone, to help with all activities of daily living, such as dressing and eating (USGAO, 1989). Because the population of older persons, those 65 years of age and older, is expanding rapidly, and at the same time growing proportionately older (USGAO, 1989), more and more older persons will need some type of long-term care. Long-term care refers to a set of health, mental health, social, and residential services provided to temporarily or chronically disabled persons over a sustained period of time with the goal of enabling them to maintain as high as possible a level of independent functioning (Evashwick, 1988).

Total spending for long-term care has been growing considerably faster than the rate of inflation and is projected to continue increasing well into the next century (Soldo & Manton, 1985). In 1985, \$45 billion were spent nationally on all types of formal long-term care services, but primarily on nursing home care. Twenty percent of older persons needing long-term care were cared for in nursing homes and accounted for 80% of the expenditure (USGAO, 1989). Nursing home expenditures accounted for 6.3% of all national health expenditures in 1970 and 8.3% in 1985 (USGAO, 1989), a growing share of a sector that is a growing share of the total gross national product. Spending for long-term care is expected to reach \$77.5 billion by 2005 and \$132.4 billion by 2020 (U.S. Department of Health and Human Services, 1991).

Although 80% of older persons needing long-term care in 1985 lived at home, only 20% of long-term care expenditures (\$9 billion) went for formal home-health benefits. Long-term care

expenditures for older persons at home are, however, increasing--they accounted for only 2% of the Medicare budget in 1980 and 3% in 1985 (Davis, 1987). Additionally, the number of Medicare-certified home-health agencies increased from 2,212 in 1972 to about 5,800 in 1985 (USGAO, 1989). A number of factors suggest that the use of home-health care will increase even more. These factors include widespread negative publicity about the quality of nursing home care (Institute Of Medicine, 1986; Vladek, 1980), predictions of a substantial increase in the numbers of people requiring long-term care (USGAO, 1989), and Medicare's Prospective Payment System for hospital reimbursement, which makes it economically imperative for providers to find suitable alternatives to inpatient hospital services (Davis, 1987; Wood & Estes, 1990). In addition, policy research has emphasized preventing people from going into nursing homes and getting people out of nursing homes (e.g., the Social Health Maintenance Organization, the National Long-Term Care Channeling Demonstration, and Oregon's Medicaid Waiver Program) (Greenberg, Leutz, Greenlick, Malone, Ervin, & Kodner, 1988; Kemper, Applebaum, & Harrigan, 1987; USGAO, 1989). Finally, home-health care can be expected to expand because a majority of impaired older Americans prefer to stay at home rather than enter institutions (American Association of Retired Persons, 1984). Because potentially explosive costs are feared by many, innovative methods of health care delivery that are both cost-effective and efficacious will be a high priority for the 21st century (Anderson, 1990; Oktay & Volland, 1990).

Despite the demand for formal long-term care services, much long-term care is supplied by family members, friends, and other informal sources of support. Informal caregivers provide 70 to 80% of all long-term care for older people, and play a pivotal role in maintaining older people in the community (Horowitz, 1985; Liu, Manton, & Liu, 1985; Kavesh, 1986), yet the cost of informal caregiving is not known. Informal caregivers often support the elderly at home through great personal sacrifice yet express a desire to provide care as long as they are able because

they are caring for loved ones (Archbold, Stewart, Greenlick, & Valanis, 1988; Shanas, 1979; Zarit, Todd, & Zarit, 1986). Informal caregivers often experience emotional stress, restrictions on time and freedom, and considerable physical and financial costs (Archbold, 1982; Brody, 1985; George & Gwyther, 1986; Horowitz, 1985; Liu et al. 1985). Breakdowns in the informal care system can lead to institutionalization. A comprehensive response to long-term care needs should consider both formal and informal long-term care sectors. A vision of long-term care policy is needed which establishes and nurtures a partnership between informal and formal caregivers.

Home-health nurses are in a good position to establish a partnership with informal caregivers to assist them in caring for disabled older persons in the home setting. It has been suggested that home-health interventions function primarily as a support system for informal caregivers, resulting in reduced stress for them (Dunlop, 1980; Weissert, 1985). Yet clearly, home-health interventions are needed which go beyond support, to improve caregivers' abilities to manage caregiving activities and problems, to relieve caregiver strain, and to assist with joint caregiver/care receiver management of the caregiving situation. In addition, well-designed evaluations are needed to test the effects and costs of different types of home-health care on caregiver as well as on care receiver outcomes.

The PREP (preparedness, enrichment, predictability) intervention and its evaluation were designed to meet these needs. The PREP Evaluation Study was the third in a series of studies conducted by Drs. Patricia G. Archbold and Barbara J. Stewart focusing on family caregivers to older persons. As a result of their first two studies, Drs. Archbold and Stewart began to recognize the salience of the nature and complexity of the caregiver role. This led them to design an intervention for caregivers which took into account the subtleties and complexities of the caregiver role and to focus on caregiver competence to perform caregiving activities. Because group approaches for caregiver education and support had failed to demonstrate

reduced caregiver burden, the usual outcome measure used in such studies, the PREP intervention featured an individualized approach to each caregiver to meet her/his particular caregiving needs. Because they thought that predictability and control were important in relieving the need for constant vigilance and in reducing stress, the intervention included elements to increase predictability and control. Because of their findings that some caregivers attached positive meaning to caregiving activities and that most caregivers could identify at least one benefit of caregiving, they thought that an intervention for caregivers should include elements to enhance the positive aspects of caregiving.

The PREP intervention was an expansion of the standard home-health Medicare benefits available to older health maintenance organization (HMO) enrollees and their caregivers. Because many caregivers take on caregiving responsibilities with little preparation, PREP was designed to enhance the overall caregiving situation. Specifically, the purposes of PREP were to improve the preparedness and competence of family members in providing long-term care to frail older people, to make the caregiving processes more predictable, and to enrich caregiving.

Preparedness is the caregiver's evaluation of how well-prepared she/he is for tasks and stress of the caregiving role. For example, a caregiver who is prepared to manage a care receiver's behavior problem, has specific strategies to manage the behavior, has an understanding of reasons for the behavior and the care receiver's control of the behavior, knows what aggravates the behavior, and understands her own feelings about the behavior.

Predictability refers to the stability of caregiving patterns and routines. An example of predictability in caregiving is that caregiving activities are performed in the same sequence and at the same times every day. Enrichment is the process of enhancing caregiving through the pleasurable, the aesthetic, or the ceremonial. Enrichment might include special bathing or bedtime rituals, taking a drive to a favorite park on the way to a doctor's appointment, or sharing

past experiences.

Nursing is unique in its ability to support caregivers and to increase preparedness, predictability, and enrichment. Nurses possess knowledge and skills in personal care, symptom control, planning care routines, providing emotional support, and in evaluating the need for and obtaining community services. They are able to adapt methods of providing care to specific disease processes. They also have skills in evaluating health problems and in determining when a client needs emergency care or needs to be seen by a primary care provider. Thus, nurses are especially qualified to implement PREP, manage health problems of care receivers, and provide ongoing support for caregivers.

Study Aims

PREP offers an alternative to standard home health in managing the health problems of older people in the home setting. The major social issue in evaluating PREP is whether PREP is affordable as an add-on benefit. In this era of cost containment, new programs such as PREP face careful scrutiny. Data is needed regarding the efficiency effects and equity effects of PREP. Efficiency effects should show that adding PREP services produces a healthier and happier caregiver and a healthier and happier care receiver, at modest or no extra cost, or with lower total health care costs. Equity effects of PREP should reduce the inequities of support for low-income families.

This dissertation was a supplemental study to the larger 2-year PREP Evaluation Study, which was funded by the National Center for Nursing Research (Archbold et al. 1988). The 2-year PREP Evaluation Study was the pilot phase of a larger clinical trial to be proposed for 1994-1999. PREP was refined and its feasibility evaluated in this pilot phase. The 2-year PREP Evaluation Study did not include the development and evaluation of cost measures; this supplemental study developed an extension of the PREP evaluation to incorporate economic issues. The purposes of this supplemental study were to develop and refine cost and service

utilization measures for PREP, to develop a protocol for a cost analysis of PREP and standard home health, and to compare the costs and outcomes of PREP with the costs and outcomes of standard home health. Dyads composed of older persons and their family/friend caregivers in the special intervention group received standard home health benefits plus the additional services of PREP. Dyads in the usual-care control group received standard home health.

The specific aims of this study were to:

1. develop methods to measure and compare patterns of utilization of PREP nursing services by intervention dyads with patterns of utilization of standard home health nursing services by control group dyads;
2. develop methods to measure and compare the cost of implementing PREP in intervention dyads with the cost of standard home health in control dyads;
3. develop measures of utilization and cost of non-PREP health and social services by intervention and control dyads;
4. develop an evaluation plan to compare health and social service costs in PREP dyads and usual-care control dyads; and
5. select and evaluate a subjective caregiving outcome measure for the PREP intervention program.

Developing methods to measure and compare the utilization, costs, and outcomes in this supplemental study will be useful to researchers in identifying needed changes in the intervention and research design to allow more efficient use of resources in the subsequent clinical trial. Also, cost measures developed in this supplemental study can be used to analyze the cost of the subsequent clinical trial. Careful analysis of costs and caregiver outcomes for an enhanced home-health program could be useful to HMO administrators in making decisions regarding the inclusion of PREP as a home-health benefit. Finally, these methods serve as a model for looking at costs and outcomes of other types of home care.

The next chapter presents the conceptual similarities and differences between PREP and standard home health, reviews research literature to show how PREP fits with other recent home health nursing interventions, and describes the conceptual basis of the cost analysis and outcome measure of PREP. In Chapter 3, the methodology for collecting service utilization and cost data and for pricing the health services used by study participants is presented. The methodology for measurement of the PREP outcome is also presented. Chapter 4 is a description of the actual implementation of PREP with intervention dyads. Chapter 5 is a presentation of the results, the comparison of utilization and cost of health services in the intervention and control group and a comparison of the groups on the PREP outcome measure. Chapter 6 presents a discussion of utilization and cost differences between the two study groups and discussion of the data collection methodologies. The final chapter presents recommendations for the future clinical trial of PREP.

CHAPTER 2

CONCEPTUAL FRAMEWORK

Introduction

PREP was an expansion of home-health nursing designed to meet the long-term health care needs of older people and to assist family members and friends who care for them. As a basis for understanding PREP, standard home-health nursing is described below. Next, the PREP intervention and the differences between PREP and standard home health are described in detail. Next, a review of recent literature describing other home-health interventions is presented to provide a context for the PREP intervention. The chapter concludes with a derivation of several hypotheses regarding the effects of PREP on health care utilization and cost and on caregiver outcomes.

Standard Home Health Nursing

Standard home-health nursing is the short-term (usually less than 60 days) treatment of acute, chronic, or terminal illnesses or injuries by several disciplines, including nurses, physical therapists, occupational therapists, speech therapists, social workers, home health aides, and homemakers. The locus of care is the home. Registered nurses provide skilled care or care that is temporary and intermittent in nature, which is of sufficient complexity that it cannot be performed by the average non-medical person, and which is necessary for the treatment of the illness or injury outside of a formal licensed health care facility (U.S. Department of Health and Human Services, 1989). Services are provided primarily through means of home visits. Most referrals to home health occur during hospitalization, but some also occur as a result of outpatient visits to the physician. When the care receiver's health condition is stabilized and when the care receiver or caregiver can manage the treatment regimen without assistance, the care receiver is discharged from standard home health. The major domains of home-health nursing include assessment of physical and emotional health, physical examination, performance of skilled tasks, education of caregiver/care receivers, medication management,

and supervision of home health aides and homemakers.

The PREP Intervention

The PREP intervention was an expansion of standard home health in which dyads received long-term follow-up from a registered nurse to assist with ongoing health problems and caregiving needs. PREP focused on three primary objectives: (a) to increase the joint preparedness and competence of the family (caregiver, care receiver, and other family members if appropriate) for the caregiving activities they performed; (b) to increase the predictability of unpredictable caregiving situations and environments; and (c) to enrich caregiving relationships through pleasurable, aesthetic, or ceremonial activities. The model of caregiving for PREP was based in part on a qualitative study of adult-child caregivers by Archbold (1982) and in part on role theory (Archbold et al. 1988; Burr, Leigh, Day, & Constantine, 1979). The model of caregiving in PREP views the caregiving role from the adult developmental perspective as a normative transition and expected life event in the lives of adults and families.

Assuming the caregiver role, however, is a transition that is often associated with negative consequences. A series of findings by study investigators in a previous study, the Caregiver Relief Study, influenced the design of PREP (Archbold & Stewart, 1988). In the Caregiver Relief Study, interviews were conducted with 103 dyads 6 weeks, 6 months, and 9 months after the older person was discharged to home from the hospital. Findings from the Caregiver Relief Study and their influence on the design of PREP follow.

The first finding from the Caregiver Relief Study, that most caregivers want to perform caregiving activities, supported designing an intervention which could better prepare caregivers for caregiving activities. The second finding was that caregivers learn the caregiving role while in it, in contrast to other roles that people learn before role entry. Even though a majority of caregivers reported caring for another ill family member, most reported that they did not learn much from the experience about how to take care of an older person's physical or emotional needs or how to handle the stress of caregiving (Archbold & Stewart, 1991). This likely occurs

because care receivers experience a wide variety of diseases and disabilities, and caregiving needs vary, depending on the nature and severity of the disease. The next finding was that the more caregiving activities performed by the caregiver, the more caregiver role strain they experienced. Role strain is the amount of difficulty experienced by individuals in performing the role of caregiver (Archbold & Stewart, 1988). This finding, in combination with the previous one, suggested that PREP should be targeted to people who had been referred to home health, because at the time of referral, the caregiver would either be entering the caregiving role for the first time or would be confronting a change in the nature of caregiving.

The next finding was that after controlling for variables commonly associated with caregiver role strain (the caregiver being female vs. male, the caregiver being a spouse vs. non-spouse, the physical and cognitive impairment of the older person, and the amount of direct care provided by the caregiver) plus controlling for mutuality, a relatively unexplored predictor, preparedness for caregiving was a powerful predictor of the lack of strain. Preparedness for caregiving was defined as the caregiver's evaluation of how well-prepared she/he was to meet the older person's physical and emotional needs and to handle the stress of caregiving. Because of this finding, one of the aims of PREP was to increase the caregiver's feelings of preparedness in the caregiving activities they performed.

Another finding from the Caregiver Relief Study was that caregivers who reported that their lives were basically predictable and that they felt in control of their lives, also reported significantly lower levels of caregiver role strain. Several aspects of the intervention were guided by these findings. First, increasing the predictability of the caregiving processes became one of the aims of PREP. In addition, when possible, control of some aspects of the intervention were given to the dyad. Dyads determined what they wanted to work on through a process of mutual negotiation with the PREP nurse. Finally, visits and calls by the PREP nurse to the dyad were scheduled to take into account the dyad's usual daily routine.

Another finding from the Caregiver Relief Study was that mutuality and rewards of

caregiving were associated with lower levels of caregiver strain, and over time, mutuality declined in caregivers. Mutuality was conceptualized as the positive quality of the caregiver/care receiver relationship, characterized by affective closeness, shared pleasurable activities, reciprocity, and shared values (Archbold & Stewart, 1988). Enrichment interventions, which focused on making caregiving activities more meaningful, satisfying, or pleasurable were designed to increase the rewards of caregiving and to prevent declines in mutuality.

The finding that caregiving was a complex phenomenon with a high degree of individual and family variability led PREP investigators to plan PREP as an individualized intervention, in which specific needs and preferences of each dyad were taken into account. The finding that caregiving was often characterized by a series of transitions (in health, living situation, and assistance patterns) that were difficult for the caregiver, supported the need for ongoing assistance to dyads over an extended period of time. Finally, the finding that the HMO's Advice Nurse was used a great deal by caregivers in the Caregiver Relief Study, and was evaluated very positively, supported the inclusion of a PREP Advice Line for study participants to answer caregiving and health-related questions.

The PREP intervention, with a focus on preparedness, predictability, and enrichment, was implemented with caregivers and care receivers at the time of admission of the care receiver into home health after discharge from the hospital, after discharge from a skilled nursing facility, or after contact with an HMO physician. It featured four structural components: (a) the In-home Component; (b) the Keep-in-Touch Component; (c) the Completion Component; and (d) the PREP Advice Line. These components are described below.

In-home Component

The In-home Component involved a series of in-home visits by the PREP nurse and had three purposes: (a) to increase the caregiver's feelings of preparedness in performing the specific caregiving tasks needed by the care receiver, (b) to enrich the caregiving experience, and (c) to establish a predictable pattern of caregiving activities (Archbold et al. 1988).

Operationalization of the In-home Component called for PREP nurses to conduct an in-depth assessment of the caregiving situation, including the nature of caregiving tasks, the caregiver's perceptions of preparedness to perform caregiving tasks, the aspects of the tasks that were difficult, the meaning of caregiving tasks to the caregiver and care receiver, their ideas about what would make the activities aesthetically pleasing, the pattern of daily activities, mutuality, negative consequences of caregiving (caregiver role strain), caregiver health, caregiver resources, including financial and health resources, and the amount of help from other people. Development of a therapeutic nurse/dyad relationship was central to this component.

After the initial assessment, which was to be completed in the first one or two home visits, the PREP nurse was to assist the caregiver in identifying caregiving tasks and issues in which they wanted improved competence and to choose goals for the performance of each task and activity. An individualized plan for each task was to be developed and implemented based on current literature related to the task. First, the nurse was to conduct an in-depth assessment of the task or problem to determine the direction for intervention. The assessment was to focus on caregiver, care receiver, and environmental variables. Through the process of mutual negotiation the nurse and dyad were to decide on the caregiving issues to address and the intervention strategies to pursue. Clinical consultants in physical therapy and mental health were to be used to develop strategies for problems in which the research and clinical literature was weak and in situations in which intervention strategies were not working well. Participants completed the In-home Component when the caregiving situation was stable, when the caregiver felt prepared to manage caregiving activities, or when the PREP nurse determined that further intervention in the form of home visits was not necessary, but that monitoring caregiving situations by telephone was adequate. When the In-home Component was completed, participants were transferred to the Keep-in-Touch Component.

The Keep-in-Touch Component

The Keep-in-Touch Component involved an ongoing monitoring system in which the

PREP nurse maintained regular telephone contact with dyads. The goals of Keep-in-Touch were to identify and treat areas of caregiver role strain that had increased or remained high after completion of the In-home Component, to monitor transitions, to assess caregiving problems, and to provide reassurance.

The Keep-in-Touch Component was to be operationalized by PREP nurses calling caregivers once a week for 2 weeks, once every other week for 4 weeks, once every 3 weeks for 6 weeks, then once a month, unless she judged that calls were needed more frequently. PREP nurses were to assess six types of strain in the caregiver, including worry, lack of resources, role conflict, tension in the relationship, negative changes in health, and problematic caregiving activities. For types of strain that were high, nurses could either handle the problem over the telephone, using appropriate intervention strategies, conduct a one-time home visit, or re-open the dyad to the In-home Component for more intensive in-home management of the problem.

The Completion Component

Because of the long-term nature of the nurse-dyad relationship, a Completion Component was designed to minimize the stress of the transition at the end of PREP. The purposes of the Completion Component were to prepare dyads for the end of the intervention, to provide continuing care if needed, and to give feedback to dyads about the progress they made in resolving caregiving issues.

The Completion Component was to be operationalized by three activities near the end of the intervention. First, the nurse reflected on her experiences with each dyad and wrote a summary of their strengths and their progress while in PREP. Next, during a final home visit or telephone call, the nurse was to discuss with the dyad their perceptions of what they had learned from PREP. Then, the nurse was to compose a letter to the family summarizing the family's strengths, the progress the dyad had made while in PREP, and what the nurse had learned from the dyad. The letter was to be sent as the last contact with the PREP intervention team.

The PREP Advice Line

The goal of the PREP Advice Line was to provide advice and reassurance to participants when needed. An important aspect of the PREP Advice Line was that the nurse who answered the phone knew the participants and what they had been working on in PREP.

The PREP Advice Line was to be operationalized by utilizing a paging system. One PREP nurse was to be available by phone from 8AM to 5PM Monday to Friday, to answer caregiver-, care receiver-, or family-initiated questions about problems related to caregiving throughout the 1-year intervention. Participants were to be instructed (verbally by the nurse and in writing in the Family Health Diary) how to call the page number and how to enter their own telephone number into the page. Participants were also to be given a magnet for their refrigerator with the PREP page number on it. Early in their home visits, PREP nurses were to rehearse paging procedures with the participants.

Differences Between PREP and Standard Home Health

PREP included all standard home health nursing responsibilities and added new ones. Several characteristics distinguished nursing activities in PREP from those in standard home health. First of all, there were differences in the focus of nursing care. In PREP, the caregiver/care receiver dyad was the focus of nursing care. Nursing assessment included assessment of the caregiver and care receiver both independently and jointly, assessment of their relationship to each other, and an in-depth assessment of the overall caregiving situation. In PREP, the dyad was the primary decision-making unit, and the nurse acted as a facilitator and expert advisor. Goals of care were mutually set by the PREP nurse and the dyad. PREP nurses took the attitudes and values of the dyad into account when implementing interventions.

Standard home health was an individual health plan benefit of Medicare whose primary goal was to provide short-term, acute care to older people until their health condition stabilized and the older person or a family member could learn and take over the treatment regimen. The focus of nursing care was almost exclusively the care receiver and her/his health condition.

Caregivers were the recipient of care only in the sense that nurses taught them how to manage the care receiver's treatment regimen. Nursing assessments were focused on assessment of the care receiver and on assessment of the specific health problems identified on the care plan. Assessments of the caregiver were conducted only with respect to her/his ability to perform specific tasks of the treatment regimen prescribed by the physician. Goals of nursing care were determined by the home health nurse.

In managing a dressing change, for example, PREP nurses would assess not only the condition of the wound and how the caregiver performed the dressing change, but would also assess how the dyad interacted in relation to the dressing change, would assist the dyad in incorporating it into their daily routine, would assess any special meaning associated with the dressing change for either the caregiver or care receiver, and would assist them to find ways to make it more pleasurable, such as incorporating special skin care. A standard home health nurse would focus primarily on the condition of the wound, the caregiver's or care receiver's ability to change the dressing, and on teaching dressing change techniques and symptoms of wound infection.

A second major difference was the type of problems addressed. In PREP, any health problem or caregiving issue identified by the dyad was appropriate for intervention. It was anticipated that many of the problems identified by caregivers would be non-skilled according to standard home health definitions, such as activities of daily living and behavior management. In standard home health, care receiver problems needing home health nursing services were determined by the physician not by the caregiver or care receiver, on the basis of skilled medical needs. Problems addressed by home health nurses had to meet strict skilled care requirements, that is, they had to be of sufficient complexity that they could not be performed by the average non-medical person, such as changing a catheter or dressing, or evaluating the effects of medications.

A third difference between PREP and standard home health was in the scope of their

concerns in caregiving. PREP focused more globally on increasing predictability in the caregiving process and on enriching the caregiving environment relative to standard home health. Standard home health was more narrowly focused on the care receiver's health condition which required skilled nursing care.

The fourth difference between PREP and standard home health was the role of the nurse with dyads vis-à-vis the rest of the HMO. PREP nurses functioned in part as primary providers because they developed a long-term therapeutic relationship with the dyad and because they were accessible to dyads by telephone. For each dyad, one PREP nurse functioned as the primary nurse, and another PREP nurse as a backup, so that someone who was familiar with the dyad provided assistance in the absence of the primary nurse. Questions by caregivers about changes in care receiver health were conveyed to the PREP nurse for evaluation. Then, after assessment by the PREP nurse, the problems were either treated by the nurse and/or caregiver or referred to another entity within the HMO. In standard home health, due to the relatively short duration of home health services, it was not possible for home health nurses to develop the relationship needed as a primary provider--usually, after a few visits, care receivers were discharged from home health. Frequently, a different nurse visited dyads at consecutive home visits. Caregivers called the clinic Advice Nurse when changes in health status occur. The HMO's Advice Nurse service was a group of nurses and there was no continuity with one nurse. In fact, calls were independently managed by each individual Advice Nurse.

The fifth difference was in the intervention strategies utilized by nurses, the basis of intervention strategies, and the frequency and purpose of meetings conducted to plan these strategies. PREP called for twice-weekly meetings of nurses and supervisory staff to discuss caregiving issues that were being addressed with each dyad. The goal of care planning was to treat any caregiving issue as comprehensively as possible and until the caregiver or dyad thought they could manage the issue satisfactorily. This meant that in addition to teaching the dyad how to perform or manage a specific task or issue, PREP nurses were to help dyads fit

tasks within the daily caregiving routine and to plan for ways to enrich tasks. PREP nurses were to recognize and incorporate knowledge the dyad already possessed and to address any concern the dyad had about the intervention strategies that would be tried. PREP nurses were to try as much as possible to give choices to dyads in the interventions used. PREP nurses were encouraged to read the scientific and clinical literature in order to provide dyads with the most comprehensive knowledge about a caregiving issue.

Standard home health staff met monthly for care planning purposes. The goal of care planning was to treat the problems which required skilled care to the extent that it stabilized the care receiver's health status and provided safety. Standard home health contained a strong teaching component in which nurses taught dyads about the care receiver's disease or about the specific skilled care tasks so that the dyad could safely assume responsibility for managing the disease and the tasks. For example, if the care receiver had diabetes, the nurse would teach the dyad about the diet, insulin and other medications, testing the blood for sugar, signs and symptoms of hyper- and hypo-glycemia, and when to see the doctor. Nurses were not encouraged to read current literature to incorporate current findings.

The sixth difference between PREP and standard home health was the focus on caregiver health. PREP nurses assessed caregiver health at the beginning of the intervention, monitored caregiver health problems throughout the study, and intervened as needed. In standard home health, the focus was on the care receiver's health problems and caregiver health problems were not addressed, because Medicare was an individual health benefit scheme.

The final difference was in the documentation of information provided to dyads. PREP provided dyads with a Family Health Diary, which was kept in the home. It was used for documenting the activities and problems identified by the dyad that were addressed by the PREP nurse, specific strategies the dyad used in managing the problem, evaluation notes by the dyad and nurse regarding the effectiveness of the strategies, as well as any health information that the dyad wanted to record. The purposes of the Family Health Diary were to remove the mystery of

the health management process, provide an opportunity for the dyad to manage their own health problems, and create an active rather than a passive role for the dyad. Information in standard home health was largely given verbally, although some written instructions regarding specific health problems or treatment regimens were left in the home.

In summary, PREP utilized a long-term care model, which focused on both caregiver and care receiver to address any caregiving issue that was a concern to the dyad and on caregiver health. Standard home health focused primarily on the care receiver and addressed skilled care needs for acute health problems as ordered by the physician. PREP focused broadly on the caregiving situation, on predictability in caregiving processes, and on enriching caregiving. Standard home health focused more narrowly on the care receiver health problem for which she/he was referred to home health. The PREP nurse functioned as a primary care provider and developed a long-term therapeutic relationship with the dyad. Although the standard home health nurse functioned as a primary nurse, the relationship was usually of short duration and ended when the care receiver was discharged from home health. In PREP, frequent care planning meetings were held to plan intervention strategies, and caregiving issues were addressed as comprehensively as possible. In standard home health, monthly care planning meetings were held, and health problems were addressed more narrowly.

PREP and standard home health represent two methods of managing health problems of older people who have a family/friend caregiver. More and longer involvement of nurses as called for by PREP suggests that it would require more resources than the system of standard home health. Differences in PREP and standard home health also suggest that the expected outcomes of each program would be different. The focus of PREP on the caregiving dyad, on caregiver preparedness, and on predictability and enrichment, suggest that outcomes which measure these concepts are important. The focus of standard home health on stabilizing acute care receiver health problems suggest that expected outcomes should focus on care receiver health status. Thus, it is important to evaluate the differences in the costs and outcomes of

PREP compared to standard home health as a method to manage health problems of older people.

Effects of Home Health Programs on Utilization, Costs, and Outcomes

New interventions such as PREP should be evaluated in a number of different ways. Two of the primary questions asked about a new intervention are "Did it have a beneficial effect?" and "How much did it cost?" When evaluating effects of interventions on participants, one not only wants to see positive effects but also an absence of untoward effects. Benefits should be conceptually linked to contents of the intervention and should have the capacity to change.

Costs of an intervention are based on the amount of intervention services utilized by those who receive it. In order to obtain comparable costs across study participants, it is important to adjust costs for inflation and for the amount of time participants remain in the study (length of follow-up). Evaluations of intervention costs often include the cost of non-intervention services because it is either hoped or expected that the services offered in the intervention will affect the utilization, and thus the cost, of non-intervention services. Ideally, when evaluating the effects and costs one hopes to see a beneficial effect and lower costs in the intervention group.

Several home-health intervention studies have recently been conducted in which utilization, costs, and outcomes were evaluated. Five home-health intervention studies in which utilization, costs, and outcomes of the intervention were evaluated in comparison groups are reviewed below.

Home-Health Nursing Intervention Studies

Four of the five studies reviewed utilized experimental designs. The fifth study utilized a quasi-experimental design in which comparison subjects were recruited first and followed for 1 year, and then treatment subjects were recruited and followed for 1 year. Home-health nursing intervention studies in this review include those which featured nursing services alone and nursing services in combination with other services. The review includes intervention studies

which featured registered nurses and those which featured nurse clinicians with advanced degrees. Studies were conducted with special and general populations of older people. Follow-up was provided in these studies for periods of 6 months to 1 year. Each study is described below including the nature of the intervention, the length of follow-up, the educational preparation of the nurse, other professions included in the intervention protocol, and treatment received by the comparison groups. Study design, sample, intervention descriptions, and types of provider utilized in each study are summarized in Table 2.1.

Description Of Treatments

Zimmer, Groth-Juncker, and McCusker (1984) designed an intervention in which a team composed of a physician, a medical nurse practitioner, and a social worker, provided primary health care to home-bound, chronically or terminally ill, or disabled patients for whom transportation to the clinic had become too costly or cumbersome. In addition, team members provided informal caregivers with physical and psychological support and education so that they could take on or continue home care. A 24-hour telephone service was also offered by the team to answer health-related questions and handle emergencies. Subjects received the intervention for 6 months. Care for the control group was not described.

In a study by Bergner et al. (1988), three treatments were compared in patients with chronic obstructive pulmonary disease (COPD). Subjects were followed for 1 year. One group received home visits by home-health nurses with special training in respiratory home care. Specific interventions by the respiratory home care nurses included complete medical history specific to respiratory disease, complete chest examinations, instruction in programs to improve activity tolerance, and instruction in the use of equipment. Frequency of home visits was determined by the nurse, but at least once-a-month visits were required. Contents of the special training were not described. The second treatment group received standard home care from regular home-health nurses. The third group received whatever care they needed through office visits to their physicians.

Table 2.1

Reference, Design, Sample, Intervention Description, and Providers in Five Home-Health Nursing

Intervention Studies

<u>Reference and Design</u>	<u>Sample</u>	<u>Intervention Description</u>	<u>Providers</u>
Zimmer, Groth-Juncker, & McCusker, 1984 Experiment Follow-up for 6 months	E = 85 C = 82 Home-bound, chronically or terminally ill or disabled adults	Provided primary health care, physical and psychological support and education to informal caregivers, 24-hour telephone service to answer health-related questions and handle emergencies	Team of physician, medical nurse practitioner with master's degree, social worker
Bergner et al. 1988 Experiment Follow-up for 1 year	Respiratory home care program = 99 Standard home care = 102 Office Care = 100 Home-bound patients with chronic obstructive pulmonary disease, ages 40-75	At least monthly home visits by a nurse. Activities of nurses included history of respiratory related parameters, complete chest examination, instruct in methods to improve activity tolerance, instruct and supervise in use of equipment	Home health nurse with special training in respiratory disease
McCorkle et al. 1989 Experiment Follow-up for 6 months	3 Groups, total N = 78 1. Specialized oncology home care program 2. Standard home care program by health care team 3. Office care (physician-only)	Personalized care to persons with advanced cancer and care to their families in the home setting. Specialized services by other disciplines as needed.	Master's prepared registered nurses, with preparation in symptom management, cancer treatments, pain management, advanced assessment, grief and mourning theory, communications systems, community resources and

Table 2.1 Continued

<u>Reference and Design</u>	<u>Sample</u>	<u>Intervention Description</u>	<u>Providers</u>
McCorkle et al. continued	Home-bound patients with lung cancer ^a		agencies, systems analysis, self support, professional role development, pathophysiology of death, and research theory and methodology
Hughes et al. 1990 Experiment Follow-up for 6 months	E = 119 at baseline C = 114 at baseline Severely disabled and terminally ill adult veterans referred to VA Hospital Based Home Care	Comprehensive, continuous care to patients at home	Team of physician, nurse, social worker, physical therapist, dietitian, and health technicians
Oktay & Volland, 1990 Quasi-experimental Follow-up for 1 year	E = 62 C = 48 Patients discharged from the hospital with chronic, long-lasting problems	Services included assessment, case management, skilled nursing, counseling, referrals, respite, education, support group, medical back-up, and on-call help	Registered nurse/social worker team, plus other in-home services as needed

^a Sample size not reported.

Hughes, Cummings, Weaver, Manheim, Braun, and Conrad (1990) compared a Veteran's Administration (VA) hospital-based home care (HBHC) team with customary care. The HBHC team was composed of a physician, nurse, social worker, physical therapist, dietitian, and aide technicians and provided comprehensive continuous in-home care to severely disabled and terminal veterans. The physician on the team was the primary physician for patients in the treatment group. The HBHC program also provided medications and supplies. The

interventions were not otherwise described nor was the education level or special training of nurses. The control group received customary care from either VA or non-VA providers. The intervention was provided for 6 months.

Oktaf and Volland (1990) designed a home-health intervention study which focused on meeting the health care needs of the older person and on education of the caregiver. The intervention provided post-hospital support to frail older persons and their families by a social worker and registered nurse team for 1 year. The amount of service provided depended on need, but all subjects received a minimum one nurse and one social worker visit per month. Support by nurses included traditional home-health nursing activities such as physical assessment, dressing changes, monitoring of medications, simplifying medication regimens, and communicating with physicians about changes in medications. Social workers became involved if there were family problems and if outside support was needed. The intervention also included a support group for caregivers and additional services such as respite care which were provided to families who needed them. A geriatric fellow (physician) and a psychogeriatric nurse provided consultation to staff at weekly staff meetings. Neither educational preparation for nurses nor special training was described. This is the only study which utilized a quasi-experimental design. Comparison group subjects entered the study the first year and received customary care. Treatment subjects entered the study in the second year.

McCorkle, Benoliel, Donaldson, Georgiadou, Moinpour, & Goodel (1989) compared three treatment conditions in patients with progressive lung cancer. One group received care from oncology home care nurses, one group received standard home care from regular home-health staff, and one group received whatever care they needed, except home care, from their physician during office visits. Intervention services were offered for 6 months. The specialized oncology home care program was delivered by nurses with a master's degree who were educated in care of patients with advanced cancer and in the care of patients' families. The specifics activities of the nurses were not described, but the educational preparation of the

nurses included symptom management, cancer treatments, pain management, physical assessment, psychosocial assessment, grief and mourning theory, communications systems, community resources and agencies, systems analysis, self support, professional role development, pathophysiology of death, and research theory and methodology. This treatment group also received specialized services by other disciplines.

Standard home care was delivered to the second group by a team composed of registered nurses, physical therapists, home health aides, medical social workers, occupational therapists, and speech therapists. Although the patient was assigned to team members appropriate to meet the patient's needs as identified on the referral, the entire team discussed treatment and case management plans, coordination of visits, length and intensity of services, need for consultation, coordination with physician, family and community resources, and discharge from care. The third group, which was considered the control group, received traditional treatment by physicians and did not receive any type of home care.

Study Design and Results

Each of these five studies examined the utilization of non-intervention services, and all but one (McCorkle et al. 1989) compared costs in intervention and comparison groups including costs of non-intervention services. All studies evaluated hospital and outpatient physician utilization, but varied on other utilization parameters evaluated. Some studies did not adjust for inflation or for the length of follow-up when imputing costs. Each study is reviewed below in relation to the length of time that utilization and cost data were collected, sample size, utilization parameters, utilization patterns, costs, and study outcomes. Outcomes, utilization parameters, and costs for each study are summarized in Table 2.2.

Zimmer et al. (1984), reported utilization, costs, and outcomes at 6 months. The sample size at 6 months was 51 in the intervention group and 47 in the control group. Utilization and costs were both adjusted for inflation and for length of follow-up. Utilization parameters included hospital admissions, nursing home admissions, physician office visits, emergency room visits,

Table 2.2

Reference, Outcomes, Utilization Parameters, and Costs in Five Home-Health Nursing Intervention

Studies

<u>Reference</u>	<u>Outcomes</u>	<u>Utilization</u>	<u>Costs</u>
Zimmer, Groth-Juncker, & McCusker,	Physical health--NS Psychosocial health--NS Morale--NS Patient Satisfaction-- Higher, NS Caregiver satisfaction-- Higher, p=.002	Hospital--Lower, NS Nursing home--Lower, NS Emergency room--Higher, NS Other out-of-home services--Lower, NS Outpatient--Lower, NS Home care--Higher, NS	Total Day-Costs-- Lower, NS Out-of-Home Day- Costs--Lower, NS In-Home Day- Costs--Higher, p=.008
Bergner et al.	Physical health--NS Mobility--Higher than standard home care group, lower than office care group, p=.02 Psychological Health--NS Walking rate--NS General well-being--NS	Not Reported	Total Health Care Costs--Higher, p=.02 Hospital--Higher, p<.05 Home Nursing-- Higher, p<.05 Special Needs-- Higher, p<.05 Outpatient--NS Emergency--NS Nursing Home-- Lower, NS Prescription Drugs--Higher, NS Other Home Services-- Higher, NS
McCorkle et al.	Pain Control--NS Symptom distress-- Lower, p<.03 Current Concerns--NS	Hospital Admissions-- Lower, NS. Hospital days--Lower, NS	Not Reported

Table 2.2 Continued

<u>Reference</u>	<u>Outcomes</u>	<u>Utilization</u>	<u>Costs</u>
McCorkle et al. Continued	Mood state--NS Enforced social dependency--Lower, $p<.02$ Health perception--Lower, $p<.05$	Hospital Admissions-- Lower, NS Hospital Total Length of Stay--Lower, NS Hospital Mean Length of Stay--Higher, NS	
Hughes et al.	Morale--NS Patient Satisfaction--NS Caregiver Satisfaction--Higher, $p=.01$ ADL--NS Mental Status--Higher, $p=.04$	Hospital Days-- Lower, NS Emergency Room-- Lower, NS Nursing Home-- Higher, NS Outpatient--Lower, $p=.001$ Home Care--Higher, NS	Hospital--Lower, NS Total Institutional Costs--Lower, NS Outpatient--Lower, $p=.0001$ Total Home Care Costs--Higher, $p=.001$ Total Costs--Lower, NS
Oktaay and Volland	Mortality--NS ADL--NS Mental Status--NS Caregiver Stress-- Lower, NS	Hospital Days-- Lower, NS Nursing Home Days-- Lower, NS Outpatient--NS	Total Costs--Lower, NS

Note: Significant results are reported for the intervention group.

ambulance rides, chairmobile rides, and in-home care by physician, nurse, social worker, LPN, home health aide, homemaker, home lab tech, and Meals on Wheels. All out-of-home services, except emergency room, were utilized at a higher rate by the comparison group subjects, and all in-home services were utilized at a higher rate by the treatment group subjects, but the differences were not significant. Although in-home service costs were significantly higher in the

treatment group, the average cost per day for all services (including intervention services) was less for intervention subjects than for control subjects, but the difference was not significant.

Outcomes measured by Zimmer et al. included patient physical and psychosocial health status, morale, and satisfaction with care, and caregiver satisfaction. There were no significant differences in physical and psychosocial health status, patient satisfaction, or patient morale. Caregiver satisfaction was significantly higher in the treatment group. In this study, lower, but not significantly lower, costs in the treatment group were accompanied by an increase in caregiver satisfaction with medical care.

Bergner et al.(1988) reported utilization, costs, and outcomes at 1 year. Sample size at 1 year was not reported. At baseline 301 subjects were entered in the study, with 99 subjects randomly assigned to the respiratory home care group, 102 subjects to the standard home care group, and 100 subjects to the office care group. Utilization and costs were adjusted for inflation, but not for length of follow-up. Utilization parameters included hospital and nursing home stays greater than one full day, and outpatient physician and emergency room visits. Utilization rates were not reported. Overall costs for the 1-year period were significantly higher for the respiratory treatment group than for either of the two comparison groups and were accounted for primarily by home nursing and hospital costs. Because costs were not adjusted for length of follow-up, the cost results are very difficult to interpret.

Outcomes measured by Bergner et al. included physical and psychosocial functioning, general well-being, and walking tolerance. The respiratory treatment group scored significantly higher on one mobility measure. Mean walking rate was virtually identical across treatment groups at 1 year. The respiratory treatment group scored higher than either comparison group on seven health subscales and lower on five health subscales, but none of these differences was significant.

Hughes et al. (1990), reported utilization, costs, and outcomes at 6 months. Six-month sample size was not reported, but at baseline the treatment group contained 119 subjects and

the control group contained 114 subjects. Utilization and costs were adjusted for inflation but were not adjusted for length of follow-up. Utilization parameters included VA and non-VA hospital, extended care, and nursing home admissions, emergency room and outpatient visits, and home care visits. Treatment group subjects utilized significantly more VA Intermediate Care bed days and significantly fewer VA outpatient visits. Treatment group subjects also utilized fewer non-VA hospital days and community nursing visits, more nursing home days, and fewer emergency room visits. VA costs were not significantly different in the two groups, but non-VA costs were significantly lower in the treatment group. Overall health care costs (VA and non-VA) were lower for the treatment group than for the control group, but the difference was not significant. Because costs were not adjusted for length of follow-up, conclusions about costs in this study cannot be made.

Outcomes measured by Hughes et al. included patient physical and cognitive functioning, and patient and caregiver morale and satisfaction. The treatment group scored significantly higher on cognitive status than the control group. Significant differences in physical functioning, patient morale and patient satisfaction were not found. No differences were found in caregiver morale, but caregiver satisfaction was significantly higher in the treatment group.

Okta & Volland (1990) reported utilization, costs and outcomes at 1 year. Sample size at the 1-year data collection was 62 in the treatment group and 48 in the control group. Utilization and costs of non-intervention services were adjusted for inflation, but costs of the intervention services were not. In addition, some utilization and costs were adjusted for length of follow-up and some were not, and both adjusted and unadjusted costs were combined in the analysis of total costs. Utilization parameters included hospital and nursing home days, physician and emergency room visits, home health nurse, home health aide, and social worker home visits, respite care, transportation, and other in-home services. Actual costs were available only for intervention services. Costs for hospital, nursing home, emergency room and physician services were estimated for both groups using average costs of the service in the

study's geographical area for 1 year during the study period. Costs for transportation, respite care, and home care were estimated for the control group, but actual cost for these services were used in the treatment group. It was reported that the overall cost per year for the treatment group was \$4,585 less than the cost for the control group and that this difference was not significant. During the course of the study the Diagnostic Related Groups (DRG) system of hospital reimbursement was implemented, which may have resulted in lower hospital costs in the treatment group. Because of this important threat of history to the internal validity of the study, because some costs were not adjusted for length of follow-up, and because the cost analysis was based on both adjusted and unadjusted costs, conclusions about costs in this study cannot be made.

Outcomes measured by Oktay and Volland included caregiver stress and patient physical and mental functioning. ADL and IADL functional status and mental status were not significantly different in the two groups. Caregiver stress was lower in the treatment group, but the difference was not significant.

McCorkle et al. (1989) reported only utilization and outcomes at approximately 5 months. A sample of 166 patients were entered in the study, and 78 patients were included in the 5-month analysis. Because utilization results were reported only on subjects who completed the fourth interview, adjusting for the length of time in the study was not required. Utilization parameters included hospital admissions and hospital days. The average number of hospitalizations and the total length of hospital stay was lower in the oncology home care group, but the differences were not significant. The average length of hospital stay was higher for the oncology home care group than the two comparison groups. Thus, fewer subjects in the oncology home care group were admitted to the hospital, but when admitted, they were hospitalized for longer periods of time. Although costs of hospitalization were not reported, it is likely that costs were less for the oncology home care treatment group.

Outcomes measured by McCorkle et al. included symptom distress, pain, current

concerns, mood states, functional status, health perceptions, and complications. The three groups did not differ significantly on pain, current concerns and mood states and the two home care groups were very similar in all outcome measures. Both home care groups scored significantly better on symptom distress, and experienced symptom distress later than the office care group. The office care group experienced social dependency earlier than the two home care groups, but also reported improved health perceptions over time, which neither home care group reported. In this study, home care was effective in reducing symptom distress and social dependency, and the type of home care did not make a difference.

In summary, none of the studies reported a significant negative effect for the treatment group, that is subjects were not harmed as a result of the intervention. Significant beneficial effects for the older person in treatment groups were reported for mobility, mental status, and patient satisfaction. No significant differences were reported for mortality, ADL, IADL, physical and psychosocial health status, morale, general well-being, and patient satisfaction. For caregivers, significant differences were reported for satisfaction. One reason for lack of effects can be a poor conceptual link between the intervention and the outcome. In these studies, because intervention protocols were either not specified or poorly specified, and because the conceptual underpinnings of the interventions were not explicit, it is difficult to draw conclusions about the effects of the interventions on study outcomes.

Three of the five studies reported cost savings for the treatment group that were non-significant. However, cost estimates were derived without adjusting for length of follow-up in two studies and without adjusting for inflation in the other, and by mixing adjusted and nonadjusted costs. The fourth study reported significantly higher costs for the treatment group. The fifth study report only utilization, and not costs. The three studies that reported lower costs for the treatment group, also reported lower hospital utilization rates for the treatment group. The two interventions that included a physician reported fewer physician offices visits, presumably because physicians were making home visits. Due to the lack of specificity of intervention

protocols, poor conceptualization of the links between the intervention and study outcomes, and methodological weaknesses in the measurement of utilization and costs, a gap remains in our knowledge of the effectiveness and costs of home-health nursing interventions designed to meet the long-term health care needs of older people.

Hypothesized Effects of PREP on Outcomes, Health Service Utilization, and Service Costs

This study used a three-variable framework of utilization, cost, and caregiver outcome to compare two alternative means of providing home-health care to older people and their caregivers. The two alternatives were PREP and standard home health. This section begins with a description of caregiver outcomes of interest in this study followed by the hypothesized utilization and cost effects of PREP.

PREP Outcomes

Outcomes measured in previous research on the more broadly focused community care programs as well as in the more narrowly-focused home-care programs reviewed above have generally not shown improvements in treatment group subjects compared to control group subjects (Bergner et al. 1988; Hedrick, & Inui, 1986; Hughes et al. 1990; McCorkle et al. 1989; Oktay & Volland, 1990; Weissert, 1985; Zimmer et al. 1984). Outcomes typically have included physical functioning, mental functioning, nursing home placement, and longevity. The prevalence of these variables in available studies probably reflects their perceived importance, as well as the judgment that they are most likely to be affected by the provision of home care services. However, three weaknesses of these studies make it difficult to evaluate the reasons for lack of effects. First, intervention protocols for specific intervention services have not been specified. Second, the conceptual underpinnings of interventions have not been specified and thus the link between the intervention and outcomes is unclear. Third, the sensitivity of outcome measures has seldom been addressed, and many measures, especially measures of functioning, are probably not very sensitive to small clinical changes (Stewart & Archbold, 1992a, 1992b).

The outcomes of interest in this study were caregivers' perceptions of preparedness,

predictability, and enrichment in caregiving. These outcomes were selected because they were the concepts underpinning the intervention. PREP nurses focused their activities on improving caregivers' preparedness, on the predictability of caregiving routines, and on enriching caregiving. PREP was theoretically based on role theory in which caregiving was viewed as a role to be learned. The overall purpose of interventions by PREP nurses was to assist caregivers in performing their role as caregiver.

Preparedness was defined as the caregiver's evaluation of how prepared she/he was to meet the care receiver's needs and handle the stress of caregiving. In an earlier study, the Caregiver Relief Study, investigators found that caregivers were often not prepared to assume the role (Archbold & Stewart, 1988). Thus a primary focus of the intervention was on the preparedness of caregivers to provide the care needed by the care receiver. Nurses addressed caregiver preparedness in the following areas: personal care (e.g., lifting, dressing); housekeeping (e.g., meal preparation); protection (e.g., preventing falls); transportation (e.g., taking to appointments); financial, legal, and health decisions (e.g., assisting with banking); behavior problems (e.g., repetitive questions, yelling); and medically-related areas (e.g., medications, pain management, equipment). Study investigators hypothesized that increased preparedness by caregivers would reduce the amount of caregiver role strain.

Predictability was defined as stable caregiving patterns or routines. Nurses' activities designed to improve predictability included assessment of daily routines and suggestions regarding ways to simplify them or organize them differently. Predictability in caregiving could: (a) relieve the need for constant vigilance allowing for rest and relaxation; (b) require less attention so that effort could be directed toward specific tasks or activities, and (c) reduce the stress response in times of turbulence or transition, such as the transition from hospital or nursing home to home (Archbold et al. 1993).

Enrichment was defined as the process of enhancing caregiving through the pleasurable, the aesthetic, or the ceremonial. Nursing activities to enrich caregiving included encouraging

participants to plan activities they enjoyed, to include something pleasurable or meaningful in caregiving tasks, and to modify previously satisfying rituals to current circumstances. Study investigators found that most caregivers could identify at least one benefit of caregiving but they were unable to find literature focused directly on increasing the positive aspects of caregiving. Enhancement of positive aspects of caregiving could serve to minimize the negative consequences and increase the rewards experienced by caregivers.

The amount of preparedness, predictability, and enrichment experienced by caregivers was expected to influence the utilization and thus the cost of health services. Overall, dyads who were well-prepared, had predictable caregiving routines, and experienced enrichment in caregiving were expected to use fewer health services. For example, caregivers who were well-prepared were expected to handle new symptoms or health problems themselves, because they would understand the disease process and how to manage a variety of problems associated with a particular disease. Conversely, caregivers who were not well-prepared to manage all or most aspects of caregiving were expected to see the doctor or visit the emergency room when new symptoms or problems occurred because they would not know the seriousness of the new problems or what to do about them. Caregivers who were not well-prepared were expected to use more hospital services because they would wait too long to seek treatment for new symptoms, which could then progress into serious problems requiring hospitalization. In the extreme, some caregivers who were not well-prepared were expected to provide unsafe care resulting in accidents or complications requiring physician care, emergency care, ambulance services, hospitalization, and/or nursing home care.

Predictability in caregiving functions to reduce stress (Archbold et al. 1993). Dyads who were less stressed were expected to be healthier and thus to use fewer health services. Caregivers who developed strategies to enrich caregiving and who appreciated the positive rewards of caregiving were expected to continue caregiving longer, thus avoiding long-term institutional placement.

Utilization and Cost Effects of PREP

A comparison of the patterns of utilization of PREP and standard-home-health nurses by intervention and control dyads was the primary focus of this study. Utilization refers to the actual quantity of a service that is consumed and includes measures of contact (e.g., intensity) and volume (Shortell, 1984). The analysis of utilization patterns aids the understanding of the relationship between use of services and health status outcomes (Shortell, 1984). Utilization of PREP and standard home health included measures of contact and volume for all activities of PREP and standard-home-health nurses in the delivery of nursing care to study participants.

It was hypothesized that PREP would influence the utilization and thus the cost of many health and social services by study participants. Older people with long-term health problems utilize many different health and social services in efforts to manage their health problems and to relieve some of the burdens of informal caregivers. When new services, such as PREP, are added, they can have the effect of reducing the utilization of some non-intervention services and increasing the utilization of others. Interventions which utilize nurses can be particularly influential on the use of non-intervention services because of nurses' unique knowledge and skills among long-term care providers. They have knowledge and skills for evaluating and managing the health problems themselves, and as well as the knowledge and skills for evaluating the need for other health and social services.

It was hypothesized that the PREP intervention would offset the utilization of some services and induce demand for other services. Thus, the cost of PREP was conceptualized as the cost of nursing services as well as the cost of a comprehensive group of non-nursing services. In the sections which follow, hypothesized offset effects of PREP on service use are described, followed by its hypothesized induced demand effects.

Offset Effects of PREP on Care Receiver Service Utilization

It was hypothesized that PREP would offset the utilization of the following care receiver services: hospitals; emergency services; nursing homes and other long-term care institutions;

Advice Nurse; and pharmacy. The hypothesized offset effects for each service is described below.

Offset effects on hospitalization. It was hypothesized that PREP would reduce the utilization of hospitals by care receivers for a number of reasons. First, if caregivers felt more prepared for caregiving as a result of PREP, they would be able to take the care receiver home from the hospital sooner. Second, the availability of the PREP nurse, who was familiar with the dyad and with the caregiving situation could facilitate earlier discharge through preparation of the caregiver and through monitoring of the dyad after discharge. Third, the availability of the PREP nurse via the PREP Advice Line could help the caregiver to resolve problems, which otherwise might require rehospitalization. Fourth, the PREP nurse, by communicating with hospital physicians and discharge planners, could facilitate earlier authorization for discharge by the care receiver's physician. Finally, it was expected that assessment of health problems by PREP nurses would result in referral to physicians for outpatient management and thus prevent health problems from becoming so acute as to require hospital care.

Four of the five studies reviewed earlier reported reduced hospital utilization for patients receiving enhanced home-health care by nurses. In addition, telephone intervention studies utilizing registered nurses have been successful in decreasing hospitalization rates. Schler, Granadillo, & Vargas 1985, in a trial of a 24-hour telephone advice service for home care patients by an interdisciplinary team, found that 76% of problems could be solved by telephone alone, and that hospital admissions decreased 91% from 22 in the 4-month control period to 2 in the 4-month intervention period. Weinberger et al. (1988) evaluated an intervention in which registered nurses followed patients closely after discharge from the hospital and attempted to resolve problems. They found that the greatest reduction in hospital use occurred in a high-risk subgroup and attributed these reductions in hospital use to shorter, less intensive hospital stays rather than fewer admissions.

Offset effects on emergency services. It was hypothesized that PREP dyads would use

fewer emergency room and urgency care services for several reasons. First, it was anticipated that PREP caregivers would become more prepared to handle some emergencies, particularly those that occurred repeatedly. Second, it was anticipated that through ongoing PREP nurse assessments, health problems would be discovered early, before they became emergencies, and referred to clinic physicians. In addition, it was expected that the PREP nurse would be able to prevent some emergency utilization by answering caregiver questions on the PREP Advice Line. As noted above, Schler et al. (1985) reported that a majority of problems could be handled by telephone alone. They also reported emergency room use decreased 63%, from 38 in 4-month control period to 14 in the 4-month intervention period. Because hospital, emergency, and urgency care services would be decreased, it was hypothesized that ambulance service utilization also would also be reduced.

Offset effects on nursing home utilization. PREP was hypothesized to offset nursing home utilization by delaying nursing home and other long-term institutional placement for some dyads. If PREP caregivers felt more prepared to care for the care receiver and experienced less strain, they would be able to continue caregiving longer, thus delaying nursing home placement. This hypothesis was supported by evidence from the intervention study by Oktay and Volland (1990), in which mean nursing home days for the comparison group was 146, compared to 86 for the treatment group. On the other hand, it was also expected that PREP nurses would encourage some caregivers to think about institutionalization because of high strain, low mutuality and low rewards, and a lack of help in caregiving, thus resulting in higher costs for long-term institutional care.

Offset effects on Advice Nurse utilization. It was hypothesized that because of the availability of the PREP Advice Line, the HMO's Advice Nurse would be utilized less frequently by intervention dyads.

Offset effects on outpatient pharmacy utilization. It was hypothesized that medication utilization would decrease as a result of PREP because PREP nurses would emphasize

reductions in medication use and simplification of medication regimens.

Induced Demand Effects of PREP on Care Receiver Utilization

PREP was expected to induce demand for several services, including outpatient primary care services (physician, nurse practitioner, and physician assistant), community social services, mental health/counseling, durable medical equipment, and medical supplies. These effects are described below.

Induced demand effects on outpatient primary care utilization. It was hypothesized that PREP would result in the increased utilization of outpatient primary care services. PREP used registered nurses with home health experience to provide its services. Nurses at this level can be expected to identify new health problems or health problems which need medical attention, but they are not educationally prepared to treat these problems. Although it was expected that some health problems would be managed by the nurse after telephone contact with the physician, it seemed likely that PREP nurses would more often refer care receivers to their physicians to assess health problems, so that the overall effect would be higher utilization for PREP subjects. This hypothesis is supported by Oktay and Volland (1990), and Bergner et al. (1988) who also reported higher outpatient utilization rates in the treatment groups. It also seems more likely that physicians, once they are aware of new or exacerbated problems, would want to evaluate them directly. Two home-health intervention studies that reported lower outpatient utilization rates in the treatment group each utilized a team approach which included a physician, and in one study, the physician made home visits (Hughes et al. 1990; Zimmer et al. 1984).

Induced demand effects on community social service utilization. It was hypothesized that PREP would result in an increase in the utilization of community social services, such as respite care, adult day care, and home-delivered meals, because PREP nurses would try to improve caregiving by enhancing services. This would be especially true for caregivers who experience high strain or caregivers who provide a lot of care with little assistance from informal

sources.

Induced demand effects on mental health/counseling service utilization. It was hypothesized that PREP would increase the utilization of mental health/counseling services. PREP nurses were expected to assess care receivers' mental health and because of their long-term follow-up would be more likely to encounter mental health problems than home health nurses. It was also expected that PREP nurses would be aggressive in obtaining treatment for these problems.

Induced demand effects on durable medical equipment and medical supply utilization. It was hypothesized that PREP would increase the utilization of durable medical equipment because PREP nurses would either get additional equipment in order to make caregiving easier for the caregiver or would encourage caregivers to obtain equipment themselves. For example, a hoist lift might be obtained to assist the caregiver in getting the care receiver out of bed and to prevent musculoskeletal injuries in the caregiver. Similarly, it was hypothesized that PREP would result in higher utilization of medical supplies because PREP nurses would recommend supplies to caregivers to make caregiving easier or safer.

Effects of PREP on Caregiver Utilization

It was hypothesized that PREP would offset hospital and nursing home utilization by caregivers because their health problems would be monitored and treated by physicians in the outpatient setting. Thus, health problems could be prevented from becoming acute enough to require hospital treatment.

It was hypothesized that PREP would induce demand for outpatient primary care services for caregivers. PREP researchers found in the Caregiver Relief Study that 20% of caregivers delayed seeking help for their own health problems. Because PREP focused on caregiver health and PREP assessments also included assessment of the caregiver's health, it was expected that PREP nurses would encourage caregivers to see their physicians in order to stay healthy so that they would be able to continue to provide care. It was also hypothesized that

PREP caregivers would utilize more mental health/counseling services. Because PREP nurses would be assessing caregiver health over an extended period of time, they would encounter more mental health problems and would also recommend or try to obtain treatment for some caregivers.

Summary

The hypothesized effects of PREP on care receiver and caregiver service utilization are summarized in Table 2.3. Because the costs associated with the services hypothesized to be

Table 2.3

Hypothesized Effects of PREP on Care Receiver and Caregiver Service Utilization

User	Offset Effects	Induced Demand Effects
Care Receiver	Hospital	Outpatient Primary Care
	Emergency/Urgency Care	Community Social Services
	Long-term Care Institutions	Mental Health/Counseling
	Advice Nurse	Durable Medical Equipment
	Pharmacy	Medical Supplies
	Ambulance	
Caregiver	Hospital	Outpatient Primary Care
	Nursing Homes	Mental Health/Counseling

offset by PREP were generally higher than those hypothesized to be increased by PREP, the cumulative effect would be one of cost offsetting and PREP would save money on non-PREP

services. If cost savings on non-PREP services are more than the additional costs of adding PREP nursing services, then the overall cost of PREP, including the cost of non-PREP services, would be less than standard home health. Then PREP would be a less expensive method of managing long-term health problems in older people than standard home health.

CHAPTER 3

METHOD

The focus of this supplemental pilot study was on the development of methods to measure utilization, costs and outcomes that could be used to compare the PREP intervention with standard home health in a larger clinical trial. These methods are described in this chapter. The chapter begins with a description of the study design in the two phases of this study--the developmental phase and the pilot clinical trial. Next, the study setting is described, followed by a description of the study sample in each of the two phases. Data collection methods are then presented by study aim. First, methodology for collecting PREP nurse and home health nurse utilization data are presented. Next, methodology for pricing PREP nurse and home health nurse services is presented. Next, methodology for collecting utilization data and for pricing non-PREP services is presented, followed by the evaluation plan for comparing total health care costs in PREP dyads and usual care control dyads. Data collection methods for the outcome of PREP, as measured by a single caregiver outcome scale, concludes this chapter.

Design

The PREP Evaluation Study and this supplemental cost and outcome study were conducted in two phases: (a) the developmental phase; and (b) the pilot clinical trial. Based on the results of this pilot clinical trial, PREP investigators plan to revise the intervention and test it in a larger randomized clinical trial.

Developmental Phase

The purpose of the developmental phase was to implement the intervention with a small purposive sample of caregiving dyads in order to develop the clinical recording procedures for the PREP nurse visits and test the feasibility of the intervention's caregiver support protocols. In addition, the purpose of this supplemental study in the developmental phase was to collect non-HMO health service utilization and expense data from dyads in order to evaluate data collection methods and refine procedures and instruments to be used in the pilot clinical trial. Because

these dyads were recruited only for developmental purposes, they were not included in the comparison of PREP with standard home health in the pilot clinical trial.

The developmental phase began on February 1, 1991. Developmental dyads remained in the study throughout the first six months of the pilot clinical trial until December 31, 1991. This provided some experience with longer term implementation of the intervention and showed the feasibility of collecting service utilization and expense data from caregivers over a longer time period.

Pilot Clinical Trial

The pilot clinical trial utilized a quasi-experimental design to compare PREP with standard home health. Dyads (N=25) meeting identified criteria were recruited from home health referrals and non-randomly assigned to the control and experimental conditions. Three dyads were lost to follow-up. The control group (N=11) received standard home health; the intervention group (N=11) received standard home health plus the additional services of PREP. Protocols for an economic analysis to compare PREP with standard home health were developed. Costs in the intervention and control groups were based on total health and social service utilization by care receivers and selected health service utilization by caregivers. A single caregiver outcome was compared in the two groups.

Setting

The setting for this study was the home health department of a large pre-paid group-practice HMO in the Pacific Northwest. At the time of this study--1991--the number of HMO members age 65 and older was increasing. In 1989, 43,257 of the 366,275 (12%) HMO members were 65 years of age or older, and in 1991, 47,880 of the 372,000 (13%) HMO members were 65 years of age or older (Kaiser Permanente, 1992). The HMO participated in national programs and offered special benefit packages aimed at meeting the health care needs of its older members. It participated in a Medicare Risk contract with the Health Care Financing Administration, which paid the HMO a capitated amount for Medicare benefits. This allowed the

HMO to design alternative benefit packages for older persons within the capitated amount. The HMO was a participant in the National Social HMO Demonstration Project (S/HMO), which covered Medicare Part A and B services, physical exams, drugs, eyeglasses, hearing aids, and an expanded chronic care benefit for people who would otherwise qualify for admission to nursing homes under rather strict State of Oregon criteria. The HMO also offered a less comprehensive expanded benefit package, Medicare Plus, which covered eyeglasses, hearing aids, and prescription drugs in addition to standard Medicare benefits.

The HMO home health department was a combined home health/hospice agency. At the time of this study, the number of older persons served by the home health department was increasing. From 1990 to 1992 the active caseload for the average week increased from 350 to 450 clients. Approximately 75% of these were over the age of 65. The percentage of home visits to clients over the age of 65 increased from 72% to 76% during the same time. Twenty percent of home visits in 1991 were made to members with S/HMO benefits and 42% of home visits were made to members with Medicare Plus benefits.

Sample

The sample for this pilot study was obtained from the population of HMO members referred to the HMO's home health department. Subjects for this supplemental study were recruited differently in the two study phases. Sample recruitment and sample characteristics in each phase is described below.

Sample Recruitment--Developmental Phase

This supplemental study was approved after the developmental phase of the PREP Evaluation Study began and three dyads were receiving PREP services. These three developmental dyads were approached to participate in this supplemental study of the costs associated with PREP. The three dyads had been recruited for the developmental phase while the care receiver was in the hospital. Although the care receivers did not qualify for home health, they had problems appropriate for PREP services. Specifically, they met the following

criteria: (a) the care receiver was over the age of 65; (b) the care receiver had a caregiving problem for which a PREP protocol had been developed; (c) the care receiver had an identified primary caregiver; (c) the care receiver lived within a 20-mile radius of the research center; and (e) both caregiver and care receiver gave written informed consent to receive the PREP intervention.

A letter (see Appendix A) was sent to each of the developmental dyads explaining that they would be contacted by telephone by the researcher to ask them to participate in a supplemental study to evaluate the costs associated with PREP. The researcher then called caregivers on the telephone to explain the study (see Appendix B for script), and if the caregivers consented verbally, arranged a home visit. One caregiver declined to participate when contacted by telephone and two agreed. The caregiver who refused to participate cared for her mother and worked in her husband's business, and said she was too busy to participate in the supplemental study. A home visit was made by the researcher to the two dyads who agreed, the study was explained again, and the consent (see Appendix C) was read and signed by both the caregiver and care receiver.

Sample Recruitment--Pilot Clinical Trial

In the pilot clinical trial, subjects were recruited to participate in both the evaluation of PREP and this supplemental methodological study to develop measures of utilization, costs, and outcomes of PREP. Consent for the pilot clinical trial included consent for both studies (see Appendix D). Twenty-five caregiving dyads were recruited to participate in the PREP study and this supplemental study. Subjects were recruited from all referrals to the HMO home health department from two HMO hospitals, from skilled nursing facilities, and from HMO outpatient clinics. Eight of the 25 referrals were initiated when the care receiver was discharged from the hospital. Ten were initiated when the care receiver was discharged from a skilled nursing facility following hospitalization, and seven were initiated after outpatient physician contact.

The first 17 dyads were recruited during July through October, 1991 and remained in the

study until December 31, 1991. Of these 17, nine were assigned to the intervention group and eight were assigned to the control group. Two were lost to follow-up. The next four dyads, all control dyads, were recruited by the end of November, 1991, and remained in the study for approximately three months until three caregiver interviews, spanning 10 weeks, were completed. The remaining four dyads, all intervention dyads, were recruited in January, 1992, and remained in the study until it ended, on March 31, 1992. One of these was lost to follow-up.

Recruitment Criteria

Subjects in the pilot clinical trial met the following criteria: (a) the care receiver was 65 years of age or older; (b) the care receiver needed daily assistance at home for one month or more in at least one of four areas (personal care, behavior management, medical management, or protection); (c) there was an identified primary caregiver; (d) the care receiver lived within a 20-mile radius of the research center; (e) and either both the care receiver and caregiver gave written informed consent, or the caregiver gave written proxy consent for care receivers who were unable to consent because of cognitive or physical limitations.

Because the PREP Evaluation Study was a pilot study, additional exclusion criteria had to be added for a number of reasons. PREP nurses were involved in other aspects of the intervention than providing direct service to participants, such helping to write clinical protocols, designing participant tracking procedures on the computer, designing charting forms, and writing a paper for presentation at a national gerontology meeting. Because of the time constraints these additional activities imposed, several additional exclusion criteria were developed which eliminated participants who would require frequent nursing visits. In addition, in order to prevent confounding of results, participants who were already receiving expanded home care benefits, such as the S/HMO or hospice were also excluded. These additional exclusions eliminated many prospective participants, who could have been served by PREP, but were not because of the pilot nature of the study. In the full clinical trial these exclusions will not apply.

Subjects were excluded for the following additional reasons: (a) they were receiving

hospice services; (b) they were receiving expanded home care benefits of the S/HMO; (c) they required a high intensity of care, such as daily or weekend visits; (d) they needed specialized acute care; and (e) the continuation of caregiving at home seemed uncertain and/or care receivers seemed likely to be admitted to a nursing home or hospice.

Most care receivers referred for physical therapy only (PT only) were excluded as well. PREP Evaluation Study investigators decided that some PT-only referrals could be asked to participate in PREP even though they had no nursing orders, because they were appropriate in all other respects and because the investigators wanted to implement the intervention in a variety of caregiving situations. On the other hand, they did not want all PT-only participants. If one of the PREP nurses was ready to admit another dyad, and PT-only referrals were the only ones available, they were recruited. Thus, PT-only participants were recruited, depending on whether the nurses needed to add participants and depending on the number of PT-only participants included already. The reasons dyads did not meet study criteria are summarized in Table 3.1.

Recruitment Procedures

All referrals to the HMO home health department were reviewed daily by the PREP nurse assigned to recruitment. The referral form contained the following information: (a) care receiver demographic information; (b) medical diagnoses and surgical procedures; (c) dates of hospitalization and nursing home stay; (d) orders for home health care providers; (e) the name of the caregiver; (f) current medications; and (g) prognosis. After reviewing the referral, the PREP nurse called caregivers who met study criteria and asked them to participate in PREP (see Appendix E for script). If they agreed, a home visit was arranged by the PREP nurse to explain the study in depth and obtain written consent. The recruitment summary is displayed in Figure 3.1. Refusals represent refusal to participate in the research study, not refusal for home health.

Table 3.1

Reasons Dyads Did Not Meet Study Criteria

	N	Percent
S/HMO	195	28.2
Adult Foster Home	88	12.7
Hospice	80	11.5
Intermediate Care Facility	80	11.5
Special Acute Care Needs	77	11.2
Location > 20 Miles	53	7.6
Lack of Caregiver/Inappropriate Caregiver	42	6.0
Physical Therapy Only	42	6.0
Uncertain Continuation of Caregiving	16	2.3
Daily/Every Other Day Visits	12	1.8
Other	8	1.2
Total	<u>693</u>	<u>100.0</u>

Loss to Follow-up

Three of the 25 dyads who agreed to participate in PREP were lost to follow-up before any data could be collected. One caregiver decided within days after signing the consent that she did not want to participate because her husband, the care receiver, was readmitted to the hospital. She thought his medical condition was too unstable, that there was already too much confusion in their home, and that there would be too much additional stress if they participated in the study. In the second case, the care receiver refused to cooperate with the study protocols for

Figure 3.1

Recruitment Summary

Dyads Screened			
736			
Ineligible		Recruitment Phone Call	
675		61	
Ineligible	Refused	Scheduled for Home Visit	
16	12	33	
	Ineligible	Refused	Consented
	2	6	25
		Control	Intervention
		12	13

data collection--he would not allow his wife, the caregiver, to answer questions in the interview unless he was present. The third family was dropped from the study by the PREP investigators because the identified caregiver left the care receiver's home shortly after entering the study and did not participate in caregiving on a consistent basis. She was physically unable to complete the first interview and was unavailable for subsequent interviews. Twenty-two subjects consented to participate and remained in the study. The intervention and control groups each included 11 dyads.

Sample Characteristics--Developmental Phase

The caregiver in the first developmental family was an 82-year-old, African-American male. He was a friend of the care receiver and lived with her in her house. The care receiver was an 89-year-old, African-American female who had congestive heart failure and anasarca. The caregiver in the second developmental family was a 24-year-old, Caucasian great-niece of the care receiver. They lived together in the care receiver's home. The care receiver was a 94-year old Caucasian female who had cardiac disease, hypertension, and pleural effusions.

Sample Characteristics--Pilot Clinical Trial

The sample of care receivers as a whole (N=22) was 50% female and predominantly Caucasian (95%). Most were married (82%) and had a high school or greater education (73%). Most lived with a spouse (82%), and the rest lived with an adult child (18%). Care receiver demographic and social characteristics by group are summarized in Table 3.2. Control care receivers were more often female and Caucasian and less often married and living with a spouse than intervention care receivers, but these differences were not significant. Control care receivers were significantly younger ($M = 74$, $SD = 6.0$) than intervention care receivers ($M = 80$, $SD = 5.3$), $t(19.68) = 2.17$, $p < .05$.

The primary medical diagnosis for the 11 control care receivers included the following:

- cerebral vascular accident (N=4)
- fractures (N=3)
- diabetes mellitus (N=2)
- amyotropic lateral sclerosis (N=1)
- dementia (N=1)

One care receiver had an additional diagnosis of end stage renal disease and was receiving renal dialysis treatments. Three control care receivers were referred to home health following surgery--coronary artery bypass surgery, below the knee amputation, and internal fixation of fractures.

Table 3.2

Care Receiver Demographic and Social Data

	Control Group	Intervention Group
Gender (% Female)	55%	27%
Age		
Range	66-84	70-87
Mean*	74	79
Marital Status (% Married)	73%	91%
Ethnicity (% Caucasian)	100%	91%
Living Arrangements (% Living with Spouse)	73%	91%
Education (% High School Grad or Greater)	73%	73%

* $p < .05$, two-tailed.

The primary medical diagnosis for the 11 intervention care receivers included the following:

- cerebral vascular accident (N=5)
- dementia (N=2)
- rheumatoid arthritis (N=2)
- cancer (N=1)
- diabetes mellitus (N=1)

One intervention care receiver was referred following surgery for total knee arthroplasty, and one following a craniotomy.

Care receivers were referred to the home health department for a variety of home health services. Nine care receivers were referred for PT only. Six care receivers were referred for

skilled nursing only. Seven care receivers were referred for physical therapy and skilled nursing. One care receiver was referred for skilled nursing, occupational therapy, and speech therapy, and two were referred for skilled nursing, physical therapy and occupational therapy.

The sample of caregivers as a whole (N=22) was 77% female and predominantly Caucasian (86%). All caregivers were married and their relationship to the care receiver was most often that of spouse (82%). Most had a post-high school education (68%) and were retired (64%). The estimated annual income of a majority of the sample was less than \$20,000 per year (64%). Caregiver demographic and social characteristics by group are summarized in Table 3.3. Although not significantly different, control caregivers were more likely to be Caucasian and have a greater than high school education and less likely to be a spouse of the care receiver and to have an annual income of less than \$20,000. Control caregivers were significantly younger ($M = 62, SD = 11.6$) than intervention caregivers ($M = 74, SD = 8.3$), $t(18.14) = 2.62, p < .02$.

Assignment to Group

Whenever possible, participants were assigned to the control and intervention group, using a table of random numbers (see Appendix F for randomization procedure). At the outset of the project, sealed envelopes numbered 1 to 24 each contained an A (control) or a B (intervention) code, with 12 numbers assigned to each group. Several unforeseen events, however, prevented random assignment from occurring. These events all related to scheduling conflicts with PREP nurses; dyads were not assigned to groups based on any assumption that PREP would or would not benefit them. The reasons for non-random assignment follow. First of all, because of unexpected illness of one of the PREP nurses and family problems in another, two of the PREP nurses were not available when the first subjects were recruited. Therefore, the first two subjects were assigned to the control group. Secondly, the third PREP nurse was a home health nurse who did not have experience with the HMO home health department and it was thought that it would take too much time and too many resources to orient her. It was decided that she could see patients who met study criteria but were referred to home health for

Table 3.3

Caregiver Demographic and Social Characteristics

	Control Group	Intervention Group
Gender (% Female)	73%	82%
Age		
Range	39-77	52-80
Mean*	62	74
Marital Status (% Married)	100%	100%
Relationship to Care Receiver (%Spouse)	73%	91%
Ethnicity (% Caucasian)	91%	82%
Education (% High school grad or greater)	82%	64%
Employment Status (% Retired)	64%	64%
Annual Income (% Less than \$20,000)	50% ^a	90% ^a

^a N=10

* $p < .05$, two-tailed.

PT only and had no skilled nursing needs. In order to assure that she actually had some dyads to see, these PT-only dyads were not randomly assigned. (PT-only dyads were also assigned to the control group.) A third factor was that some of the care receivers lived in a neighboring state (Washington), and two of the nurses did not have a nursing license for that state. While waiting for PREP nurses to obtain a valid nursing license, one care receiver was assigned to the control group. Finally, after the first admission for each nurse, investigators realized that it would be difficult for nurses to admit more than one dyad at the same time or near to the same time. In an

attempt to space admissions for PREP nurses, some dyads were assigned to the control group.

Because subjects were not randomized into the intervention and control groups, it is likely that the groups were not equivalent. Equivalency of the groups at baseline was tested by comparing them on a number of demographic, social, functional, and health characteristics. Care receiver characteristics at baseline are summarized in Table 3.4. Intervention care receivers were significantly older ($M = 80, SD = 5.3$) than control care receivers ($M = 74, SD = 6.0$), $t(19.68) = 2.17, p < .02$. There was no significant difference between the groups on all other measured characteristics. However, non-statistically significant differences were observed. Care receivers in the intervention group were more likely to be male, married, less dysfunctional in ADL, more dysfunctional in IADL, and have more cognitive impairment.

Caregiver characteristics at baseline are summarized in Table 3.5. Caregivers in the intervention group were significantly older ($M = 74, SD = 8.3$) than control group caregivers ($M = 62, SD = 11.6$), $t(18.14) = 2.62, p < .02$. Intervention caregivers also experienced significantly less difficulty managing the care receiver's medical needs ($M = 1.8, SD = .7$) than control caregivers ($M = 2.6, SD = 1.0$), $t(15.78) = 2.17, p < .05$. There was no significant difference between the groups on a large number of demographic, social, health, and caregiving variables. However, non-statistically significant differences were observed. Caregivers in the intervention group were more often female, a spouse, and had less education than control group caregivers. Intervention caregivers had been caregiving longer, experienced less mutuality with the care receiver, provided more direct care, experienced less predictability in caregiving, but also experienced less strain and greater rewards from caregiving than control caregivers. Intervention caregivers were less physically healthy but more emotionally healthy than control caregivers.

The differences in baseline characteristics, though small, when taken together could have clinical relevance and could affect the utilization of health services, including PREP, and

Table 3.4

Care Receiver Characteristics at Baseline

	Control Group (N=11)	Intervention Group (N=11)
Age*	74 (6.0)	79 (5.3)
% Female	55%	27%
% Married	73%	91%
% High School or More Education	73%	73%
% Caucasian	100%	91%
Income Ability	3.25 (.7) ^c	3.5 (.5) ^d
Health		
Compared to Others	2.0 (1.1)	2.3 (0.9) ^b
Compared to 1 Year Ago	2.1 (1.0)	2.0 (0.9)
Mental Status	23.5 (6.0) ^a	21.5 (8.2) ^c
ADL Difficulty		
Showering	1.8 (1.1)	1.9 (1.0) ^a
Dressing	1.3 (1.3)	1.7 (1.7) ^a
Eating	0.9 (0.9)	0.7 (0.7) ^a
Getting In/Out of Bed/Chair	1.5 (0.8)	0.8 (1.1) ^a
Walking	1.6 (0.9)	1.4 (1.0) ^a
Getting Outside	1.7 (1.0)	2.3 (1.2) ^a
Using Toilet	1.0 (1.2)	0.9 (1.3) ^a

Table 3.4 Continued

	Control Group (N=11)	Intervention Group (N=11)
IADL Difficulty		
Preparing Meals	2.3 (1.3)	2.3 (1.2) ^a
Shopping for Personal Items	2.5 (1.0)	3.0 (0.0) ^a
Managing Money	1.5 (1.3)	2.2 (1.2) ^b
Using Telephone	0.6 (1.1)	1.7 (1.5) ^a
Light Housework	2.1 (1.0)	1.9 (1.4) ^a
10 Steps without Resting	2.4 (1.1)	2.8 (0.4) ^b
Standing for 2 Hours	2.5 (0.9)	2.8 (0.4) ^a
Stooping or Crouching	2.5 (0.9)	2.4 (0.8) ^a
Reaching Over Head	1.1 (0.7)	1.1 (1.2) ^a
Lifting 25 Pounds	2.5 (0.8)	2.8 (0.4) ^a

Note: All table entries are means (with standard deviations in parentheses) unless otherwise indicated.

Note: INCOME ABILITY (1=I can't make ends meet, 2=I have just enough, no more, 3=I have enough, with a little extra sometimes, 4=I always have money left over); HEALTH COMPARED TO OTHERS (1=Poor, 2=Fair, 3=Good, 4=Excellent); HEALTH COMPARED TO ONE YEAR AGO (1=Much better, 2=A little better, 3=About the same, 4=A little worse, 5=Much worse); MENTAL STATUS (Folstein Mini Mental Status); ADL/IADL DIFFICULTY (0=None, 1=Some, 2=A lot, 3=Unable)

^aN=10. ^bN=9. ^cN=8. ^dN=6.

* $p < .05$

Table 3.5

Caregiver Characteristics at Baseline

	Control Group (N=11)	Intervention Group (N=11)
Age*	63 (1.7)	74 (8.4)
% Female	73%	82%
% Married	100%	100%
% Spouse of Care Receiver	73%	91%
% High School Grad or Greater	82%	64%
% Retired	64%	64%
Years Known Each Other	41 (17.2)	52 (14.0)
Duration of Caregiving (Years)	3.6 (6.8)	5.7 (7.3)
Communication Problems		
Number	1.9 (1.1)	1.6 (1.1)
Difficult Managing	1.8 (1.2)	1.9 (1.5)
Amount of Direct Care		
Personal Care	6.2 (4.0)	7.0 (3.0)
Housekeeping	3.0 (0.0)	2.9 (0.3)
Protection	3.1 (0.6)	3.3 (0.8)
Transportation	2.4 (1.2)	4.7 (1.0)
Behavior Problems	1.5 (1.2)	1.4 (1.5)
Little Extras	2.2 (1.1)	2.5 (0.8)

Table 3.5 Continued

	Control Group (N=11)	Intervention Group (N=11)
Amount of Direct Care, Continued		
Medical Management	6.5 (3.8)	5.7 (2.4)
Financial/Legal/Health	4.6 (1.6)	4.7 (1.0)
Total Direct Care	29.7 (10.6)	30.3 (5.8)
Strain From Direct Care		
Personal Care	2.0 (0.8) ^a	1.8 (0.6)
Housekeeping	2.0 (1.0)	1.7 (0.4)
Protection	1.8 (0.7)	2.0 (0.5)
Transportation	1.9 (0.7)	1.9 (0.7)
Behavior Problems	2.8 (0.9) ^c	3.0 (0.6) ^d
Little Extras	1.8 (0.8) ^a	1.4 (0.5)
Medical Management*	2.1 (0.7)	1.9 (0.5)
Financial/Legal/Health	2.1 (0.6)	2.0 (0.5)
Predictability of Caregiving	2.7 (0.9)	2.6 (0.8)
Role Conflict	1.9 (0.9)	1.8 (0.8)
Strain from Economic Burden	2.0 (1.4)	2.1 (0.8)
Strain from Worry	2.5 (0.9)	2.5 (0.7)

Table 3.5 Continued

	Control Group (N=11)	Intervention Group (N=11)
Strain from Lack of Resources	1.2 (0.9)	1.1 (0.9)
Strain from Manipulation	1.5 (0.7)	1.5 (0.8)
Amount of Negative Lifestyle Change	3.1 (1.1)	2.9 (1.0)
Global Strain	2.9 (1.0)	2.5 (0.8)
Family Conflict	1.5 (0.9)	1.4 (0.7)
Rewards of Caregiving (Meaning)	2.9 (0.9)	3.1 (0.6)
Mutuality	3.1 (1.0)	2.9 (0.8)
Preparedness for Caregiving	2.7 (0.8)	2.7 (0.5)
Health Compared to Others	2.0 (0.6)	1.8 (0.6)
Health Compared to a Year Ago	2.8 (1.1)	3.2 (0.4)
Mobility	2.7 (0.3)	2.4 (0.4)
Number of Medical Problems	2.0 (1.3)	2.4 (1.4)
Bothered by Medical Problems	1.2 (0.1)	1.2 (0.2)
Negative Health Behaviors	0.9 (0.6)	0.6 (0.5)
Depression (CESD)	1.4 (0.4)	1.5 (0.5) ^a
Optimism	3.0 (0.7)	2.8 (0.6)

Table 3.5 Continued

	Control Group (N=11)	Intervention Group (N=11)
Emotional Health (POMS)		
Total	0.9 (0.5) ^a	0.9 (0.4) ^b
Depression	0.6 (0.5) ^a	0.5 (0.5) ^b
Tension	1.1 (0.7) ^a	0.9 (0.5) ^a
Anger	0.5 (0.4) ^a	0.4 (0.3) ^b
Vigor	2.4 (0.8) ^a	2.1 (0.8) ^a
Fatigue	1.9 (1.0) ^a	1.5 (0.8) ^b
Confusion	0.6 (0.5) ^a	0.8 (0.9) ^b
Social Desirability	0.7 (0.1)	0.7 (0.2)

Note: All table entries are means (with standard deviation in parentheses) unless otherwise indicated.

Note: COMMUNICATION PROBLEMS/DIFFICULTY OF MANAGING (0=Not at all, 1=A little, 2=Some, 3=Quite a bit, 4=A great deal); STRAIN FROM DIRECT CARE (1=Easy, 2=Not too hard, 3=Pretty hard, 4=Very hard); PREDICTABILITY OF CAREGIVING (1=Not at all predictable, 2=Somewhat predictable, 3=Pretty predictable, 4=Very predictable); ROLE CONFLICT, STRAIN FROM WORRY (1=Not at all, 2=a little, 3=Some, 4=A lot); STRAIN FROM LACK OF RESOURCES (0=Not a problem, 1=A small problem, 2=A moderate problem 3=A big problem); STRAIN FROM MANIPULATION, AMOUNT OF NEGATIVE LIFESTYLE CHANGE (1=Not at all, 2=A little, 3=Moderately, 4=A lot, 5=A great deal); GLOBAL STRAIN (1=No stress,

2=A little stress, 3=Some stress, 4=A lot of stress, 5=Overwhelming stress); FAMILY CONFLICT (1=No disagreement, 2=Just a little disagreement, 3=Some disagreement, 4=Quite a bit of disagreement); REWARDS OF CAREGIVING (Meaning), MUTUALITY (0=Not at all, 1=A little, 2=Some, 3=Quite a bit, 4=A great deal); PREPAREDNESS FOR CAREGIVING (1=Not too well prepared, 2=Somewhat well prepared, 3=Pretty well prepared, 4=Very well prepared); HEALTH COMPARED TO OTHERS (1=Excellent, 2=Good, 3=Fair, 4=Poor); HEALTH COMPARED TO A YEAR AGO (1=Much better, 2=A little better, 3=About the same, 4=A little worse, 5=Much worse); MOBILITY (1=Yes, limited a lot, 2=Yes, limited a little, 3=No, not limited at all); BOTHERED BY MEDICAL PROBLEMS (1=Not at all, 2=A little, 3=Some, 4=A lot); NEGATIVE HEALTH BEHAVIORS (0=Not at all, 1=A little, 2=Some, 3=A lot, 4=A great deal); DEPRESSION (CESD); DISPOSITIONAL OPTIMISM (Life Orientation Test); EMOTIONAL HEALTH (POMS); SOCIAL DESIRABILITY (Marlowe-Crowne Social Desirability Scale).

^aN=10. ^bN=9. ^cN=8. ^dN=7

* $p < .05$

the outcome of PREP. Longer duration of caregiving, less mutuality, more direct care, less predictability, and less caregiver physical health in the intervention group all suggest a more difficult caregiving situation. Yet, caregivers in the intervention group reported less strain, greater rewards, and more emotional health. These data in combination with the increased likelihood that intervention caregivers were spouses, could be interpreted to mean that intervention caregivers were more committed to caregiving and to continuing caregiving than control caregivers, even though their caregiving situations were more difficult. If this is an accurate interpretation, intervention caregivers might be especially accepting of interventions by PREP nurses if they were viewed as supporting further continuation of caregiving.

The interpretation that intervention caregivers were more committed to caregiving than control caregivers, could also affect their utilization of some health services, thus affecting the

overall cost of PREP. They might be reluctant to use institutional services, especially long-term care institutions. They might be more likely to utilize other services, e.g., adult day care or respite care, that would further support caregiving in the home. They might be more likely to purchase or rent equipment or supplies that would enable them to care for the care receiver longer. They also might be more willing to utilize health services for their own health problems if they thought it would enable them to continue caregiving longer.

In order to control for potential confounding by baseline non-equivalency between the study groups, a multivariate regression analysis was performed using the statistical software package, SPSS/PC (Norusis, 1990). The regression equation incorporated two measures of baseline status as predictors of use and costs of care: care receiver age; and the amount of direct care which is a caregiver variable, but also measures the degree of care receiver care needs.

Data Collection

To construct the cost protocol--total health and social service costs for care receivers and selected health service costs for caregivers--a comprehensive service utilization profile was developed for each dyad for the study period. Utilization data were collected from three different sources: HMO computerized data files; patient charts and records; and from caregivers. PREP nurse utilization data were abstracted from PREP charts, forms, and meeting minutes. Utilization data for services provided by the HMO (hospital, outpatient, pharmacy, emergency, durable medical equipment, and home health) were collected from existing HMO computerized data files and from member records. Non-HMO service utilization data were collected from caregivers during monthly interviews with study participants. All utilization was converted to dollars. This was accomplished in different ways, depending on the service and the type of utilization and cost data available. The outcome of PREP was measured by a single caregiver outcome scale. In the sections which follow, data collection instruments and procedures are described by study aim.

Health service costs are based on the amount of service utilization. Health service costs reflect the costs of the resources (labor and capital) needed to provide the service and they reflect the intensity (frequency and duration) of service use. Evaluation of program costs require the identification, measurement, and comparison of all relevant costs (Lewin, 1983; Warner & Luce, 1982). The relevant costs in this study included the costs of PREP, the costs of standard home health and the costs of a comprehensive set of non-PREP health and social services. The conceptualization of PREP costs included the costs of non-PREP services because it was hypothesized that interventions by PREP nurses with caregiving dyads over the 1-year study period would offset the utilization and thus the cost of some health and social services and induce the demand for and thus the cost of others.

Cost data were imputed where direct expense information was not available. Already existing cost data were available in some HMO computer data files, including costs for outpatient pharmacy, durable medical equipment, and outside claims. Likewise, data collected from participants for non-HMO services usually contained expenses. Cost-finding algorithms were developed for PREP, home health, and some services on HMO computer files (hospital, outpatient, and emergency services). A cost per visit was calculated for PREP nursing and home health nursing based on the cost of labor and non-labor inputs used in the production of these services. Cost coefficients developed by Hornbrook, Goodman, and Brown (1992) for all utilization parameters of the HMO hospital, emergency room, and outpatient clinics were used to calculate the cost of these services. Service cost coefficients and data sources are summarized in Table 3.6.

In the sections which follow, procedures for collecting PREP nurse and home health nurse utilization data and for pricing PREP and home health nursing are described, followed by procedures for collecting non-PREP utilization data and pricing of non-PREP services.

PREP Nurse and Home Health Nurse Utilization

The first study aim was to develop methods to measure and compare the patterns of

Table 3.6

Service Cost Coefficients and Data Sources

Service	Source	Cost Coefficient
PREP Nursing	PREP Time Sheets	\$173.73 per home visit
Home Health		
Nursing	Computer File VISIT91	\$86.65 per home visit
Physical Therapy	Computer File VISIT91	\$75.01 per home visit
Occupational Therapy	Computer File VISIT91	\$87.81 per home visit
Speech Therapy	Computer File VISIT91	\$104.51 per home visit
Social Work	Computer File VISIT91	\$109.15 per home visit
Home Health Aide	Computer File VISIT91	\$55.84 per home visit
Homemaker	Computer File VISIT91	\$70.33 per home visit
HMO Hospital	Computer File ADT	Sum of Average Costs Critical Care Days Routine Days Operating Room Minutes Recovery Room Minutes
HMO Outpatient	Computer File KARE	Average cost per provider type times average time per visit type for persons over 65 years of age
HMO Outpatient Social Work	Computer File KARE	\$32.76 based on 1/2 hour visits
Advice Nurse	Outpatient Charts	\$5.12 per call

Table 3.6 Continued

Service	Source	Cost Coefficient
HMO Emergency Room	Computer File ED Log	\$125.82 per visit
HMO Urgency Care	Computer File ED Log	\$95.06 per visit
HMO Pharmacy	Computer File TOPS	Pharmacy cost plus dispensing fee
HMO Durable Medical Equipment	Computer File DME Database	Amount billed by supply company
Skilled Nursing Facility	Computer Files ADT, OSCAR	Amount billed by facility
Non-HMO Services	Computer File OSCAR, Dyads	Amount billed

utilization of PREP nursing services by intervention dyads with patterns of utilization of home health nursing services by control dyads. In order to compare PREP nurse utilization with home health nurse utilization, data were collected on all activities of PREP nurses and home health nurses. PREP nurse activities included home visits to dyads, telephone calls, charting, twice-weekly care planning meetings with PREP investigators to plan intervention strategies for dyads, monthly interdisciplinary care planning meetings with other home health staff, patient errands, library study related to specific patient problems, patient chart review, family conferences, and consultation with specialists. Home health nurse activities included home visits, charting, telephone calls, and monthly interdisciplinary care planning meetings. In the paragraphs which follow, sources of and procedures for collecting nursing utilization data are described.

Home Visits

PREP nurses recorded the date and duration of home visits on a time sheet developed for this study (see Appendix G). Time sheets were reviewed approximately monthly and data

regarding the date and duration of the visit and the amount of time spent in charting were recorded on the Home Health Chart Abstract Form developed for this study (see Appendix H).

Home health nurses recorded the date and duration of home visits (which included time spent in charting) on daily itineraries which were entered onto a computer data file called VISIT91. Utilization data were abstracted from this computer file and recorded on the Home Health Chart Abstract Form.

In addition to these utilization data, the caregiving problems addressed by nurses during home visits and the intervention strategies developed for each problem were obtained from PREP charts, PREP care planning meeting minutes, and home health charts, and recorded on the Home Health Chart Abstract Form. Because PREP charting procedures were not refined, charting was haphazard and it was difficult to identify specific caregiving problems and intervention strategies, especially in the first eight dyads. Because of this difficulty, PREP nurse charting was analyzed independently by two raters--this researcher and one of the PREP Evaluation Study investigators. Problems addressed by the PREP nurse were categorized using a problem list which was developed shortly before the final three subjects began the study. The independent categorization of problems and intervention strategies were compared by the two raters. Where there was disagreement, the issue was discussed until agreement was reached. This procedure was not necessary in reviewing home health charts because health problems and intervention strategies were easily identified.

Telephone Calls

PREP nurses and home health nurses recorded the date and content of telephone calls and the person called on care receiver charts. The date and content of the call and the person called were obtained through chart review and recorded on the Home Health Chart Abstract Form. Additional data collected for Keep-in-Touch calls included the problems addressed by the nurse and intervention strategies. Telephone calls made to set up appointments with participants were not counted.

Telephone calls were also rated for their intensity. High intensity calls were those in which an in-depth assessment of a caregiving issue was conducted or in which two or more caregiving issues were addressed. Low intensity calls were those which were made to convey or seek limited amounts of information, to follow-up briefly on a particular issue, or to briefly assess a single caregiving issue. Because Keep-in-Touch calls involved extensive assessments by the PREP nurse, they were counted as high intensity calls.

Interdisciplinary Care Planning Meetings

PREP nurses and home health nurses recorded monthly interdisciplinary care planning meetings on care receiver records. The date of the meeting was obtained from the chart and recorded on the Home Health Chart Abstract Form.

Other PREP Nursing Activities

PREP nurses recorded all other activities on their time sheets. The date and the amount of time spent in the following activities were recorded: reading scientific and clinical literature related to specific caregiving problems; reviewing outpatient charts; meeting with consultants; attending family conferences; and attending care receiver funerals. The date, the activity performed, and the amount of time spent were recorded by the researcher onto the Home Health Chart Abstract Form.

Problems in Data Collection

One problem encountered in collecting these data was inconsistent record keeping by PREP nurses on the nurse time record. The researcher checked time records two to three times per month and met with PREP nurses to reinforce accurate record keeping and to work out difficulties with the procedure. All time records were checked against charts to verify accuracy. If the time record was not consistent with charting records, it was reviewed with the PREP nurse and the appropriate record was amended. Despite these efforts some data for the amount of time spent in some activities was missing. In these cases mean substitution for the amount of time spent in a specific activity (e.g., telephone calls to caregivers) was used.

A second problem, mentioned briefly above, was that data about the content of home visits were difficult to obtain reliably because there was no well-established problem list for PREP nurses to use for charting. It was difficult to determine both the problems addressed and the interventions strategies used by the nurse. In addition the charting forms were revised over the course of the study so that data were not always the same. This problem was addressed by developing a problem list that was used with the final three intervention subjects. For these three subjects, the researcher met with PREP nurses every week to talk about the caregiving problems they had identified, the data that supported the identification of the problem and the interventions strategies they were using. This greatly increased the consistency of charting.

PREP Nurse and Home Health Nurse Pricing

The second study aim was to develop methods to measure and compare the cost of implementing PREP in intervention dyads with the cost of standard home health in control dyads. The home health department cost reporting system contained nursing costs per home visit. In order to compare PREP costs with home health costs, the home health department's methodology for determining nursing cost per home visit was used to compute the cost per PREP nurse home visit. The home-health nursing cost per home visit was computed by totaling expenditures for labor and non-labor inputs, adding a regional overhead fee (for office space rental and maintenance and various administrative services), and dividing total expenditures by the number of home visits. Home health labor expenditures included salary and benefits for nurses, executive staff, supervisors, office staff, medical records, and quality assurance. Non labor expenditures included expenditures for medical supplies, travel, and office supplies. The nursing visit cost for 1991, \$86.65, was used to compute the cost of standard home health nursing.

Similarly, all labor and non-labor expenditures for PREP were added together and divided by the number of home visits, to arrive at a cost per visit of \$173.73. Labor costs included salary and benefits for three part-time registered nurses and one part-time supervisory

staff. Costs for registered nurses were computed by adding all the time spent in PREP activities, taken from PREP nurse time sheets and by adding 20% for non-productive time. The 1991 salary figure (obtained from the home health department) for a public health nurse, Grade 12, mid-scale, plus 40% for benefits was used to calculate PREP nurse costs.

The supervisory function was fulfilled by the PREP Evaluation Study principal investigator and one co-investigator at .25 FTE. Costs for the supervisory function were calculated using the 1991 salary for a home health supervisor, Grade 14, mid-scale, plus 40% for benefits. This salary figure was also obtained from the home health department.

Labor expenditures also included fees for clinical consultants utilized by PREP nurses to assist with difficult care problems at \$50/hour. Consultant time was obtained from PREP nurse time records and from care planning meeting minutes.

Non-labor expenditures for mileage, medical supplies, office supplies, and regional overhead were also included in nursing costs. Mileage costs were obtained from project mileage records. Mileage was reimbursed at .275 cents per mile. Medical supply expenses of \$3.00 per visit were also added. This figure was roughly half of the 1991 non-labor costs per visit of the home health department. Because non labor cost for home health included mileage costs, which were added separately for PREP, and because six PREP care receivers were referred for PT only and thus did not use any home health medical supplies, an estimate, lower than home health cost for the same supplies, was used. Office supply costs of \$1.10 per visit, which was the same as 1991 home health cost of office supplies per visit. The rationale for using this figure was that comparable amounts of office supplies would be used on a per visit basis. The HMO's regional overhead fee, \$3.00 per visit added to the cost of each visit in home health, was also added to the cost of each PREP nurse home visit.

Non-PREP Service Utilization and Cost Data Collection

The third study aim was to develop measures of utilization and cost of non-PREP health and social services by intervention and control dyads. Non-PREP service utilization and cost

data were collected in both the developmental phase and the pilot clinical trial. In the developmental phase, utilization and cost data were collected only for non-HMO services from study participants. In the pilot clinical trial, utilization and cost data were collected for the following classes of health and social services: (a) non-nursing home health services; (b) institutional services; (c) outpatient services; (d) community social services; (e) pharmacy; (f) durable medical equipment; and (g) medical supplies. Care receiver and caregiver services included in each class are summarized in Table 3.7.

Non-PREP utilization and cost data were collected from three sources: (a) HMO computer files; (b) member outpatient records; and (c) study participants. In the sections which follow each data source is described followed by a description of the instruments (when appropriate) and procedures used to collect the data.

HMO Computer Systems

Most utilization data and some cost data for non-PREP HMO services were abstracted from seven different HMO computer files. The Inpatient Discharge Abstract System (ADT) was an automated inpatient scheduling system which contained information about hospitalizations and admissions to skilled nursing facilities. ED Log was an automated file containing records for each arrival at the two emergency rooms operated by the HMO and two hospital-based after-hours urgency care clinics. KARE was an automated appointment scheduling system for the HMO's medical offices. It contained clinic appointment data for all provider types, e.g., physicians, physical therapists, audiologists. The outpatient pharmacy system (TOPS) was an automated system which contained information about each prescription dispensed from HMO outpatient pharmacies. OSCAR was the HMO's automated claims process system for covered services provided by non-HMO providers on a fee-for-service basis. OSCAR contained information about the utilization of ambulance services, skilled nursing homes, psychological services, chronic renal dialysis, non-HMO emergency services, and non-HMO physician

Table 3.7

Care Receiver and Caregiver Services

CARE RECEIVER SERVICES		
<u>Home Health Services</u>	Congregate Meals	Chiropractor
Home Health Nursing	Adult Day Care	Foot Care Specialist
Physical Therapy	Respite Care	Eye Doctor
Occupational Therapy	Friendly Visitor	Dentist
Speech Therapy	Phone Reassurance	Mental Health/Counseling
Social Work	Outreach Worker from a	Emergency Care
Home Health Aide	Senior Center	Urgency Care
Homemaker/Housekeeper	Volunteer	<u>Institutional Services</u>
<u>Community Social Services</u>	Ambulance	Hospital
Homemaker/Housekeeper	Other Transportation	Nursing Home
Chore Service	<u>Outpatient Services</u>	Adult Foster Home
Live-in Paid Helper	Physician	<u>Pharmacy</u>
Delivery Service for	Nurse Practitioner	<u>Durable Medical Equipment</u>
Groceries	Physician's Assistant	<u>Medical Supplies</u>
Home-delivered Meals	Advice Nurse	
CAREGIVER SERVICES		
<u>Outpatient Services</u>		<u>Institutional Services</u>
Physician	Physician's Assistant	Hospital
Nurse Practitioner	Emergency Care	Nursing Home

services. The DME data base system tracked all Medicare-covered durable medical equipment provided to HMO members. VISIT91 data base system contained home visit information for home health staff. Home visit data were abstracted for physical therapist, occupational therapist, speech therapist, social worker, home health aide, and homemaker services. Selected variables, which indicated the date and type of utilization, were abstracted from each of these computer files for the time period dyads were entered in the study.

Utilization data were abstracted from HMO computer files rather than collected from caregivers for two reasons. First of all, in a preliminary qualitative study (Miller, 1991), some caregivers indicated that asking them to provide utilization and expense data might require too much additional work. Obtaining as much data as possible from the HMO computer files minimized the amount of work caregivers were asked to do. In addition, some health care utilization studies indicated that people were not always able to recall service use accurately (Jobe, White, Delley, Mingay, Sanchez, & Loftus, 1990; Means & Loftus, 1991). Abstracting data from existing computer files reduced the need to obtain a large number of the utilization data from caregivers, thus increasing the accuracy of the data.

Utilization and cost variables for each computer file were down-loaded from the HMO's mainframe computer onto a floppy disk and uploaded to a personal computer for analysis (see Appendix I for variables needed in each file).

Outpatient Charts

Care receiver outpatient charts were reviewed in order to obtain utilization data for Advice Nurse services. Only chart entries for actual advice were included. Calls to Advice Nurses for prescription renewal and for scheduling appointments were not included. Charts were reviewed for the time period that participants were entered in the study. The number of advice calls per participant, including the date of the call, was recorded.

Study Participants

A variety of methods have been used to collect utilization and cost data from

community-dwelling older persons and their families. Methods include the following: (a) asking families to keep service utilization diaries (Houts et al. 1984; Cummings et al. 1990; Zimmer et al. 1984); (b) reviewing provider charts and records (Hughes, Manheim, Edelman, & Conrad, 1985; McCorkle et al. 1989; Moscovice, Davidson, & McCaffrey, 1988; Scitovsky, 1989; Weinberger, Smith, Katz, & Moore, 1988); (c) reviewing insurance company or other third party payer records (Bergner et al. 1988; Moscovice et al. 1988); (d) asking families to write service utilization on a calendar (Rice et al. 1991); (e) asking families to save bills and receipts for services used (Bergner et al. 1988); and (f) retrospective recall of the older person or family member (Hughes et al. 1985; McCorkle et al. 1989; Moscovice et al. 1988; Scitovsky, 1989).

One important issue in collecting service use and cost data from older frail persons is the amount of burden such data collection places on respondents. Caregiving is often stressful, and many caregivers have little extra time or energy for the additional work of providing utilization and cost data on an ongoing basis. Because data collection for service use and costs was planned for an extended period of time, and because the PREP Evaluation Study already placed additional burden on caregivers to complete three comprehensive monthly interviews, it was decided that data collection for service use and costs should place as little additional burden on participants as possible.

Another important issue in collecting utilization data from older persons and their families is the accuracy of the data. Jobe et al. (1990) found that in a sample composed of 53% over the age of 65, respondents who were asked to recall medical-provider visits for the preceding 6 months underreported the number of visits by 20 percent. Means and Loftus (1991) found that HMO subscribers were unable to recall episodically their medical-provider visits for the same condition when the number of visits in the reference period exceeded four. Scitovsky (1989) recommends obtaining as much utilization data as possible from provider records in order to maximize accuracy of the data.

Several methods have been employed to improve the accuracy of utilization and cost

data. Patients and/or families have been contacted monthly to either monitor utilization record-keeping or to collect utilization and cost data for the previous month (Cummings et al. 1990; Rice et al. 1991). Data have been collected from other sources in addition to patients and families in order to verify utilization (Bergner et al. 1988; Cummings et al. 1990; Zimmer et al. 1984). Methods used to ensure that families would continue to provide data over long periods of time are not reported.

The feasibility of collecting utilization and cost data using any of the above methods, the acceptability of various methods to older persons or their family members, and compliance with data collection procedures have not been reported. Because of this lack of information, this researcher conducted a preliminary study to determine caregivers' preference for providing utilization and cost data (Miller, 1991). Seventeen caregivers were interviewed and asked about three methods of collecting utilization and cost data aimed at maximizing accuracy of the data. The methods were keeping a diary of utilization, saving bills, receipts, or other written documentation of service utilization and cost, and obtaining data directly from providers. Saving written documentation was acceptable to more caregivers (15) than the other two methods and was unacceptable to the remaining two caregivers only if the bills or receipts were removed from the home. Keeping a diary was unacceptable to four caregivers, and obtaining data directly from providers was unacceptable to three caregivers.

Data collection procedures developed for this study were based on methods that would assure the greatest accuracy and that were most acceptable to caregivers. Caregivers in both the developmental phase and in the pilot clinical trial were interviewed in their home approximately monthly to collect non-HMO service utilization and cost data. The same instruments were used for collecting these data in both phases but data collection procedures differed slightly.

Instruments. The service utilization questions on the caregiver interview, developed by PREP Evaluation Study investigators, was used to collect utilization data (see Appendix J). The

care receiver utilization question contained a comprehensive list of 37 health and social services. Service classes for the care receiver included home health services, institutional services, outpatient services, community social services, pharmacy, durable medical equipment, and medical supplies. The caregiver utilization question contained a list of six health services. Service classes for the caregiver included institutional and outpatient services. The reader is referred to Table 3.7 for a listing of caregiver and care receiver services by service class.

The care receiver service list was adapted from a list used in the Caregiver Relief Study, the previous caregiving study by PREP investigators (Archbold et al. 1988.). The list contained primarily community-based health and social services. It contained no institutional services and few outpatient services. Caregivers in the Caregiver Relief Study reported using each service except delivery service for groceries and adult day care. These two items were retained for this study because both services were more available when this study began than when the Caregiver Relief Study was conducted. Institutional services added included hospital and nursing home. Outpatient services added included physician, nurse practitioner/physician's assistant, eye doctor, other medical specialist, outpatient pharmacy, medical supplies, medical equipment, emergency room, and urgency care. Transportation services on the Caregiver Relief Study list was revised to make two items--ambulance and other transportation to distinguish transportation used for emergency purposes from transportation used for in non-emergency situations.

Two data collection forms were developed to collect non-HMO service utilization and expenses from caregivers. The Cost Tracking Form was left in the caregiver's home to assist the caregiver in remembering the type of documentation to keep (see Appendix K). The name of each non-HMO service was recorded in the first column and the type of documentation of service utilization the caregiver agreed to keep was recorded in the second column. The Utilization Worksheet was used by the researcher to record service utilization and expense data during caregiver interviews from the documentation kept by caregivers (see Appendix L).

A form was developed for the researcher to evaluate the feasibility of collecting utilization and expense data from caregivers (see Appendix N). It contained open-ended questions about the caregiver's understanding of the data collection, difficulties encountered in data collection, and consistency of the data collection over time. This form was completed by the researcher after each interview.

Developmental phase data collection procedures. Service utilization and cost data were collected in the developmental phase for non-HMO services in order to refine data collection procedures for the pilot clinical trial. These data were collected from caregivers during monthly home visits by the researcher. At the first home visit, caregivers were asked the service utilization questions from the caregiver interview. Caregivers were asked to keep track of the utilization of all non-HMO services and how much they cost by saving bills, receipts, canceled checks, or other written documentation of service use and cost. The researcher wrote the name of the service and the type of documentation the caregiver agreed to save on the Cost Tracking Form and placed the form in a folder which was left in the home. Caregivers were asked to keep documentation in this folder until the next data collection.

At monthly follow-up visits, caregivers were interviewed again, using the same service utilization questions. Documentation of service utilization and expenses saved by caregivers since the previous interview were reviewed and recorded by the researcher on the Utilization Worksheet. Only one data collection was completed in the developmental phase before the pilot clinical trial began. There were no substantive changes in the data collection procedures for the pilot clinical trial based on that first data collection.

Several procedures were used to aid the caregiver in recalling service use. Probes were used with questions about supply and equipment use. Specific types of supplies were cited (e.g., incontinence products, disposable bed pads, dressings) to assist in identifying supplies they used. In addition, supplies pertinent to the care receiver's illness or disease were suggested, e.g., blood sugar testing supplies for diabetics. Specific types of equipment were cited to aid

recall (e.g., wheelchair, walker, hospital bed, cane, portable toilet, special toilet seat, and safety rails for the bathroom). When caregivers were asked what services they used since the previous interview, the researcher reminded the caregiver of previous utilization and dates of previous utilization. In addition, the researcher reminded the caregiver of events such as holidays or trips to the doctor and their dates and tried to help caregivers associate service use with specific events and dates. If a caregiver mentioned at one interview that a service was going to be used in the future, a note was made of this and it was followed up at the next interview. Likewise, if a service was indicated as used at one interview, and not at the subsequent interview, the researcher reminded the caregiver of previous use, and asked if the service was used again.

Pilot clinical trial data collection procedures. In the pilot study, non-HMO service utilization data were collected during three in-home caregiver interviews conducted for the main PREP Evaluation Study and during monthly interviews for utilization and cost data collection thereafter. The first interview was conducted 9 to 14 days after dyads signed the consent, the second interview was conducted 5 weeks after the first interview, and the third interview was conducted 5 weeks after the second. Service utilization and cost data collection for non-HMO services continued monthly after the first three interviews until subjects ended the study.

Initially, procedures for collecting data from caregivers were the same as in the developmental phase, except that service utilization questions were asked as part of the larger caregiver interview. However, procedures were revised after two caregivers experienced difficulty with them. One caregiver had only recently assumed responsibility for paying bills and managing finances when the care receiver became ill, and the caregiver did not have a bill-paying system worked out. He could not find some documentation. Another caregiver was mildly cognitively impaired, but this was not evident until after the first two interviews. He was not able to carry out the task of saving documentation of service use and did not always know about utilization or cost. Because of these two caregivers, the procedure was changed by asking caregivers at the first interview who normally paid the bills. Data were then collected from that

person.

Non-PREP Service Pricing by Service Type

Pricing for non-PREP services was determined in a number of different ways. Some of the computer data files contained cost data in addition to utilization data. Other files contained only utilization data and the cost associated with the utilization was computed using special formulas. Some services were priced as the amount paid by the HMO or caregivers to non-HMO providers. When appropriate, costs were adjusted for inflation. The following sections describe the pricing of services by service type. The reader is referred to Table 3.6 for a summary of service cost coefficients and data sources.

Non-Nursing Home Health Pricing

The cost per home visit for each of the non-nursing home health provider was obtained from home health department yearly cost reports. The home health department computed a cost per home visit for each type of provider for each calendar year. The cost per visit included the provider's salary and benefits, administrative staff salary and benefits, mileage, medical supplies, and office supplies, and an administrative overhead fee for office space rental and administrative services. The 1991 home visit costs were used for all home visits made in 1991 and 1992.

Institutional Service Pricing

Institutional services included hospital, nursing home (skilled nursing facility, intermediate care facility), and adult foster home.

Hospital Pricing. HMO hospitalization pricing was based on a system developed by the HMO's Center for Health Research (Hornbrook, Goodman, Brown, 1992) to compute annual hospital costs for individual members. In this system, an average cost was developed for each of four hospital utilization parameters--days in critical care (ICU,CCU), days of routine care, minutes of operating room (OR) time, and minutes of recovery room (RR) time. To calculate the cost of each hospitalization, the average cost per parameter was multiplied by the duration (in

days or minutes) of contact. The cost of each of these utilization parameters was then added together to obtain the total cost of the hospitalization. Critical care days and minutes in OR/RR were abstracted from the ADT computer file. Routine days were calculated by subtracting the number of critical care days from the total length of stay in the ADT computer file. Because these average costs were developed using 1989 dollars, they were converted to 1991 dollars using the consumer price index for hospitals and related services (U.S. Department of Labor, 1992).

Nursing home and adult foster home pricing. Nursing home pricing was determined in two different ways. Skilled nursing home services, covered by the HMO, were priced as the amount paid by the HMO. These costs were obtained from the OSCAR data file. Nursing home stays not covered by the HMO, but paid by the caregiver, were priced as the amount billed to the caregiver. Adult foster home utilization was also priced as the amount billed to the caregiver. Costs for nursing home and adult foster home utilization in 1992 were converted to 1991 dollars using the consumer price index for medical care (U.S. Department of Labor, 1992).

Outpatient Service Pricing

Outpatient services included HMO and non-HMO outpatient services, non-HMO counseling services, Advice Nurse services, and emergency/urgency care services. Each of these is described below.

Outpatient Clinic Pricing. HMO outpatient expenses were based on a system developed by the HMO's Center for Health Research (Hornbrook et al. 1992) for computing visit-based expenses. In this system, an average time in minutes for appointment type (routine vs. special procedure visit) and an average cost per minute for each provider type in each department were developed. Average appointment times were developed for two groups of members--those under 65 years of age and those over 65--to account for longer appointment times for older persons. To calculate the cost of each office visit, the average visit time for persons over 65 years of age was multiplied by the average cost of the provider type. Because these average

costs were developed using 1989 dollars, they were converted to 1991 dollars. Rates for physician services were adjusted using the consumer price index for physician services, and rates for all other outpatient services were adjusted using the consumer price index for other medical professionals (U.S. Department of Labor, 1992).

Non-HMO outpatient services were priced as the amount billed to study participants and adjusted to 1991 dollars when appropriate.

HMO Outpatient social work pricing. Although utilization data for visits to social workers in outpatient clinics was available on the KARE computer file, expenses for outpatient social work services were not included in visit-based expense system. After consultation with the Director of the Social Work Department, an average time of 30 minutes per contact with a social worker was estimated and was priced at the 1991 average hourly rate for social workers plus 40% for benefits.

Advice Nurse pricing. Advice Nurse calls were priced at the average rate of an after-hours advice call. This rate was determined by the HMO by conducting an analysis of the number of advice calls during a specified period in January, 1992 and by computing the cost of the nursing staff, including benefits, during the same time period. The cost of advice calls was not adjusted for inflation because Advice Nurse salaries were based on 1991 figures.

Emergency Services Pricing. The HMO's Center for Health Research also developed a pricing system for emergency services (Hornbrook et al, 1992). Two average costs were developed--one for emergency visits which resulted in admission to the hospital and one for visits which did not result in a hospital admission (urgency care). Because these average costs were developed using 1989 dollars, they were converted to 1991 dollars, using the consumer price index for hospitals and related services (U.S. Department of Labor, 1992).

Community Social Services Pricing

Community social services, with the exception of ambulance service, were not covered by the HMO. Community social services were paid either out-of-pocket by caregivers or they

were free to dyads. Services that were paid out-of-pocket were priced as the amount paid by caregivers. Some community social services were provided at no charge to dyads and these were assigned costs in various ways. One care receiver received physician services and adult day care from the Veteran's Administration (VA). These were priced as the cost to the VA and were obtained by calling the VA outpatient clinic and adult day care center. The VA computed an average cost per visit for all physician clinics. Because the type of physician seen by the care receiver was unknown, the average cost for a general medicine clinic visit was used. The VA adult day care computed an average daily cost based on direct and indirect cost of personnel. Adult day care was priced as the average daily cost during the time the service was used.

Other services that were free to dyads were assigned an average cost of comparable services. One dyad received the services of a home health aide for 28 hours a month as part of another research project and was not charged for this service. Hourly charges were obtained from three agencies which provide home health aide services and averaged to obtain the cost coefficient for this study.

Costs for community social services utilized in 1992 were converted to 1991 dollars, using various consumer price indices. Chore service costs were adjusted using the consumer price index for maintenance and repair services, respite care costs were adjusted using the consumer price index for household services, and ambulance costs were adjusted using the consumer price index for medical care (U.S. Department of Labor, 1992).

Pharmacy, Durable Medical Equipment, and Medical Supply Pricing

HMO outpatient pharmacy pricing was abstracted from the HMO computer file TOPS and reflected prices at the time of use. The cost represented cost of drugs to the pharmacy plus a dispensing fee. Pharmacy costs for 1992 purchases were converted to 1991 dollars using the consumer price index for prescriptions drugs (U.S. Department of Labor, 1992).

The costs for durable medical equipment were abstracted from the DME database file. They reflected prices at the time of use. Durable medical equipment costs for 1992 were

converted to 1991 dollars using the consumer price index for nonprescription medical equipment and supplies (U.S. Department of Labor, 1992).

Medical supply costs incurred by home health staff were included in home health costs. Medical supplies purchased by caregivers were priced as the amount paid by caregivers. Medical supply costs for 1992 were converted to 1991 dollars using the consumer price index for non-prescription medical equipment and supplies (U.S. Department of Labor, 1992).

Cost Evaluation

The fourth study aim was to develop an evaluation plan to compare health and social service costs in PREP dyads and usual care control dyads. A cost per group was computed for the intervention group and control group for each single service for each of the 6 study months. In addition, a group cost for each study month was computed for each of five classes of service: home health services; institutional services; outpatient services; community social services; and pharmacy, durable medical equipment, and medical supply services. Finally, a total cost per group for each of the 6 study months was computed by summing all costs by group for each month.

In addition to these cost totals, an average monthly cost per service class was computed for each of the five classes listed above. This procedure adjusted for the length of follow-up. This adjusted cost was computed by dividing the total cost of services in the service class by the number of months of follow-up for each group. T-tests were used to determine differences between the groups on all cost totals.

PREP Outcome

The fifth study aim was to select and evaluate a subjective caregiving outcome measure for the PREP intervention program. The outcome variables for this study were preparedness for caregiving, predictability of caregiving processes, and enrichment of caregiving relationships. The degree to which the intervention increased preparedness, predictability, and enrichment was measured by the PREP Effectiveness Scale (PES) (see Appendix N for intervention and control

group versions of the PES). In addition, qualitative data from exit interviews with eight intervention caregivers were used to describe the implementation of the intervention and the beneficial effects of PREP.

The PES was a 40-item scale which used a 5-point response format: 1--not at all, 2--a little, 3--some, 4--quite a bit, and 5--a great deal. A scale score was computed by averaging the responses to the 40 items. In addition, the PES included a single-item scored on a scale of 1 to 10 to measure the overall usefulness of assistance by PREP nurses or standard home health nurses and/or physical therapists for the two groups.

The PES was developed during this pilot study. Items on the scale were derived from three sources. Six items were derived from the Preparedness Scale, developed previously to measure preparedness for caregiving (Archbold, Stewart, Harvath, & Lucas, 1986). These items measured the amount of preparedness caregivers thought they had to take care of physical needs, to take care of emotional needs, to set up services, to handle emergencies, to handle the stress of caregiving, and to get the help and information needed from the health care system. Several items were theoretically derived to capture predictability and enrichment. The remaining items were derived inductively from responses to open-ended questions asked by PREP nurses during the final visit with dyads about how they had benefited from PREP. Some of the ways caregivers said they benefited from PREP included managing the care receiver's symptoms better, managing specific caregiving problems, experiencing less anxiety about managing difficult situations, understanding more about what the care receiver needed, improving the quality of care, finding solutions for difficult situations with the care receiver, and feeling reassured that they were doing a good job.

In order to detect effects of interventions, outcome measures must be sensitive to change. Guyatt (1990) defines sensitivity as responsiveness or the ability to detect clinically important change. He adds that in order to be responsive, a measure must be reproducible, that is, it must yield the same results when repeated in stable subjects, and it must be changeable,

that is, it must register changes in scores when subjects' health status improves or deteriorates. Stewart and Archbold (1992a & 1992b) made several recommendations in selecting outcome measures that are sensitive to change. First, the link between the intervention and the outcome should be strong and adequately specific. Second, the outcome variable should be amenable to change. Third, the content validity of the outcome measure should be adequate for detecting the effect of the proposed intervention. Fourth, construct validity should be determined by the measure's ability to detect change. Fifth, the measurement units should be adequately fine-grained to detect a treatment effect. Sixth, correlational stability over time should not necessarily be high (e.g., .30-.60) because higher correlations could indicate a highly stable attribute that is unlikely to change.

Although the PES was not tested before this study it fulfilled some of these recommendations for evaluating the sensitivity of outcome measures. First, there was a strong link between the conceptualization of PREP and the items on the scale. Second, because the items were derived from PREP concepts and from caregivers' perceptions of the benefits of PREP, the scale had high content validity. The measure's ability to meet other recommendations for choosing outcome measures was evaluated in this study.

The PES also had some limitations. Because it had not been used before, no psychometric data were available. In addition, the inductively derived items were based on qualitative data from only 11 caregiving dyads.

The PES was mailed to all intervention and control caregivers in early November, 1992, by PREP investigators. Fourteen caregivers returned the completed PES within a few weeks. Two additional caregivers completed the PES in December, 1992, during the final caregiver interview conducted by a PREP research assistant. Two caregivers sent the PES back and refused to complete it. The remaining four caregivers were called in January, 1993, and reminded to complete the PES and send it back, which none of them did. Thus, eight caregivers in each group completed and returned the PES.

CHAPTER 4

DESCRIPTION OF PREP IMPLEMENTATION WITH INTERVENTION DYADS

In this chapter, the implementation of PREP with intervention dyads is described, and data are presented from qualitative interviews with caregivers which were conducted several months after the intervention ended. Because the PREP Evaluation Study was a pilot study, several aspects of its implementation changed over time. Work with the first eight intervention dyads was quite developmental and led to changes in PREP services with the last three dyads. In the sections which follow, the first eight dyads, who were recruited during the first 3 months of the study and remained until the end of the 6th month, are referred to as Group 1 dyads. The last three dyads, who were recruited during the 7th month of the study and remained until the end of the 9th month, are referred to as Group 2 dyads.

PREP was implemented over a 9-month period with 11 dyads by three part-time registered nurses and part-time administrative staff. The PREP principal investigator and one of the co-investigators functioned as part-time administrative staff. Activities of PREP nurses with intervention dyads included the following: 1) making home visits to intervention dyads; 2) making telephone calls to and from caregivers/care receivers, agencies, and other professionals; 3) charting home visits and telephone calls; 4) attending care planning meetings; 4) researching the literature related to specific caregiving problems; 5) reviewing outpatient charts; 6) meeting with consultants; 7) attending family conferences; and 8) attending care receiver funerals. The activities of the administrative staff included supervising the PREP nurses and conducting care planning meetings.

PREP was implemented in three components: (a) the In-home Component, an intensive series of home visits by PREP nurses designed to improve the caregivers' knowledge and skills, to enhance the predictability of caregiving routines, and to enrich caregiving; (b) the Keep-in-

Touch Component, a less intensive monitoring of the caregiving situation through telephone calls with the caregiver; and (c) the Completion Component, the final contact with dyads before discharge from PREP. Dyads were admitted into the In-home Component of PREP and received home visits until caregiving issues were stable or until the study ended. When caregiving issues became stable, dyads were transferred to the Keep-in-Touch Component. The PREP Advice Line was available to intervention dyads throughout the intervention. Each nurse had primary responsibility for the dyads assigned to her and developed a long-term therapeutic relationship with them.

In-home Component

The in-home component of PREP consisted of a series of home visits in which PREP nurses assisted caregivers to identify caregiving problems and to improve their caregiving skills and knowledge. This component began with admission to the study and was followed by active treatment of caregiving issues.

Admission

The admission process was usually completed during the first two to three home visits in the first 1 or 2 weeks after entry into the study. The primary purposes of the admission were: 1) to assess the preparedness of the caregiver and the predictability and enrichment in the caregiving situation; 2) to conduct an in-depth assessment of the caregiving environment; 3) to identify problems in caregiving that the caregiver wanted to address; 4) and to identify caregiving strengths. Nurses approached each caregiving situation with the attitude that the caregiver possessed much knowledge about her own caregiving situation, that she possessed caregiving skills and that the role of the nurse was to supplement her knowledge and skill. The admission process included two in-depth assessments: 1) the Caregiver Activities List (CAL) (see Appendix O); and 2) the General Assessment Protocol (GAP) (see Appendix P). During admission home visits, nurses also implemented any skilled nursing orders from the home health referral, began

to develop the long-term therapeutic relationship with the dyad, oriented the dyad to the PREP project, explained the principles of preparation, predictability, and enrichment, and explained the PREP Advice Line.

The CAL was an assessment of the PREP concept of preparedness for caregiving. It contained a comprehensive list of caregiving tasks and activities and care receiver behaviors that might be managed by caregivers. It contained the following eight categories of activities: (a) personal care (e.g., bathing); (b) housekeeping (e.g., meal preparation); (c) protection (e.g., protect from falls); (d) transportation (e.g., take to medical appointments); (e) financial, legal and health decisions (e.g., decide major health decisions); (f) management of behavior problems (e.g., manage repetitive questions); (g) medically related tasks (e.g., manage medications, pain, skin conditions, medical equipment); and (h) little extras (e.g., participate in leisure activities).

The CAL assessment was used differently in the two groups of caregivers. In Group 1, the assessment form was given to the caregiver at the first home visit and she was asked to indicate all the items on the list that she performed or managed and to indicate how well-prepared she thought she was to perform the task or activity or manage the behavior before the next home visit. Several caregivers did not complete the CAL and it was finished jointly by the nurse and caregiver. The nurses discovered that conducting the assessment with the caregiver led to a discussion of the task/activity/behavior and that they could get a much better assessment of the nature of the difficulty experienced by the caregiver. In Group 2, the CAL was completed jointly by the nurse and caregiver at the first home visit.

The GAP contained questions designed to assess the total caregiving environment. It included questions about the care receiver's health status, the caregiver's emotional and physical health status, the history of caregiving, the amount of informal support available to assist with caregiving, caregiver role strain, mutuality between caregiver and care receiver, usual daily routines, family rituals, and pleasurable activities. Predictability was assessed with the questions

about daily routine. Enrichment was assessed with questions about family rituals and pleasurable activities.

A third assessment, the caregiving profile, was added to the admission assessment with Group 2 dyads (see Appendix Q). The caregiving profile contained a summary of the data collected by the research team in the first caregiver interview conducted between the 7th and 12th day after dyads entered the study. The caregiving profile included data on the number and difficulty of caregiving tasks and activities performed by the caregiver, communication problems between caregiver and care receiver, predictability in caregiving, worry, rewards of caregiving, stress in the caregiver/care receiver relationship, feelings of being manipulated negative changes in lifestyle, preparedness for caregiving, family conflict around caregiving, and physical and emotional health of the caregiver. The profile displayed caregivers' scores from very low to very high on each concept.

The research team was able to conduct the caregiver interview, enter the data into the computer, and develop the profiles within 10 days of dyad entry into the project, which was still during the admission process. PREP nurses used the caregiving profile with Group 2 caregivers to augment the CAL and GAP. For example, the caregiver interview contained a scale on mutuality, which was a measure of the caregiver's perception of love, shared values, shared pleasurable activities, and reciprocity from the care receiver. Most caregivers scored high on this scale. Knowing that a caregiver had low mutuality with the care receiver was useful in that, if the caregiving situation was perceived as very difficult by the caregiver, the nurse might encourage the caregiver to get more help in caregiving, to get respite, or even to consider alternative placement for the care receiver. On the other hand, in situations with high mutuality, the nurse might be more likely to help the caregiver change and improve her/his own caregiving practices.

The admission process and its comprehensive assessment concluded with the

identification of potential follow-up issues and caregiving problems based on the assessment data which were summarized in a Follow-up List. With the Group 1 dyads, naming of caregiving problems was not always consistent or conceptually clear. Over time, as caregiving problems were discussed in care planning meetings and nurses intervened with caregivers, the nurses conceptually understood PREP better and were able to articulate caregiving problems they were encountering much more consistently. Experience with Group 1 caregivers led to the development of a standardized list of conceptually and clinically derived caregiving problems (see Appendix R).

Specification of an individualized problem list was more formalized and consistent in Group 2 caregivers. The PREP nurses formulated a Follow-up List of all caregiving issues from the three assessments, the CAL, the GAP, and the caregiving profile. Problems on the list included the following: 1) all caregiving activities/tasks/care receiver behaviors on the CAL that caregivers thought they were "very unprepared for" or "somewhat unprepared for"; 2) all items on the caregiving profile that were in a high or very high problematic range; and 3) problems noted on the GAP. This process resulted in a long list of caregiving issues for each of the three dyads. A shorter problem list was formulated jointly by the caregiver and nurse. The caregiver chose issues from the CAL that she thought she was unprepared for and that she wanted most to improve with the help of the nurse. The nurse added issues of predictability and enrichment in caregiving, caregiver health, and caregiver strain. As issues were resolved, other issues on the Follow-up List were addressed as desired by the caregiver and sometimes new issues were added to the list.

Active Treatment

Active treatment activities by PREP nurses included home visits, telephone calls, twice weekly care planning meetings, and other activities. Each of these is described below.

Home Visits.

After the admission was completed, home visits were conducted by nurses to resolve the issues on the Follow-up List. The pattern of visit frequency varied among dyads. In general, the frequency of home visits was once to twice per week for the first 6 to 8 weeks after dyads entered PREP. Visits became less frequent over time, decreasing from twice per week to once per week, to every other week, and finally to every several weeks. In three cases, the frequency of home visits increased temporarily after they had begun to decrease. Reasons for this change were the development of new health problems in the care receiver and hospitalization of the care receiver, requiring reassessment by the nurse. In the seven caregivers who remained in the In-home Component throughout the study period, the number of home visits in the first 8 weeks ranged from 7 to 13, with a mean of 9.6. In the four dyads transferred to Keep-in-Touch, home visits stopped after 3 to 6 weeks. The number of home visits ranged from 4 to 9, with a mean of 6.3.

Nursing Assessments. In the active treatment phase of the In-home Component, nurses assessed each caregiving issue in depth, planned individualized intervention strategies with the caregiver, and evaluated effects of strategies with the caregiver. First, an in-depth assessment of each of the caregiving issue on the Follow-up List was conducted. This included assessment of the most upsetting or difficult aspect of the problem, caregiver knowledge about the problem, current management strategies, and management strategies that had been tried but were not effective. Nurses placed emphasis on assessing care receiver patterns. For example, caregivers who were managing behavior problems were instructed in tracking the specific behavior on a calendar over several days or a week. This enabled them to see the actual frequency of the behavior. One caregiver, who had to manage agitation and yelling at night, which often kept her awake, was able to see that the care receiver actually slept every other or every third night and that she could plan her caregiving to take advantage of a good night's

sleep. In some instances, the nurse's assessment of a particular aspect of caregiving was itself enough to lead to a resolution of a problem by the caregiver before the next home visit.

A variety of caregiving problems were identified and included in the Follow-up List of the 11 dyads. The number of problems per dyad ranged from 2 to 14, with a mean of 9.2. All caregivers thought they were unprepared in at least one caregiving task/activity/behavior. Unpreparedness was most often identified in the area of medically related problems, such as skin conditions, constipation, and managing medical equipment. All but two caregivers experienced some type of caregiving strain. A total count caregiving problems across all dyads is presented in Table 4.1.

Intervention strategies. PREP nurses used traditional nursing strategies of teaching caregivers how to perform tasks and assess for complications and to know when to call the PREP nurse or the doctor. In addition, they used a number of other strategies to increase caregiver preparedness, and predictability and enrichment in caregiving.

PREP nurses used the concepts of "local" and "cosmopolitan" knowledge to intervene with dyads. Local knowledge refers to information that is unique to the individual care receiver and cosmopolitan knowledge refers to general knowledge of gerontological nursing (Harvath et al. 1993). Whenever possible, PREP nurses acknowledged and affirmed adequate local knowledge, developed local knowledge when it was inadequate, and helped caregivers apply local knowledge. They also supplemented the caregiver's local knowledge with cosmopolitan knowledge. One example of supplementing local knowledge with cosmopolitan knowledge was a family in which the care receiver was demented and often became increasingly agitated in the evening and wanted to find his keys and check the locks on the doors and windows. The caregiver interpreted this behavior as being related to the care receiver's previous job as a security guard. The PREP nurse supported this interpretation and helped the caregiver to

Table 4.1

Count of Caregiving Problems Across All Dyads

Caregiving Problem	N
<u>Unprepared--Personal Care</u>	
Urinary Incontinence	2
Bathing	1
Trim Fingernails/Toenails	2
Help at Night	1
Toileting	1
<u>Unprepared--Housekeeping</u>	
Laundry	1
<u>Unprepared--Protection</u>	
Protect from Falls	6
Keep One Eye On	2
Assist with Walking	4
<u>Unprepared--Transportation</u>	
Shopping	1
Medical Appointments	2
<u>Unprepared--Financial, Legal, Health Decisions</u>	
Legal Matters	1
<u>Unprepared--Behavior Problems</u>	
Repetitive Questions	2
Agitation/Restlessness	2
Aggressiveness	2
Yelling	4
Crying	1
Paranoia	1
<u>Unprepared--Medically Related Problems</u>	
Constipation	4
Nocturia	1
Abdominal Fullness	1
Blood Pressure	2
Eating the Right Foods	1
Medical Equipment	4

Table 4.1 Continued

Caregiving Problem	N
<u>Unprepared--Medically Related Problems (continued)</u>	
Skin Conditions	4
Pain	2
Medication Management	1
General Physical Health	1
Right Amount of Liquids	1
Fatigue	1
Emotional Ups and Downs	2
Diabetic Management	1
Breathing Problems	1
Reportable Signs and Symptoms	2
<u>Unprepared--Get Help from HMO System</u>	5
<u>Unpredictability</u>	
Caregiving Routine	4
Disease Process Trajectory	1
<u>Low Enrichment</u>	4
<u>Caregiver Health Problems</u>	6
<u>Caregiver Strain</u>	
Tension in the Relationship	3
Worry	2
Manipulation	2
Lack of Resources	3
Strain from Direct Care	2
General Strain	1
Role Conflict	1

develop a variety of strategies that focused on dissipating his energy and reassuring him of his safety. These strategies included giving him a set of keys, walking him around the perimeter of the house, and letting him check the locks on the doors and windows.

If a particular strategy did not work the nurse suggested additional strategies or sought

consultation with expert practitioners until an effective strategy could be found. If a satisfactory resolution to an issue could not be found, the nurse helped the caregiver minimize the effects of the caregiving issue and to learn to accept it. It was important to caregivers that nurses kept trying to find to solutions to their caregiving problems. One caregiver reported, "(Nurse) kept saying this wasn't working. So she called the doctor and tried something else. She kept trying". Another caregiver said, "she had lots of ideas". Sometimes it was most helpful to the caregiver to know that even though the problem was difficult to manage, she was "doing the right thing".

PREP nurses also used rehearsal and role-play with some caregivers. In several situations where the caregiver felt unprepared to discuss questions with a health care provider, the nurse assisted them to clarify the questions they wanted to ask and to role-play several different scenarios of conversations. In one instance, a caregiver rehearsed taking care of the care receiver for one day by herself, without the assistance of her daughter-in-law, who helped with caregiving and was planning to move shortly. In another instance, the PREP nurse used role-play with a care receiver to discuss obtaining a referral to see a rheumatoid specialist from her primary care provider.

Emphasis was placed on recording and evaluating the patterns associated with some caregiving problems. Caregivers recorded elimination patterns, behavior patterns, and sleep patterns. One caregiver reported, "we used a calendar to chart and help him get more regular. This helped us keep track and then we would know when to start the laxatives".

Strategies to make caregiving more predictable focused primarily on making daily routines predictable and in managing acute episodes or emergencies. One caregiver was very anxious that her husband would develop pneumonia and have to go to the hospital, which had happened several times in the past. Because of the care receiver's dementia and advanced age, the symptoms of pneumonia were not always obvious. The PREP nurse taught the caregiver the signs and symptoms of pneumonia to assess, including subtle changes in mental

status. The caregiver was able to detect an episode of pneumonia early, call the PREP nurse and treat the pneumonia with oral antibiotics and thus prevent a trip to the hospital.

PREP nurses used several strategies aimed at enhancing enrichment. Enrichment activities often centered around eating, bathing, and bedtime rituals. Two caregivers were assisted in planning bedtime rituals to help calm the care receivers so that they would go to bed. PREP nurses facilitated discussions about activities that were personally meaningful to dyads and encouraged them to think about ways they could incorporate these activities into their daily or weekly routine. The nurse assisted one caregiver to set up some plants for the care receiver to tend indoors when she could no longer go outside to work in the garden. One caregiver in the qualitative interview relayed the following story about enrichment:

"She made me feel better about the situation. (Nurse) said we were supposed to enrich. We'd laugh about that. He'd get in the bathroom but wouldn't make it in. He'd go all over the floor. We used to get really upset before (nurse). Now we laugh and ask each other if this was being enriched. We were able to see the humor. You need to keep your humor to stop from going crazy."

Family Health Diary. The Family Health Diary, a notebook which contained pages for entering health information, was designed by PREP staff and given to each dyad. PREP nurses used the diary most for recording specific intervention strategies that they wanted caregivers to try or to show to family members who lived nearby. The diary was used by caregivers to record patterns of the occurrence of specific caregiving issues, such as problematic behavior, and for keeping track of certain medications, such as pain medications. In the qualitative interviews, several caregivers reported that the diary was very helpful to them in remembering how to manage caregiving issues, especially at first when they had a lot to remember. One caregiver reported that the PREP nurse "wrote explanations about his catheter, how to take care of his skin and how and what to feed him". Another caregiver reported that the PREP nurse "wrote something about cutting his toenails and giving his baths and medications, and what I should do at bedtime. I still use the diary to try and find something else to try when he's upset and agitated".

Telephone Calls

Although home visits constituted the primary nursing activity in the In-home Component, nurses engaged in many other activities. In between home visits, nurses made phone calls to caregivers to follow-up on problems discussed at previous home visits. They also received phone calls from caregivers when caregivers had questions about caregiving or about the care receiver's health. They communicated by phone with the physician, outpatient social workers, home health staff, hospital and nursing home staff, social service agencies, other family members, and HMO departments such as membership services and the Durable Medical Equipment Department.

Other PREP Nurse Activities

Nurses also attended twice weekly care planning meetings. The purposes of these meetings were to discuss the implementation of the intervention with each dyad and to plan intervention strategies. Nurses also consulted with other professionals. A mental health nursing specialist with expertise in behavior management was consulted about problem behavior in three care receivers with dementia. A physical therapist was consulted regarding the rehabilitation program for one care receiver. Nurses reviewed care receiver outpatient records to gain a better understanding of their medical history. They reviewed literature in the library pertinent to specific care problems. Very infrequently they ran errands for the caregiver and attended family conferences. One nurse attended the funeral of the one care receiver who died.

If a care receiver was institutionalized, the nurse continued involvement with the dyad. Very often the nurse made calls to the institutional staff and/or the physician to obtain progress reports or to provide pertinent information. Usually she kept in contact with the caregiver and helped to coordinate a return home. In one instance, the nurse met with the nursing home staff and caregiver to resolve some problems the caregiver encountered in the nursing home and also to plan for discharge. In another instance, the nurse continued to work on some caregiving

problems while the care receiver was in a hospital and nursing home for 5 weeks.

Active treatment ended when the nurse determined that the caregiving situation was stable and when the caregiver thought that the caregiving problems were resolved or manageable. Dyads were then transferred to the Keep-in-Touch Component, in which nurses assisted caregivers primarily by telephone contact.

Keep-in-Touch Component

Four dyads were transferred to the Keep-in-Touch Component. Of all eleven dyads, the four care receivers transferred to KIT were the most functionally independent, and the caregiving situations the most objectively stable and non-difficult. Two care receivers were recovering from surgery and showed improvement back to pre-surgery status. They required decreasing caregiving assistance as they recovered. One care receiver was very stable after a CVA several years previously and had very few caregiving problems. His wife, a retired nurse, thought she was well-prepared in the areas that he needed help. The fourth care receiver was functionally very independent throughout the time he was enrolled in PREP and the caregiver actually provided very little care.

The primary nursing activity in Keep-in-Touch was a telephone call to the caregiver. The purpose of the Keep-in-Touch call was to screen for new caregiving and health issues and to follow-up on previous issues. A special Keep-in-Touch assessment form was used to assess for new care receiver health problems, caregiver health, caregiver role strain, changes in the household, preparation, predictability, and enrichment (see Appendix S). The frequency of Keep-in-Touch calls varied among the four dyads. One caregiver received two calls in 22 weeks, one received five calls in 11 weeks, one received six calls in 15 weeks, and one received five calls in 10 weeks. In addition, in two of these dyads, the Keep-in-Touch calls were conducted with care receivers. These calls focused on the care receivers health problems, not on caregiving problems.

Dyads in the Keep-in-Touch Component continued to be discussed at care planning meetings and nurses still made telephone calls regarding the dyad in addition to the Keep-in-Touch assessment calls. In addition, a small number of home visits were made to dyads in Keep-in-Touch to provide additional assessment and treatment of a mobility problem. None of the dyads was reactivated to the In-home Component after transfer to Keep-in-Touch.

Completion Component

PREP nurses prepared dyads for the completion of PREP throughout the intervention by clearly stating the completion date and by discussing how caregiving issues would be managed after the completion of PREP. As the completion date approached, these discussions occurred more often. Near the end of the intervention, PREP nurses engaged in the following completion activities. First, they reflected on their experiences with each dyad and wrote a summary of the dyad's strengths and their progress while in PREP. During a final home visit or telephone call, they asked dyads questions about their perceptions of what they had learned while in PREP. Then, they composed a letter to the dyad summarizing the dyads strengths, the progress they had made while in PREP, and what the PREP nurses had learned from the dyad. The letter was sent to the dyad as the last contact with the PREP intervention team.

Response to the letter in qualitative interviews with caregivers was especially positive. One caregiver stated, "The letter was nice. I like to re-read it. So many things are going on. There are so many problems to think about. Then I read the letter and it calms me". Another caregiver said, "It was a great letter. She gave me a lot of accolades. She said I was doing a beautiful job. Don't change that". Another said, "I remember the letter. It was very nice, a good letter. She said in the letter that she saw so much love in our family. I like to think that that's true. And, she saw it".

PREP Advice Line

Eight of the 11 intervention caregivers used the PREP Advice Line to contact the PREP

nurse about new problems. One caregiver reported using the Advice Line, "when we weren't sure if we should come in and see a doctor--trying to avoid the trip and expense of seeing a doctor". Another said, "We used it when we were in big trouble. I didn't know whether to call the urologist. I'd call [nurse] and we'd decide together. I couldn't get rid of the ulcers. They kept getting bigger. I'd call [nurse] and she'd suggest something else". Another said, "The information I got was helpful and knowing I got it from someone that knew his condition made the information better".

Caregiver Evaluation of PREP

The overall evaluation of the seven caregivers who completed qualitative interviews was very positive. Caregivers reported that one of the greatest benefits of PREP was that it made the caregiver feel more secure and confident in caregiving. Caregiver comments included: "made me feel like I could take care of my husband"; "she took the weight off my shoulders"; "it was comforting"; "sharing of helpful information"; "gave us assurance that we were making the right decisions and giving the right care"; "the most important was having that feeling of support"; and "having someone that understood what I was going through".

Another benefit to some caregivers was that the nurse was readily available when questions arose. Caregivers commented, "I knew she would help and be there for me", "someone was there when I needed someone for questions, advice, and support", "just having her beeper number and knowing that if I had a big problem, I could beep her, and she'd come" and "she was available".

Caregivers appreciated PREP nurses' attempts to obtain additional help, whether it was from formal or informal sources. Caregivers commented "she contacted physical therapy, she called the doctor, she tried to set up day care, she set up a special bus ride", "she kept talking about getting our sons involved in his care, she talked about using (HMO)", and "she talked to my nieces about helping me. Another said, "She got us in contact with the sight-impaired. They

sent talking records. This was very comforting to mother and it gave us time. This help was very important to us".

One caregiver made the following comments about the most important things the PREP nurse did to help her family:

"The sharing of the helpful information, the assurances that she gave us, that we were making the right decisions and giving the right care. We weren't used to taking care of such a sick elderly person. Help and information were available when we needed it. When my mother first came home, we had so many questions. The doctor had a large load and we didn't want to bother him. (Nurse) answered our questions about what was going on with my mother's physical condition".

"(Nurse) took the pressure off of us. She got help for us. She gave us lots of suggestions on how to give better care and to handle her and our feelings about her. (Nurse) gave us little hints of all kinds. She just made things simpler".

CHAPTER 5

RESULTS

Results of the utilization and costs of health and social services by intervention and control dyads and caregiver outcomes are presented in this chapter. The chapter begins with a report of caregivers' compliance with data collection procedures. Results are then presented by study aim. First, patterns of utilization of PREP nursing in the intervention group are compared with patterns of utilization of standard home health nursing in the control group. Next, the cost of PREP nursing services is compared with the cost of standard home health nursing services. Next, the utilization and cost of all non-PREP health services in each study group is presented for the following classes of service: (a) non-nursing home health services; (b) institutional services; (c) outpatient services; (d) community social services; and (e) pharmacy, durable medical equipment, and medical supply services. Care receiver utilization and costs are presented first followed by caregiver utilization and costs. A summary of total health care costs by service class and the PREP outcome concludes this chapter. We begin with a description of loss to follow-up in the two study groups.

Length of Follow-up

The length of follow-up ranged from 83 to 173 days (2.8 to 5.8 months) in the control group and 67 to 173 days (2.2 to 5.8 months) in the intervention group. The total number of study days was almost equivalent for the two groups--1,302 days for the intervention group and 1,337 days for the control group. Six months of utilization and cost data were collected for two dyads in each group, five months of data were collected for five dyads in the control group and six dyads in the intervention group, four months of data were collected for eight dyads in each group, and three months of data were collected for all 22 dyads.

Compliance With Data Collection Procedures

Caregivers' compliance with data collection procedures was evaluated throughout the data collection period for all caregivers in the pilot clinical trial and two caregivers from the developmental phase. These caregivers agreed to save written documentation of the utilization

and cost of non-HMO health services. Written documentation included bills, receipts, canceled checks, check book records, and data written on a calendar.

All care receivers and 3 caregivers utilized at least one non-HMO service. These services included housekeeping, chore service, transportation, respite care, live-in paid helper, home-delivered meals, adult day care, volunteer, physician, dentist, nursing home, medications, durable medical equipment, medical supplies, and adult foster home. Because non-HMO service utilization and cost data were collected monthly for the preceding month, data regarding compliance were grouped by month. Each month that a single non-HMO service was utilized at least once was counted as one service-month. Documentation was required for 130 service months of non-HMO service utilization.

In the pilot clinical trial, caregivers actually provided written documentation of non-HMO service utilization and cost in 60 (46%) of the 130 service-months but relied on caregiver recall to provide data in 70 of 130 (54%) service-months. Caregivers saved bills or invoices in 26 (43%) of the 60 service-months for which documentation was available, canceled checks in 10 (17%) of service-months, and receipts in 18 (30%) of service-months, and provided other checkbook records in 1 (2%) service-month. In 5 (8%) of service-months, caregivers used a blank calendar provided by the researcher to document utilization and cost.

Data were provided through caregiver recall for several reasons, and caregivers actually infrequently forgot to save documentation when they said they would. For 13 of the 70 (18.5%) service-months for which data were provided through caregiver recall, data were collected at the first interview when some services had already been purchased and before caregivers had been asked to save documentation. For 28 of the 70 (40%) service-months, the service was one that had been used regularly for a long time, the caregiver knew the utilization and cost, and his/her report was accepted without documentation. Service purchases in this group included twice monthly housecleaning, home-delivered meals (Monday through Friday), respite care (Monday through Friday), a live-in paid caregiver, and a monthly purchase of incontinence products. For 4 of the 70 (6%) service-months, durable medical equipment was purchased. Because the price

was quite high and the caregiver knew the price, and it was accepted without documentation. For 2 of the 70 (3%) service-months, the services were new and caregivers did not realize they needed to save documentation. For 5 of the 70 (7%) service-months, caregivers paid cash for the service, had no documentation and did not think to write the utilization or cost down. For 13 of the 70 (18.5%) service-months, caregiver recall was relied upon for utilization data and the cost of the service was obtained by calling the vendor. This group of services included physician and adult day care provided by the Veteran's Administration, respite care provided as part of another research project, and wheelchair rental. The reason for the lack of documentation for 2 of the 70 (3%) service-months could not be determined.

Caregivers forgot to save documentation for 3 of the 70 (4%) service-months after they had agreed to do so, but did not refuse to try to recall utilization and cost. In each case the caregiver was somewhat uncertain about the cost of the service but was able to provide an estimate of the cost.

One caregiver (from the developmental phase) did not provide data about his utilization of physician outpatient services after repeatedly telling the researcher he would do so. He lived in a separate residence from the care receiver and had to bring physician bills to the care receiver's home. He agreed to bring his bills to the care receiver's home at several prearranged appointment times, but then did not follow through. He made several visits to the physician, but was unable to recall when they occurred or how much they cost.

Patterns of Utilization of PREP and Standard Home Health Nursing

The first study aim was to develop methods to measure and compare patterns of utilization of PREP nursing services by intervention dyads with patterns of utilization of standard home health nursing services by control dyads. PREP was implemented in the intervention group by three part-time registered nurses (PREP nurses) and part-time administrative staff (study investigators). PREP nurses provided standard home health nursing services as well as additional caregiving support services over an extended period of time. Activities of PREP nurses with intervention dyads included the following: (a) making home visits; (b) making

telephone calls to/from caregivers/care receivers, agencies, and other professionals; (c) charting; d) attending twice weekly care planning meetings for PREP staff; (e) attending monthly interdisciplinary care planning meetings with home health staff; (f) researching the literature related to specific caregiving problems; (g) reviewing outpatient charts; (h) meeting with consultants; (i) attending family conferences; and j) attending care receiver funerals. The activities of the administrative staff included supervising the PREP nurses and conducting care planning meetings.

The control group received standard home health services by the HMO's home health nurses or physical therapists and included the following activities: (a) making home visits; (b) making telephone calls to/from caregivers/care receivers, agencies, and other professionals; (c) charting; and (d) attending monthly interdisciplinary care planning meetings with other home health staff.

Home Visits

All 11 dyads in the intervention group received home visits from PREP nurses, and eight dyads in the control group received home visits from home health nurses. Three care receivers in the control group were referred to the Home Health Department for PT only and therefore received no nursing visits.

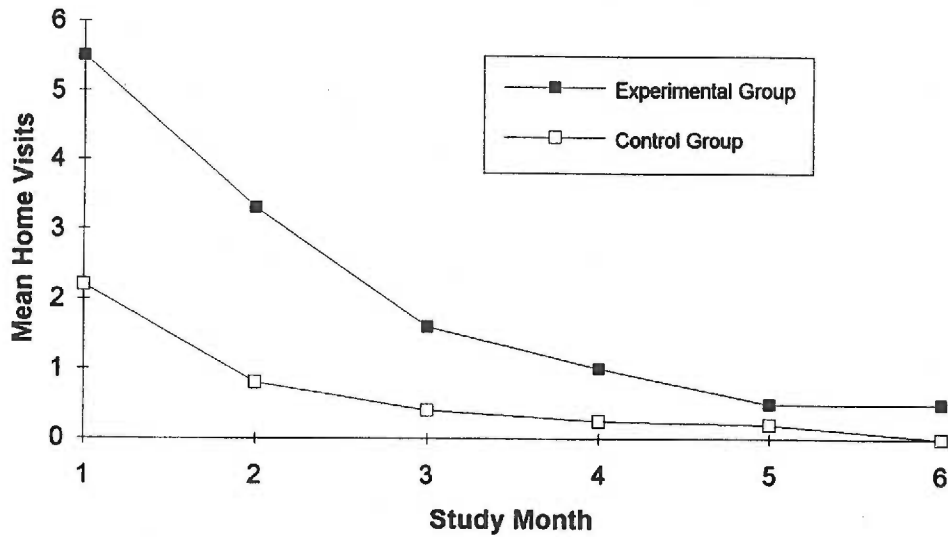
Home Visit Frequency

During the study period, PREP nurses made 127 home visits, compared to 40 home visits by home health nurses. The number of home visits per dyad in the intervention group ranged from 4 to 21, with a mean of 11.5. In the control group, the number of home visits per dyad ranged from 1 to 14 with a mean of 4.9.

Mean home visits per study month by group are displayed in Figure 5.1. The pattern of home visits was similar in the two groups; the number of home visits started higher in the first months after dyads were enrolled in the study and decreased in succeeding months. In the first three study months, intervention dyads utilized significantly more home visits than control dyads.

Figure 5.1

Mean Home Visits By Nurses Per Month by Group



	Control Group			Experimental Group		
	n	M	SE of M	n	M	SE of M
Month 1***	11	2.2	0.8	11	5.5	0.5
Month 2**	11	0.8	0.5	11	0.3	0.6
Month 3*	11	0.4	0.3	11	1.6	0.6
Month 4	8	0.3	0.2	8	1.0	0.5
Month 5	5	0.2	0.2	6	0.5	0.2
Month 6	2	0.0	0.0	2	0.5	0.5

*** $p < .003$, two-tailed.

** $p < .004$, two-tailed.

* $p < .08$, two-tailed.

During the remaining three study months, intervention dyads also utilized more home visits than control dyads, but the differences were not significant. Because of the exploratory nature of this study, significance levels below .10 are reported.

The pattern of home visits demonstrates a transition in caregiving, with increased care receiver needs in the beginning, followed by a gradual resolution and stabilization of health and caregiving issues. The beginning of the transition in the intervention group was characterized by greater number of home visits for assessment, development of the therapeutic relationship, and intensive work in resolving caregiving issues. Then, as the care plan was implemented, issues were resolved, and telephone calls substituted for some home visits, home visits decreased. In the control group, the transition is also characterized by a higher intensity of home visits at the beginning, primarily for the stabilization of acute care receiver health problems. The purpose of home visits in the control group in Study Months 4-6 was to supervise the home health aide, as required by Medicare, and no other nursing interventions were implemented. Continuing home visits in Study Months 4-6 in the intervention group represented ongoing nursing involvement with dyads and also included the final home visit made when dyads completed the project.

Home Visit intensity

The intensity of home visits refers to the range and complexity of nursing activities performed in providing care to dyads and includes the following areas: (a) the number of issues identified for each care receiver or dyad; (b) the number of issues addressed at each home visit; (c) the nature of issues addressed; and (d) intervention strategies. Intervention and control dyads differed in the intensity of home visits.

Number of problems identified for each dyad. The number of problems identified by PREP nurses in 11 intervention dyads ranged from 2 to 14, with a mean of 9.2. In the control group, problems were not identified by nurses in three dyads because the care receiver was referred for physical therapy only. In three additional cases, nurses made one evaluation only home visit, and because the care receiver had no skilled nursing needs, a problem list was not developed. A single problem was identified in 4 of the remaining 5 care receivers, and the 5th care receiver had 4 problems identified. For the care receiver with four problems, two problems were not actually addressed by home health nurses on an ongoing basis; these problems entitled the care receiver to the services of a home health aide and a homemaker. In the control group,

all problems were identified at the first home visit. In the intervention group, new problems were added to the Follow-up List as they were identified.

Number of problems addressed at each visit. In the control group, home health nurses addressed each problem at every home visit. In the intervention group, problems addressed at each home visit varied according to the desires and needs of the dyad and ranged from 1 to 8, with a mean of 3.3.

Nature of problems addressed and intervention strategies. In standard home health, the nurses focused very narrowly on care receiver health problems. The care receiver was required to have skilled nursing needs, which were short-term, acute, and medical in nature, requiring services that were inherently complex and could be safely performed by professional nurses (USDHS, 1989). Care receiver problems were identified by the home health nurse based on the orders of the referring physician. Interventions were short-term and aimed at assessing the medical problem and providing skilled nursing care for a short period of time and/or teaching care procedures to caregivers. For example, in one case, the home health nurse gave a weekly injection to the care receiver for about six weeks, until he was able to resume clinic visits to obtain the injections.

In the intervention group, PREP nurses focused not only on the care receiver but also on the caregiver. PREP nurses addressed not only health problems, but also a wide range of other issues encountered in long-term caregiving situations, such as functional abilities/deficits, behavior problems, instrumental activities of daily living, financial, legal and health decisions, caregiver strain, caregiver health, predictability in caregiving, and enrichment in caregiving. The care receiver was not required to have skilled nursing needs, but any health or caregiving problem could be addressed, including long-term as well as acute problems. In addition, various aspects of a problem could be addressed, such as fitting a particular task within a caregiving routine or dealing with the frustrations of a specific issue. Issues addressed were identified jointly by the caregiver and the PREP nurse. The goals of intervention were to increase the caregivers feelings of preparedness for caregiving, to enhance predictability in the caregiving routine, and

to enrich the caregiving situation for both caregiver and care receiver. A broad range of intervention strategies were often tried. PREP nurses provided help with a specific problem until the caregiver thought she could manage it to her satisfaction. For example, in one case, the PREP nurse used 21 different intervention strategies over a 3-month period to help one caregiver manage the care receivers behavior problems better.

A complete listing of the problems addressed and intervention strategies utilized by PREP and home health nurses in each intervention and control dyad, as well as the number of home visits and length of stay in home health or PREP, can be found in Appendix T. One representative case from each group will be described here to illustrate the differences between standard home health nursing and PREP nursing.

Care receiver #301 in the control group was a 74-year-old woman who was cared for by her 75-year-old husband. After a hospitalization for a coronary by-pass surgery with a complication of cerebral vascular accident, she was referred to home health with physician orders for the home health nurse to assess the home situation. The home health nurse made three home visits in a 16-day period. The only problem on the home health problem list was Knowledge Deficit--Insulin Dependent Diabetes Mellitus (IDDM). At each home visit the care receivers vital signs were taken, and the nurse assessed aspects of care directly related to IDDM--capillary blood glucose (CBG), healing of the surgical incision, the caregivers ability to use the syringe for Insulin administration, and foot care. Also at each home visit, the nurse taught the caregiver about one or two specific aspects of IDDM--appropriate glucose range, exchange diet, CBG testing, signs, symptoms, and causes of hyper- and hypo-glycemia, and high and low CBG's to report to the physician. The care receiver was then discharged from home health.

Care receiver #308 in the intervention group was an 81-year-old man with dementia, who was cared for by his 79-year-old wife. He was referred to home health after a 10-day hospitalization for acute renal failure and probable pneumonia. Physician orders for skilled nursing were to assess the home situation, assess cardio-pulmonary function, review

medications, and provide urinary catheter care. Ten issues were included on the PREP Follow-up List: (a) Unprepared to protect from falls; (b) Unprepared to manage behavior problems (repetitive questions, agitation/restlessness); (c) Unprepared to manage urinary catheter; (d) Unprepared to manage constipation; (e) Unprepared to manage skin conditions; (f) Unprepared to assist with bathing; (g) Unprepared to access the HMO; (h) Unpredictability of the disease process; (i) Caregiver strain; and (j) Caregiver health problems. The PREP nurse made 20 home visits in the almost 5-month period the dyad was in the study. In addition, one home visit was made by a home health nurse to draw blood when the care receiver became ill. Seven home visits were made in the Study Month 1, four visits in Study Month 2, seven visits in Study Month 3, 1 visit in Study Month 4, and 2 visits in Study Month 5. The number of problems addressed at each home visit ranged from 1 to 7, with a mean of 3.1.

The number of different interventions per caregiving issue ranged from 1 to 20, with a mean of 5.6. Home visits were characterized by a wide range of intervention strategies. First of all, the PREP nurse assessed various aspects of a problem when it was identified and at subsequent, though not at every, home visit. For the problem Unprepared--Protection from falls, the nurse assessed the care receivers strength, his activity, the safety of his ambulation, the caregiver's knowledge of what to do in case of a fall, and the immediate environment and equipment in the home.

Understanding the pattern of the occurrence of caregiving problems was emphasized. For example, the nurse helped the caregiver to document on a calendar the occurrence of behavior problems and frequency of bowel movements, then evaluated the patterns with the caregiver and based further strategies on the observed patterns. In the case of behavior problems, this information was used to associate escalation of the behavior with other environmental stimuli or events. Specific intervention strategies that the caregiver was to use with the care receiver were written in the Family Health Diary, and the caregiver was encouraged to show the health record to a daughter who lived nearby and visited frequently.

Some strategies were aimed at increasing enrichment. For example, in managing skin conditions, the caregiver was encouraged to give the care receiver a back rub. In protecting the care receiver from falls the nurse tried to increase enrichment by combining ambulation with something that was pleasurable for the care receiver, like going to the front door or going to the dining table.

The PREP nurse assessed the caregiver's health and her health promotion activities. She encouraged the caregiver to see her physician about a health problem that had been bothering her for some time, and she evaluated the caregiver's understanding of information received from the physician after a clinic visit. She assessed the amount of strain experienced by the caregiver in six different visits and assessed the amount of help from other nearby family members.

The unpredictability of the care receiver's disease trajectory was an important focus of nursing intervention. The caregiver was particularly frightened by and unprepared for changes in the care receivers physical condition which in the past had resulted in hospitalizations and deterioration in the care receiver's physical abilities, which made it more difficult for the caregiver to care for him. The PREP nurse assessed physical parameters that had been problems in the past in order to detect early changes. She taught the caregiver the symptoms of health status changes that are different in persons with dementia. She initiated a discussion with the caregiver about her commitment to caregiving, her wishes regarding placement of the care receiver, resuscitation status of the care receiver, the care receiver's prognosis, and goals for long-term management of the care receiver. This information helped the nurse to plan intervention strategies to support the caregiver in keeping the care receiver at home.

Another difference between PREP nursing and standard home health nursing was evident in a comparison of the above intervention dyad and a different control dyad. This difference was that PREP nurses continued to try new strategies and actively sought new solutions to problems that did not respond well to usual or accepted strategies, while home health nurses seemed to rely on standard approaches. In the intervention dyad above, the

behavior problems were particularly difficult for the caregiver and some strategies for managing them did not work. The PREP nurse consulted a mental health nursing expert and used the literature to develop additional strategies. In the control group, on the other hand, one care receiver received 14 home visits from home health nurses over a 5 1/2 week period because she was not eating. Even though the care receiver continued not eating, at every home visit, the home health nurse assessed the amount of food the care receiver was eating and at every home visit instructed the caregiver to give small, frequent meals and fluids. Efforts to find other solutions to the problem were not evident, and in the final two home visits, there was no charting about actions the caregiver could take to improve the problem.

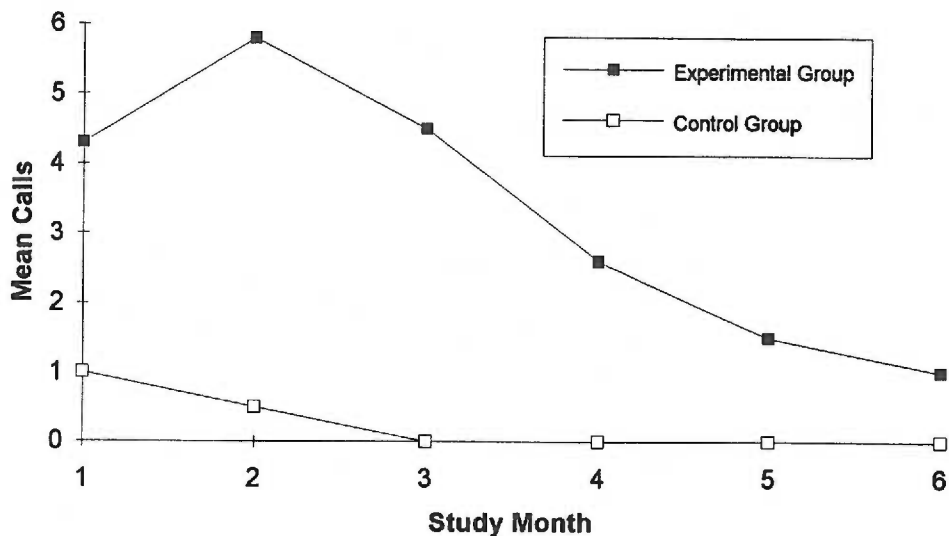
Telephone Calls

While telephone calls were an important part of the intervention for PREP nurses and dyads in the intervention group, relatively few calls were made by home health nurses. Home health nurses made a total of 16 telephone calls--4 to caregivers, 11 to physicians, and 1 to an institutional provider. PREP nurses, on the other hand, made or received a total of 193 calls--78 calls to caregivers and 10 calls to care receivers, 12 calls from caregivers and 2 calls from care receivers, 11 calls to physicians, 13 calls to other agencies, 4 calls to institutional providers, 2 calls to other family members, 10 calls to other home health staff, 8 calls to outpatient staff other than physicians, 2 calls to consultants, 1 call to Member Services, and 1 call to the Durable Medical Equipment Department. In addition, 18 Keep-in-Touch assessment calls were made by PREP nurses. In 21 cases, data regarding the nature of the telephone call was missing.

Mean telephone calls per study month for each group are displayed in Figure 5.2. The number of calls in each of the study months was greater in the intervention group than in the control group, and was significantly greater in Study Months 1 and 2. After the first two months, home health nurses made no telephone calls regarding dyads in the control group. In the intervention group telephone calls increased in Study Month 2 and then decreased in succeeding months, but never reached a level of zero.

Figure 5.2

Mean Telephone Calls By Nurses Per Month by Group



	Control Group			Experimental Group		
	n	M	SE of M	n	M	SE of M
Month 1*	11	1.0	0.7	11	4.3	1.4
Month 2**	11	0.5	1.2	11	5.8	1.6
Month 3	11	0.0	0.0	11	4.5	1.4
Month 4	8	0.0	0.0	8	2.6	0.8
Month 5	5	0.0	0.0	6	1.5	0.6
Month 6	2	0.0	0.0	2	1.0	1.0

* $p < .06$, two-tailed.

** $p < .007$, two-tailed.

The pattern of telephone calls provides a view of the essential difference between PREP and standard home health. PREP clearly became more involved in the beginning and stayed more involved, and was more oriented toward long-term management of the care receiver's health problems. Standard home health, on the other hand, was much more oriented to the acute post-hospital needs of care receivers and stayed involved just long enough to make sure

that the care receivers condition was stable and that medically-related care could be adequately provided by the care receiver or a family member.

In addition to counting the number of telephone calls, calls were rated in intensity, even though charting about calls may not have always accurately reflected the content of a call. High intensity calls were those in which either an in-depth assessment of a caregiving problem was performed or two or more caregiving problems were addressed, and low intensity calls were those in which one caregiving problem was addressed briefly and no in-depth assessment was performed. Home health nurses made no high intensity telephone calls. Their telephone calls were primarily for conveying or seeking limited amounts of information. PREP nurses, on the other hand, utilized telephone calls as an adjunct to home visits, conducted in-depth assessments, followed up on intervention strategies, and gave support to caregivers. All 18 Keep-in-Touch assessment calls were rated as high intensity and 25 additional calls with caregivers and care receivers were rated as high intensity.

Interdisciplinary Care Planning Meetings

Monthly interdisciplinary care planning meetings were attended as required by Medicare rules by nurses in both groups for care receivers who were receiving skilled nursing plus one or more other types of home health services. Home health nurses attended eight and PREP nurses attended six interdisciplinary care planning meetings.

Other PREP Nursing Activities

In addition to home visits, telephone calls, and monthly interdisciplinary care planning meetings, PREP nurses performed many other activities in implementing the intervention. The amount of time spent in all PREP nursing activities is summarized in Table 5.1. In the Table, charting time is separated out from home visit time. A majority of nursing time was spent in the actual home visit, travel, and charting. Very small amounts of time were spent on errands, chart review, library study, consultation, family conferences, funerals, and interdisciplinary meetings with other home health staff.

Table 5.1

Time Spent by PREP Nurses in Nursing Activities

Nursing Activity	Total Hours
Home Visits	188.3
Charting	103.5
Travel	88.75
Care Planning Meetings	35.6
Telephone Calls	
Keep-in-Touch Calls	7.5
All Other Calls	44.25
Errands	0.5
Chart Review	5.0
Library Study	2.75
Consultation	2.75
Family Conferences	4.25
Funerals	2.0
Interdisciplinary Meetings with Other Home Health Staff	1.75

Nurse Caseload and Duration of Home Visits

Patient caseload, or the average number of home visits per day, was considerably less for PREP nurses than for home health nurses. The average number of home visits per day by PREP nurses was 1.8. In 1991, the average number of home visits, including hospice visits, for home health nurses was 4.5. The average duration of home visits including charting time was 2.2 hours in the intervention group and 1.1 hours in the control group.

The Cost of PREP Nursing and Standard Home Health Nursing

The second study aim was to develop methods to measure and compare the cost of implementing PREP in intervention dyads with the cost of standard home health in control dyads. The cost of PREP nursing in the intervention group is summarized in Table 5.2. In order

Table 5.2

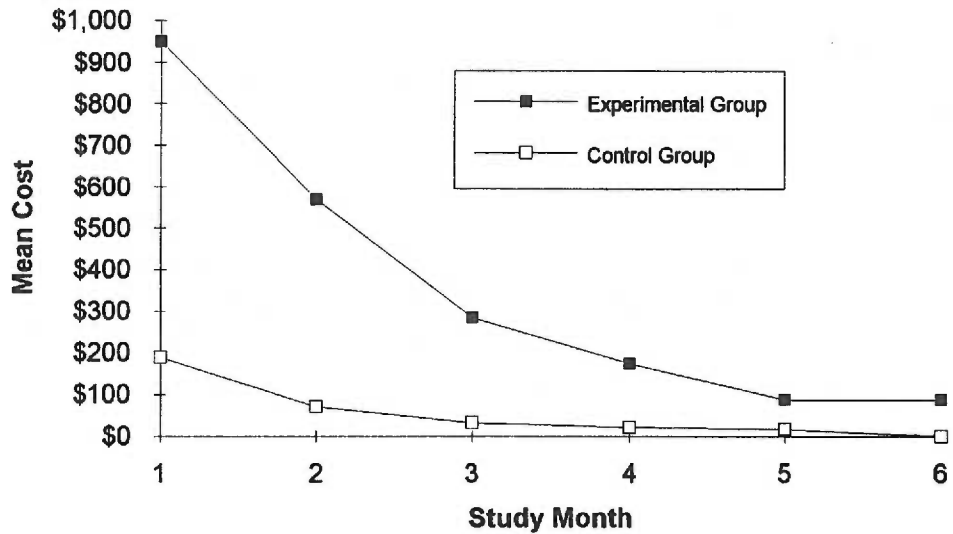
PREP Nurse Costs

Cost Category	Total Cost
Nurse Salary and Benefits	\$17,759.46
Administrative Staff Salary and Benefits	4,199.20
Consultant Fees	187.50
Office Supplies	135.30
Mileage	843.96
Medical Supplies	569.00
HMO Administrative Overhead	369.00
Total Cost	\$22,063.42
Cost Per Visit (127 Visits)	\$173.73

to obtain a cost for PREP nursing that was comparable to standard home health nursing, the cost per visit was calculated by dividing the total cost of PREP nursing by the number of home visits. This means that the cost of all nursing activities is included in the visit cost. The total cost of PREP nursing was \$22,063.42 and the cost per home visit was \$173.73. The total cost of home health nursing in the control group was \$3,466.44 and the cost per home visit was \$86.65. Mean nursing costs per study month by group is displayed in Figure 5.3. The cost of nursing services was higher in the intervention group than in the control group in every study month and was

Figure 5.3

Mean Cost of PREP and Standard Home Health Nursing Per Month by Group



	Control Group			Experimental Group		
	n	M	SE of M	n	M	SE of M
Month 1**	11	\$189	\$70	11	\$948	\$104
Month 2**	11	71	42	11	569	125
Month 3*	11	32	24	11	284	136
Month 4	8	22	14	8	174	109
Month 5	5	17	17	6	87	49
Month 6	2	0	0	2	87	109

** $p < .000$, two-tailed.

* $p < .04$, two-tailed.

significantly higher in Study Months 1, 2, and 3. Mean monthly nursing costs closely follow mean monthly nursing utilization patterns, with high costs at the beginning of the intervention when assessments were conducted and more intensive problem-solving occurred. Costs declined over time as care receivers recovered and their health conditions stabilized and as caregiving issues were resolved.

Utilization and Cost of Non-PREP Health Services for Care Receivers

The third study aim was to develop measures of utilization and cost of non-PREP health and social services by intervention and control dyads because it was hypothesized that PREP would offset the utilization of some services and increase the utilization of others. Utilization and cost data for care receivers are presented for the following classes of services: (a) non-nursing home health services; (b) institutional services; (c) outpatient services; (d) community social services; and (e) pharmacy, durable medical equipment, and medical supply services.

Non-Nursing Home Health Utilization and Cost

Home visits by non-nursing home health staff were made to all but one intervention care receiver. These staff included physical therapy, occupational therapy, speech therapy, social work, home health aide, and housekeeping. The number of home visits by non-nursing home health staff per care receiver in the control group ranged from 1 to 66, with a mean of 9.7. In the intervention group the number of home visits per care receiver ranged from 0 to 36, with a mean of 8.8. Table 5.3 provides a summary of the number of care receivers who utilized non-nursing home health services, the number of home visits by each type of provider, and the cost of each service by group.

Mean home visits by non-nursing home health staff per study month by group is displayed in Figure 5.4. Although both groups utilized the same number of home visits during Study Month 1, the intervention group utilized slightly fewer home visits in Study Months 2, 3, and 4. None of the differences was significant. Utilization rates for physical therapy and occupational therapy were considerably higher in the control group, due largely to one care receiver who received ongoing therapy after a stroke. Home health aides were utilized considerably more by the intervention group. The number of visits declined in both groups after the first month reflecting improvements in the care receiver and resolution of health problems. Because of Medicare regulations regarding the provision of home health services, it does not seem likely that PREP nurses influenced their utilization. However, the higher

Table 5.3

Number of Care Receivers Who Utilized Non-Nursing Home Health Services, Number of Home Visits, and Service Cost by Group

	Control Group			Intervention Group		
	Care Receivers	Home Visits	Cost	Care Receivers	Home Visits	Cost
Non-Nursing Service						
Physical Therapy	10	49	\$3,680	6	19	\$1,427
Occupational Therapy	2	35	3,073	2	5	444
Speech Therapy	0	0	0	2	3	318
Social Work	2	3	327	0	0	0
Home Health Aide	2	16	893	5	70	3,893
Home maker	1	4	281	0	0	0
Total		107	\$8,254		97	\$6,082

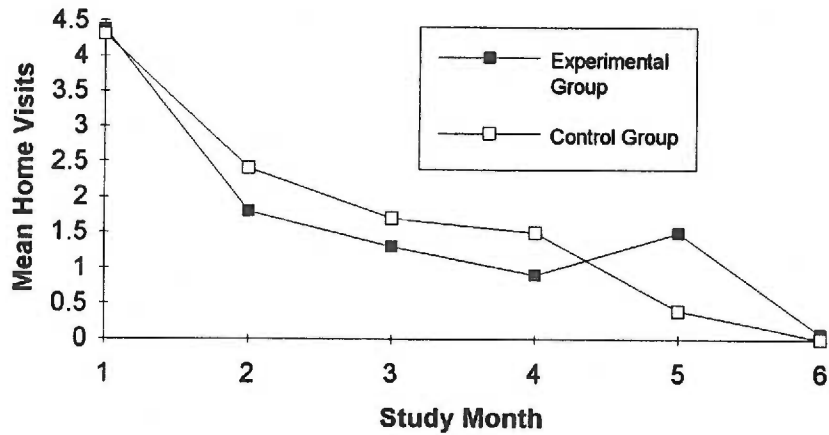
utilization rate for home health aides by PREP dyads may reflect their efforts to ensure maximum amount of home health aide visits in order to help caregivers.

The cost of non-nursing home health services per care receiver in the control group ranged from \$75 to \$5,137, with a mean of \$801. The cost per care receiver in the intervention group ranged from \$0 to \$2,049, with a mean of \$553. The total cost in the control group was \$8,810 and \$6,077 in the intervention group.

Mean non-nursing home health costs by group per study month are displayed in Figure 5.5. The cost of non-nursing home health services was somewhat lower in the intervention group in each of the first four study months, and the cost pattern over the 6-month study period showed the same pattern of decline as the utilization of these services. The cost of non-nursing

Figure 5.4

Mean Home Visits by Non-Nursing Home Health Staff Per Month by Group

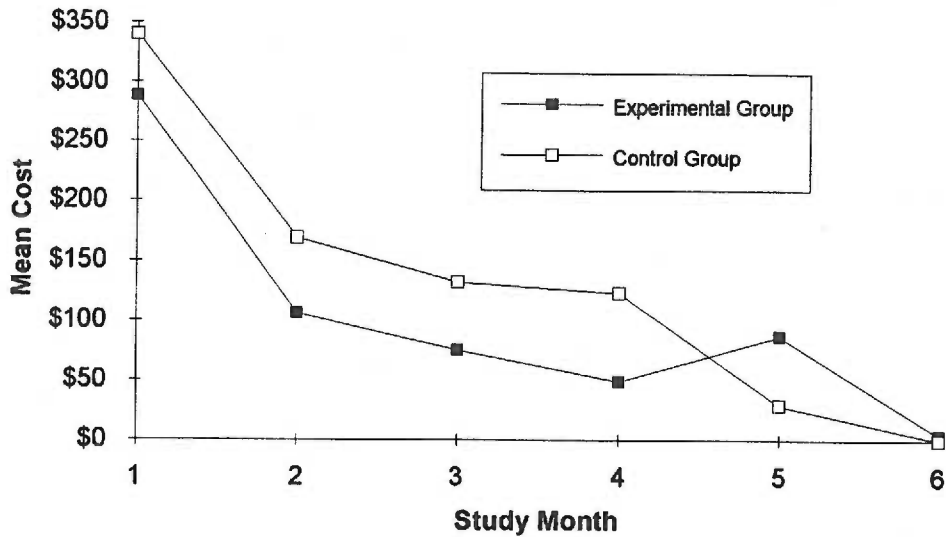


	Control Group			Experimental Group		
	n	M	SE of M	n	M	SE of M
Month 1	11	4.3	1.4	11	4.3	1.1
Month 2	11	2.4	1.7	11	1.8	0.8
Month 3	11	1.7	1.7	11	1.3	0.8
Month 4	8	1.6	1.5	8	0.9	0.9
Month 5	5	0.4	0.4	6	1.5	1.3
Month 6	2	0.0	0.0	2	0.0	0.0

home health services did not differ significantly in the two groups in any study month. Lower costs in the intervention group reflect the greater utilization of home health aides, with a relatively low cost per visit, and less utilization of physical therapy and occupational therapy, with a relatively high cost per visit.

Figure 5.5

Mean Non-Nursing Home Health Home Visit Cost Per Month by Group



	Control Group			Experimental Group		
	n	M	SE of M	n	M	SE of M
Month 1	11	\$340	\$117	11	\$288	\$69
Month 2	11	169	127	11	106	47
Month 3	11	132	132	11	75	44
Month 4	8	123	123	8	49	49
Month 5	5	29	29	6	87	73
Month 6	2	0	0	2	0	0

Institutional Service Utilization and Cost

Care receivers utilized both acute and long-term care institutional services, including hospitals, nursing homes, and adult foster homes.

Hospital Utilization and Cost

Five care receivers in the control group were hospitalized during the study; one care receiver was admitted twice. Six care receivers in the intervention group were hospitalized, and

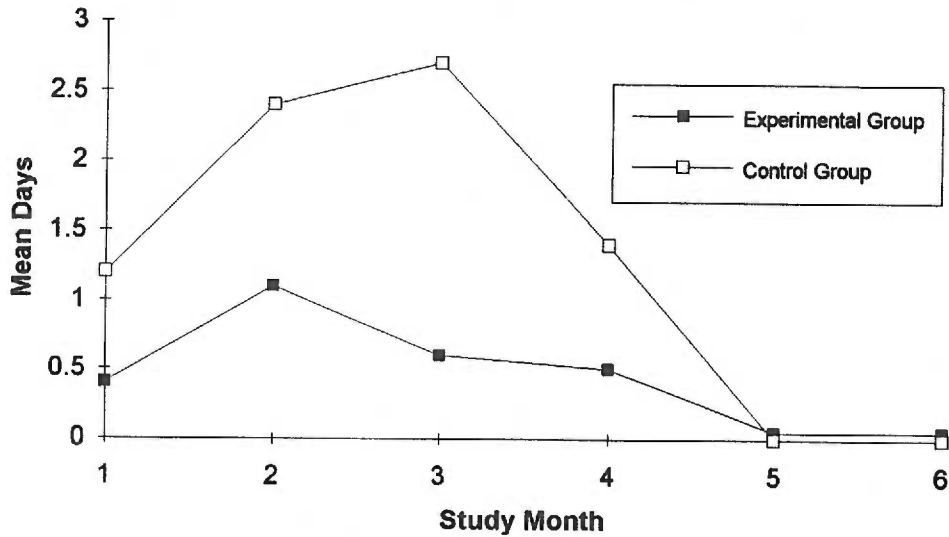
each was admitted once. Although the number of hospital admissions was the same for each group, the total number of hospital days was 80 in the control group and 27 in the intervention group. Length of stay in the control group ranged from 1 to 36 days with a mean of 13.3 days. Length of stay in the intervention group ranged from 2 to 7 days, with a mean of 4.5 days.

Hospital utilization is displayed in Figure 5.6 as the mean number of hospital days per study month by group. Hospital utilization in the control group was higher than the intervention group in Study Months 1, 2, 3, and 4, but the difference was not significant in any study month. The higher mean in the control group in Study Months 2 and 3 was due to long stays by two care receivers—one 30-day stay and one 24-day stay. Because neither of the care receivers with a long hospital stay had been originally admitted to home health from the hospital, but rather were referred by outpatient clinic staff, these long stays do not indicate re admission after inappropriate hospital discharge. However, both situations did indicate a caregiving situation in major transition, with caregivers who either were not prepared or were feeling overwhelming strain from the situation and unable to access appropriate assistance.

Care receiver #319 carried a diagnosis of dementia and was declining cognitively. The caregiver clearly did not fully appreciate the degree of his wife's disabilities nor understand how to take care of her. She received one evaluation-only home visit from the home health nurse, and was discharged because she had no skilled needs. This care receiver was hospitalized after she fell and broke her hip. Care receiver #315 was declining physically and emotionally due to several consecutive spontaneous vertebral fractures accompanied by severe pain. She received 14 home visits by the home health nurse and visits by a homemaker and home health aide. The caregiver was not sure what kind of help her mother needed but sought help from HMO social workers and physicians and from community agencies and also initiated psychological assistance in an effort to stop her mother's decline. The caregiver experienced a great deal of strain and was frustrated that nothing she did helped her mother. This care receiver died in a nursing home immediately after her long-stay hospitalization.

Figure 5.6

Mean Hospital Days Per Month by Group



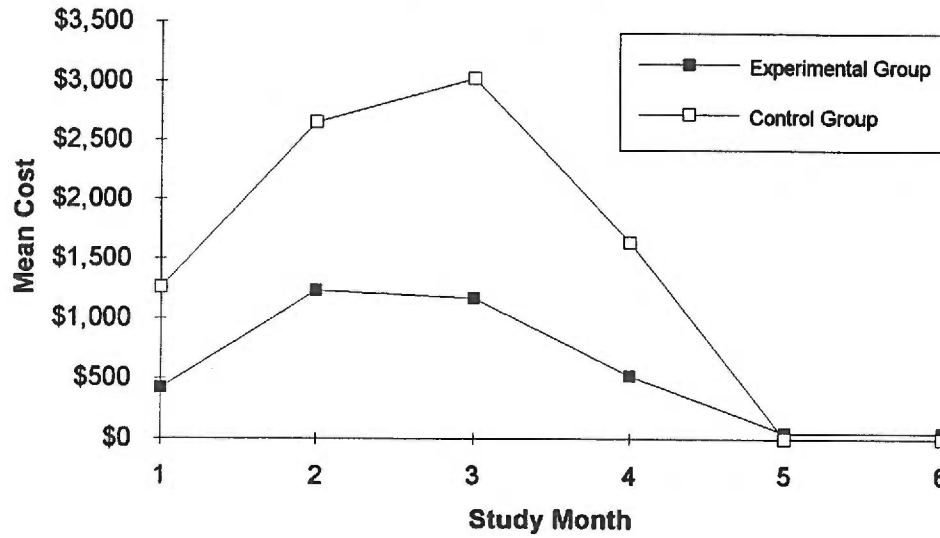
	Control Group			Experimental Group		
	n	M	SE of M	n	M	SE of M
Month 1	11	1.2	0.6	11	0.4	0.4
Month 2	11	2.4	2.2	11	1.1	0.7
Month 3	11	2.7	2.7	11	0.6	0.6
Month 4	8	1.4	0.9	8	0.5	0.5
Month 5	5	0.0	0.0	6	0.0	0.0
Month 6	2	0.0	0.0	2	0.0	0.0

The cost per hospitalization in the control group ranged from \$1,047 to \$39,453 with a mean of \$14,658. In the intervention group the cost per hospitalization ranged from \$2,093 to \$12,788 with a mean of \$5,786. Total hospital costs for the control group were \$87,945 and \$34,716 for the intervention group.

The mean hospital cost per study month by group is displayed in Figure 5.7 and reflects the hospital utilization pattern except Study Month 3. The hospital utilization pattern would

Figure 5.7

Mean Hospital Cost Per Month by Group



	Control Group			Experimental Group		
	n	M	SE of M	n	M	SE of M
Month 1	11	\$1258	\$632	11	\$418	\$418
Month 2	11	5452	2420	11	1232	776
Month 3	11	3020	3020	11	1163	1163
Month 4	8	1641	1084	8	523	523
Month 5	5	0	0	6	0	0
Month 6	2	0	0	2	0	0

suggest a lower cost in the intervention group in Study Month 3 than actually occurred. This discrepancy represents a high intensity of resource consumption during the hospitalization of one care receiver in the intervention group. Hospital costs were considerably higher in the control group than the intervention group in the first 4 study months but the differences were not significant in any study month. The long hospital stays described above accounted for a large share of hospital costs in the control group.

Long-term Institutional Service Utilization and Cost

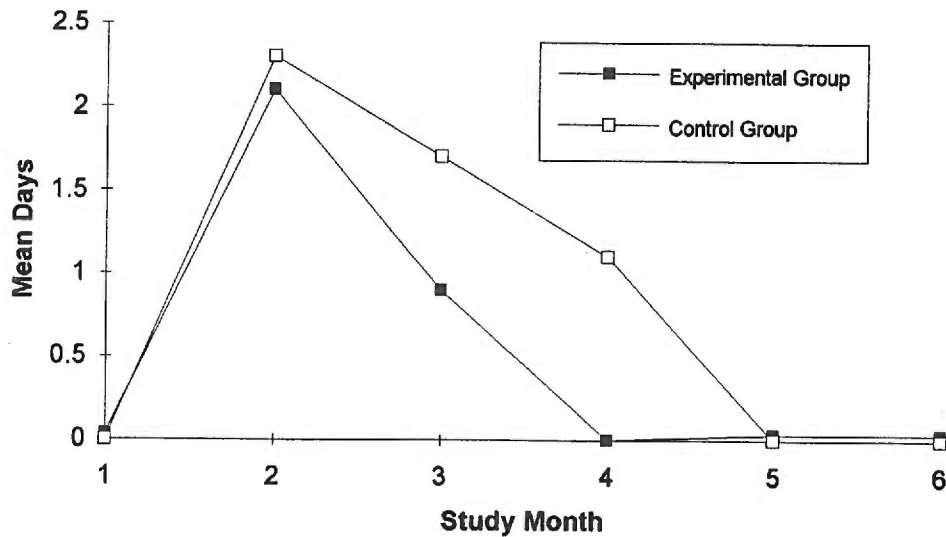
Long-term institutional services utilized by care receivers included nursing homes and adult foster homes. Utilization and cost data for these two services were combined because there was very little difference between the two with respect to impairment of clients or to care provided. Three care receivers in the control group and one care receiver in the intervention group were admitted once to a nursing home. One care receiver in the control group was admitted once to an adult foster home. No other long-term institutional services were used by care receivers in either group. The total number of long-term institutional days for the control group was 53 and 33 for the intervention group. The length of stay in the control group ranged from 1 to 24 days with a mean of 13.25. One care receiver in the control group died after one day in the nursing home. The remaining three care receivers all returned home after their nursing-home stay.

Mean long-term institutional days per study month by group are displayed in Figure 5.8. The pattern of utilization was similar in both groups--no utilization in Study Month 1 followed by a sharp rise in Study Month 2 followed by a decline in Study Months 3 and 4. The intervention utilization for both groups was due to a single admission and reflected stressful caregiving situations and in the intervention dyad reflects low mutuality between the care receiver and caregiver. Control group care receiver #315 was admitted to an adult foster home. The caregiver was exhausted not only from trying to find services but also from caring for her mother during the night. The nursing home stay for the intervention care receiver (#322) occurred after a hospitalization for gastrointestinal bleeding. This caregiver experienced very high strain seemed ambivalent about caregiving and had quite low mutuality with the care receiver compared with other dyads. This caregiver had institutionalized the care receiver on other occasions because the strain was too great and at the time of admission to PREP was trying to care for him at home after approximately 6 months in a nursing home.

The total cost of long-term institutional services for the control group was \$6,023 and \$3,220 for the intervention group. The mean cost of long-term institutional care per study month

Figure 5.8

Mean Nursing Home and Adult Foster Home Days Per Month by Group

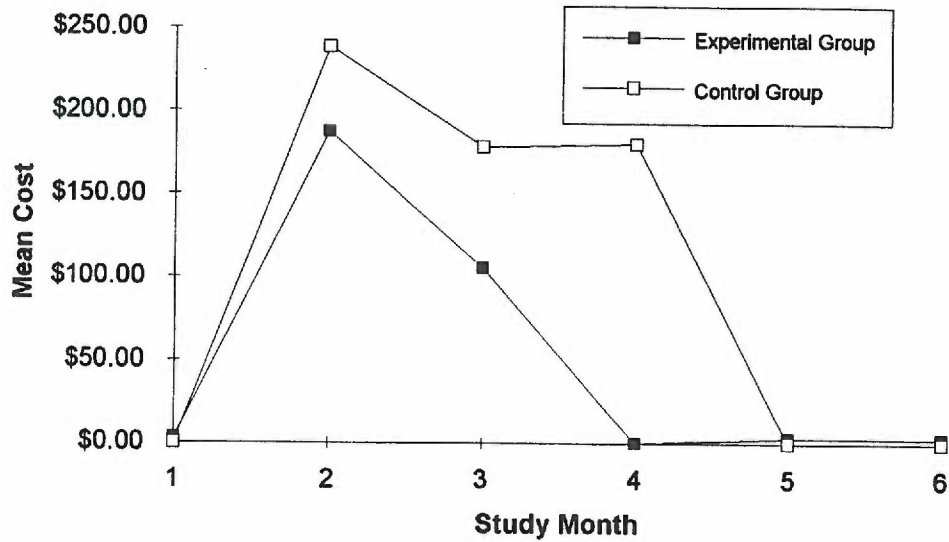


	Control Group			Experimental Group		
	n	M	SE of M	n	M	SE of M
Month 1	11	0.0	0.0	11	0.0	0.0
Month 2	11	2.3	1.8	11	2.1	2.1
Month 3	11	1.7	1.7	11	0.9	0.9
Month 4	8	1.1	1.0	8	0.0	0.0
Month 5	5	0.0	0.0	6	0.0	0.0
Month 6	2	0.0	0.0	2	0.0	0.0

by group is displayed in Figure 5.9. Costs for the control group in Study Month 4 increased slightly over Study Month 3 unlike its utilization which decreased during the same time period. This either reflects differences in basic charges of two skilled nursing facilities or differences in resource consumption of the two care receivers who utilized the facilities. Costs were greater for

Figure 5.9

Mean Nursing Home and Adult Foster Home Cost Per Month by Group



	Control Group			Experimental Group		
	n	M	SE of M	n	M	SE of M
Month 1	11	\$0	\$0	11	\$0	\$0
Month 2	11	238	192	11	187	187
Month 3	11	178	178	11	105	105
Month 4	8	180	159	8	0	0
Month 5	5	0	0	6	0	0
Month 6	2	0	0	2	0	0

the control group In each study month the services were used but none of the differences was significant.

Outpatient Service Utilization and Cost

Outpatient services utilized by care receivers included primary care (physician nurse practitioner physician's assistant) emergency/urgency care dental audiology optometry mental health/counseling social work RN LPN Advice Nurse and chronic renal dialysis. The only service

on the service utilization interview question that was not utilized by any care receiver was chiropractor.

Outpatient Primary Care Utilization and Cost

Utilization and cost data for clinic visits to physicians nurse practitioners and physician's assistants are combined because these providers are treated as substitutes within the HMO's primary care and specialty clinics. Eight of the 11 control care receivers and all but one intervention care receiver utilized the outpatient clinic at least once during the study period. The total number of clinic visits in the control group was 44 and in the intervention group 46. The number of visits per care receiver in the control group ranged from 0 to 10 with a mean of 3.7 In the intervention group the number of visits per care receiver ranged from 0 to 12 with a mean of 4.1.

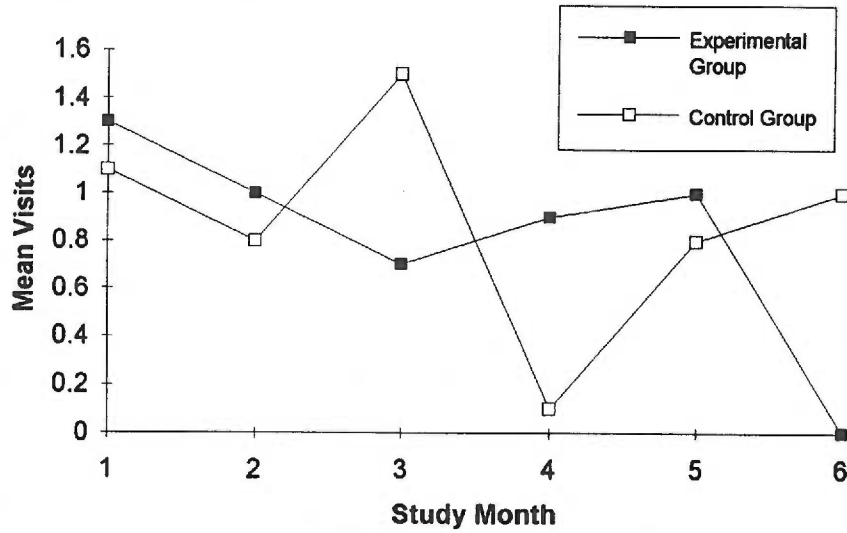
The mean number of clinic visits per study month by group is displayed in Figure 5.10. The intervention group utilized slightly more clinic visits than the control group in Study Months 2 and 5 but the difference was not significant in any of the study months. The pattern of monthly outpatient utilization suggests that clinic visits were more stable in the Intervention group and were more variable less predictable in the control group. These patterns could reflect a control group with more unstable health problems. They could also reflect efforts by PREP nurses in the intervention group to encourage regular follow-up by the primary care provider or to refer to the provider for treatment of new problems, which in the control group would not have been treated.

The cost per outpatient clinic visit in the control group ranged from \$4 to \$397, with a mean of \$48. The cost per visit in the intervention group ranged from \$4 to \$293, with a mean of \$53. The total cost of outpatient physician, nurse practitioner, and physician's assistant services was \$3,293 in the control group and \$3,389 in the intervention group.

The mean clinic visit cost per study month by group is displayed in Figure 5.11. Costs were slightly lower in the intervention group than in the control group in Study Months 1 and 2 and moderately lower in Study Month 3. The differences between the groups were not significant

Figure 5.10

Mean Outpatient Physician, Nurse Practitioner, Physician's Assistant Clinic Visits Per Month by Group



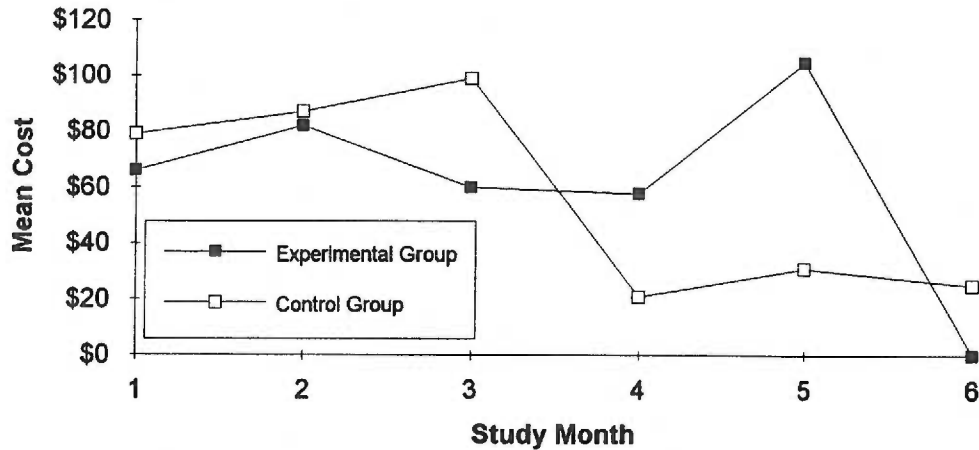
	Control Group			Experimental Group		
	n	M	SE of M	n	M	SE of M
Month 1	11	1.1	0.3	11	1.3	0.4
Month 2	11	0.8	0.3	11	1.0	0.2
Month 3	11	1.5	0.5	11	0.7	0.4
Month 4*	8	0.1	0.1	8	0.9	0.4
Month 5	5	0.8	0.5	6	1.0	0.5
Month 6	2	1.0	0.0	2	0.0	0.0

* $p < .08$

for any study month. Costs remained relatively stable in the intervention group in first four study months. In the control group, costs remained stable during the first three study months, dropped, and remained stable at a lower level. Cost patterns differ considerably from the utilization

Figure 5.11

Mean Outpatient Physician, Nurse Practitioner, Physician's Assistant Cost Per Month by Group



	Control Group			Experimental Group		
	n	M	SE of M	n	M	SE of M
Month 1	11	\$79	\$26	11	\$66	\$17
Month 2	11	87	40	11	82	30
Month 3	11	99	34	11	60	41
Month 4	8	21	21	8	58	27
Month 5	5	31	23	6	105	75
Month 6	2	25	5	2	0	0

patterns. These differences represent differences in the average appointment time and average cost of the provider type.

Emergency/Urgency Care Utilization and Cost

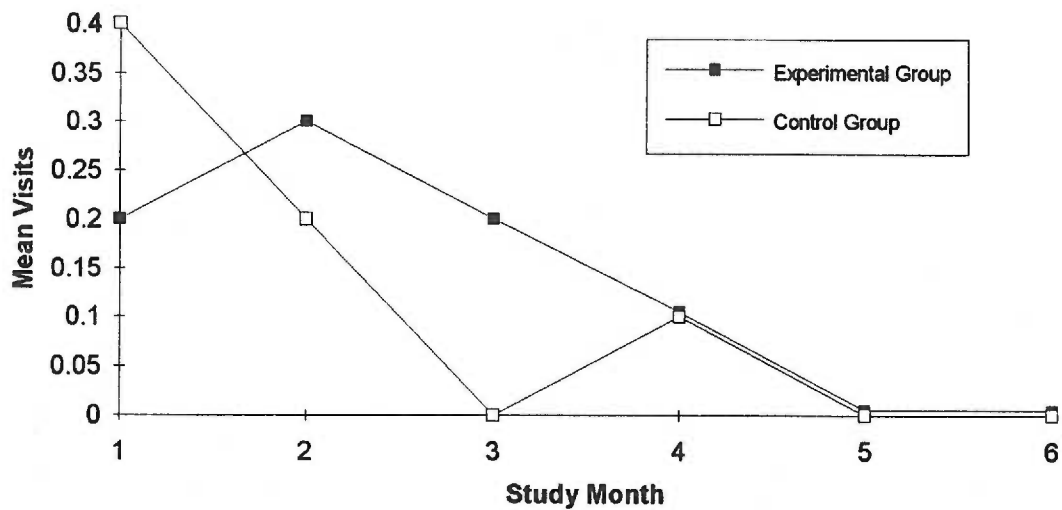
Emergency/urgency care visits are combined because they both likely reflect after-hours care. Six care receivers in the control group were admitted to an emergency room or urgency

care center seven times; one care receiver had two admissions. Six care receivers in the intervention group were admitted eight times; two care receivers had two admissions.

Mean emergency/urgency care visits per study month by group is displayed in Figure 5.12. Control care receivers did not differ significantly from intervention care receivers in

Figure 5.12

Mean Emergency Room and Urgency Care Visits Per Month by Group



	Control Group			Experimental Group		
	n	M	SE of M	n	M	SE of M
Month 1	11	0.4	0.2	11	0.2	0.1
Month 2	11	0.2	0.2	11	0.3	0.1
Month 3	11	0.0	0.0	11	0.2	0.1
Month 4	8	0.1	0.1	8	0.1	0.1
Month 5	5	0.0	0.0	6	0.0	0.0
Month 6	2	0.0	0.0	2	0.0	0.0

emergency/urgency care utilization in any of the study months. After an increase in utilization in Study Month 2, utilization in the intervention group decreased. Control group utilization showed a declining pattern over time. Here again, a somewhat more stable pattern of utilization is seen in the intervention group, and a more variable, unpredictable pattern of utilization is seen in the control group. These patterns of emergency/urgency care service utilization reflect the intermittent nature of health problems in this population.

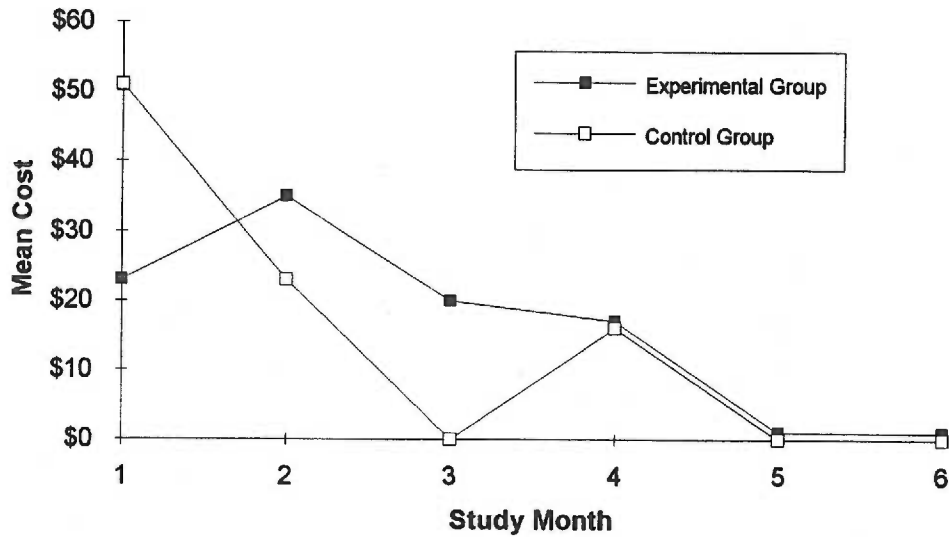
The cost of emergency/urgency care services per admission in the control group ranged from \$126 to \$183, with a mean of \$134. The cost per care receiver in the intervention group ranged from \$95 to \$128, with a mean of \$123. The total cost in the control group was \$938 and \$981 in the intervention group. The mean cost of emergency/urgency care services per study month by group is displayed in Figure 5.13. The control group did not differ significantly from the intervention group in any of the study months. The pattern of emergency/urgency care cost by study month was almost identical to the utilization pattern. The slightly different pattern in Study Month 3 in the intervention group represents utilization of less costly urgency care.

Other Outpatient Utilization and Cost

The remaining outpatient services were represented by various utilization units. Utilization of dental, optometry, audiology, RN, LPN, social work, physical therapy, and occupational therapy services were counted as clinic visits. Mental health/counseling utilization was counted as home visits because the mental health practitioner treated the care receiver in the adult foster home. Advice Nurse utilization was represented by telephone calls. Renal dialysis was represented by dialysis treatments. The number of care receivers who utilized non-physician, non-emergency services, the number of contacts, and the service costs are summarized in Table 5.4. These services were used infrequently by both groups. The total cost of non-physician, non-emergency/urgency outpatient services was \$19,688 in the control group, and in the intervention group, it was \$1,026. The cost difference was due almost entirely to renal dialysis used by one care receiver.

Figure 5.13

Mean Emergency Room and Urgency Care Cost Per Month by Group



	Control Group			Experimental Group		
	n	M	SE of M	n	M	SE of M
Month 1	11	\$51	\$22	11	\$23	\$15
Month 2	11	23	23	11	35	18
Month 3	11	0	0	11	20	14
Month 4	8	16	16	8	16	16
Month 5	5	0	0	6	0	0
Month 6	2	0	0	2	0	0

Community Social Service Utilization and Cost

Community social services utilized included ambulance, other transportation, chore service, housekeeping, home-delivered meals, respite care, adult day care, volunteer, and live-in paid helper. Community social services not utilized by any dyads included delivery service for groceries, congregate meals, outreach worker from a Senior Center, friendly visitor service, and

Table 5.4

Number of Care Receivers Who Utilized Non-Physician, Non-Ambulance Outpatient Services,
Number of Clinic Visits, and Service Cost by Group

Service	Control Group			Intervention Group		
	Care Receivers	Home Visits	Cost	Care Receivers	Home Visits	Cost
Dental	3	5	\$323.00	1	1	\$69.00
Optometry	2	3	195.78	2	2	127.42
Audiology	1	1	125.72	1	1	133.87
Mental Health/Counseling ^a	1	3	327.00	0	0	0.00
Advice Nurse ^b	8	17	102.00	8	19	114.00
Social Work	2	6	196.56	1	1	32.76
RN	1	1	69.79	1	2	414.09
LPN	0	0	0.00	1	1	73.91
Physical Therapy	2	21	1,340.35	1	1	193.06
Occupational Therapy	1	13	620.94	0	0	0.00
Renal Dialysis (Chronic) ^c	1	38	16,583.69	0	0	0.00
Total Cost	3		\$19,884.8			\$1,159.01

^a Utilization unit is a home visit.

^b Utilization unit is a telephone call.

^c Utilization unit is a dialysis treatment.

phone reassurance. The number of dyads who utilized these services and service costs are summarized in Table 5.5. Community social services were utilized by few care receivers in either group. The total cost of community social services was \$4,845 in the control group and \$2,124 in the intervention group. Higher costs in the control group was largely the result of the utilization of adult day care by one care receiver and a live-in paid helper by another.

Table 5.5

Number of Dyads Who Utilized Community Social Services, Service Costs by Group

Community Service	Control Group		Intervention Group	
	Number of Dyads	Cost	Number of Dyads	Cost
Housekeeping	1	\$400.00	1	\$162.00
Chore Service	1	220.00	1	235.00
Live-in Paid Helper	1	1,000.00	0	0.00
Home-delivered Meals	1	82.00	1	204.00
Adult Day Care	1	1,754.06	0	0.00
Respite Care	3	1,343.75	3	1,466.88
Volunteer	1	0.00	0	0.00
Transportation	1	45.00	1	56.50
Total Cost		\$4,844.81		\$2,124.38

An ambulance was used by six care receivers in the control group and three care receivers in the intervention group. The total number of ambulance rides for the control group

was 23 and for the intervention group, 4. The number of ambulance rides per care receiver in the control group who utilized the service ranged from 2 to 10, with a mean of 3.8. Two care receivers in the intervention group utilized an ambulance once and one care receiver utilized an ambulance twice.

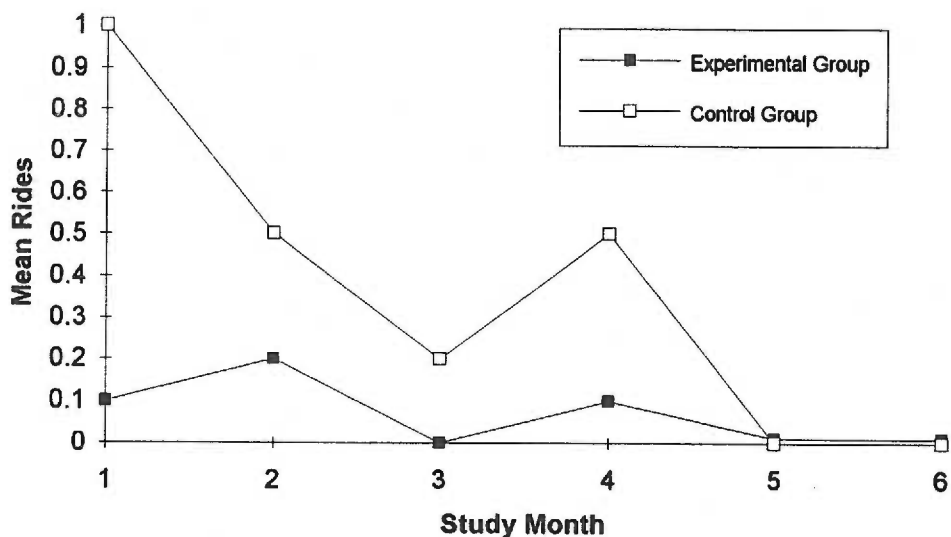
The mean number of ambulance rides per study month by group is displayed in Figure 5.14. Ambulance utilization was higher in the control group than in the intervention group in the first four study months and was significantly higher in Study Month 1. Utilization in the control group was highest in Study Month 1, followed by a decrease in Study Months 2 and 3, with an increase in Study Month 4. Utilization in the intervention group was highest in Study Month 2, and no ambulance services were utilized in Study Months 3, 5, and 6. Utilization was more stable for the intervention group and was more variable and unpredictable for the control group. Ambulance costs in the control group ranged from \$37 to \$782, with a mean of \$202. In the intervention group ambulance costs ranged from \$37 to \$170, with a mean of \$135. The total ambulance cost for the control group was \$4,643, and for the intervention group total ambulance cost was \$541. The mean cost of ambulance services per study month by group is displayed in Figure 5.15. The cost of ambulance services was higher in the control group than in the intervention group in each of the first four study months and was significantly higher in Study Month 1. The pattern of costs is almost identical to the utilization pattern in the intervention group. However, in the control group, high cost emergency ambulance services were used in the first two study months and less expensive transportation levels of service were used in the third and fourth study months.

Pharmacy Utilization and Cost

All care receivers in both groups utilized outpatient pharmacy services for prescription medications. The total number of dispensings (new and refill) in the control group was 213 and 137 in the intervention group. The number of dispensings per care receiver in the control group

Figure 5.14

Mean Ambulance Rides Per Month by Group



	Control Group			Experimental Group		
	n	M	SE of M	n	M	SE of M
Month 1*	11	1.0	0.4	11	0.1	0.1
Month 2	11	0.5	0.4	11	0.2	0.2
Month 3	11	0.2	0.2	11	0.0	0.0
Month 4	8	0.5	0.3	8	0.1	0.1
Month 5	5	0.0	0.0	6	0.0	0.0
Month 6	2	0.0	0.0	2	0.0	0.0

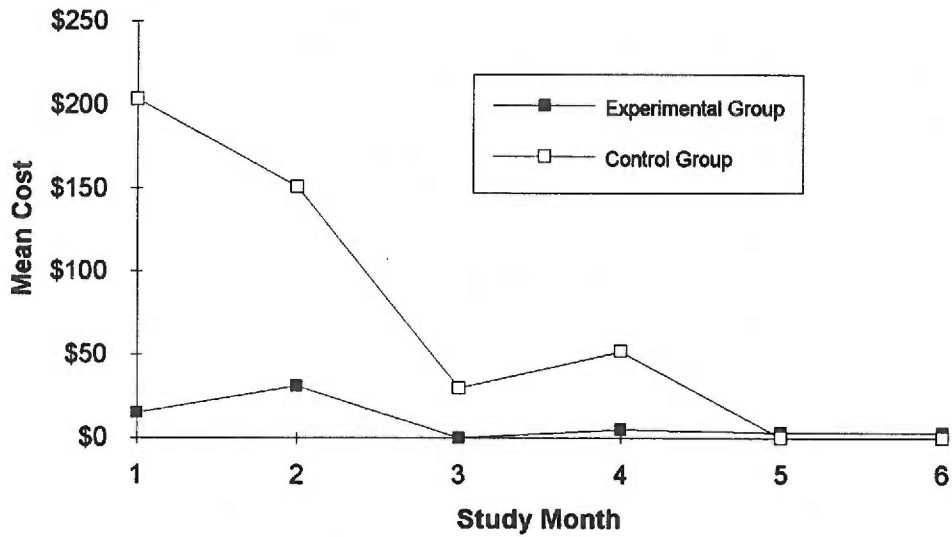
* $p < .04$, two-tailed.

ranged from 2 to 51, with a mean of 19.4. The total number of dispensings in the intervention group ranged from 1 to 23, with a mean of 12.5.

The mean number of outpatient pharmacy dispensings per study month by group is displayed in Figure 5.16. These data represent the number of dispensings and not the number

Figure 5.15

Mean Ambulance Costs Per Month by Group



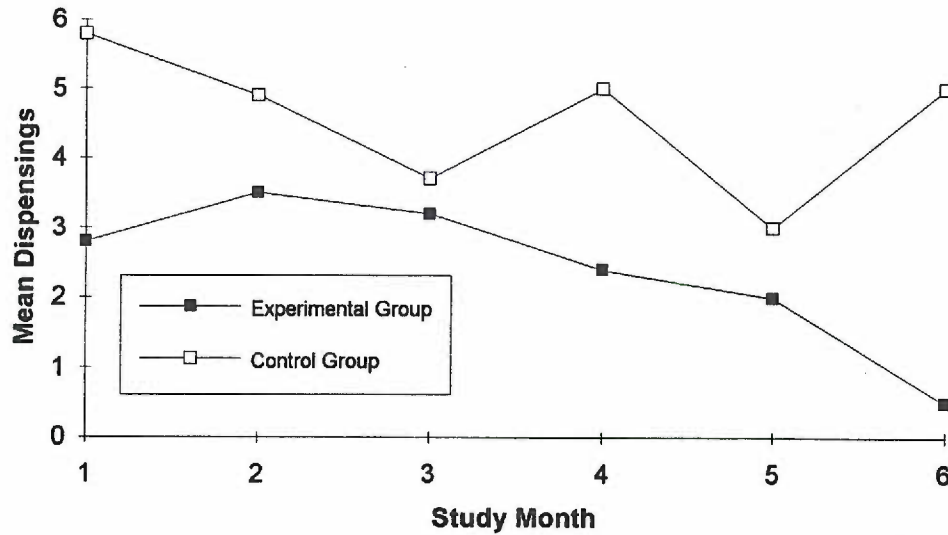
	Control Group			Experimental Group		
	n	M	SE of M	n	M	SE of M
Month 1*	11	\$203	\$87	11	\$15	\$15
Month 2	11	151	132	11	31	31
Month 3	11	30	30	11	0	0
Month 4	8	52	41	8	5	5
Month 5	5	0	0	6	0	0
Month 6	2	0	0	2	0	0

* $p < .06$, two-tailed.

of medications per month. Many medications were dispensed in quantities of 50 or 100, so that the amount of utilization during any given month depended on the number of pills dispensed per prescription and the number of pills taken per month. Pharmacy dispensings gradually declined

Figure 5.16

Mean Number of Pharmacy Dispensings (New and Refill) Per Month by Group



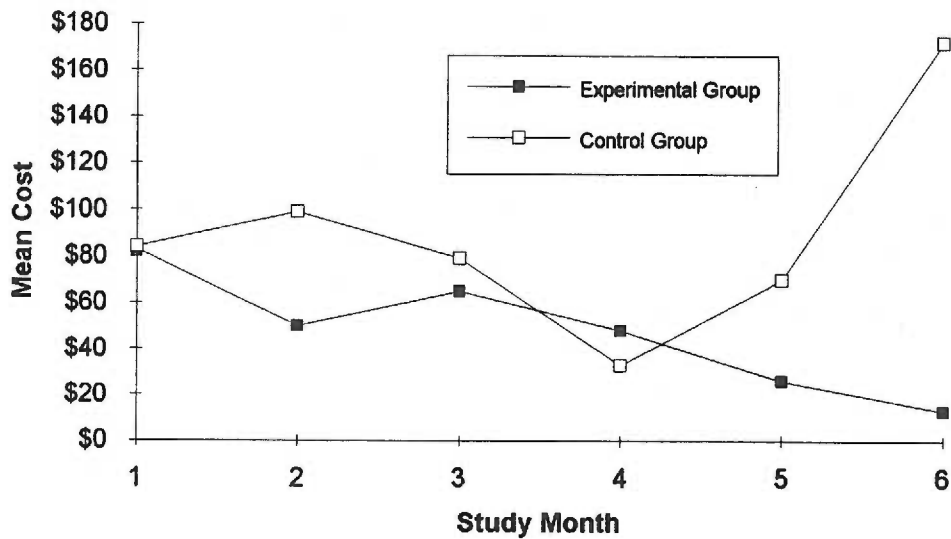
	Control Group			Experimental Group		
	n	M	SE of M	n	M	SE of M
Month 1	11	4.8	1.6	11	2.8	0.7
Month 2	11	4.9	1.5	11	3.5	1.4
Month 3	11	3.7	1.3	11	3.2	0.9
Month 4	8	5.0	2.6	8	2.4	0.6
Month 5	5	3.0	1.5	6	2.0	0.6
Month 6	2	5.0	2.0	2	0.5	0.5

over the 6-month study period for the Intervention group. In the control group, the pattern of utilization was uneven. The control group utilized more pharmacy service than the intervention group in each study month, but the differences were not significant. Because the intervention group started out with fewer dispensings, and because PREP nurses did not routinely try to simplify medication regimens, it is likely that lower utilization in the Intervention group was due to random effects and not due to intervention effects.

Total pharmacy cost in the control group was \$3,843 and \$2,742 In the Intervention group. Pharmacy cost in the control group ranged from \$.02 to \$186, with a mean of \$18. Pharmacy cost in the intervention group ranged from \$.12 to \$98, with a mean of \$20. Mean pharmacy cost per study month by group is displayed in Figure 5.17. Costs were higher in the

Figure 5.17

Mean Pharmacy Cost Per Month by Group



	Control Group			Experimental Group		
	n	M	SE of M	n	M	SE of M
Month 1	11	\$84	\$29	11	\$83	\$23
Month 2	11	99	41	11	50	21
Month 3	11	79	25	11	65	19
Month 4	8	33	10	8	48	12
Month 5	5	70	35	6	26	12
Month 6	2	172	57	2	13	13

control group in all study months except Study Month 4, and the difference was not significant in any study month. Variations in costs likely represent variations in the quantity dispensed with each dispensing.

Durable Medical Equipment Utilization and Cost

All care receivers except one in each group used some durable medical equipment. Equipment utilized included wheelchairs, hospital beds, walkers, commodes, canes, oxygen concentrators, an orthotic device, a stump shrinker, a hearing aid, bathroom bars, blood pressure equipment, glasses, and exercise machines. Total durable medical equipment cost for the control group was \$5,004 and \$4,698 for the intervention group. The cost of equipment by study month by group is displayed in Figure 5.18. The pattern of equipment costs over the 6-month study period was similar for both groups; the highest cost month was Study Month 1, followed by a sharp decrease in Study Months 2 and 3 and an increase in Study Month 4. The difference in group equipment costs was not significant in any study month. Cost patterns during the first 3 study months demonstrates the initial acuity of the care receivers health condition and gradual improvement, requiring less durable medical equipment. The increase in costs in Study Month 4 reflects the purchase of some equipment by the HMO (e.g., hospital beds) that had been rented for the preceding 3 months.

Medical Supply Utilization and Cost

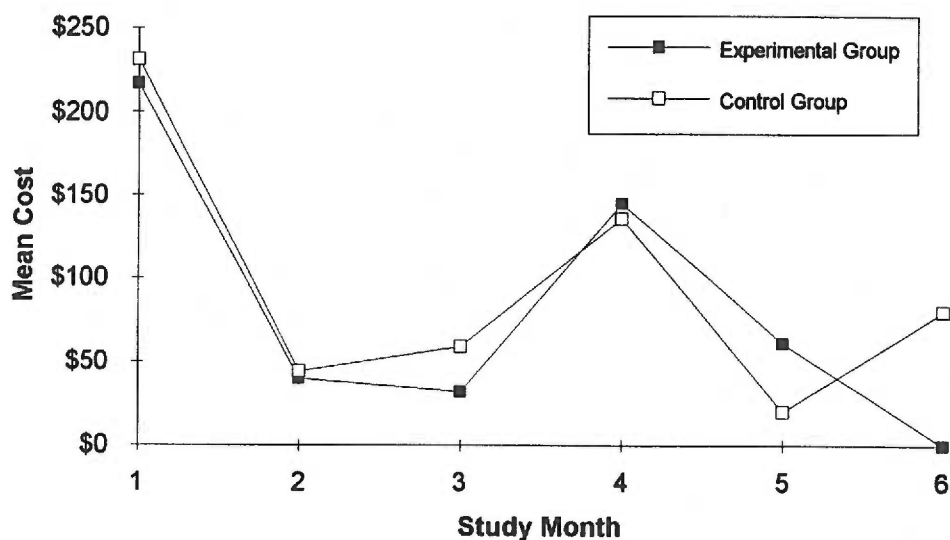
Supplies purchased by dyads included incontinence products, first aid supplies, thermometer, ace bandages, catheters, alcohol, paper tape, cotton balls, diabetic test strips, nutritional supplements, turn sheet, and baby wipes. Three dyads in the control group purchased medical supplies. The total cost was \$372. Six dyads in the intervention group purchased medical supplies. The total cost was \$517.

Utilization and Cost of Non-PREP Services for Caregivers

Outpatient services utilized by caregivers included physician, nurse practitioner, physician's assistant and optometrist. Five control caregivers had 17 outpatient visits and nine intervention caregivers had 14 outpatient visits. Six caregivers in the control group and two

Figure 5.18

Mean Durable Medical Equipment Cost Per Month by Group



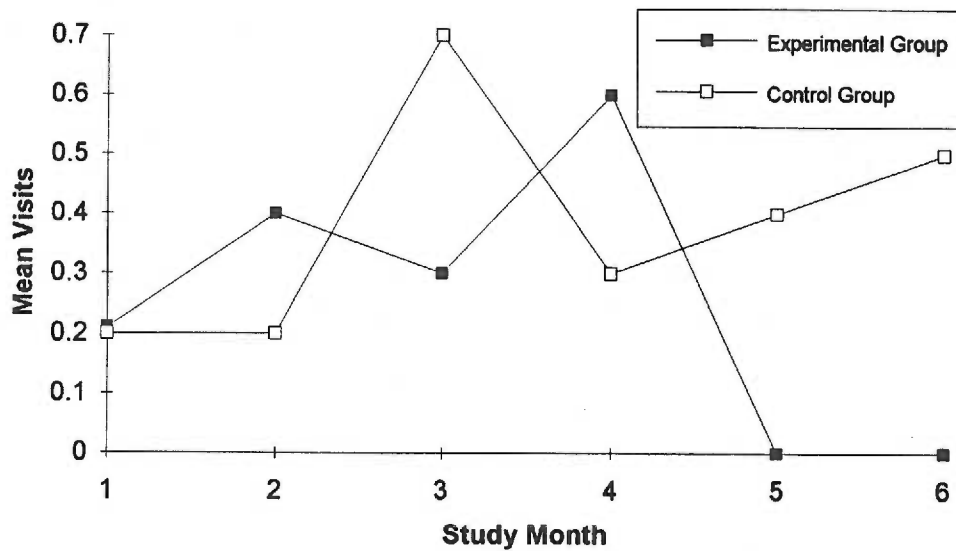
	Control Group			Experimental Group		
	n	M	SE of M	n	M	SE of M
Month 1	11	\$231	\$169	11	\$217	\$83
Month 2	11	42	16	11	40	21
Month 3	11	59	29	11	32	22
Month 4	8	136	118	8	145	111
Month 5	5	20	11	6	61	53
Month 6	2	80	80	2	0	0

caregivers in the intervention group did not utilize any outpatient services during the study. The number of outpatient visits per caregiver in the control group ranged from 0 to 7, with a mean of 1.5. The number of outpatient visits per caregiver in the intervention group ranged from 0 to 3, with a mean of 1.3. One control caregiver accounted for 7 of the 17 control group outpatient visits.

Caregiver outpatient utilization per study month by group is summarized in Figure 5.19. Utilization was variable in both groups. Utilization was equal for the groups in Study Month 1 and higher in the control group than in the intervention group in Study Months 3, 5, and 6, but the groups did not differ significantly in utilization in any study month. In the control group, utilization remained unchanged in Study Month 2 but increased sharply in Study Month 3. In the

Figure 5.19

Mean Outpatient Visits By Caregivers Per Month by Group



	Control Group			Experimental Group		
	n	M	SE of M	n	M	SE of M
Month 1	11	0.2	0.2	11	0.2	0.1
Month 2	11	0.2	0.2	11	0.4	0.2
Month 3	11	0.7	0.3	11	0.3	0.2
Month 4	8	0.3	0.2	8	0.6	0.3
Month 5	5	0.4	0.2	6	0.0	0.0
Month 6	2	0.5	0.5	2	0.0	0.0

intervention group, utilization was higher in Study Months 2, 3, and 4 than Study Month 1, and sharply higher in Study Month 4, but then fell to zero in Study Months 5 and 6. Because intervention caregivers were significantly older than control caregivers, and because PREP nurses addressed caregiver health with most subjects, it was expected that intervention caregivers would use more outpatient services than control caregivers.

The cost of caregiver outpatient services in the control group ranged from \$8 to \$703 per visit, with a mean of \$166. In the intervention group, the cost ranged from \$20 to \$169 per visit, with a mean of \$103. Total cost in the control group was \$2,825 and \$1,437 in the intervention group. More caregivers in the intervention group utilized outpatient services, but the number of contacts was less and overall costs were less. One control caregiver accounted for a large share of outpatient costs.

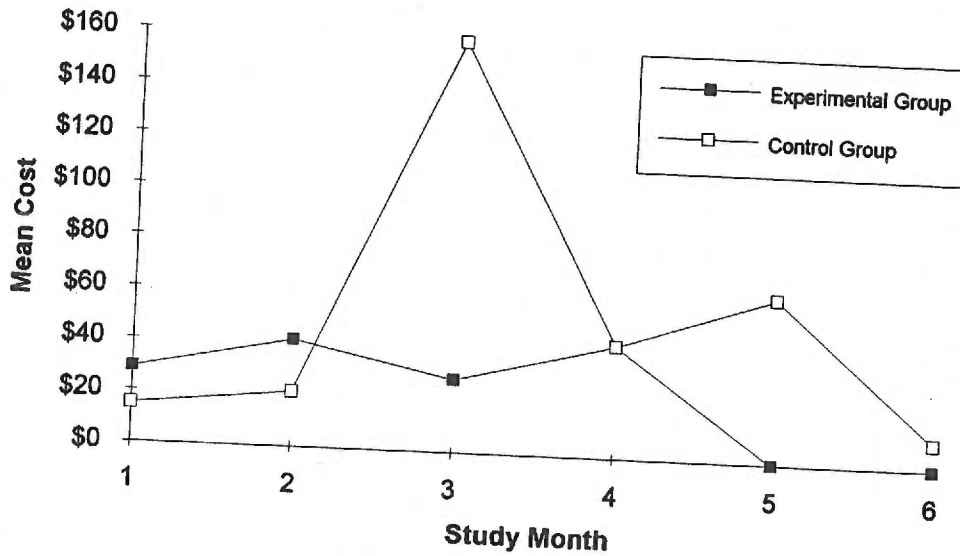
The monthly mean costs of caregiver outpatient services are displayed in Figure 5.20. The difference in costs between the groups was not significant in any study month. Intervention group costs were higher than control group costs in Study Months 1 and 2, but lower or equal in Study Months 3 and 6. Control group costs in Study Month 3 were sharply higher than in Study Month 2 due largely to two office visits to non-HMO providers by one caregiver. 143

Cost Summary and PREP Outcome

The fourth study aim was to develop an evaluation plan to compare health and social service costs by intervention dyads and usual care control dyads. The fifth study aim was to select and evaluate a subjective caregiving outcome measure for the PREP intervention program. In the following sections, total costs per study month per group are presented for the following classes of service: home health services (including PREP); institutional services; outpatient services; community social services; and pharmacy, durable medical equipment, and medical supplies. This is followed by a comparison of total costs per group. This section concludes with a report of outcomes.

Figure 5.20

Mean Caregiver Outpatient Cost Per Month by Group



	Control Group			Experimental Group		
	n	M	SE of M	n	M	SE of M
Month 1	11	\$15	\$15	11	\$29	\$20
Month 2	11	21	21	11	41	19
Month 3	11	158	91	11	28	21
Month 4	8	43	29	8	43	20
Month 5	5	63	61	6	0	0
Month 6	2	10	10	2	0	0

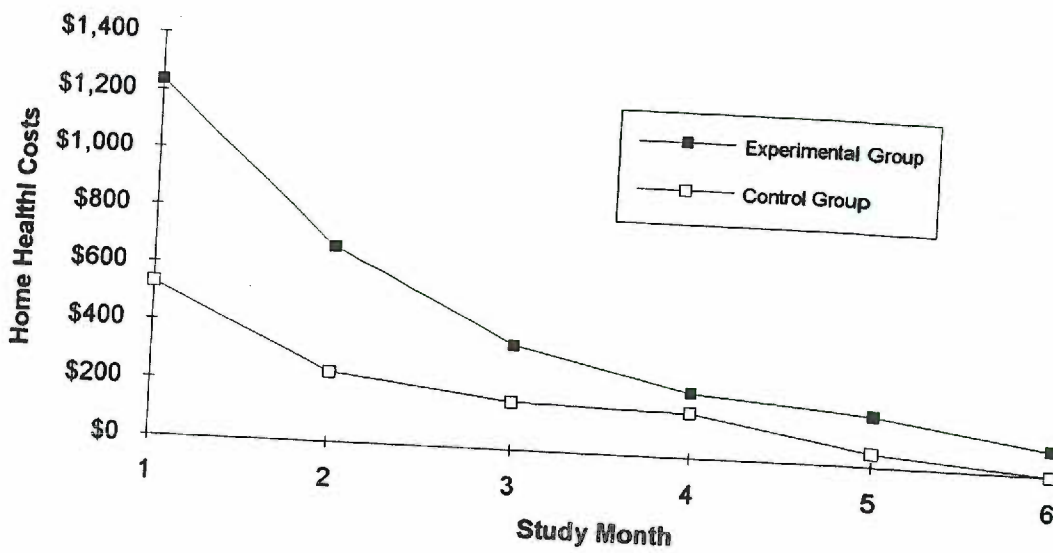
Cost Summary for Home Health Services

Costs for all home health services included costs for PREP nursing, standard home health nursing, physical therapy, occupational therapy, speech therapy, social work, home health aide, and homemaker. Average home health costs, adjusted for the length of follow-up, were \$231.29 per month per dyad in the control group and \$595.79 per month per dyad in the

intervention group. Mean total home health costs per each of 6 study months per group are displayed in Figure 5.21. The pattern of total costs is similar to the pattern of nursing costs presented earlier, with higher costs for both groups in the beginning and tapering off of costs over the 6-month period. The difference between the groups is significant for Study Months 1 and 2, compared with a significant difference in nursing costs in the first three study months. In addition, the level of significance is less in Study Month 2 when all home health costs are

Figure 5.21

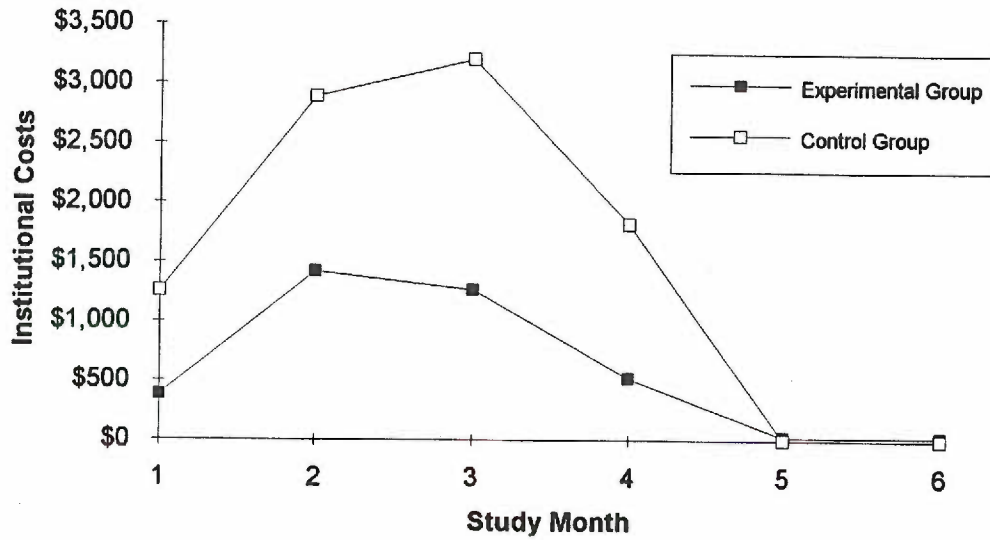
Mean Home Health Costs Per Month by Group



	Control Group			Experimental Group		
	n	M	SE of M	n	M	SE of M
Month 1	11	\$529	\$119	11	\$1234	\$106
Month 2	11	240	154	11	675	136
Month 3	11	164	155	11	360	149
Month 4	8	154	133	8	223	111
Month 5	5	46	46	6	174	95
Month 6	2	0	0	2	87	87

Figure 5.22

Mean Institutional Costs Per Month by Group



	Control Group			Experimental Group		
	n	M	SE of M	n	M	SE of M
Month 1	11	\$1258	\$632	11	\$381	\$381
Month 2	11	2889	2472	11	1420	949
Month 3	11	3198	3007	11	1268	1157
Month 4	8	1822	1219	8	523	523
Month 5	5	0	0	6	0	0
Month 6	2	0	0	2	0	0

control group costs are still higher in each of the first three study months, but only slightly so.

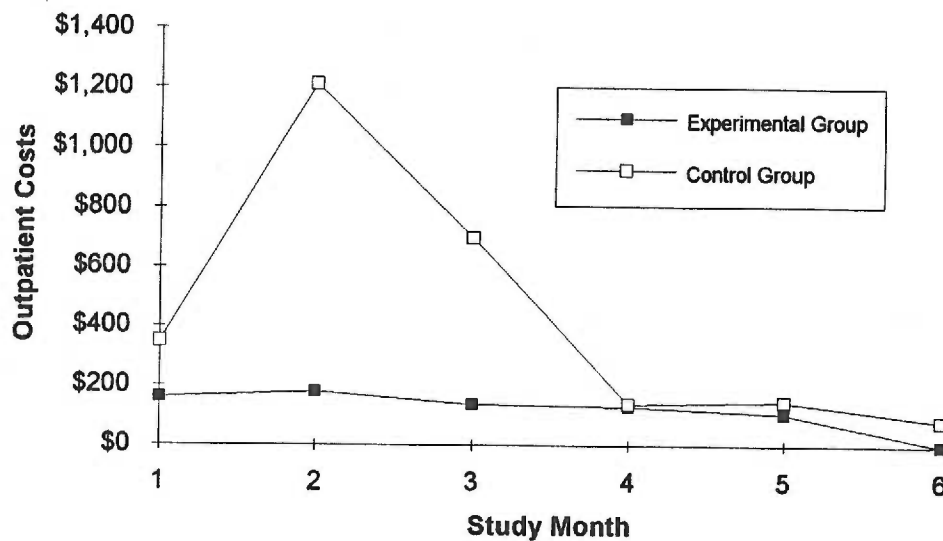
Without renal dialysis costs, the cost pattern is very stable for both groups.

Cost Summary for Community Social Services

Costs for community social services included costs for ambulance, other transportation, chore service, housekeeping, home-delivered meals, adult day care, respite care, volunteer, and live-in paid helper. Average community social service costs, adjusted for the length of follow-up

Figure 5.23

Mean Outpatient Costs Per Month by Group

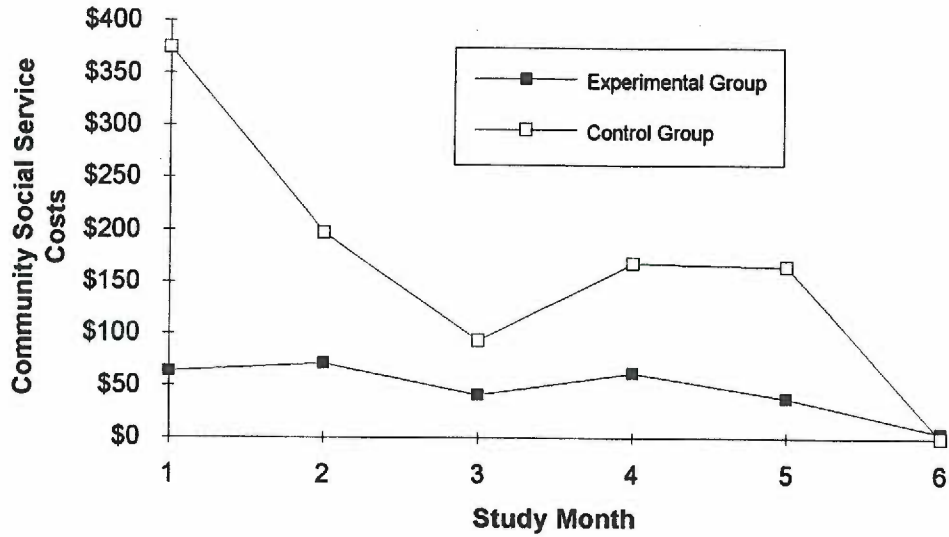


	Control Group			Experimental Group		
	n	M	SE of M	n	M	SE of M
Month 1	11	\$158	\$47	11	\$349	\$177
Month 2	11	1211	954	11	179	57
Month 3	11	699	364	11	135	72
Month 4	8	137	66	8	128	38
Month 5	5	145	57	6	105	75
Month 6	2	81	12	2	0	0

were \$212.43 per month per dyad in the control group and \$57.30 per month per dyad in the intervention group. Mean total community social service costs per each of the 6 study months per group are displayed in Figure 5.24. Costs were higher in the control group in every study month, but the differences were not significant. The pattern of costs in this figure is very similar to the pattern of ambulance costs and the difference between the groups was largely due to ambulance costs. Costs were quite low and the cost pattern remained quite stable in the

Figure 5.24

Mean Community Social Service Costs Per Month by Group



	Control Group			Experimental Group		
	n	M	SE of M	n	M	SE of M
Month 1	11	\$374	\$173	11	\$64	\$48
Month 2	11	197	134	11	71	32
Month 3	11	93	42	11	41	23
Month 4	8	168	89	8	62	47
Month 5	5	165	165	6	38	29
Month 6	2	0	0	2	0	0

intervention group. In the control group, the cost pattern was more uneven. In Study Month 5 costs remained high in the control group due to the utilization of adult day care by one dyad.

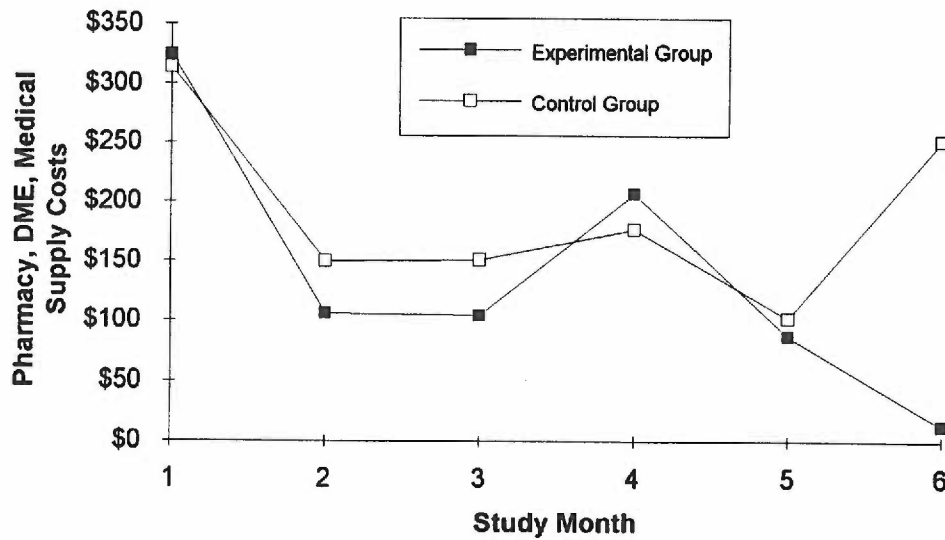
Cost Summary for Pharmacy, Durable Medical Equipment, and Medical Supplies

Average costs for pharmacy, durable medical equipment, and medical supplies, adjusted for the length of follow-up, were \$185.81 per month per dyad in the control group and \$159.36

per month per dyad in the Intervention group. Mean total costs for pharmacy, durable medical equipment, and medical supplies for each of the 6 study months are displayed in Figure 5.25. Costs were higher in the control group in 4 of the 6 study months, but the difference was not significant in any study month. This cost pattern was similar to the cost pattern of durable medical equipment, with highest costs for both groups in Study Month 1, lower costs in Study

Figure 5.25

Mean Costs for Pharmacy, Durable Medical Equipment, and Medical Supplies Per Month by Group



	Control Group			Experimental Group		
	n	M	SE of M	n	M	SE of M
Month 1	11	\$374	\$173	11	\$64	\$48
Month 2	11	197	134	11	71	32
Month 3	11	93	42	11	41	23
Month 4	8	168	89	8	62	47
Month 5	5	165	165	6	38	29
Month 6	2	0	0	2	0	0

Months 2 and 3, followed by a rise in costs in Study Month 4.

Summary of Total Costs

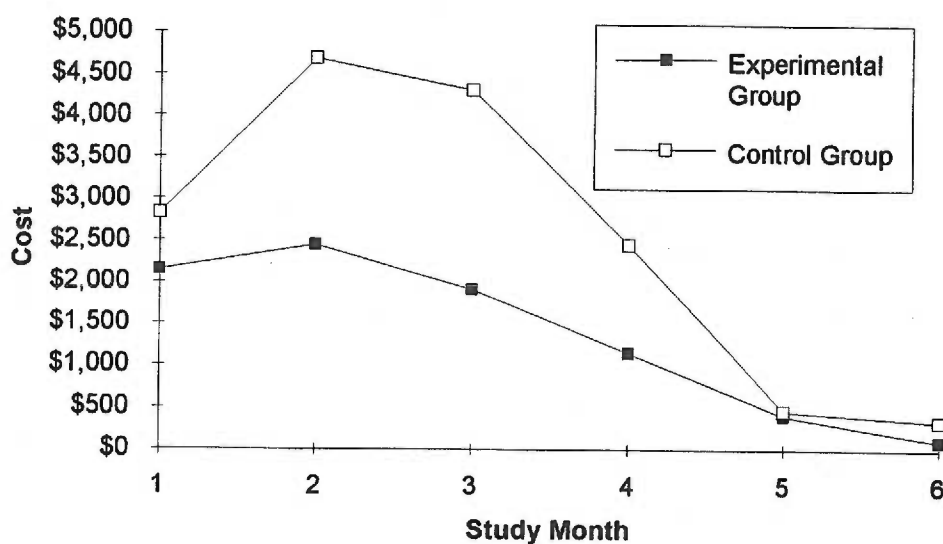
Mean total health and social service costs, adjusted for length of follow-up were \$3,649.02 per month per dyad in the control group, and \$1,892.74 per month per dyad in the intention group. Total mean costs per each of the 6 study months per group are displayed in Figure 5.26. Mean total costs were higher in the control group in each of the first 4 study months, but none of the differences were significant. Hospitals were used by care receivers in each group during these 4 months, and accounted for much of the overall costs. The percentage of total mean costs accounted for by hospital costs ranged from 44.5% to 70.1% in the control group, and from 19% to 60.9 % in the intervention group. In Study Months 5 and 6, hospitals were not used by any care receivers and the total mean costs are only slightly different in the two groups.

Stepwise hierarchical multiple regression was used to control for: (a) baseline differences between the groups on care receiver age; (b) the effects of the amount of direct care by the caregiver on total cost; and (c) the effects of months of follow-up on total cost. The independent variables entered in order included care receiver age, the amount of direct care, the number of months of follow-up, and treatment group. The dependent variable was total dyad costs. Care receiver age was included in the regression because the groups differed significantly on this variable. The amount of direct care, or the number of caregiving tasks performed by the caregiver, was included because it reflected the degree of disability of the care receiver, and it was expected that those who were more disabled would use more health services and thus cost more. Likewise, it was expected that participants who remained in the study longer would also cost more. Thus, the number of months of follow-up was included as an independent variable.

The beta weights, standard error of B, Beta, *t* scores, the Significance of *t*, and R^2 for each step of the regression are summarized in Table 5.6. Although not significant, age and amount of direct care were positively associated with costs as would be expected, but months of follow-up was negatively associated with total cost, which was contrary to the direction expected.

Figure 5.26

Mean Monthly Costs for All Services by Group



	Control Group			Experimental Group		
	n	M	SE of M	n	M	SE of M
Month 1	11	\$2826	\$956	11	\$2150	\$431
Month 2	11	4687	2537	11	2451	963
Month 3	11	4306	3063	11	1909	1215
Month 4	8	2457	1198	8	1144	671
Month 5	5	458	127	6	403	157
Month 6	2	334	11	2	100	74

This unexpected result was likely due to the fact that care receivers who had shorter follow-up were also the most frail. After controlling for these three predictors, being in the intervention group was associated with lower costs, which were \$6,444.51 lower than the control group on the average [$t(17) = -.104, p = .32$].

Table 5.6

B, SE of B, Standardized Beta, *t*, Significance of *t*, *R*² for Each Variable Entered in Each Step of the Hierarchical Regression

	B	SE of B	Standardized Beta	<i>t</i>	Sig. <i>t</i>	Change <i>R</i> ²
<u>Step 1</u>						
<u>Variables Entered</u>						
Age	169.18	468.87	.08	.36	.72	.006
(Constant)	-2,217.09	35,807.98				
<u>Variables Not Entered</u>						
Amount of Direct Care			.34	1.46	.16	
Months of Follow-up			-.26	-1.10	.28	
Group			-.34	-1.41	.18	
<u>Step 2</u>						
<u>Variables Entered</u>						
Age	-64.37	483.10	-.03	-.13	.90	.10
Amount of Direct Care	517.55	353.49	.33	-1.5	.16	
(Constant)	14.69	34,859.44				
<u>Variables Not Entered</u>						
Months of Follow-up			-.25	-1.07	.30	
Group			-.30	-1.27	.22	
<u>Step 3</u>						
<u>Variables Entered</u>						
Age	-249.42	511.72	-.12	-.49	.63	.05
Amount of Direct Care	500.15	352.60	.32	1.42	.17	
Months of Follow-up	-2912.55	2732.08	-.25	-1.07	.30	
(Constant)	27,467.63	43,239.73				
<u>Variables Not Entered</u>						
Group			-.26	-1.04	.31	

Table 5.6 Continued

	B	SE of B	Standardized Beta	t	Sig. t	Change R ²
Step 4						
<u>Variables Entered</u>						
Age	37.64	579.92	.02	.07	.95	.05
Amount of Direct Care	460.40	353.80	.30	1.30	.21	
Months of Follow-up	-2,242.45	2800.11	-.19	-.80	.43	
Group	-6444.51	6178.22	-.26	-1.04	.31	
(Constant)	13,519.03	45,159.59				
Total R ²						21%

PREP Outcome

The effectiveness of the intervention--the degree to which it increased preparedness, predictability, and enrichment--was based on PES scale scores for eight caregivers in each group. Caregiver perception of increased preparedness, predictability, and enrichment in the intervention group ($M = 4.1$, $SD = .6$) was significantly higher than the in the control group ($M = 3.1$, $SD = 1.3$), $t(10.09) = -1.92$, $p < .04$. PES scale scores for three control caregivers fell between 1 (not at all) and 2 (a little), while none of the intervention caregivers fell in this range. The lowest scale score for intervention caregivers was 3.08, which was above 3 (some). Two control caregivers and four intervention caregivers had scale scores above 4 (quite a bit). The overall usefulness of the assistance caregivers received (as measured by a single 10-point item, where 1 = not at all useful, and 10 = extremely useful) was also significantly higher in the intervention group ($M = 9.8$, $SD = .7$) than in the control group ($M = 6.6$, $SD = 2.0$), $t(7.32) = -4.01$, $p < .003$. Scores on this item were based on the responses of seven caregivers in the control group and eight caregivers in the intervention group.

In summary, the PREP intervention resulted in less, but not significantly less, overall health and social service costs and a significantly better outcome when compared with standard home health.

CHAPTER 6

DISCUSSION

This chapter begins with an interpretation of the study results, including comparisons between findings from this study and other research studies. Issues related to the validity of the findings and limitations of the study follow. Because of the pilot nature of this study and the small sample size, some differences are discussed even if not statistically significant if thought to be clinically important.

Summary and Interpretation of the Results

Scores on the PREP outcome measure--the PREP Effectiveness Scale--were significantly higher in the intervention group than the control group. In addition, caregivers indicated in qualitative interviews that the help they received from PREP nurses was very beneficial and that they were still using many of the nurses' suggestions 8 to 11 months after completing PREP. They reported that as a result of PREP they felt better about their situation, had more confidence in their ability to care for the care receiver, and felt reassured that they were doing the right things, making the right decisions, and giving the right care.

The cost of total health and social services, including the cost of PREP and standard home health, was less for intervention dyads than for control dyads, suggesting that PREP had a cumulative offset effect on the utilization of non-PREP services. Average monthly costs per group by service class are summarized in Table 6.1. The average monthly costs were higher in the control group for every service class including average total cost for all services. The higher control group costs were not significant. The significantly higher PES scores and overall lower costs for the intervention group suggest that PREP has promise as a cost-effective intervention for providing long-term care to older people and their families.

Utilization of PREP and Standard Home Health

As expected, intervention dyads utilized substantially more nursing services than control dyads. The total number of home visits, the average number of home visits per dyad, and the

average number of home visits per month were all higher in intervention dyads than in control dyads.

Table 6.1

Average Monthly Costs by Group by Service Type

Service Type	Control Group		Intervention Group	
	Adjusted Cost	SD	Adjusted Cost	SD
Home Health Services*	\$231.29	\$334.84	\$595.79	\$305.69
Institutional Services	2,309.60	4524.60	935.34	1343.78
Outpatient Services	709.88	1640.44	144.95	117.95
Community Social Services	212.43	296.07	57.30	87.91
Pharmacy, Durable Medical Equipment, Medical Supplies	185.81	195.95	159.36	101.93
All Services	3,649.02	4867.49	1,892.74	1566.97

* $p = .02$, two-tailed

The pattern of home visits in intervention dyads was representative of a long-term care model in which chronic conditions are managed over an extended period of time. The pattern of home visits in control dyads was representative of an acute-care model which stresses short-term management and stabilization of health problems. Intervention dyads averaged 11.5 home visits (2.9 per study month) and control dyads averaged 4.9 home visits (.9 per study month); the average time in the study was a little under 4 months for intervention dyads and a little over 4

months for control dyads. The average duration of a home visit was twice as long for intervention dyads (2.2 hours) as it was for control dyads (1.1 hours).

Continuity of Care

During the time they were enrolled in the PREP Evaluation Study, dyads in each group experienced intermittent problems in caregiving related to changes in the health of the care receiver. Standard home health nurses were not able to address these problems because they occurred after discharge from home health. PREP nurses, on the other hand, because of their availability to dyads over a period of several months and because of their relationship with dyads, were able to assist dyads as new health problems and caregiving issues occurred. PREP nurses assessed a variety of new health symptoms in care receivers, including fever and cough, bloody stools, skin breakdown, rashes, depression, changes in appetite and fluid intake, and nocturia. They also assisted with ongoing caregiving problems which were not easily resolved in short periods of time, including mobility of the care receiver, safety, behavior management, management of pain, constipation, resistance to going to bed at night, and accessing services within the HMO system. The primary activities PREP nurses performed in implementing the intervention were home visits, telephone calls, and care planning meetings.

Access to Nurses

Telephone calls between dyads and PREP nurses were an important aspect of the intervention. PREP nurses used telephone calls to dyads as adjuncts to home visits to address caregiving issues. PREP nurses made 25 high-intensity phone calls to dyads in which an in-depth assessment of a caregiving problem occurred or two or more caregiving problems were addressed. Although caregivers did not often call the nurse on the PREP Advice Line, caregivers, in qualitative interviews, indicated that the availability of the nurse was very important to them because access was not only quick, but the assistance came from someone who knew the care receiver's condition. A call on the PREP Advice Line sometimes prevented a telephone call to the physician. Telephone calls by PREP nurses to physicians were also very important to caregivers, because they thought that physicians accepted the assessment of the

nurse over the assessment of the caregiver, because the nurse could access the physician relatively quickly, and could translate information to the physician. Keep-in-Touch calls to dyads, designed to monitor dyads after intensive home visits were completed, were utilized in varying degrees, depending on the needs of dyads. Some dyads were not called for 2 months and some had weekly calls for short time periods. Because of the therapeutic relationship that developed between the PREP nurse and the dyad developed during the In-home component, problems could be assessed and managed over the telephone in the Keep-in-Touch component quite effectively.

Comprehensiveness of Care

The scope of caregiving issues addressed by PREP nurses was much broader and more comprehensive than the scope of care receiver problems addressed by home health nurses. PREP nurses identified an average of 9.2 caregiving issues for 11 dyads. Home health nurses developed a problem list in 5 of 8 dyads and identified an average of 1.6 problems. Most often PREP nurses focused on issues of preparedness and assisted caregivers with management of a wide variety of caregiving issues including incontinence, behavior problems, personal care, risk of falling, mobility, managing medical equipment, and understanding medical conditions. PREP nurses also encouraged caregivers to maintain a predictable routine and helped them to incorporate new intervention strategies so that caregiving routines were not disrupted. Less frequently nurses worked with dyads on enriching the caregiving situation, but when they did, it improved the relationship between caregiver and care receiver and helped them to see the positive aspects of their situation.

Individualization of Care

PREP nurses individualized intervention strategies for each dyad. Sometimes merely discussing a particular issue enabled the caregiver to resolve it her/himself. Some caregiving issues were worked on for two or three home visits and others required many weeks and a variety of strategies. One of the important aspects of the interventions strategies that caregivers reported in qualitative interviews was that PREP nurses suggested many different strategies for

caregivers to try, that the nurse returned with additional strategies, and that she kept trying when a problem was difficult to resolve. Home health nurses used standardized intervention strategies developed by the home health department for specific health problems and did not try any others if these were not effective.

Strengths of the Intervention

The strengths of the PREP intervention include the focus on preparedness of the caregiver, predictability of caregiving routines, and enrichment of caregiving relationships, the therapeutic relationship between the PREP nurse and dyad, the long-term management of health problems, the family focus, the focus on all aspects of caregiving, the Family Health Diary, and the letter to dyads from PREP nurses at the end of the study. Each of these is discussed below.

Focus on preparedness, predictability, and enrichment. A major strength of the intervention was its focus on preparedness, predictability and enrichment in caregiving. PREP nurses intervened effectively in each of these areas as evidenced by differences between the intervention and control groups on the overall PREP Effectiveness Scale, by differences on individual items on the scale which measured each concept, and by comments of caregivers in qualitative interviews conducted several months after PREP ended. On the PREP Effectiveness Scale, caregivers in the intervention group reported significantly higher levels of perceived changes in preparedness for caregiving than control caregivers. Intervention caregivers scored significantly higher than control caregivers ($p < .05$) on 20 of the 40 items on the PREP Effectiveness Scale. In addition, several comments in the qualitative interview indicated that caregivers felt more prepared to care for the care receiver as a result of PREP services. Comments included that the PREP nurse "helped find easier ways to provide care"; "made me feel like I could take care of my husband"; "assured me that I was making the right decisions and giving the right care"; and "helped me understand my husband's behavior and gave me suggestions for handling him".

PREP nurses found several ways to intervene to improve the predictability of caregiving. They designed individualized bedtime routines for two caregivers who were having trouble

putting the care receiver to bed at night. They helped two caregivers plan for changes in the caregiving routine which occurred when a family member who was helping with caregiving left to return to their own homes. They stressed predictability in the management of many caregiving problems such as constipation, toileting, and behavior problems. One PREP nurse helped a caregiver with the unpredictable nature of the exacerbation of the care receiver's health problems by teaching her how to evaluate changes in the care receiver's condition.

PREP nurses addressed enrichment in caregiving with all caregivers to some extent. They encouraged dyads to identify pleasurable activities they enjoyed in past and helped them adapt these activities to current constraints or to resume them if possible. They encouraged and helped some caregivers, who were almost totally constrained by caregiving, to pursue activities for their own enjoyment. They encouraged the use of humor to relieve the stress of the situation. Intervention caregivers scored significantly higher than control caregivers ($p < .05$) on all three items on the PREP Effectiveness Scale which measured enrichment.

Therapeutic relationship. Another major strength of the intervention was the therapeutic relationship developed by PREP nurses with intervention dyads. This relationship enabled the nurse to intervene quickly and confidently when new problems arose because she was familiar with the dyad and their situation. This was especially important with care receivers who continued to develop new symptoms or health problems. The relationship also helped caregivers feel secure that help was available from someone they knew. Caregivers reported that they felt supported by PREP nurses and that PREP nurses really cared about them personally. Caregivers were willing to try intervention strategies suggested by the nurse and to keep trying to find effective strategies for problems that were difficult to manage, in part because they trusted their PREP nurse. In some cases, it was only after several home visits by the PREP nurses that caregivers conveyed very personal information.

Knowing the dyad was important for PREP nurses to intervene effectively for several reasons. First, when assessing the care receiver she could take into account the past medical history, co-morbidities, effects of medications, and other information which is very important in

managing chronic conditions. One caregiver reported that relaying pertinent health information to several different providers was emotionally exhausting. Second, when implementing her own or physician treatment regimens, she could take into account the characteristics of the caregiving situation, the capabilities and limitations of the caregiver, and the informal support available. She could understand better those situations when the caregiver needed extra support or additional information. Third, knowing the dyad also helped the nurse to distinguish between problems that she could monitor, those that needed her immediate attention, and those that needed to be seen by a physician. It enabled her to know when a problem could be handled over the telephone and when a home visit was required.

The structure of the HMO did not allow for long-term relationships between providers and members. The development of provider/member relationships, however, is important for people with chronic health problems because prescribing appropriate treatment depends on a knowledge of the history of the care receiver's illness, knowledge of capabilities and limitations of the caregiver, and knowledge of important co-morbidities. As was demonstrated in this pilot study, many care receivers experienced intermittent health problems. PREP nurses were able to manage many of these intermittent health problems in intervention care receivers because they had knowledge of health and caregiving history and current situation. PREP caregivers reported that this relationship relieved them of a great deal of stress and anxiety.

Focus on long-term management of health problems. Because PREP nurses intervened with dyads over an extended period of time, they were able to assess new health problems and initiate appropriate treatment. Several caregivers in the qualitative interview said how important this was because they did not know how to evaluate new symptoms and were uncertain about calling the doctor. Dyads in the control group struggled with new symptoms because they were not sure the symptoms were serious enough to warrant a clinic visit, and calls to the HMO Advice Nurse often resulted in long waits, which discouraged some caregivers from calling. In the qualitative interviews, some PREP caregivers expressed that it was very helpful that the nurse tried repeatedly to help with a particular problem and came back several times with new

suggestions. This was possible in part because of the extended period of time PREP services were offered. Such an approach of trying multiple strategies for a problem may also have been a useful general model for caregivers to use in the absence of the PREP nurse.

Family focus. It was obvious, even in this small sample, that the primary caregiver was often not the only family member involved in caregiving. PREP nurses interacted with other family members and encouraged some caregivers to seek additional help from these informal caregivers. Interacting with other family members also helped the PREP nurses to understand the family better, and enabled them to intervene more effectively.

Broad focus on all aspects of caregiving. Another strength of the intervention was its broad focus on all aspects of caregiving. Many caregivers wanted help with problems which did not meet traditional skilled care criteria, such as behavior problems and personal care. This focus on all aspects of caregiving helped to convey the feeling that the PREP nurse cared for, and was concerned about, each individual situation and gave legitimacy to caregivers' concerns. Willingness to address any concern of the dyad facilitated communication and helped to create an atmosphere of openness and acceptance. Caregivers' feelings of confidence and preparedness improved as they realized that they were performing some caregiving tasks well and as they learned to improve their preparedness for other tasks.

Family Health Diary. The Family Health Diary was an important communication tool. Several caregivers in the qualitative interview reported that the Diary was very beneficial and that they still referred to it months later to review suggestions written by the PREP nurse. In standard home health, information was usually given verbally to caregivers. Information given verbally can be easily forgotten, especially in an older population, and especially if a lot of information is conveyed.

PREP nurse letter to participants in the Completion Component. The letter sent to participants summarizing family strengths and the progress the family had made while in PREP was a surprisingly positive experience for caregivers. Several caregivers commented in

qualitative interviews that the letter was very meaningful to them, and some still referred to it months later when they needed some reassurance.

Weaknesses of the Intervention

The weaknesses of the intervention included that it was too expensive, predictability and enrichment were inconsistently operationalized, charting was open-ended, it was limited to business hours, there were limited benefits for long-term care, there was a lack of coordination with primary care physicians, routine assessments of vision, hearing, and oral health were not conducted, and PREP nurses were not well-enough prepared in mental health of older persons.

Too expensive. PREP nursing services cost approximately twice as much as standard home health nursing services. In this pilot phase of PREP, emphasis was placed on refining the intervention, evaluating different intervention strategies, and interacting with the dyad as much as possible. Thus, efficient use of nursing resources was not a primary goal. A number of changes in the full clinical trial can be made to decrease the expense of nursing visits. These are discussed in Chapter 7. The PREP nurse caseload of 1.8 dyads per day in this pilot needs to be increased to at least 3 and probably 4 per day to approach the same costs as standard home health nursing, which should be feasible with streamlined charting and well-developed clinical protocols.

Inconsistent operationalization of predictability and enrichment. Despite the fact that PREP nurses intervened effectively in the areas of predictability and enrichment, a major weakness of the intervention was the lack of clarity by PREP nurses about the central concepts of strain, predictability, and enrichment. This led to inconsistent operationalization of these concepts in practice. The assessment questions and intervention strategies for these concepts were only roughly developed at the beginning of the study. The plan was to refine assessments and intervention strategies as the study progressed and as nurses intervened with dyads. Nurses were not always clear about whether they were dealing with problems of unpreparedness, strain, unpredictability, or lack of enrichment.

This lack of clarity made it difficult to know when caregiving issues were resolved. Because the nurses were not clear about the problems they were addressing with their dyads nor when the problems were resolved, it was difficult to determine when dyads could be transferred to Keep-in-Touch. Some of this issue was resolved by developing a PREP-specific problem list that was used with Group 2 dyads. Additional consideration should be given to developing criteria or guidelines for the number of home visits needed to develop the therapeutic relationship, for when dyads can be managed mainly by telephone, and when dyads should be transferred to Keep-in-Touch.

Open-ended charting. Charting forms were very lengthy and primarily utilized an open-ended format. Not only was this very time-consuming, but PREP nurses did not always understand the type of information being sought.

Intervention limited to business hours. PREP nurses were available to dyads and the Advice Line functioned only during business hours. Care receivers with chronic disabilities have needs for care at night and on weekends. A PREP nurse home visit on a Saturday to replace a urinary catheter that came out, could have prevented a trip to the emergency room. The fact that one PREP nurse called one caregiver on weekends, when close monitoring of the effects of medication was necessary, indicates that a nurse needs to be available every day.

Limited benefits for long-term care. Nursing was the only service offered by PREP. Several caregivers who had little help from other informal caregivers could have benefited greatly from regular assistance with personal care and could have used respite care. Both of these services should be considered strongly for the full clinical trial.

Lack of coordination with primary care physicians. Although a communication note from the PREP nurse, stating that the care receiver was participating in the PREP Evaluation Study, was placed in her/his outpatient chart, physicians were not informed about the nature of PREP nor included in planning the coordination of PREP with physician staff. It will be important in the full clinical trial to have a strong relationship between PREP nurses and physician staff in order to facilitate primary management of the dyad by the PREP nurse.

No routine assessment of vision, hearing, and oral health. Routine assessment of vision, hearing, and oral health should be standard practice of gerontological nursing in order to optimize the communication, sensory status, and appetite of the older person. Nursing assessment in these areas and assistance in obtaining appropriate referrals should be a routine part of the PREP nursing assessment.

Limited PREP nurse preparation in mental health of older persons. Both PREP nurses and standard home health nurses were not well-prepared to manage mental health problems or problems associated with dementia. Behavior problems of dementia occurred in four of the 11 intervention care receivers, and PREP nurses obtained consultation for each case. One standard home health nurse's charting showed a lack of understanding of depression in older people. Because dementia and depression are likely to be encountered relatively frequently, nurses in the full clinical trial will need strong skills in assessing and managing these problems.

Steep learning curve. Work with eight dyads over several months was required for PREP nurses to gain a good understanding of how to implement PREP. This occurred in large part because the process for identifying caregiving issues was not well-developed and changed several times at the beginning of pilot, and because of a lack of a PREP-specific problem list. As the PREP principles became better operationalized and with the development of the PREP problem list, PREP nurses had a better understanding of PREP.

The Cost of PREP and Standard Home Health

It was hypothesized that PREP would offset the utilization of some health and social services and induce demand for other services. Because of these hypothesized effects of PREP on non-PREP services, the cost of non-PREP services was included in the overall cost of PREP and standard home health. PREP affected the utilization of some services as hypothesized, but did not affect the utilization of others as hypothesized. The cost of non-PREP services are discussed in the sections which follow according to the hypothesized effect of PREP on them. First, services hypothesized to be offset by PREP are discussed, followed by a discussion of

services hypothesized to be affected by induced demand. We begin with a discussion of the cost of nursing in PREP and standard home health.

PREP and Standard Home Health Nursing Costs

As expected, costs for PREP nursing services were higher than costs for standard home health nursing services, primarily because PREP nurses provided more home visits of longer duration. The cost per visit for PREP nurses was approximately twice that of standard home health. The average monthly nursing costs were higher in the intervention group than in the control group in every study month, and was significantly higher in Study Months 1, 2, and 3. PREP nurse activities that contributed most to the costs were home visits and charting. Travel, care planning meetings, and telephone calls also contributed substantially to costs, but less than home visits and charting. PREP nurse activities that contributed little to overall nursing costs because they occurred relatively infrequently included errands, library study, chart review, consultation, family conferences, care receiver funerals, and interdisciplinary meetings with home health staff. In the control group, home health nursing costs were attributed primarily to home visits and charting.

The costs of PREP nursing were higher in part because this was a pilot study, and the intent was to gain as much experience as possible implementing the intervention with dyads in a variety of different caregiving situations. In-depth and comprehensive interventions by PREP nurses were emphasized. PREP nurses were encouraged to intervene with dyads as much as they thought they needed to and to try a variety of strategies in resolving caregiving issues. They were encouraged to think about and analyze their interventions with dyads and to be as thorough as possible in charting and describing what they were doing. In-depth discussions were encouraged in care planning meetings. Several steps could be taken to improve the efficiency of the intervention for the clinical trial. These will be discussed as recommendations in Chapter 7.

Computing a cost per visit was necessary because visit costs were the only cost data available from the HMO home health department. However, including the cost of all PREP

nurse activities in the cost of home visits does not adequately describe cost distribution. Specifically, it does not show the cost of the Keep-in-Touch component activities, primarily telephone calls.

Offset Effects of PREP

A number of non-PREP services were utilized less by PREP dyads than by control dyads, lending support to the hypothesis that PREP services would offset the utilization of some non-PREP services. One care receiver in the control group accounted for a large part of the overall costs and the costs of several individual services. Utilization and costs of individual dyads are discussed in order to clarify utilization patterns and explore reasons for differences in these patterns.

Hospital use likely prevented in PREP dyads. A large difference between PREP and standard home health in utilization and cost of non-PREP services was seen in hospital utilization. The number of hospital days and hospital costs were higher in the control group than the intervention group in the first 4 study months, though the differences were not statistically significant. Higher hospital costs were attributable to longer stays rather than more intensive stays. Given the small sample size, it is difficult to attribute the differences to the effects of PREP. However, a qualitative review of several dyads in each group suggests that PREP may have prevented higher hospital utilization rates in intervention dyads and may have been able to prevent some hospital utilization in control dyads if PREP services had been available to them.

Two PREP care receivers might easily have utilized more hospitalization without the services of PREP. Both care receivers had moderate to severe cognitive impairments and needed assistance with most ADL. Assessment of new symptoms by the PREP nurse and early treatment may have prevented some hospitalizations from occurring. Dyad #308 had been hospitalized several times for pneumonia before he was admitted to PREP. The PREP nurse routinely assessed the care receiver's respiratory status, assessed respiratory symptoms as they occurred, and facilitated and encouraged increased physical activity. She also taught the caregiver about the respiratory symptoms she needed to observe and how changes in cognitive

status that could be interpreted. The caregiver called the PREP nurse when new symptoms of pneumonia were evident. Although the care receiver was hospitalized once for pneumonia, evaluating pneumonia symptoms early may have prevented a more serious pneumonia and longer hospitalization or may have prevented additional hospitalizations.

Care receiver #310 also developed several new symptoms over time that were assessed by the PREP nurse, including skin rash, bloody stools, and increased somnolence. These were monitored by the nurse and some were treated by calling the doctor. Because of the increased confidence of this caregiver in her ability to manage the care receiver well at home as a result of PREP and her acceptance of the eventually terminal outcome, she may have become more comfortable with and less anxious about new symptoms that developed. Close monitoring of the many drugs that were tried to control behavior problems prevented toxic side-effects from occurring, and thus probably prevented hospitalization. As both of these caregivers were successful in managing new symptoms with the help of the PREP nurse, their confidence grew and they were less anxious about additional new symptoms. This increased confidence and decreased anxiety argue well for a decrease in hospital utilization by dyads receiving PREP services.

Preventable hospital use in control dyads. Two dyads in the control group contributed most to hospital utilization and costs. Care receiver #319 had a 26-day hospital stay and care receiver #315 had one 5-day stay and one 36-day stay. HMO services were inadequate to meet the health and caregiving needs of these dyads. Neither of these care receivers had been hospitalized at the time of referral to home health, but were referred from the outpatient clinic, and both were experiencing a deterioration in health. Care receiver #319 received an evaluation-only home visit by the home health nurse and was discharged because she had no skilled nursing needs. About one month later she fell and broke her hip and required hospitalization. She eventually recovered and returned home. It was clear to the project director who conducted the caregiver interviews, that the caregiver had a very poor understanding of the care receiver's cognitive deficits or what she needed from him as a caregiver. In fact, because

of the project director's concern, the home health department conducted another home visit to evaluate the safety of the situation, and no additional services were available. It is possible that PREP services could have helped the caregiver to understand the care receiver's cognitive deficits and what he needed to do to compensate for those deficits. Safety would likely have been a central concern and the fall might have been prevented, thus preventing the hospitalization.

Care receiver #315 received 14 home health nursing visits because of pain from spontaneous vertebral fractures and because of her decline in food and fluid intake. Although the care receiver was taking an antidepressant, depression was not addressed by the home health nurse. While the care receiver was receiving home health services, she fractured another vertebrae, which exacerbated the pain and deepened the depression. The caregiver sought help from many sources both before and after the home health referral, including clinic physicians and social workers and community agencies. She obtained psychiatric counseling for the care receiver from a non-HMO source and respite care so that she could take a few days off. The care receiver was admitted to an adult foster home when the caregiver became too exhausted to care for her anymore, where she continued to decline and was then admitted to the hospital. She died in a nursing home one day after her discharge from the hospital. It is not clear that a PREP nurse could have prevented the care receiver's hospitalization and eventual death, especially in view of the fact that the care receiver was already quite depressed at the time of the referral and then experienced another fracture. This case was very complex both in terms of the care receiver's health problems and in terms of caregiver strain. The caregiver scored quite high on the depression scale. A PREP nurse could have helped the caregiver understand the complexity of her mother's condition, the various treatment options available to treat her mother, and the chances of their success. She could have coordinated communication with the clinic physician and social worker to obtain appropriate medical treatment and to devise a realistic plan. She could have helped with obtaining additional services, thus relieving the caregiver of that burden. She perhaps could have intervened earlier and thus more effectively in the care

receiver's depression. A retrospective account by the caregiver, who called the PREP principal investigator, was that someone should have told her that her mother was dying because it would have changed her decisions about medical care and treatment, and she probably would have brought her mother home to die.

It is not certain that PREP could have prevented the hospitalization of these two care receivers. This is true especially in the case of the care receiver who died, because it has been reported that older persons utilize the most health services during the last year of life (Lubitz & Prihoda, 1984; Scitovsky, 1989). In this case, at the time of the home health referral, the care receiver's condition was not yet terminal, and the caregiver was appropriately quite aggressive about getting the help she thought she needed to restore her mother's health.

A third care receiver, subject #301, utilized the hospital in the fourth study month which also may have been preventable with PREP nurse services. This care receiver was recovering from coronary bypass surgery and had Insulin-dependent diabetes mellitus. She was seen by a home health nurse three times, early in the first study month and was then discharged from home health. After that she intermittently experienced several additional symptoms, some of which were treated in the outpatient clinic. During caregiver interviews conducted by this researcher, the caregiver expressed frustration with managing the medically related aspects of caregiving. Ongoing assessments of the care receiver's health problems by a PREP nurse may have detected the problem that resulted in hospitalization when it first occurred. Early treatment could perhaps have prevented hospitalization.

Literature supports the hypothesis that PREP should offset some hospital utilization. Interventions that have provided both short-term and long-term post-hospital follow-up by registered nurses have been effective in reducing hospitalization from readmission, especially when the intervention included comprehensive discharge planning (Naylor, 1990; Oktay & Volland, 1990; Weinberger et al. 1988). In this study, the sub-sample of care receivers who were discharged from the hospital when they entered the PREP study was too small to draw any conclusions about the effect of PREP on readmission. Four control care receivers were

discharged from the hospital to home health and none were readmitted to the hospital. Two intervention care receivers were discharged from hospital to home health and one was readmitted in Study Month 2 for 2 days, and one was admitted in Study Month 4 for 4 days. Oktay and Volland (1990) thought that the reductions in hospital length of stay in intervention subjects in their intervention study were due in part to study nurses working with discharge planners to facilitate discharge. In the full clinical trial, it will be important to have discharge planning protocols describing how to intervene when study care receivers are admitted to the hospital.

In summary, PREP services may have offset hospital utilization in intervention dyads because new health problems were detected and treated earlier, thus preventing a worsening of the problem. By increasing the preparedness and confidence of caregivers new symptoms may have been treated at home under the supervision of the PREP nurse, rather than in the hospital after they became more serious. Some hospitalization may have been prevented by teaching safe caregiving and preventing problems from occurring in the first place.

Long-term institutional use likely prevented in PREP dyads. Two different types of long-term institutionalization are addressed here: post-hospital, short-term placement; and permanent placement. In terms of post-hospital placement, is important to note that of the five control care receivers who were admitted to the hospital, three were subsequently admitted to a nursing home, and of the six intervention care receivers admitted to the hospital, only one was subsequently admitted to a nursing home. For the same reasons that PREP may have decreased the length of hospital stays, it may also have been able to prevent admission to or shorten the length of stays in nursing homes post-hospitalization. That is, the increased preparedness and confidence experienced by PREP caregivers and the availability of PREP nurses after discharge from the hospital may have prevented post-hospital nursing home placement. This seems very likely in at least two instances, dyads #308 and #310, discussed above in the section on hospital use. Some post-hospital nursing home use was likely prevented by preventing hospitalization in the first place. In addition, because caregivers' commitment to

taking care of the care receiver at home was reinforced by knowing that they were providing the right care and by having the PREP nurse available, post-hospital nursing home use may have been prevented.

Permanent placement may also have been prevented in the two dyad examples above, but this hypothesis is more difficult to support. Because both care receivers were in a nursing home shortly before entry into the PREP study, and because both caregivers were very unhappy with the quality of care they received, they seemed determined to keep the care receiver at home. On the other hand, their increased confidence in caregiving may have bolstered their resolve enough to make their desires a reality. The intervention study by Oktay and Volland (1990) supports the hypothesis that PREP should delay permanent placement.

Preventable long-term institutional use in control dyads. Three control care receivers were admitted to a nursing home, one of whom was also admitted to an adult foster home. These were the same three care receivers discussed in the above sections on hospital utilization. The care receiver admitted to a foster home and later to a nursing home, died in the nursing home. The other two care receivers were admitted to skilled nursing facilities after a hospitalization and both returned home again. If PREP services had been offered to the two control care receivers above who returned home after placement, avoidance of nursing home utilization could perhaps have been avoided altogether in one case (subject #301) and shortened in the other (subject #319).

One control care receiver could be considered to have been permanently placed in an institution. This was care receiver #315 who went to an adult foster home before being admitted to the hospital and subsequently dying. If the caregiver's retrospective assessment is accurate, that if she had known her mother was going to die, she would have brought her home, it seems likely that PREP would have been able to accomplish this because of the PREP nurse's in-depth knowledge of care receiver's health condition, caregiver capabilities and desires of the dyad. Thus, the admission to the adult foster home may have been prevented.

Offset effects on emergency/urgency services. Although emergency/urgency care was hypothesized to be offset by PREP services, this did not occur, and intervention care receivers utilized more emergency/urgency services in Study Months 2, 3, and 4 than control care receivers. Total cost for the two groups were almost equal, with the intervention group costing slightly more. Five of eight emergency admissions in the intervention group and four of six admissions in the control group resulted in subsequent hospitalization. Three of the eight admissions in the intervention group were for catheter problems after regular PREP hours.

One design issue for the full clinical trial is whether PREP should be an 8-hour/day, 5-day/week program or a 24-hour/day, 7-day/week program. A 24-hour/day, 7-day/week program would likely have prevented some of the emergency/urgency utilization that occurred in this pilot. Schler et al. (1985) and Zimmer et al. (1984) found that when a health care provider who knew the patient was available by telephone, a high percentage of problems could be handled by telephone alone. Some of the problems which prompted emergency/urgency utilization in this pilot could have been handled by a nurse home visit. In addition, it was clear from caregiver qualitative interviews that caregivers encountered numerous new caregiving problems and that it was very important to them that the PREP nurse was available to them to answer their questions about these problems.

Offset effects on Advice Nurse utilization. The hypothesis that PREP would offset Advice Nurse utilization was not supported, and intervention caregivers actually called the Advice Nurse more often than control caregivers, but the difference was not great. It is probable that many of the advice calls were made after clinic hours when PREP nurses were not available via the PREP Advice Line. It could be expected that with a 24-hour PREP Advice Line available in the larger clinical trial, that intervention caregivers would use the HMO Advice Nurse much less.

Offset effects on pharmacy utilization. The effects of PREP on pharmacy utilization are difficult to evaluate. Intervention care receivers had fewer dispensings overall and in all study months. Although it was evident from charting records that PREP nurses monitored medications

frequently, it was not evident that simplification of medication regimens, which might have resulted in less utilization, was the goal. This would suggest that the lower utilization in the intervention group was not a result of PREP nurse interventions. Because of potential drug interactions, drug side effects, and the increased likelihood of abnormal responses to drugs in older people, it is clinically desirable to simplify drug regimens as much as possible. In the full clinical trial, medication management protocols should place emphasis on simplifying regimens for clinical reasons and also for cost savings reasons.

Offset effects on caregiver institutional utilization. The hypothesis that PREP would offset the utilization of hospitals and nursing homes by caregivers was neither supported nor rejected; caregivers in both groups did not utilize these services. Some institutional service utilization by caregivers will likely occur with a larger sample and longer follow-up in the larger clinical. Experience with intervention caregivers in this pilot study suggests that PREP might not offset institutional utilization by caregivers. First, one of the PREP nurses, although unsuccessful, worked very hard to convince one caregiver to have her prolapsed bladder surgically repaired, because it interfered with her ability to lift her husband as she needed to. It can be anticipated that more caregiver health problems will occur in a larger study and PREP nurses may be more successful in getting them taken care of because of longer follow-up. Second, if PREP is as successful in the larger clinical trial as it was in this pilot study in getting caregivers to see their primary care providers for routine check-ups and treatment of health problems, it is probable that more health problems which require hospitalization will be discovered. Thus, the emphasis on caregiver health in PREP may result in higher utilization of hospitals for intervention caregivers but result in long term benefits for the individual caregiver and the family.

Induced Demand Effects of PREP

It was hypothesized that interventions by PREP nurses would result in induced demand for some health and social services, including outpatient primary care (for both care receivers and caregivers), dental, optometry, audiology, mental health/counseling, community social

services, durable medical equipment, and medical supplies. Each of these is discussed in the following section.

Induced demand for outpatient primary care services. It was hypothesized that PREP would induce demand for outpatient primary care services (physician, nurse practitioner, physician's assistant). Some data suggest that PREP did increase the utilization of these services, but some data also suggest that PREP offset the utilization of these services. The slightly higher utilization of outpatient services by the intervention group indicates that PREP did not offset their utilization. The average number of clinic visits per study month for the intervention group was 1.06. The average number of clinic visits per study month for control care receivers was .98. In addition, ten of 11 intervention care receivers (91%) had at least one clinic visit and eight of 11 control care receivers (73%) had at least one clinic visit. The slightly higher utilization in the intervention group may have occurred as a result of PREP nurses encouraging care receivers to make and keep routine follow-up appointments or as a result of referring new health problems to the primary care provider for treatment. However, some data suggest that PREP nurses did in fact prevent clinic visits. In qualitative interviews with caregivers, two caregivers indicated that they called the PREP nurse instead of the physician to solve a new health problem and that the nurse was able to solve the problem without an office visit. In addition, PREP nurses did assess many new symptoms and health problems during regular home visits, and may have prevented clinic visits by either recommending treatment or by calling the primary care provider themselves for treatment recommendations. One PREP nurse also gave a flu immunization to a dyad, thus avoiding a visit to the clinic. The cumulative effect of offsetting some and increasing some primary care service utilization in this pilot study was higher (but not significantly higher) utilization in the intervention group. This supports findings in other home-health nursing interventions which reported higher rates of physician utilization in treatment groups over comparison groups. (Bergner et al. 1988; Oktay & Volland, 1990; Weinberger et al. 1988).

By analyzing the total number of clinic visits, the hypothesis that PREP caregivers would utilize more outpatient services was not supported. The average number of clinic visits per month of follow-up was .32 for the intervention group and .38 for the control group, which was not significantly different. However, by analyzing the number of caregivers who had at least one clinic visit, the hypothesis is supported. Nine intervention caregivers (82%) visited the outpatient clinic at least once and only five control caregivers (45%) visited the outpatient clinic at least once. PREP nurses directly intervened with six caregivers about their health problems and encouraged four of them to seek medical care. The emphasis in PREP regarding caregiver health should not be on substituting for the primary care provider, but rather on encouraging caregivers to utilize their primary care providers when they have health problems and on supplementing the primary care provider when possible. Such an emphasis will likely result in higher primary care utilization rates for caregivers.

Induced demand for dental, optometry, and audiology services. The hypothesis that PREP would result in an increase in the utilization by the care receiver of dental, optometry, and audiology services was not supported, but this hypothesis was made with assumption that PREP nurses would routinely assess vision, hearing, and dental health and refer health problems in these areas to the appropriate provider in order to optimize the care receiver's functioning. It was not evident from PREP nurse charting that these assessments occurred. The utilization rate was low in both groups, with the control group using slightly more dental and optometry services and the same number of audiology services as the intervention group. An important aspect of long-term care for older people is enhancement of sensory status and maintenance of oral health. Thus, assessment protocols for vision, hearing, and oral health should be included in the nursing assessment protocols and referral for impairments found should be encouraged. Such an emphasis should result in higher utilization rates for optometry, audiology, and dental services in the intervention group.

Induced demand for mental health/counseling services. The hypothesis that intervention care receivers would utilize more mental health and counseling services than control care

receivers was not supported. Mental health and counseling services were used by only one control care receiver and not used by any intervention care receivers, despite the fact that depression was a problem with three of them. To some extent this was a result of PREP nurses providing emotional support directly. In addition, the PREP nurse referred one care receiver to a cancer support group to help her deal with her feelings about having cancer, which the care receiver did pursue. Another care receiver would have been inappropriate for counseling because she was aphasic. Utilization of mental health and counseling services is likely to be low in the larger clinical trial because such services are expensive and because they may not be acceptable to many older people. Intervention dyads may consequently utilize PREP nurses for many mental health needs. Involvement of a mental health practitioner at the clinical level would be very helpful in meeting the mental health needs of participants and in determining when participants should be referred to a professional therapist.

Induced demand for community social services. The hypothesis that PREP would increase the utilization of community social services was not supported. Community social services were used by a very small number of dyads in each group. Community social service costs were paid almost exclusively by dyads, which most likely accounts for the low rates of utilization. Adult day care used by one control care receiver was provided by the Veteran's Administration and was free to the dyad. In the larger clinical trial, I would still hypothesize that PREP nurses will increase the utilization of community social services because in this pilot study, PREP nurses were much more aggressive about finding additional services for caregivers with the last three caregivers. By the time these caregivers entered the study, PREP nurses had a better understanding of how to intervene and were more confident in identifying the need for additional services when the need existed. I think especially in difficult caregiving situations and where there is very little informal support for the caregiver, that PREP nurses will try very hard to find affordable community services to assist the caregiver. In the full trial, emphasis should be placed on generating and maintaining a list of sources of community services and perhaps have regular consultation from a social worker with expertise in that area.

Induced demand for durable medical equipment and medical supplies. The hypothesis that PREP would increase the utilization of durable equipment was not supported. The cost of durable medical equipment was very similar in the groups during every study month. Although more intervention caregivers bought medical supplies than control caregivers, the total costs for supplies was very small in each group.

The PREP Outcome

Perceptions of helpfulness of PREP/home health nurses, as measured by the PREP Effectiveness Scale, were significantly higher in PREP caregivers than in control caregivers. Evaluating the PREP Effectiveness Scale with the sample of caregivers in this study, with criteria described by Stewart and Archbold (1992) for selecting outcome measures, shows the scale to have several desirable qualities related to its sensitivity to detect change. First, differences between the intervention and control groups showed that the underlying construct is amenable to change. Second, examination of individual items, showed that 20 of the 40 items on the scale were significantly higher in PREP caregivers ($p < .05$) than in control caregivers, supporting the content validity of the items, or their ability to capture treatment effects. Six additional items reached significance levels between .05 and .10, which are sufficiently high for a new measure, tested on a small sample, to support their content validity. The remaining 14 items need to be examined carefully for their content validity. Some items seem too broad and non-specific, such as the extent to which the PREP/home health nurse helped the caregiver feel more relaxed, feel better about overall situation, think things through, and open up about things. The lack of significant findings on two of three items measuring predictability could either represent poor items or the weakness of intervention strategies in this area, or both.

Third, there was some evidence for the measure's construct validity. The main question that must be asked about a measure's construct validity is "valid for what purpose?". Stewart and Archbold (1992b) argue that in intervention studies, the purpose is to measure change on the outcome variable produced by the treatment and thus the main interest is in validity for

change. Thus, evidence for the construct validity of the PREP Effectiveness Scale lies in its ability to detect change as a result of the intervention.

The PREP Effectiveness Scale, because it has a strong conceptual and empirical base and appears to be sensitive to the intervention, is an important outcome measure for the larger clinical trial of PREP. One issue to consider is the timing of the administration of the instrument with the control group. Over a 1-year study period it is possible that care receivers could be referred to home health two, three, or more times. Measurement error could occur if the scale is administered at the end of the 1-year study period, because caregivers might have some difficulty recalling the specific home health episode when they entered the PREP study and thus have difficulty evaluating the services they received. Because standard home health services are usually delivered for very short periods of time, most caregivers would have to recall services they used 10 or 11 months previously. On the other hand, if the scale is administered immediately after discharge from the home health, measurement error from administration variations could also occur (Polit and Hungler, 1978) because administration would occur at different times for each subject. Administering the scale approximately 3 months after entering the clinical trial, when most care receivers would be discharged from home health, would result in the least amount of measurement error from difference in administration variations. It would also reduce the amount of error as a result of faulty recall. Repeating the measure every 3 or 4 months would reduce random effects of a one-time measure and provide important data about caregivers' perceptions of preparedness for caregiving, predictability in caregiving routines, and enrichment of caregiving processes.

Targeting PREP

The question of targeting PREP is raised because it is necessary to target interventions to appropriate subgroups in order to avoid including subjects who are unlikely to respond to the intervention (Applegate & Curb, 1990). Participation in PREP was not limited to specific subgroups, and because the PREP pilot sample was small, analysis of subgroups was not

possible. However, one way to evaluate the need to target the intervention is to analyze the characteristics and outcomes of high and low users of PREP services.

The lowest users of PREP were the four dyads transferred to Keep-in-Touch. They received the fewest home visits from PREP nurses (average visits per study month=1.4). In two of the four situations the care receiver was normally quite independent, but required assistance from the caregiver temporarily, after a surgical procedure. The third care receiver was independent in all ADL and even planned and prepared his own diabetic meals. In the fourth situation, the care receiver was physically and cognitively impaired, but caregiving had been long-standing and relatively stable, and the caregiver, a retired nurse, thought she was well-prepared to care for the care receiver. Three of these care receivers were cognitively intact. Although two care receivers developed new symptoms during the study period, they were relatively quickly resolved by talking to the caregiver on the telephone and by making one additional home visit. These four dyads suggest that caregiving situations where the care receiver is functionally independent, or only temporarily dependent due to a surgical procedure, and situations where the caregiver feels very well-prepared have less need for PREP services. Utilization and costs of non-PREP services was also lower for these dyads--total costs for all four of these dyads were well below the mean for the group, and two dyads had the lowest total costs in the group. This suggests that their overall health care needs were lower.

Three dyads who received the most visits from PREP nurses (mean visits per study month=4.4) on the other hand, were functionally quite dependent, one because of cognitive deficits, and two because of a combination of physical and cognitive deficits. They all required almost constant supervision by caregivers because of their cognitive deficits and unpredictable and unsafe actions. All three care receivers had long-term health problems that were not expected to improve, but rather were expected to decline over time. Two of the three of the care receivers continued to develop several new symptoms over the time they were in the study, which required the attention of the PREP nurse, and they had caregiving problems that did not resolve easily and required ongoing intervention. This suggests that more dependent care

receivers, and care receivers with unstable or changing health status, with ongoing caregiving problems that are not easily resolved, and with cognitive deficits have a greater need for PREP services. Two of these care receivers utilized more non-PREP services than others in the intervention group, and had average total costs above the average total costs for the group.

One subgroup that may not benefit as well from PREP, at least in terms of offsetting the utilization of non-PREP services, is the subgroup of care receivers who die while in PREP. Although this subgroup may benefit from PREP in terms of helping the caregiver, PREP may have little influence on its utilization of non-PREP services. PREP then would only add to overall costs of this subgroup. People who die consume a disproportionate amount of medical resources, and use of services becomes more intensive as death approaches (Lubitz & Prihoda, 1984). An analysis of the two care receivers who died while in the study suggests that PREP may not be able to offset utilization and costs of non-PREP services in this subgroup. The care receiver and her caregiver in the intervention group who died was in the In-home Component at the time of her death. The PREP nurse and caregiver were working on a number of caregiving problems. It is unlikely that the PREP could have prevented or shortened the final 4-day hospitalization for acute renal failure, which accounted for over 50% of her total costs.

An analysis of the care receiver in the control group who died, requires the researcher to hypothesize about what might have happened if the dyad had been recruited into the intervention group. This care receiver was admitted to home health after suffering a vertebral fracture from which she experienced severe pain. She was also depressed. While in the study she suffered another fracture, which exacerbated her pain and deepened her depression. She was either in the hospital, adult foster home, or nursing home for 62 of the 96 days she remained in the study. In addition she used an ambulance 10 times and the emergency room twice. She had 14 visits from a home health nurse, homemaker and home health aide visits, and three visits by a psychiatric nurse clinician while in the adult foster home to treat the depression. This dyad had the highest total costs and highest average cost per month of all dyads in the study.

A PREP nurse would have had to assess the complexity in this situation and the seriousness of the care receiver's decline quickly in order to prevent the utilization of high-cost non-PREP services. Even so, the decline may have been too advanced for the nurse to improve the care receiver's condition. A PREP nurse could have offset the high utilization of non-PREP services in two different ways. First, she could have intervened early enough to obtain effective and appropriate treatment, enabling the care receiver to recover without the need for utilization of institutional services. Second, if the care receiver was far advanced in her decline, the PREP nurse could have helped the caregiver to understand the futility of treatment and assisted her plan for her mother's final days in a less expensive setting, and one more personally preferable to this caregiver, than the hospital. In the proposed clinical trial, PREP will be recruiting care receivers in all stages of recovery and decline and it will take exceptional assessment skills and knowledge of geriatric nursing to accurately assess some situations. Because it will be impossible to foretell which care receivers will die in the clinical trial, some thought should be given to a separate analysis for the subgroup which dies.

In terms of offsetting the utilization of non-PREP services, PREP was not very effective with intervention dyad #322, where the caregiver experienced extremely high strain from caregiving and low mutuality with her husband, the care receiver, and in general seemed ambivalent about taking care of the care receiver. Before entry into PREP the care receiver had been in an intermediate care facility for approximately 5 months. Previous to that, the caregiver had taken care of him for several years after a stroke. After coming home, he was admitted twice to the hospital and was referred to home health on the second admission. He stayed home about 1 month, was admitted to the hospital for 7 days due to gastrointestinal bleeding, and from there went to an intermediate care facility because the caregiver was too exhausted and did not want to bring him home, even though the services of PREP were available to her. After approximately 1 month in the care facility he came home again for one day when the study ended. Within 6 months, the care receiver was placed in an adult foster home. The care receiver was hospitalized or in a nursing home for 40 of the 75 days the dyad remained in the

study. It is possible that longer involvement by the PREP nurse may have helped the caregiver to learn to manage the situation better and allow the care receiver to remain at home. Caregiving situations with high strain and low mutuality, such as this one, should be monitored closely in the clinical trial for abuse of the care receiver and for unacceptable strain in the caregiver. Permanent placement may be a better alternative in some situations and should be recommended when appropriate. PREP needs to be careful to avoid supporting unsafe situations.

Validity of the Findings

Internal validity of study design is the extent to which the researcher is able to reach unambiguous conclusions about the relationship between the independent and dependent variables (Woods & Catanzaro, 1988). Internal validity is very important in this pilot study, because study results will be used to plan the larger clinical trial. If conclusions of the pilot are reached in error, the basis for the clinical trial will be in doubt. Threats to the internal validity of study design addressed in this study included failure to randomize, small sample size, and poor compliance with study protocols.

Randomization

The purpose of randomization is to control the extraneous variance caused by variables other than the independent variable of interest (Kerlinger, 1986). Although randomization procedures were developed and used with some subjects in this study, not all subjects were randomly assigned to the treatment and control groups. According to Meinert and Tonascia (1986), an important virtue of randomization is the protection it provides against patient or clinician selection biases in the treatment assignment process. However, he also argues that randomization is not necessarily needed, provided the method of assignment is free of treatment-related biases. The fact that subjects in this pilot were recruited by one of the PREP nurses who also implemented the intervention, represented a potentially serious violation of randomization procedures. However, randomization procedures were not adhered to only when

a PREP nurse was not available to take a new dyad. In these cases, dyads were assigned to the control group and selection bias was not an issue.

The differences at baseline on a large number of caregiver and care receiver variables showed that there were slight but non-significant differences between the groups on a number of characteristics. The only significant differences were care receiver and caregiver age, and the amount of difficulty managing the care receiver's medical needs. According to Meinert & Tonascia (1986), small differences in baseline characteristics of treatment groups are not unusual, but it is a good idea to adjust for differences, even if small. The regression analysis performed to control for differences at baseline showed that after controlling for one care receiver characteristic (age), one caregiver characteristic (amount of direct care), and the length of follow-up, being in the intervention group was associated with lower costs, on the average.

Sample Size

A pilot study is a small-scale version of a major study, whose function is to obtain information for improving the project or for assessing its feasibility (Polit & Hungler, 1978). Thus, small sample sizes are appropriate for pilot studies. The small sample size in the pilot study of PREP was adequate to evaluate the feasibility of implementing it with older participants. However, for purposes of evaluating the costs and outcomes of PREP, the small sample size presents two primary limitations. First, the estimates of mean values are less precise and lack power, so that if differences occur, they are not as easily detected. Second, outliers can have a more pronounced effect with small sample sizes. At the same time, although a small sample is limiting, interventions that are powerful, such as PREP, do not need as large a sample as less powerful interventions to show an effect.

Compliance With Study Protocols

Any departure from the study treatment protocol, regardless of the nature of the departure, reduces the chance of finding a treatment difference (Meinert & Tonascia, 1986). Two aspects of compliance with study protocols are discussed below: compliance with intervention protocols; and compliance with data collection protocols.

Compliance with Intervention Protocols

Study protocols for implementation of the intervention were not adhered to with two dyads. In these two cases, the PREP nurse intervened with the care receiver rather than the caregiver, and in both cases this occurred after initial interventions with the caregiver. As the care receiver's health improved, the caregiver became less involved and the care receiver began to deal directly with the PREP nurse. This occurred for a different reason in each dyad. In one dyad, as the care receiver recovered from surgery, the caregiver became less and less involved in caregiving, eventually went back to work full-time, and stopped meeting with the PREP nurse. The care receiver, however, continued to call the PREP nurse about some of her physical problems and her feelings of depression, which she had not communicated to the caregiver. In the second dyad, the caregiver had some mild cognitive deficits. As the care receiver recovered from surgery, the care receiver took more and more responsibility for managing her own care and after several visits, the PREP nurse intervened directly with the care receiver rather than the caregiver. A decision was made to continue intervening with the care receiver in each case because study investigators thought they had an ethical obligation to do so and because they wanted to evaluate the natural progression of caregiving in such cases. When interventions with care receivers occurred the focus of the intervention changed from caregiving to a more traditional individually-focused health care. In such cases the caregiver outcome is less appropriate, or ambiguous, because both can be caregiver, resulting in reduced chances of finding a treatment difference. This suggests a need to develop protocols for handling reversals of the caregiving relationship.

Compliance with Data Collection Procedures

Overall, caregivers complied quite well with data collection procedures. All caregivers agreed to save documentation of service utilization and costs. When documentation was not saved, it was usually for a good reason. This researcher and the project director who conducted the caregiver interviews thought that one of the control caregivers, in an effort to show us her need to receive the intervention, overstated her utilization. The requirement of documentation of

service utilization and costs resolved this difficulty. One caregiver did not provide data after agreeing to even after repeated meetings with the researcher. Some measurement error likely occurred with the caregivers who were asked to estimate some service costs for which they did not save documentation. Because of the availability of much utilization data from HMO computer files, caregivers were not required to report utilization of many services. Because many services were used on a regular schedule they were easy for caregivers to remember. Although originally the procedure was to collect service utilization and cost data from caregivers, it was soon apparent that in some dyads, the care receiver paid the bills and was a more reliable source of data. The procedure was changed to collect data from either caregiver or care receiver, and should be changed in the full clinical trial to collect it from the family member or friend who normally pays the bills.

Several aspects of the data collection procedures were important in maximizing the accuracy of utilization and cost data. Monthly data collection was important because the researcher could review procedures and encourage continued participation. Even with monthly data collection, some caregivers had difficulty recalling some utilization or cost data. A recent study of the accuracy of self-reported out-patient utilization by older persons the preceding 6-month period, found that 8.4% of subjects either under- or over-reported contacts with physicians (Glandon, Counte, and Tancredi, 1992). The fact that most utilization and cost data were collected from HMO computer files meant that participants were responsible for providing data for a small number of services. In addition, their service utilization was somewhat stable. Thus, the burden placed on participants was kept to a minimum.

Three caregivers in each group did not complete the PREP Effectiveness Scale. Some caregivers left the HMO, some felt it did not apply, and some did not return the completed questionnaire. The refusal rate was similar across the intervention and control groups.

Limitations of the Study

In addition to the threats to design validity noted above, limitations of this study include reliance on nurse charting for utilization data, lack of uniform time records, lack of a formalized

caregiving issues list for intervention dyads, and the fact that dyads were not provided with a written list of services for which they needed to keep utilization and cost data.

Reliance on Nurse Charting for Utilization Data

Reliance on PREP and home health records for utilization data yielded different types of nursing utilization data in the two groups. Home health records provided only limited detail in describing a nurse home visit, while PREP charting records encouraged such description. Thus, it is likely that more data were available from PREP charts than from home health charts. And, it is possible that home health charting underreports the activities of nurses. In the larger clinical trial of PREP, charting procedures should be as uniform as possible so that a more accurate comparison can be made.

Uniform Time Records

Differences in the information recorded by PREP and home health nurses on time records meant that the data from PREP nurses was much more detailed than data from home health nurses. Specifically, PREP nurses recorded time spent in all their activities, and home health nurses recorded time spent only in home visits. The amount of time spent in telephone calls or other activities was not known for home health nurses. It was not known whether they even performed any other activities. In the full clinical trial, time records should be expanded to include all the activities of PREP, (e.g., staff meetings, funerals), and they should be used by both PREP and home health nurses.

Caregiving Issues List

The lack of a caregiving issues list with the first eight dyads meant that PREP nurse charting was often haphazard, issues were not followed up, and the nurses were confused about the caregiving issues they were addressing with their dyads. The caregiving issues list developed for use with the last three dyads, allowed the nurses to be much more focused on a set of issues, to follow up on issues until they were resolved, and would have assisted in the decision to transfer dyads to Keep-in-Touch if they had remained in PREP long enough. The caregiving issues list needs further work, specifically, criteria for including an issue on the

Follow-up List (making a diagnosis) need to be developed, particularly for caregiver strain.

Definitions need to be reviewed and revised so that regular home health nurses can easily understand them, and assessment questions need to be reviewed to make sure that a nurse has enough information to determine that each issue needs to be addressed.

Service List

The final limitation of this pilot study was that a written service list was not provided to dyads that they could refer to if they had questions about the services we were interested in. Such a list may have been helpful in reminding dyads to keep records of service use and cost. In the clinical trial such a list should be provided to dyads at the first interview.

CHAPTER 7

RECOMMENDATIONS AND IMPLICATIONS

In this chapter, recommendations for the larger clinical trial in the areas of research design, measurement, and implementation of the intervention are presented. These are followed by the implications of the study for theory, practice, and research.

Recommendations

A summary of recommendations for research design, measurement, and implementation of the intervention with rationale can be found in Table 7.1.

Recommendations for Research Design

Research design recommendations are included for sample selection, sample size, caregiver interviews, and subgroup analysis. Each of these is discussed below.

Sample Selection

In this pilot study, all referrals to home health were reviewed to obtain the sample, yet only 31 of these met all eligibility criteria. The main study criteria for participation in the study were appropriate and should be continued in the full clinical trial, including: (a) care receiver was 65 years of age or older; (b) the care receiver needed daily assistance at home for one month or more in at least one of four areas (personal care, behavior management, medical management, or protection); and (c) there was an identified primary caregiver. Several of the additional exclusion criteria that were used in this pilot study can be eliminated. Care receivers with special care needs, who live more than 20 miles from the research center, require daily visits, or are referred for PT only can all be included in the full clinical trial.

Some consideration should be given to eliminating the remaining exclusions as well, including care receivers admitted to adult foster homes and long-term care facilities, and those at home receiving hospice or S/HMO benefits. Caregivers often provide much care to care receivers after they have been admitted to adult foster homes or long-term care facilities. Thus, PREP nurse services to better prepare caregivers to provide such care and to monitor the care receiver's health condition might be very beneficial. In addition, PREP nurses might be able to

Table 7.1

Recommendations with Rationale for the Clinical Trial of PREP

<u>RECOMMENDATION</u>	<u>RATIONALE</u>
RESEARCH DESIGN	
1. Sample selection should be expanded to include PT-only referrals to home health and other dyads known by clinic staff to be in transition but not eligible for home health.	1. Assure adequate sample size, access dyads in transition.
2. Sample size should be based on power analysis using cost and other outcome variables .	2. Sample sizes estimates using total costs as the outcome were quite high. Costs are not the only outcome of interest.
3. Avoid duplication of research and clinical data.	3. Reduce likelihood of intervention effects by research staff, improve consistency of data, conserve resources.
4. Analyze PREP data for subgroups--high and low users of PREP, care receivers who die and those who do not.	4. Aid in understanding when PREP is most and least effective and most and least costly.
MEASUREMENT	
1. Obtain utilization and cost data from HMO computer files as much as possible.	1. Insure accuracy, minimize the burden on families.
2. Design similar charting records for PREP and home health.	2. Consistency of data, save resources needed for duplicate charting.

Table 7.1 Continued

<u>RECOMMENDATION</u>	<u>RATIONALE</u>
MEASUREMENT, (Continued)	
2. Keep comprehensive service list.	2. Little is known about the effects of home-health nursing on the utilization of other services. Nurses have potential to offset or induce demand for services.
3. Collect utilization and cost data from participants monthly.	3. Insure accurate data, rely less on recall, reinforce procedures.
4. Give printed service list and blank calendar to participants to record service costs for which there is no documentation.	4. Memory aid, assure documentation of costs of new services.
5. Administer PES at 3 months and every 3 to 4 months thereafter.	5. Better recall of services for control participants. Evaluate how PREP is being implemented.
IMPLEMENTATION OF PREP	
<u>A. Improve Efficiency of PREP</u>	
1. Develop standardized protocols for common caregiving issues.	1. Decrease time spent in care planning, decrease training time.
2. Substitute telephone calls for some home visits.	2. Telephone calls cost less. Many caregiving issues can be managed by telephone.

Table 7.1 Continued

<u>RECOMMENDATION</u>	<u>RATIONALE</u>
IMPLEMENTATION OF PREP (Continued)	
<u>A. Improve Efficiency of PREP</u>	
3. Streamline charting procedures.	3. Open-ended PREP charting questions required too much time.
4. Hire Clinical Nurse Specialist.	4. Expertise should help to offset more services and reduce need for consultants in some areas.
5. Hire clinical pharmacist, physician, geriatric mental health specialist to consult at weekly care planning meetings.	5. Expertise will help PREP nurses to intervene with participants in most effective way.
6. Establish strong link with primary care providers.	6. Develop time-saving protocols for common health conditions. Primary care providers control access to other services.
7. Make PREP a 24-hour/day, 7-day/week program.	7. Caregiving issues can develop at any time, nurses should be able to handle many issues with a telephone call, should save some emergency and outpatient utilization.
8. PREP nurse should continue as hospice nurse when care receiver referred to hospice.	8. Continuity of care, PREP nurse already available 24-hours/day.

Table 7.1 Continued

<u>RECOMMENDATION</u>	<u>RATIONALE</u>
IMPLEMENTATION OF PREP(Continued)	
<u>A. Improve Efficiency of PREP</u>	
9. Develop procedures for following hospitalized care receivers to facilitate discharge planning.	9. Earlier discharge from hospital and might prevent short-stay transfers to nursing homes, or reduce nursing home length of stay.
<u>B. Maximize Strength of Intervention</u>	
1. Standardize protocols for strain, predictability, enrichment and caregiver health.	1. Emphasized aspects of PREP that are different from standard home health.
2. Develop criteria for transfer to Keep-in-Touch.	2. Improve consistency in implementation.
3. Develop protocols for medication management which stress regimen simplification.	3. Prevent drug interactions, simplify work for the caregiver, save money.
4. Develop protocols for routine assessment of vision, hearing, and oral health.	4. Improve communication, maintain appetite, maximize health.

facilitate the care receiver's discharge back to the home setting again in some situations. Care receivers receiving hospice need not be eliminated because the PREP nurse could also be the hospice nurse and function as a member of the hospice team, but add the PREP services that are not included in hospice. Many dyads with S/HMO benefits could also benefit from PREP.

The S/HMO utilizes resource managers who monitor dyads by telephone, make decisions about adding home-care services, and do not provide direct service themselves. Although some resource managers are nurses, some are not. PREP nurse services of preparing the caregiver, increasing predictability, enriching caregiving, and monitoring the health of the caregiver and care receiver are not part of the S/HMO service package. Thus, PREP should benefit these dyads as much as dyads without the S/HMO benefit and may also be able to reduce the additional services provided by the S/HMO.

Some dyads were referred to home health from outpatient clinics. Some of these dyads were experiencing as great a transition in caregiving as those who were referred to home health during hospitalization and were very appropriate for inclusion in this study. Because it seems likely that there are many such dyads who are known to outpatient clinic social workers, it would be desirable in the full clinical trial to recruit potential participants with the assistance of outpatient social workers. This would help to ensure an adequate sample.

Sample Size

Power analysis was used to estimate desired sample size for the larger clinical trial of PREP (See Table 6.3). The effect size of .482 was computed by dividing the difference in control and intervention group means by the square root of the pooled variances of total costs for the intervention and control groups. Because dyad #315's total costs were so much higher than others in the control group, a second effect size was computed with dyad #315 excluded and equaled .229. Sample size estimates were determined for power levels of .80 and .90 and alpha levels of .05 and .01 using the software program Statistical Power Analysis (Bernstein & Cohen, 1988). Cohen (1977) recommends the use of a minimum of .80 for power. For an effect size of .482, the sample sizes needed to achieve the desired power ranged from 54 to 113 per group. For an effect size of .229, the sample sizes needed to achieve the desired power ranged from 236 to 497 per group. Power analyses should be performed using some of the other outcome variables measured by PREP investigators before a decision is made about sample size.

Table 7.2

Power Analysis and Sample Size Estimates for Effect Sizes Based on Total Costs Drawn from Pilot Data

		Effect Size ^a	
Alpha		.482 ^b	.229 ^c
Power	One-tailed		
.8	.05	54	236
	.01	88	384
.9	.05	74	327
	.01	113	497

$$^a \text{ES} = \frac{M_C - M_E}{\sqrt{\frac{(N_C - 1) S_C^2 + (N - 1) S_E^2}{(N_C + N_E - 2)}}$$

^b Based on cost data from 11 intervention and 11 control subjects.

^c Based on cost data from 11 intervention and 10 control subjects, with one outlier in control group omitted.

Caregiver Interviews

Because interviews by the research team were close together (5 weeks apart), and because the interview contained many of the same questions that PREP nurses asked caregivers, research staff may have had an unintentional intervention effect on intervention dyads. To reduce the likelihood of unintentional effects, duplication of research and clinical instruments should be kept to a minimum. The procedure used with the last three intervention

dyads, in which the research data from the first caregiver interview were summarized and given to the PREP nurse, was very workable and could reduce the amount of data collected by the nurses. In the larger clinical trial, this procedure should be reviewed and incorporated into the initial assessments or else PREP nurses should administer the research interview to caregivers.

Subgroup Analysis

The research design should include plans to analyze data for several subgroups. Subgroups include high- and low-users of PREP and care receivers who die. This would allow a clearer understanding of situations when PREP is least and most effective and when it costs the least and most.

Recommendations for Measurement

Recommendations for measurement relate to HMO sources of data, obtaining comparable nursing utilization data in the two study groups, the services included on the service list, the frequency of data collection from participants, the PREP outcome measure, and methods to improve adherence to data collection procedures by dyads. Each of these is discussed below.

HMO Data Sources

In order to insure the highest levels of utilization and cost data accuracy and minimize the amount of burden placed on dyads for providing data, utilization and cost data should be obtained from HMO computer files in the larger clinical trial as they were obtained for this study.

Nursing Utilization Data

In order to obtain comparable data from PREP and home health charts, and to prevent the costly duplication of charting by PREP nurses that occurred in this pilot study, similar charting procedures should be designed for PREP and standard home health.

Service List

Tracking utilization and costs for a comprehensive set of services is recommended because not a lot is known about the effect of additional nursing services on the utilization of other services. One of the problems of cost analyses of other nursing interventions is that the

effects of cost offset and cost increases are not included (Brooton et al. 1986; Naylor, 1990). Little is known about the combination of services which is most effective for the long-term management of frail older persons in the community and how much they cost. Many different types of services and combinations of services have been utilized to provide long-term care in the community to older persons. Because of the nature of their practice, some providers are much more likely to influence the utilization of non-intervention services. A nurse is one of those providers. As the PREP intervention evolved, PREP nurses were much more aggressive in finding additional services for dyads, a trend that can be expected to continue in the future clinical trial. The community services that were not utilized in this pilot clinical trial (congregate meals, outreach worker from a Senior Center, friendly visitor service, and phone reassurance) should be retained on the service list for the next study because they are more likely to be free or relatively inexpensive to dyads and they could be an important source of help for some caregivers. Even though it is expensive, delivery service for groceries should also because it is a service that is becoming more common in the study site area.

Frequency of Data Collection From Participants

Utilization and cost data should be collected from caregivers monthly, to minimize measurement errors due to recall. Collecting the first one or two months of data in person during home visits to dyads will help dyads to comply with data collection procedures and will allow the researcher to evaluate the dyad's ability to comply. After the first one or two months of data collection during home visits, the remaining months of data could be obtained by telephone interviews with most dyads. Perhaps for some dyads, though, home visits would be required because of non-compliance with procedures. Saving written documentation was easy for most caregivers. Providing them with a folder for storage of saved documentation until collected by the researcher was helpful. To improve documentation of new services, the caregiver should be given the list of services and reminded during each data collection about the list of services and about writing down any new services they use. A calendar should be given to each dyad to record data when no documentation of utilization or cost is available. Because family members

may be responsible for dyad financial affairs, the consent should be written so that data can be collected from the caregiver, care receiver, and/or whoever pays the bills.

PREP Outcome Measure

The PREP Effectiveness Scale should be used as a measure of intermediate outcomes because it was very sensitive to the intervention, and should be administered at approximately 3 months and then every 3 to 4 months throughout the study year. In addition to evaluating the differences between the groups, it could also serve as a process variable, that is a variable to evaluate whether the intervention is being implemented appropriately with intervention dyads. Because significant differences were not found on the more global measures of caregiving developed for the PREP Evaluation Study and because of variability in the number and type of health problems and caregiving issues confronting dyads, serious consideration should be given to the development of individual outcomes described by Guyatt (1988). For example, a caregiver who identifies prevention of falls as an issue she/he would like to manage better, her/his preparedness to prevent falls should be the outcome measure. The measure should include a subjective as well as an objective component.

Methods to Improve Data Collection Procedures

Although most caregivers adhered to procedures to collect utilization and cost data, a small number did not. In order to help ensure adherence to data collection procedures in the full clinical trial, data should be collected from the family member who pays the bills. Consideration should also be given to asking both caregiver and care receiver and/or other family members to assist in this data collection. Data collection procedures for the full clinical trial should include face-to-face contact between data collectors and caregivers for the first two data collection periods so that data collectors can evaluate caregivers' adherence. Caregivers who adhere well to the procedures could be followed-up at subsequent interviews by telephone. Caregivers who have difficulty adhering to procedures should be followed-up with face-to-face contact. A written list of all services for which caregivers need to provide data should be left in the home as a reminder.

Recommendations for Implementation of the Intervention

Recommendations for implementing the intervention are based on improving the efficiency of PREP so that it does not cost as much as it did in the pilot study and on maximizing the strength of the intervention so that the systematic intervention variance can be maximized.

Improving the Efficiency of PREP

Costs of PREP nursing. Several steps can be taken to improve the efficiency of PREP nursing. Development of standardized protocols, even brief ones, for common caregiving issues addressed by PREP nurses could decrease the time needed in care planning meetings to plan intervention strategies and the time needed by nurses to develop the Follow-up List. This might also aid nurses in understanding PREP concepts better and decrease the time they need to learn how to implement PREP and function at an effective level. Care planning meetings could be reduced to once a week, and structured to limit the amount of time devoted to any single dyad.

Because home visits accounted for a large share of nursing costs, substituting telephone calls for some home visits would reduce costs. It seems important that home visits in the beginning phase of the intervention would be needed to establish the therapeutic relationship. It also seems that once a relationship is established, much of the intervention could be conducted by telephone with some dyads. Telephone calls were used frequently with some dyads in this pilot, but not with others. More emphasis on establishing clear goals of the In-home Component and transferring dyads to the Keep-in-Touch Component when goals are reached might facilitate a reduction in home visits by not keeping dyads in the In-home component longer than needed.

Charting procedures were quite time-consuming in the pilot study. PREP charting forms contained primarily open-ended questions and required a lot of writing to complete. In the larger clinical trial, charting procedures should continue to be refined and questions more focused to get the responses desired. Because of strict Medicare rules regarding charting, PREP nurses sometime charted on both PREP forms and home health forms. To increase efficiency, this should be corrected. The ideal solution would be to use the same forms for charting when possible or PREP charting should be accepted by the home health department.

Costs of non-PREP services. The costs of non-PREP services could be reduced by strengthening the intervention's ability to offset more services more often. The inclusion of at least some nurses with higher levels of preparation might be required to offset more services. Nurses in advanced practice could provide the expertise in the long-term management of chronic conditions that were treated by PREP nurses in this pilot, that nurses prepared at lower levels do not have. The advantages of using an advanced practitioner are many. She could develop standardized protocols for commonly-encountered caregiving problems mentioned above. She could provide knowledgeable assessment of dyads on entry into PREP, could educate other nurses in management of chronic conditions, provide direct services to dyads with more complex caregiving situations, and help staff to utilize current research to in daily practice. It might be possible for an advanced practice clinician, with the assistance of medical staff, to develop standard protocols or guidelines to handle common medical problems. This would increase the chances that PREP nurses could handle more care receiver problems at home, and thus offset some clinic visits to primary care providers.

The addition of several types of consultants could contribute to PREP's ability to offset non-PREP services and strengthen the geriatric and long-term-care focus of the intervention. A clinical pharmacist with expertise in geriatrics to assist with simplifying drug regimens, provide information to PREP nurses about drug interactions and side effects could help offset some pharmacy utilization and possibly some primary care provider utilization. A physician consultant or advisor could be helpful in facilitating greater responsibility for management of the care receiver by PREP nurses and in developing protocols for managing common medical problems. Physician support of greater responsibility of PREP nurses in managing the care of frail older people could help offset expensive hospital utilization and outpatient clinic utilization. A psychogeriatric advanced nurse practitioner would be helpful in the management of very difficult problems of dementia, depression, and emotional problems of both caregiver and care receiver. Behavior problems provided some of the biggest challenges in this pilot of PREP. More effective management of these problems at home should help offset the utilization of institutional

and emergency services. Monthly or twice monthly attendance at care planning meetings by these three types of consultants might add relatively little to the cost of PREP yet provide valuable consultation.

A strong link with primary care providers needs to occur in the larger clinical trial. Two recommendations relate to establishing this link. First, when a dyad is admitted into PREP, information should be relayed to the primary care provider both with written materials and verbally by PREP nurses about PREP and how the provider and PREP nurse can work together to meet the health care needs of dyads. An informational brochure could be developed specifically for primary care providers. PREP staffing should also include a physician consultant and/or advisor who could advise PREP in working with medical staff, participate in care planning meetings, assist in the development of protocols (standing orders) for the treatment of common health problems by PREP nurses, explain and interpret PREP to physicians and other providers, and act as a go-between with PREP nurses and primary care staff. The inclusion of a physician will be most important if PREP is to realize cost savings, because primary care providers control access to other services.

The larger clinical trial should provide for 24-hour availability of the PREP nurse to make a home visit if necessary and to respond to caregiver questions via the PREP Advice Line. In this study, some dyads went to the emergency room for problems that could have been resolved by a PREP nurse if she had been available, i.e., one care receiver's urinary catheter came out. In addition, several studies which have examined the effect of a 24-hour telephone advice service for chronically ill older people have shown that a majority of problems that patients call about can be resolved over the telephone (Schler et al, 1985; Zimmer et al, 1984). In chronic illness, problems can arise at any time and can be quite frightening. The availability of a nurse who knows the dyad should be reassuring to caregivers. Extensive knowledge of the dyad and the caregiving situation by an on-call nurse should help to assure correct assessment of problems and appropriate treatment and follow-up.

When PREP care receivers become terminally ill and are referred to hospice, the PREP nurse should function as the hospice nurse on the hospice team and continue as the primary nurse for the dyad. It would be very disruptive to dyads to lose the PREP nurse after establishing a relationship. In addition, the continuity of care could be better maintained. If PREP becomes a 24-hour program with a nurse on call, there should be no reason not provide hospice care as well.

Procedures should be developed for the full trial for following care receivers who are hospitalized and for active involvement of PREP nurses in discharge planning. This should result in earlier hospital discharge for PREP care receivers and may also prevent short-stay transfers to nursing homes, or reduce nursing home length of stay (Oktay & Volland, 1990).

Maximize the Strength of the Intervention

According to Kerlinger (1986), one way to strengthen the treatment condition is to make it as different as possible from the comparison condition(s). Discussed below are several ways that the PREP intervention could be strengthened.

Use of consultants. Using the consultants described above would be one way to make PREP different from standard home health. Another way would be to standardize the intervention strategies for concepts specific to PREP, including strain, predictability, enrichment, and caregiver health. Unless such protocols are developed it is too easy for PREP nurses to resort to intervention strategies they learned in standard home health and the intervention will be diluted. Issues of preparedness were addressed most often with caregivers, probably because they are similar to issues addressed in standard home health in some respects and thus it was easier for nurses to intervene, much as they would have as home health nurses. Brief protocols for common caregiving problems such as behavior problems, constipation, and high risk of falling need to be developed to show how PREP is different from standard home health.

Develop criteria for transfer to Keep-in-Touch. Criteria for the transfer of dyads to the Keep-in-Touch Component should be developed for the full trial. Because criteria for transferring dyads to Keep-in-Touch were not developed in the pilot study, nurses made their

own decisions about transfer, and some dyads were not transferred who probably could have been. It will be important to have criteria in the full trial so that resources are not used for the more expensive In-home component when they don't need to be. Also, criteria will help to clarify the difference between the two components and the goals of nursing intervention and the processes of nursing care in each one. Finally, if dyads are consistently transferred from one component to the other it will aide in the evaluation of the utilization patterns of PREP.

Nurse staffing. Core nursing staff for the larger clinical trial should include one master's prepared clinical nurse specialist and a 1/2 time supervisor for every 5 staff nurses. The clinical specialist could carry a caseload of 10 dyads and admit all new dyads to PREP. Registered nurses could carry a caseload of 20 dyads. The supervisor would have responsibility for all administrative functions.

Staff training. In addition to orienting PREP staff to the basic principles of PREP, training should include spending a day with a dyad to gain an understanding of and appreciation for caregiving. This would be especially important for PREP nurses who have not functioned as a caregiver to a family member or friend. Training should include listening to video tapes of the various assessments. Nurses should be well-trained in specific aspects of gerontological nursing, including management of incontinence, mobility and falls, dementia, depression, drug toxicities and interactions, nutrition, and pressure sores. Nurses should be oriented to a wide range of community resources.

New protocols. Several new protocols should be developed. A protocol should be developed for medication management which emphasize simplification of medication regimens and minimization of side effects and drug interactions. A protocol for follow-up of hospitalized care receivers should be written to facilitate hospital discharge and reduce hospital length of stay. A protocol for assessment of vision, hearing and oral health is needed to maximize care receiver sensory status and maintain oral health so that the appetite is not adversely affected. If care receivers in adult foster homes and long-term care facilities are included in the full clinical trial, protocols for intervention with this type of participant should be written. A protocol is

needed for situations in which the care receiver needs to be transferred to hospice and for situations in which the caregiver and care receiver reverse roles or when the care receiver resumes responsibility for her/his own care.

Implications for Theory, Practice, and Research

The development of this research was guided by a conceptualization of nursing costs which included the costs for services that were hypothesized to be offset by nurses and costs for those services that were hypothesized to increase as a result of nursing interventions. A discussion of how findings from this study can be generalized back to theory follows, along with the implication for practice, and research.

Theory

Although the sample size in this study was small and subjects were not randomized into treatment groups, some tentative conclusions can be drawn from the results. Lower utilization rates and lower overall costs in the intervention group support the conceptualization that PREP nurse interventions with caregiving dyads, the utilization of other services was offset and overall costs were less. Because nursing intervention studies have not measured the utilization of a comprehensive set of services, the extent to which nurses actually do offset service utilization is not known. Especially in the area of long-term care which is composed of a myriad of medically-related and social services, the effect of adding or enhancing a service on the utilization of other services is not known. Because nursing practice contains both a medical and a psychosocial component, its ability to offset the utilization of other services is especially germane. Nurse researchers, when planning intervention studies which include an analysis of cost, should consider including the costs of services that nurses are likely to offset or increase.

Practice

The results of this study have important clinical implications. Specifically, this study suggests that home-health interventions by registered nurses designed to improve the preparedness of the caregiver, improve the predictability of caregiving processes, and enrich caregiving are effective in improving caregivers' perceptions of preparedness to manage many

aspects of caregiving. It has promise as a way to manage long-term health problems in older people who are taken care of by a family member or friend. A second clinical implication is that overall health care costs are less because nurses offset the utilization of several other health care services.

Research

The first research implication of this study is that it supports the conduct of the full clinical trial of PREP. Lower costs and better outcomes in the intervention group suggest that PREP is a cost-effective method of providing long-term care to older people and their families.

The second implication of this study is that more pilot work needs to be completed before the full trial can start. Because PREP is a complex intervention and requires extensive training, the most desirable way to conduct a second pilot is to plan it as the first year of the full trial, so that staff would have to be hired only once. The supervisor and clinical nurse specialist should be hired for the pilot phase of the clinical trial. The activities of the pilot phase of the full trial include the following:

- hire the clinical nurse specialists and supervisor
- develop written protocols for the main PREP concepts--strain, predictability, and enrichment
- develop brief protocols for commonly occurring caregiving issues
- implement protocols with a small number of dyads and revise as needed
- develop criteria for transfer to Keep-in-Touch
- develop procedures for discharge planning when care receivers are hospitalized
- revise charting forms and time sheets so that they can be used by both PREP and home health nurses
- explore the development of protocols for common health problems with primary care providers
- determine feasibility of recruiting subjects from outpatient clinics with assistance from clinic social workers
- develop procedures for conducting care planning meetings

- revise training for staff nurses
- hire and train staff nurses

The third implication of this study is that because it appears likely that a large sample will be required for the study to have sufficient power, additional sites for the study should be explored. Because data collection for utilization and cost data would become more complicated with additional non-HMO sites, perhaps HMO sites in Salem, Oregon, and Longview, Washington, could be added.

Summary

This dissertation was a supplemental study to the PREP Evaluation Study, a 2-year pilot study evaluating the effects of PREP, a home-health nursing intervention designed to support and assist older HMO enrollees with chronic disabilities and their family/friend caregivers. The PREP Evaluation Study was funded by the National Center for Nursing Research in the spring of 1990. A full clinical trial of PREP is currently being planned for 1994. The purposes of the PREP Evaluation Study were to refine the PREP intervention and evaluate its feasibility. Older people and their family/friend caregivers in the intervention group received standard home health benefits plus the additional services of PREP. The control group received only standard home health. This supplemental study developed an extension of the PREP pilot study to include an evaluation of economic issues. The aims of this study were to:

1. develop and refine cost and service utilization measures for PREP;
2. develop a protocol for a cost analysis of PREP and standard home health;
3. compare the costs and outcomes of PREP with the costs and outcomes of standard home health.

PREP was an expansion of home health Medicare benefits available to older people and their caregivers and was implemented by registered nurses. Because many caregivers take on caregiving responsibilities with little preparation, PREP was designed to enhance the overall caregiving situation. Specifically, the aims of PREP were to improve the preparedness and competence of family members in providing long-term care to their older family member or

friend, to make the caregiving processes more predictable, and to enrich the caregiving environment. Preparedness was defined as the caregiver's evaluation of how prepared she/he was to meet the care receiver's needs and handle the stress of caregiving. Predictability was defined as stable caregiving routines and patterns. Enrichment was defined as the process of enhancing caregiving through the pleasurable, the aesthetic or the ceremonial. Interventions by PREP nurses with intervention dyads focused on these three principles.

The structural components of PREP included the In-home Component, the Keep-in-Touch Component, the Completion Component, and the PREP Advice Line. The In-home Component began when caregiving dyads were admitted into the study. In this component, PREP nurses conducted home visits and addressed issues identified by caregivers as being difficult to manage using the principles of preparedness, predictability, and enrichment.

When the caregiving situation stabilized and caregivers felt prepared to manage all aspects of caregiving they had to deal with, the dyad was transferred to the Keep-in-Touch Component. In this component PREP nurses monitored their families with periodic phone calls to assess for new problems and to follow-up on problems addressed in the in-home component.

Near the end of the intervention, PREP nurses initiated the Completion Component. In this component, dyads were prepared for the transition for the ending of PREP. Nurses met with dyads for the final time to discuss what they learned while in PREP, and a letter was sent by PREP nurses to each dyad which summarized the dyads strengths, the progress they had made while in PREP, and what the nurse had learned from the dyad.

The PREP Advice Line was a paging system in which PREP families could call the PREP nurse for advice during working hours. This was available in both the In-home and Keep-in-Touch Components.

PREP used a long-term care model to manage chronic disabilities in older people over an extended period of time. PREP focused on the totality of the caregiving situation. PREP nurses developed a long-term therapeutic relationship with the dyad, addressed any caregiving issue that was of concern to the dyad, emphasized predictable caregiving routines, and tried to

enrich the environment of each family. Emphasis was placed on supporting the caregiver and on maintaining the caregiver's health. PREP nurses were assigned primary responsibility for their families and because of the long-term relationship with dyads, functioned almost as primary providers.

Standard home health used an acute-care model to manage care receiver health problems on a short-term basis until they were stabilized. Standard home health nurses focused on specific, and usually a very limited number of care receiver health problems. Nurses stayed involved long enough to stabilize acute conditions and to make sure that either the care receiver or a family member could manage any care requirements. The care receiver was the primary focus of care, and caregivers were involved only to the extent that they needed to learn to manage specific tasks or health problems as directed by the physician. Although home health nurses were assigned primary responsibility for care receivers, the relationship was brief, due to the short-term nature of home health.

The primary social policy issue of new health care programs such as PREP is their cost-effectiveness. In this era of rapidly increasing health care costs and emphasis on cost containment, new health care programs face careful scrutiny. Decisions to include PREP in a long-term care insurance benefit package require good data about the effects of PREP on care receiver and caregiver health and quality of life and on the cost of PREP.

This study used a three variable framework of utilization, cost, and outcomes to compare PREP with standard home health. It was hypothesized that PREP would affect the utilization and thus the cost of a number of health and social services for both care receivers and caregivers. Because of these hypothesized effects, the costs associated with these other services were included in the overall costs when PREP families were compared with control families.

It was hypothesized that PREP would offset the utilization of some services, that is, some services would be used less by PREP dyads because of the availability of PREP nurses.

It was also hypothesized that PREP would induce demand for other services, that is that PREP dyads would use more of some services than control dyads.

For care receivers, it was hypothesized that PREP would offset the use of hospitals by care receivers because PREP nurses would be available to assess new health problems early, before they developed into serious problems requiring hospitalization. It was hypothesized that PREP would offset the use of emergency services because PREP nurses would be able to handle many problems that otherwise would go to the emergency room. Caregivers, by becoming more prepared, would know how to handle some situations themselves. By offsetting both hospital and emergency room use, it was hypothesized that ambulance use would also be offset. It was hypothesized that long-term institutional use would be offset because caregivers would feel more prepared to handle the situation and experience less stress, and thus be able to continue caregiving longer. It was hypothesized that because PREP nurses were available to dyads by the PREP Advice Line, they would use less of the HMO's Advice Nurse. Finally, it was hypothesized that pharmacy utilization would be offset because PREP nurses would try to simplify drug regimens and thus PREP dyads would use fewer medications.

In terms of induced demand effects for care receivers, it was hypothesized that PREP would induce demand for outpatient primary care services because nurses would be assessing care receivers more frequently and would discover problems that needed the attention of the primary care provider. It was hypothesized that PREP would induce demand for a variety of community services, such as respite care, adult day care, and home-delivered meals, because PREP nurses would try to bolster caregiving situations where there was need for more support. It was hypothesized that PREP would induce demand for mental health/counseling services, because with long-term involvement by the nurse, mental health problems were more likely to be encountered and PREP nurses would be aggressive in obtaining treatment. Finally, it was hypothesized that PREP would induce demand for durable medical equipment and medical supplies because PREP nurses would try to obtain these to make caregiving easier.

For caregivers, it was hypothesized that PREP would offset the use of hospitals and nursing homes because caregiver health was an emphasis of PREP. Because PREP nurses were monitoring caregiver health, it was expected that health problems would be discovered early and referred to primary care providers, thus preventing problems from becoming serious enough to require hospitalization. It was also expected that if PREP caregivers were healthier, they would not be as likely to require the use of a nursing home.

In terms of induced demand effects of PREP on caregivers, it was hypothesized that because of the emphasis on caregiver health, PREP nurses would induce demand for primary care services by discovering neglected health problems in caregivers and by encouraging caregivers to see their primary care provider for these problems. It was also expected that PREP caregivers would use more mental health and counseling services because PREP nurses would assess caregivers over an extended period of time, would be more likely to encounter mental health problems, and would also recommend or try to obtain treatment for some caregivers.

The outcomes of interest in this study were the caregivers' perceptions of preparedness, predictability, and enrichment. These outcomes were chosen because they were the conceptual underpinnings of the intervention and were the focus of PREP nurse activities with dyads. If PREP was effective, we should expect to see differences in each of these outcomes in the two groups.

This study used a quasi-experimental design to compare PREP with standard home health. Dyads were not always randomized into the intervention and control group. The study took place in a large pre-paid, group-practice HMO in the Pacific Northwest. The HMO's home health department was a combined home health/hospice department. At the time of the study, the HMO's older membership was increasing, and approximately 75% of the home health department's 450 clients were over the age of 65. The sample for the pilot study was recruited from the population of HMO members referred to the home health department. Twenty-five dyads were recruited to participate in the evaluation of PREP and 3 dyads were lost to follow-up.

Eleven dyads were assigned to the intervention group and 11 dyads were assigned to the control group.

The sample of 22 care receivers was 50% female and predominantly Caucasian. Most were married and had a high school or greater education. Most lived with a spouse, and the rest lived with an adult child. The primary medical diagnosis of nine care receivers was stroke, 3 had fractures, 3 had dementia, and 3 had diabetes. Two care receivers had rheumatoid arthritis, and one each had amyotrophic lateral sclerosis and cancer.

The sample of 22 caregivers was 77% female and predominantly Caucasian. All caregivers were married and their relationship to the care receiver was most often that of spouse. Most had a post-high school education and were retired. The estimated annual income of 64% was less than \$20,000.

Three types of data were collected: utilization data; cost data; and PREP outcome data. A comprehensive service utilization profile was developed for each dyad for the study period and served as the basis for determining costs. The profile included services for both the care receiver and the caregiver. PREP nurse and home health nurse utilization data were collected from PREP records, home health records, and from home health computer files. Utilization data for non-PREP services were obtained from HMO outpatient records, HMO computer files, and from dyads at monthly interviews in their home. As much data as possible were collected from HMO computer files and records in order to minimize the burden placed on caregivers to provide data.

PREP outcomes were measured by the PREP Effectiveness Scale, a 40 item scale which measured the degree to which the intervention increased preparedness, predictability and enrichment. The scale used a 5-point response format and a scale score was computed by averaging the responses to the 40 items. The PREP Effectiveness Scale was completed by 8 caregivers in each group.

Services costs were based on the amount of service utilization and pricing of services was determined in several different ways. A cost per home visit was computed for PREP nurses. The PREP visit cost was computed by totaling expenditures for all labor and non labor

inputs, adding a regional overhead fee (for office space rental and maintenance, and various administrative services) and dividing total expenditures by the number of home visits. The cost per visit for PREP nurses was \$173.73. A cost per visit was also computed for home health nurses using the same formula. The visit cost for standard home health nurses was \$86.65.

Pricing for non-PREP services was determined in a number of different ways. Some of the computer data files contained cost data in addition to utilization data. Other files contained only utilization data and the cost associated with the utilization was computed using special formulas. Some services were priced as the amount paid by the HMO or by caregivers to non-HMO providers. When appropriate, costs were adjusted for inflation.

Average monthly costs were computed to adjust for the length of follow-up. As was expected, average monthly costs for home health services, which included the additional cost of PREP in the intervention group, were significantly higher in the intervention group. Average monthly costs in each of the other service classes--institutional services, outpatient services, community social services, and pharmacy, durable medical equipment, and medical supplies--were lower in the intervention group, but not significantly lower. Average total monthly costs were also lower in the intervention group, but not significantly lower. Higher institutional costs in the control group reflected higher hospital costs primarily. Higher outpatient costs in the control group reflected in part the high cost of renal dialysis. In the community service class, higher control group costs in the control group reflected high cost of ambulance services.

Scores on the PREP Effectiveness Scale were significantly higher in the intervention group ($M=4.1$) than in the control group ($M=3.1$), demonstrating that PREP was more effective than standard home health in increasing caregivers' perception of preparedness, predictability, and enrichment.

One limitation of this study was non-randomization into the control and intervention groups. Two steps were taken to evaluate the effects of non-randomization. First, *t*-tests were computed on a large number of care receiver and caregiver variables at baseline to test for differences between the groups. All were non-significant except care receiver age, caregiver

age, and caregiver strain in one area of caregiving, managing medically-related tasks. Second, a multivariate regression analysis was performed. The regression equation incorporated a measure of care receiver status (age), a measure of caregiver status (the amount of direct care, which is the number of caregiving tasks performed). The third regression variable was the number of months of follow-up. After controlling for these 3 predictors, being in the intervention group was associated with lower costs, which were over \$6,400 lower than the control group on the average.

The second limitation of the study was the small sample size. The third limitation was that in two cases, interventions by PREP nurses were conducted with care receivers and caregivers were not involved. In both cases, this occurred later in the study when the care receivers were recovered sufficiently to manage their own care and caregivers became less involved. The fourth limitation was non-uniform charting and time records in the control and intervention groups. Differences in charting records meant that PREP nurses sometimes had to chart twice for a single home visit and different types of information were charted. Differences in time records meant that utilization data for PREP and standard home health were not consistent. The fifth limitation of this study was the lack of a standardized caregiving issues list. Lack of a caregiving issues list resulted in inconsistent charting and difficulty in evaluating interventions by PREP nurses.

The conclusion of this study is that after controlling for baseline differences between groups, the intervention group (PREP) cost less (but not significantly less) than the control group (standard home health) and had a significantly better outcome. These findings suggest that PREP has promise as a cost-effective intervention for providing long-term care to older people and their families and the full clinical trial of PREP should be conducted.

Recommendations for the full clinical trial of PREP were made based on the results of this study. Recommendations for research design included recommendations for sample size, sample selection, collection of research and clinical data, and the analysis of subgroups. Recommendations for measurement included recommendations for the collection of utilization

and cost data, the design of charting records, frequency of data collection, services in the service use question, PREP-specific outcomes to measure, and procedures to collect use and cost data from dyads.

Recommendations for the implementation of PREP focused on improving the efficiency of PREP and on maximizing the strength of the intervention. Efficiency recommendations included the development of protocols for common caregiving issues, substituting telephone calls for home visits, streamlining charting procedures, using a gerontological clinical nurse specialist, using consultants in clinical pharmacy, medicine, and mental health, establishing a strong link with medical staff, making PREP a 24-hour/day, 7-day/week program, and developing procedures for the PREP nurse to continue as hospice nurse, when care receivers are transferred to hospice and for following hospitalized care receivers. Recommendations to maximize the strength of the intervention included developing standardized protocols for strain, predictability, enrichment, and caregiver health, developing criteria for transfer to Keep-in-Touch, training of PREP staff, and developing protocols for medication management, and routine assessment of vision, hearing, and oral health.

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Appendix A

Developmental Phase Recruitment Letter

June 5, 1991

Dear

You are currently receiving PREP services through Kaiser Permanente Foundation Hospitals. It is important to find out if new programs like PREP result in extra cost or in cost savings. We are conducting a study to find out about the cost of taking care of someone at home under PREP and we need your help. We would like to interview you to find out the types of in-home and medical services you use in addition to PREP, to take care of your....., We will also ask you to keep track of your out-of-pocket expenses for these services.

If you agree to volunteer for this study, you will be interviewed once every month until January, 1992. The interviews will occur in your home at a time that is convenient for you, and will be done by Lois Miller, a nurse and doctoral student. The interviews will last about 15-30 minutes. Kaiser Permanente records then be reviewed to keep track of the Kaiser Permanente services you use. You will be asked to save bills and receipts for the services that are not from Kaiser Permanente. These bills and receipts will be copied during the monthly visits.

Participating in this study is voluntary. If you choose not to participate, it will not affect your care by the PREP staff or by Kaiser Permanente.

We hope that you will decide to participate in this study. Lois Miller will call you to answer any questions you might have and to set up the first visit.

Sincerely,

Patricia G. Archbold, RN, DNSc, FAAN,
Professor

Appendix B

Telephone Script for Recruitment for Developmental Participants

SCRIPT FOR INITIAL TELEPHONE CONTACT

Hello. My name is Lois Miller. I am a doctoral student from the School of Nursing at Oregon Health Sciences University. Is _____ (caregiver's name) there? Did you receive a letter from us about the in-home and medical services you use while in PREP?

1. (IF NO): Would this be a good time to explain what was in the letter?

A. (IF NO): When would be a good time to call you back?
Thank you, I'll call you then.

B. (IF YES): The letter says that we are conducting a study about the in-home and medical services you use in addition to PREP, and how much these services cost. This information will be used to evaluate the effect of PREP on the cost of taking care of someone at home. We are asking your help to do this study. We would like to interview you to find out the types of other services you use and to ask you to keep track of your out-of-pocket expenses for these services.

If you agree to volunteer for this study, I will interview you once every month, until March, 1991, in your home at a time that is convenient for you. I am a nurse and doctoral student at the School of Nursing, working on the PREP study. The interviews will last about 15-30 minutes.

Attachment C

I will review your Kaiser Permanente records to keep track of the Kaiser Permanente services you use. You will be asked to save bills and receipts for the services you get that are not from Kaiser Permanente. I will copy these bills and receipts with a portable copier during the monthly visits to your home.

Do you have any questions about being in this study and what you are being asked to do?

(Skip to 3.)

(IF YES): Would this be a good time for me to talk to you about this study, or would you like me to call back at a more convenient time?

2. (IF NO): When would you like me to call you back?

(IF YES): As the letter says, we are interested in the types of medical and in-home services you use and in how much these services cost. Do you have any questions about being in this study and what you are being asked to do?

3. (After all the questions have been answered, ask): Would you be willing to participate in this study?

(IF NO): Thank you for your consideration and time.

(IF YES): When would be a convenient time for me to come to your home? (Arrange first home visit) I will call you on that day to make sure it is still OK to visit. Thank you. Goodbye.

FONECALL
DRAFT
MAY 2, 1991

Appendix C

Supplemental Consent form for Developmental Participants

Kaiser Permanente, Northwest Region

Evaluation of a Caregiving Support Program (PREP)

SUPPLEMENTAL CONSENT

TITLE OF STUDY: Cost of a Home Health Nursing Intervention

INVESTIGATOR: Lois Miller, RN, MN

PURPOSE AND BACKGROUND: You are being asked to participate in this study because you are receiving PREP services. Because of a concern about the high cost of health care and home care, it is important to find out if PREP adds to health care costs or results in cost savings. The purpose of this study is to find out about the in-home and medical services that are used in addition to PREP. You are being asked to provide information about how often both of you use medical and in-home services and about your out-of-pocket expenses for those services not covered by Kaiser Permanente.

PROCEDURES: If you agree to participate, you will be interviewed in your home at the beginning of the study and once each month until March 31, 1992. These interviews will last approximately 15-30 minutes. At the first interview you will be asked what kinds of medical and in-home services you are using and who provides each service. Your Kaiser records will be reviewed to keep track of how many Kaiser services you use. You will be asked to keep track of all non-Kaiser services by saving bills or receipts in an envelope provided to you for this purpose. The bills and receipts that you have saved will be copied with a portable copier once each month during a visit to your home.

RISKS AND DISCOMFORTS: It may be inconvenient for you to save bills and receipts for health care expenses and to meet monthly with Lois Miller.

BENEFITS: A summary of the services you used and their costs will be provided to you by Lois Miller at the end of the study period,

Appendix D

Consent Form for Pilot Clinical Trial

Kaiser Permanente, Northwest Region

**Evaluation of a Caregiving Support Program (PREP)
Pilot Phase 3**

Investigators

Patricia G. Archbold, RN, DNSc, FAAN, Principal Investigator
Barbara Stewart, PhD
School of Nursing, Oregon Health Sciences University
Merwyn R. Greenlick, PhD
Barbara Valanis, RN, DrPH
Center for Health Research, Kaiser Permanente

Consent Form

To be used with the 24 dyads who are enlisted to help with the pilot test of PREP interventions.

Study Explanation

PREP is a research project that has been funded by the National Institutes of Health. The purpose of PREP Phase 3 is to compare two different ways of providing in-home nursing services to older persons. PREP is a set of services, offered by home health nurses, that is designed to increase competence in caregiving activities, enrich caregiving activities, and make these activities more predictable.

Procedures

If you agree to participate, the following will happen. After signing this consent form, you will be randomly (by chance) assigned to either Group A or Group B. If you are assigned to Group A, you will receive all of the usual home health services for which you are eligible. If you are not currently eligible for in-home nursing services, you will receive at least one home health visit. If you are assigned to Group B, you will receive PREP services. PREP lasts until December 31, 1991. It includes: (a) in-home visits by a home health nurse for 4-10 weeks; (b) a Caregiving Advice Line (available until December 31, 1991; and (c) a Keep-in-Touch system in which the PREP nurse checks in on you for several months after enrollment into this program. Because PREP is new, you will be asked to share your thoughts and opinions about PREP services. Researchers will interview you once to obtain your views about how to improve PREP services. These interviews will last approximately 30-45 minutes.

In addition, participants in both groups will be interviewed on three separate occasions. These interviews will be conducted in your home during the second, seventh, and twelfth weeks of the study. The interview for the caregiver will last approximately 1 – 1^{1/2} hours each. We will ask you about your health, the kinds

of help you give your family member, your relationship with him/her, the cost of care, and how things have been going lately. The interviews with the care receiver will take 30-45 minutes each. We will ask you questions about your health, the kind of things you need help with, and how you have been feeling lately. We will also collect information on the cost of health care from you at monthly intervals following the third interview. This would involve at most 3 additional interviews.

Confidentiality

The interviews will be recorded in writing. The information you give us will be handled in a manner to ensure confidentiality. Only PREP project staff will have access to your responses. Any publication from this study will include the necessary precautions to protect your identity.

Risks and Discomforts

During the interviews, some of the questions may touch on painful experiences that may be upsetting to you. Although there are no known risks involved in the PREP services, if you are in Group B, you may find the additional services burdensome because of the increased contact with nursing personnel.

Benefits

Participation in this study may provide some benefits for you. For example, some people report feeling good that they may be helping other families in the future by participating in this research. In addition, talking to someone about your situation may be helpful to you. If you are in Group B, you may receive additional benefits from the PREP services. The focus on preparedness, enrichment, and predictability may improve the caregiving situation for both you and your family member.

Liability

Please understand that should you incur physical injury, determined by physicians of Kaiser Permanente to result from your participation in this study, all medical care and hospitalization will be provided free of charge in Kaiser Permanente facilities.

Cost of Participation

No reimbursement or compensation will be given to you as a result of your participation in this study. There is no extra charge for PREP services.

Your Rights as a Participant

Participation in this research is completely voluntary. You may refuse to participate without affecting your care at Kaiser Permanente. You may refuse to answer individual questions, or may discontinue the interview at any time without affecting the care you receive at Kaiser Permanente Medical Care Program.

If you have questions about this research, your rights and responsibilities as a research subject, you should first contact Dr. Patricia Archbold at (503) 494-5934. If you have further questions you may contact Merwyn R. Greenlick, PhD, Vice President for Research, Kaiser Foundation Hospitals, at (503) 233-5631.

Person eligible for Date
home health services

Family Member of Friend Date

Appendix E

Telephone Script for Recruitment of Pilot Clinical Trial Participants

**Evaluation of a Caregiving Support Program (PREP)
Pilot Phase 3
Telephone Screening and Recruitment of Potential Subjects
Sample Script – Care Receiver Version**

Hello, may I speak to *(CARE RECEIVER)*?

(If the person answering the phone indicates that the care receiver is unable to come to the phone, ask to speak to the person who helps him/her out. Then use the “Caregiver Version” of this script.)

My name is _____. I am a nurse from the Kaiser Center for Health Research, and I’m calling from Kaiser’s Home Health Department. Is this a good time for you to talk?

(If it is not a convenient time to talk, ask when you might call back)

I’m calling to tell you about an exciting new research project that is going on at Kaiser called the PREP project. The study, which has been funded by the National Institutes of Health, is testing some new nursing services designed to help families caring for an older person. We think that these services may be helpful to older persons who receive help from a family member or friend. Would you like to hear more about the study?

The purpose of the PREP study is to compare two different ways of providing home health nursing services to older persons. PREP is a set of services, offered by home health nurses, that is designed to increase competence in caregiving activities, enrich caregiving activities, and make these activities more predictable. We want to compare PREP services to the usual home health services that are currently available.

I understand that your doctor has just ordered home health services for you. Do you currently receive help from a family member or friend? For example, do you need someone to:

- | Yes | No | |
|-----|-----|---|
| ___ | ___ | Give you your medications or shots or help set up your pills? |
| ___ | ___ | Assist you with walking? |
| ___ | ___ | Help with shopping and errands? |
| ___ | ___ | Assist with bathing, shampooing, or dressing? |
| ___ | ___ | Help with household chores like cleaning? |

Are there any other things that you need help with?

Who is it that helps you out? _____.

(If care receiver mentions that s/he receives help from a non-relative, ask if that person is paid to provide care. If caregiver is paid, or if care receiver does not have a family caregiver, tell him/her, "Well, our project is really aimed at providing services to persons who are receiving help from a family member. Thank you very much for your time")

(If care receiver is receiving help from a family member or friend, proceed.)

Since you do receive help from a family member or friend, we would like to invite both of you to participate in our study. If you decide you would like to participate the following will happen:

1. First, I will come out to your house during the next 24 hours to have you sign a consent form.
2. After signing the consent form, you will be randomly (by chance) assigned to either Group A or Group B.
3. If you are assigned to Group A, you will receive all of the usual home health services for which you are eligible. If you are not currently eligible for in-home nursing services, you will receive at least one visit by a home health nurse.
4. If you are assigned to Group B, you will receive PREP services. PREP lasts until December 31, 1991. It includes: (a) in-home visits by a home health nurse for 4-10 weeks; (b) a Caregiving Advice Line (available until December 31, 1991; and (c) a Keep-in-Touch system in which the PREP nurse checks in on you for several months after enrollment into this program. Because PREP is new, you will be asked to share your thoughts and opinions about PREP services. Researchers will interview you once to obtain your views about how to improve PREP services. These interviews will last approximately 30-45 minutes.

5. Participants in both groups will be interviewed on three separate occasions. These interviews will be conducted in your home during the second, seventh, and twelfth weeks of the study.
6. The interview for the caregiver will last approximately 1 – 1^{1/2} hours each. We will ask your family member about his/her health, the kinds of help s/he gives to you, his/her relationship with you, the cost of care, and how things have been going lately.
7. The interviews with you will take 30-45 minutes each. We will ask you questions about your health, the kind of things you need help with, and how you have been feeling lately.
8. We will also collect information on the cost of health care from your family member at monthly intervals following the third interview. This would involve at most 3 additional interviews.

Do you have any questions about the study? Does this sound like something you would like to participate in? Would you also like to check with (CAREGIVER) to see if s/he would like to participate?

(If the family declines to participate, try to ascertain their reasons for refusing. Thank them for their time, let them know that the home health nurse will still see them (just as their doctor ordered) and say good-bye.)

I'd like to go ahead and schedule a time when I can come out to get the consent form signed. I need to do so during the next 24 hours. What would be a convenient time for me to come out?

Date: _____

Time: _____

Let me just confirm that I have the correct address for you:

Address: _____

Also, could you give me some directions on how to get to your home?

I would also like to give you our phone number in case something comes up and you need to reschedule our appointment. It is 235-6692. You can leave a message for _____.

**Evaluation of a Caregiving Support Program (PREP)
Pilot Phase 3
Telephone Screening and Recruitment of Potential Subjects
Sample Script – Caregiver Version**

Hello, are you the person who takes care of (CR)?

My name is _____. I am a nurse from the Kaiser Center for Health Research, and I'm calling from Kaiser's Home Health Department. Is this a good time for you to talk?

(If it is not a convenient time to talk, ask when you might call back)

I'm calling to tell you about an exciting new research project that is going on at Kaiser called the PREP project. The study, which has been funded by the National Institutes of Health, is testing some new nursing services designed to help families caring for an older person. We think that these services may be helpful to persons like yourself who care for an older family member. Would you like to hear more about the study?

The purpose of the PREP study is to compare two different ways of providing home health nursing services to older persons. PREP is a set of services, offered by home health nurses, that is designed to increase competence in caregiving activities, enrich caregiving activities, and make these activities more predictable. We want to compare PREP services to the usual home health services that are currently available.

I understand that home health services have just been ordered for (CR). Do you currently provide care to (CR)? For example do you:

Yes	No	
___	___	Give (CR) medications or shots or help set up pills?
___	___	Assist (CR) with walking?
___	___	Help (CR) with shopping and errands?
___	___	Assist (CR) with bathing, shampooing, or dressing?
___	___	Help (CR) with household chores like cleaning?

Are there any other things that you do to help (CR)?

(If caregiver does not provide help with any of the above activities, tell them,

“Well, our project is really aimed at providing services to families who are providing care to an older person. Thank you very much for your time”)

(If caregiver is providing help to the older person, proceed.)

Since you do provide help to (CR), we would like to invite both of you to participate in our study. If you decide you would like to participate the following will happen:

1. First, I will come out to your house during the next 24 hours to have you sign a consent form.
2. After signing the consent form, you will be randomly (by chance) assigned to either Group A or Group B.
3. If you are assigned to Group A, (CR) will receive all of the usual home health services for which s/he is eligible. If (CR) is not currently eligible for in-home nursing services, (CR) will still receive at least one visit by a home health nurse.
4. If you are assigned to Group B, you will receive PREP services. PREP lasts until December 31, 1991. It includes: (a) in-home visits by a home health nurse for 4-10 weeks; (b) a Caregiving Advice Line (available until December 31, 1991; and (c) a Keep-in-Touch system in which the PREP nurse checks in on your family for several months after enrollment into this program. Because PREP is new, you will be asked to share your thoughts and opinions about PREP services. Researchers will interview you once to obtain your views about how to improve PREP services. These interviews will last approximately 30-45 minutes.
5. Participants in both groups will be interviewed on three separate occasions. These interviews will be conducted in your home during the second, seventh, and twelfth weeks of the study.
6. The interview for you will last approximately 1 – 1^{1/2} hours each. We will ask you about your health, the kinds of help you give to (CR), your relationship with him/her, the cost of care, and how things have been going lately.

7. The interviews with (CR) will take 30-45 minutes each. We will ask him/her questions about his/her health, the kind of things s/he needs help with, and how s/he has been feeling lately.
8. We will also collect information from you on the cost of health care at monthly intervals following the third interview. This would involve at most 3 additional interviews.

Do you have any questions about the study? Does this sound like something you would like to participate in? Would you also like to check with (CR) to see if s/he would like to participate?

(If the family declines to participate, try to ascertain their reasons for refusing. Thank them for their time, let them know that the home health nurse will still see them [just as their doctor ordered] and say good-bye.)

I'd like to go ahead and schedule a time when I can come out to get the consent form signed. I need to do so during the next 24 hours. What would be a convenient time for me to come out?

Date: _____

Time: _____

Let me just confirm that I have the correct address for you:

Address: _____

Also, could you give me some directions on how to get to your home?

I would also like to give you our phone number in case something comes up and you need to reschedule our appointment. It is 235-6692. You can leave a message for _____. Thanks again for your interest in this project. We really appreciate your willingness to participate!!

Appendix F
Randomization Procedure

Randomization Procedure

Families who consent to participate will be randomly assigned to Group A (control) or Group B (experimental) using a table of random numbers. Person X from the project staff will prepare 24 envelopes numbered 1 to 24. From a table of random numbers, the first 12 numbers that appear having a value between 1 and 24 will be assigned to Group A; the remaining 12 numbers will be assigned to Group B. A small card designating Group A or Group B will be placed in each of the envelopes accordingly. Two copies of the documentation regarding randomization will be placed in locked files retained by persons XX and will remain unavailable to the Evaluation Team until the completion of the intervention phase when data analysis will begin.

Consenting families will be numbered from 1 to 24 as they enter. Once written consent is obtained, the recruiter will open the envelope for that numbered family and inform them whether they will belong to Group A or Group B. Group B names will be given to the PREP nurses who will provide the PREP interventions to these families. Group A names will receive standard home health services from the Kaiser Home Health Agency.

Appendix G

Time Sheet for PREP Nurses

Appendix H

Home Health Chart Abstract Form

Home Health Chart Abstract Form

CRID _____ Month/Year _____

Day of Contact	Day Service Number	Service Number	Vendor	Type of Contact	Nursing Problems	Nursing Interventions	Time	PREP Comp
(1)	_____	_____	_____	_____	_____	_____	_____	_____
(2)	_____	_____	_____	_____	_____	_____	_____	_____
(3)	_____	_____	_____	_____	_____	_____	_____	_____
(4)	_____	_____	_____	_____	_____	_____	_____	_____
(5)	_____	_____	_____	_____	_____	_____	_____	_____
(6)	_____	_____	_____	_____	_____	_____	_____	_____
(7)	_____	_____	_____	_____	_____	_____	_____	_____
(8)	_____	_____	_____	_____	_____	_____	_____	_____
(9)	_____	_____	_____	_____	_____	_____	_____	_____
(10)	_____	_____	_____	_____	_____	_____	_____	_____
(11)	_____	_____	_____	_____	_____	_____	_____	_____
(12)	_____	_____	_____	_____	_____	_____	_____	_____
(13)	_____	_____	_____	_____	_____	_____	_____	_____
(14)	_____	_____	_____	_____	_____	_____	_____	_____
(15)	_____	_____	_____	_____	_____	_____	_____	_____
(16)	_____	_____	_____	_____	_____	_____	_____	_____
(17)	_____	_____	_____	_____	_____	_____	_____	_____
(18)	_____	_____	_____	_____	_____	_____	_____	_____
(19)	_____	_____	_____	_____	_____	_____	_____	_____
(20)	_____	_____	_____	_____	_____	_____	_____	_____
(21)	_____	_____	_____	_____	_____	_____	_____	_____
(22)	_____	_____	_____	_____	_____	_____	_____	_____

Appendix I

HMO computer Files and Variables

HMO Computer Files and Variables

ADT Variables

CHART
HOSP
DDATE
FROM
STYPE
ADATE
DISP
LOS
CCU
PCU
SURG_MIN
REC_MIN

OSCAR Variables

CHART
REF_TYPE
CR_TYPE
NPAY_AMT
MAIN_KEY
ACF_DATE
ACT_DATE
KEY2
PAY_REAS
PBILL_AMT
PDEN_AMT

VISIT91 Variables

PATIENT_NAME
VDATE
ACT_CODE
PCODE
RTIME
OTIME

KARE Variables

CHART
FAC
DEPT
ADATE
ATYPE
PROV

TOPS Variables

HRN
REF_NR
DISP_DATE
COST
FEE
COPAY
RX_NR
PROD_NR

DME Variables

HRN
VENDOR NO.
DOSFROM
DOSTHRU
CHECK DATE
ITEM NO.
ITEM DESCRIPTION

Appendix J

Caregiver Interview Utilization Questions

Question 24 – Service Use	Column 1 Have you used (Read name of service from list)? (If NO, Code Columns 2-5 = 7)		Column 2 How helpful was that service? Would you say not at all helpful, a little helpful, pretty helpful, very helpful?				Column 3 How hard was it for you to use this service? Would you say very hard, pretty hard, not too hard or easy?				Column 4 Was the service provided by Kaiser?		Column 5 Was the service pro- vided in the clinic or at home?	
	No	Yes	Not At All	A Little	Pretty	Very	Very Hard	Pretty Hard	Not Too Hard	Easy	No	Yes	Clinic	Home
A. Home health nurse	0	1	1	2	3	4	4	3	2	1	0	1		
B. Home health aide or personal care aide	0	1	1	2	3	4	4	3	2	1	0	1		
C. Physical therapist	0	1	1	2	3	4	4	3	2	1	0	1		
D. Occupational therapist	0	1	1	2	3	4	4	3	2	1	0	1		
E. Speech therapist	0	1	1	2	3	4	4	3	2	1	0	1		
F. Social worker	0	1	1	2	3	4	4	3	2	1	0	1		
G. Homemaker or house- keeping service	0	1	1	2	3	4	4	3	2	1	0	1		
H. Chore service	0	1	1	2	3	4	4	3	2	1	0	1		
I. Live-in paid helper	0	1	1	2	3	4	4	3	2	1	0	1		
J. Delivery service for groceries	0	1	1	2	3	4	4	3	2	1	0	1		
K. Home delivered meals	0	1	1	2	3	4	4	3	2	1	0	1		
L. Congregate meals at senior center or Loaves and Fishes	0	1	1	2	3	4	4	3	2	1	0	1		
M. Adult day care	0	1	1	2	3	4	4	3	2	1	0	1		
N. Respite care	0	1	1	2	3	4	4	3	2	1	0	1		
O. Ambulance	0	1	1	2	3	4	4	3	2	1	0	1		
P. Other transportation service	0	1	1	2	3	4	4	3	2	1	0	1		
Q. Outreach worker from senior center	0	1	1	2	3	4	4	3	2	1	0	1		
R. Friendly visitor service	0	1	1	2	3	4	4	3	2	1	0	1		

Question 24 - Service Use	Column 1 Have you used (Read name of service from list)? (If NO, Code Columns 2-5 = 7)		Column 2 How helpful was that service? Would you say not at all helpful, a little helpful, pretty helpful, very helpful?				Column 3 How hard was it for you to use this service? Would you say very hard, pretty hard, not too hard or easy?				Column 4 Was the service provided by Kaiser?		Column 5 Was the service pro- vided in the clinic or at home?	
	No	Yes	Not At All	A Little	Pretty	Vary	Very Hard	Pretty Hard	Not Too Hard	Easy	No	Yes	Clinic	Home
S. Volunteer	0	1	1	2	3	4	4	3	2	1	0	1		
T. Phone reassurance	0	1	1	2	3	4	4	3	2	1	0	1		
U. Advice Nurse	0	1	1	2	3	4	4	3	2	1	0	1		
V. Physician in the clinic/office	0	1	1	2	3	4	4	3	2	1	0	1		
W. Nurse practitioner in the clinic/office	0	1	1	2	3	4	4	3	2	1	0	1		
X. Chiropractor	0	1	1	2	3	4	4	3	2	1	0	1		
Y. Foot care specialist	0	1	1	2	3	4	4	3	2	1	0	1		
Z. Eye doctor	0	1	1	2	3	4	4	3	2	1	0	1		
AA. Other medical specialist	0	1	1	2	3	4	4	3	2	1	0	1		
BB. Dental services	0	1	1	2	3	4	4	3	2	1	0	1		
CC. Hospice	0	1	1	2	3	4	4	3	2	1	0	1		
DD. Mental health/ counseling services	0	1	1	2	3	4	4	3	2	1	0	1		
EE. Hospital	0	1	1	2	3	4	4	3	2	1	0	1		
FF. Emergency room	0	1	1	2	3	4	4	3	2	1	0	1		
GG. Urgency Care Center	0	1	1	2	3	4	4	3	2	1	0	1		
HH. Nursing home	0	1	1	2	3	4	4	3	2	1	0	1		
II. Prescription medications	0	1	<i>(Do not ask "How Helpful")</i>				<i>(Do not ask "How Hard")</i>				0	1		
JJ. Medical equipment	0	1	<i>(Do not ask "How Helpful")</i>				<i>(Do not ask "How Hard")</i>				0	1		
KK. Medical supplies	0	1	<i>(Do not ask "How Helpful")</i>				<i>(Do not ask "How Hard")</i>				0	1		
LL. Other <i>(please specify)</i>	0	1	<i>(Do not ask "How Helpful")</i>				<i>(Do not ask "How Hard")</i>				0	1		

Not
Applicable

Appendix K

Cost Tracking Form

COST TRACKING FORM

ID # _____

_____ (CAREGIVER)

NAME OF SERVICE

TRACKING METHOD

_____ (CARE RECEIVER)

NAME OF SERVICE

TRACKING METHOD

Appendix L
Utilization Worksheet

Service Utilization/Cost Worksheet

CRID _____ Month/Year _____

Service Number	Service Name	Day Service Number	Number of Contacts	Vendor	Payment Method	Documentation	Notes About Service Use	Cost For Month

Notes/Instructions for Next Data Collection:

Vendor
 1=KP
 2=Agency
 3=Health Professional
 4=Private Person
 5=Store/medical supply/pharmacy
 6=Other

Payment Method
 1=Medicaid
 2=KP Insurance
 3=Other Insurance
 4=Cash
 5=Check
 6=Credit Card
 7=Gift/Donation
 8=Other

Documentation
 1=Bill/Invoice
 2=Canceled Check
 3=Receipt
 4=Call to Vendor
 5=CG/CR recall
 6=Calendar
 7=KP Records
 8=Other

Cost Per Month
 0=< \$25
 Actual amount=amount over \$25

Appendix M
Feasibility Evaluation Form

FEASIBILITY ISSUES

Main issues are accurate data and not too much burden on CG

1. Do they understand what they are being asked to do?
2. Are CG and/or CR reluctant to give out certain information?
3. Overall, is it acceptable to them? What part(s) aren't?
4. Does it take too much time - too much burden? Because of stressed CG or just a lot of services, or both?
5. Can CG find all the bills, is record keeping systematic?
6. Does someone else pay the bills, a third person?
7. Are there some services with an unknown cost?
8. Does service use change a lot?
9. Are monthly visits too intrusive?
10. Does CG need to write use data down because there are no records - when the service is paid by cash?
11. Is the CG continuing over time to keep accurate data? Does she/he quit after awhile?
12. What is the hardest part about keeping cost data for CG?

Appendix N

PREP Effectiveness Scale

Intervention Group Version and Control Group Version

ID _____

PREP Project Final Caregiver Survey
EVALUATION OF THE PREP PROJECT

November 1992

School of Nursing
The Oregon Health Sciences University
Portland, OR 97201-3098
(503) 494-3840

Kaiser Permanente
Center for Health Research
3800 N. Kaiser Center Drive
Portland, OR 97227-1098

Investigators:
Patricia G. Archbold, RN, DNSc
Barbara J. Stewart, PhD
Merwyn R. Greenlick, PhD
Barbara M. Valanis, RN, DrPH

Funded by the National Center for Nursing Research, National Institutes of Health

EVALUATION OF THE PREP PROJECT

We would like you to let us know your opinions and ideas about how working with a nurse and/or physical therapist from the Kaiser Home Health Agency in the late summer and fall of 1991 affected you and your family. Please read the following questions and **CIRCLE** the response that best describes how you feel.

To what extent did working with a nurse or physical therapist from Kaiser...

	Not at all	A little	Some	Quite a bit	A great deal
1. help you feel more prepared to handle emergencies?	1	2	3	4	5
2. increase your ability to manage your time on a daily or weekly basis?	1	2	3	4	5
3. give your confidence a boost?	1	2	3	4	5
4. make you feel more comfortable in the things you were doing to help your family member?	1	2	3	4	5
5. help you feel more prepared to take care of your family member's physical needs?	1	2	3	4	5
6. help you keep going?	1	2	3	4	5
7. help you have more patience?	1	2	3	4	5
8. help you reflect on your relationship with your family member?	1	2	3	4	5
9. help you feel more prepared to take care of your family member's emotional needs?	1	2	3	4	5
10. help you understand your true feelings about your situation?	1	2	3	4	5
11. help you feel more relaxed?	1	2	3	4	5
12. help you feel more prepared to find out about and set up services for your family member? .	1	2	3	4	5
13. help you feel reassured that you were doing a good job?	1	2	3	4	5
14. help you feel better about your overall situation?	1	2	3	4	5
15. give you helpful ideas about caregiving?	1	2	3	4	5

To what extent did working with a nurse or physical therapist from Kaiser...

	Not at all	A little	Some	Quite a bit	A great deal
16. help you manage your family member's symptoms better?	1	2	3	4	5
17. make things easier for you?	1	2	3	4	5
18. help you make things safer for your family member?	1	2	3	4	5
19. help you make caregiving more pleasurable?	1	2	3	4	5
20. help you open up about things?	1	2	3	4	5
21. help you think things through?	1	2	3	4	5
22. help you improve your communication with your family member?	1	2	3	4	5
23. improve the quality of the care you were providing to your family member?	1	2	3	4	5
24. help you find solutions for difficult situations that you had with your family member?	1	2	3	4	5
25. help you feel more in control of your life? ...	1	2	3	4	5
26. make caregiving more satisfying to you?	1	2	3	4	5
27. reduce the stress you were feeling?	1	2	3	4	5
28. increase the positive aspects of caregiving for you?	1	2	3	4	5
29. help you feel more self-assured?	1	2	3	4	5
30. help you feel more prepared to handle the stress of caregiving?	1	2	3	4	5
31. increase your ability to manage specific caregiving problems?	1	2	3	4	5
32. decrease your anxiety about managing difficult situations?	1	2	3	4	5
33. help you understand more about what your family member needed?	1	2	3	4	5

ID _____

PREP Project Final Caregiver Survey
EVALUATION OF THE PREP PROJECT

November 1992

School of Nursing
The Oregon Health Sciences University
Portland, OR 97201-3098
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Kaiser Permanente
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Barbara M. Valanis, RN, DrPH

Funded by the National Center for Nursing Research, National Institutes of Health

EVALUATION OF THE PREP PROJECT

We would like you to let us know your opinions and ideas about how working with your PREP nurse affected you and your family. Please read the following questions and **CIRCLE** the response that best describes how you feel.

To what extent did working with your PREP nurse...

	Not at all	A little	Some	Quite a bit	A great deal
1. help you feel more prepared to handle emergencies?	1	2	3	4	5
2. increase your ability to manage your time on a daily or weekly basis?	1	2	3	4	5
3. give your confidence a boost?	1	2	3	4	5
4. make you feel more comfortable in the things you were doing to help your family member?	1	2	3	4	5
5. help you feel more prepared to take care of your family member's physical needs?	1	2	3	4	5
6. help you keep going?	1	2	3	4	5
7. help you have more patience?	1	2	3	4	5
8. help you reflect on your relationship with your family member?	1	2	3	4	5
9. help you feel more prepared to take care of your family member's emotional needs?	1	2	3	4	5
10. help you understand your true feelings about your situation?	1	2	3	4	5
11. help you feel more relaxed?	1	2	3	4	5
12. help you feel more prepared to find out about and set up services for your family member? ..	1	2	3	4	5
13. help you feel reassured that you were doing a good job?	1	2	3	4	5
14. help you feel better about your overall situation?	1	2	3	4	5
15. give you helpful ideas about caregiving?	1	2	3	4	5

To what extent did working with your PREP nurse...

	Not at all	A little	Some	Quite a bit	A great deal
16. help you manage your family member's symptoms better?	1	2	3	4	5
17. make things easier for you?	1	2	3	4	5
18. help you make things safer for your family member?	1	2	3	4	5
19. help you make caregiving more pleasurable?	1	2	3	4	5
20. help you open up about things?	1	2	3	4	5
21. help you think things through?	1	2	3	4	5
22. help you improve your communication with your family member?	1	2	3	4	5
23. improve the quality of the care you were providing to your family member?	1	2	3	4	5
24. help you find solutions for difficult situations that you had with your family member?	1	2	3	4	5
25. help you feel more in control of your life? ...	1	2	3	4	5
26. make caregiving more satisfying to you?	1	2	3	4	5
27. reduce the stress you were feeling?	1	2	3	4	5
28. increase the positive aspects of caregiving for you?	1	2	3	4	5
29. help you feel more self-assured?	1	2	3	4	5
30. help you feel more prepared to handle the stress of caregiving?	1	2	3	4	5
31. increase your ability to manage specific caregiving problems?	1	2	3	4	5
32. decrease your anxiety about managing difficult situations?	1	2	3	4	5
33. help you understand more about what your family member needed?	1	2	3	4	5

Appendix O

Caregiver Activities List

PREP Nurse Name: _____
 Caregiver Name: _____
 Date: _____

Caregiving Activities Record

DO YOU.....	If NO, go to next question.	How well prepared do you think you are to do that? 4 = VERY WELL PREPARED 3 = PRETTY WELL PREPARED 2 = SOMEWHAT WELL PREPARED 1 = NOT TOO WELL PREPARED
1. Have to feed your family member? 2. Assist your family member with bathing or washing? 3. Have to clean up when your family member has a bladder accident?	NO YES NO YES NO YES	1 2 3 4 1 2 3 4 1 2 3 4 Do Not Write In This Space
4. Take care of your family member's dentures, or brush his/her teeth? 5. Assist your family member with dressing and undressing? 6. Check your family member's skin and apply lotions?	NO YES NO YES NO YES	1 2 3 4 1 2 3 4 1 2 3 4
7. Help your family member use the toilet or bed pan? 8. Assist your family member with hair care and shampooing? 9. Help trim and take care of your family member's fingernails and/or toenails?	NO YES NO YES NO YES	1 2 3 4 1 2 3 4 1 2 3 4
10. Have to clean up when your family member has a bowel accident? 11. Have to make sure your family member gets the right amount of liquids, or can he/she do that on his/her own? 12. Have to make sure your family member eats the right amount or types of food, or can he/she do that on his/her own?	NO YES NO YES NO YES	1 2 3 4 1 2 3 4 1 2 3 4
13. Do shopping and errands for your family member? 14. Have to accompany your family member as he/she does shopping & errands?	NO YES NO YES	1 2 3 4 1 2 3 4

PREP Nurse Name: _____

Caregiver Name: _____

Date: _____

Caregiving Activities Record

DO YOU.....	If NO, go to next question.	How well prepared do you think you are to do that? 4 = VERY WELL PREPARED 3 = PRETTY WELL PREPARED 2 = SOMEWHAT WELL PREPARED 1 = NOT TOO WELL PREPARED
15. Prepare meals or help prepare meals for your family member? 16. Fix things and do odd jobs to maintain your family member's house? 17. Change your family member's bed linens?	NO YES NO YES NO YES	Do Not Write In This Space 1 2 3 4 1 2 3 4 1 2 3 4
18. Do light housekeeping for your family member? 19. Help your family member use the telephone? 20. Have to assist your family member with walking (For example, do you have to give him/her your arm or get him/her a walker)?	NO YES NO YES NO YES	1 2 3 4 1 2 3 4 1 2 3 4
21. Lift or transfer your family member from one place to another (For example, do you lift him/her out of a chair, or transfer him/her from a bed to a chair)? 22. Have to keep one eye on him/her to make sure he/she is safe? 23. Protect your family member from falls?	NO YES NO YES NO YES	1 2 3 4 1 2 3 4 1 2 3 4
24. Have to watch your family member in case he/she wanders off? 25. Have to get up at night to help your family member? 26. Have to check in on your family member to make sure he/she is o.k.?	NO YES NO YES NO YES	1 2 3 4 1 2 3 4 1 2 3 4
27. Sit and spend time with your family member? 28. Read to him/her?	NO YES NO YES	1 2 3 4 1 2 3 4

PREP Nurse Name: _____

Caregiver Name: _____

Date: _____

Caregiving Activities Record

DO YOU.....	If NO, go to next question.	How well prepared do you think you are to do that? 4 = VERY WELL PREPARED 3 = PRETTY WELL PREPARED 2 = SOMEWHAT WELL PREPARED 1 = NOT TOO WELL PREPARED
<p>29. Have to monitor the number of people who come to see your family member?</p> <p>30. Participate in leisure activities with your family member to help meet his/her needs for those activities (For example, watching T.V. together, playing games, listening to music)?</p> <p>31. Do things for your family member like hold hands or rub his/her back because you think he/she needs it?</p>	<p>NO YES</p> <p>NO YES</p> <p>NO YES</p>	<p style="text-align: center;">Do Not Write In This Space</p> <p>1 2 3 4</p> <p>1 2 3 4</p> <p>1 2 3 4</p>
<p>32. Have to handle your family member's crying spells, or does he/she not have that problem?</p> <p>33. Have to handle your family member's paranoia or suspiciousness, or does he/she not have that problem?</p> <p>34. Have to handle your family member's aggressive behavior problems (For example, his/her yelling, abusive language hitting), or does he/she not have those problems problem?</p>	<p>NO YES</p> <p>NO YES</p> <p>NO YES</p>	<p>1 2 3 4</p> <p>1 2 3 4</p> <p>1 2 3 4</p>
<p>35. Have to listen to and answer repetitive questions that your family member asks?</p> <p>36. Have to handle situation when your family member doesn't remember who or where he/she is?</p> <p>37. Have to help your family member because he/she has problems with his/her eyesight?</p> <p>38. Have to help your family member with emotional ups and downs?</p>	<p>NO YES</p> <p>NO YES</p> <p>NO YES</p> <p>NO YES</p>	<p>1 2 3 4</p> <p>1 2 3 4</p> <p>1 2 3 4</p> <p>1 2 3 4</p>

PREP Nurse Name: _____
 Caregiver Name: _____
 Date: _____

Caregiving Activities Record

DO YOU.....	If NO, go to next question.	How well prepared do you think you are to do that? 4 = VERY WELL PREPARED 3 = PRETTY WELL PREPARED 2 = SOMEWHAT WELL PREPARED 1 = NOT TOO WELL PREPARED
39. Help make major decisions about your family member's health care. For example, surgery or a change in treatment? 40. Help your family member get legal matters attended to? 41. Assist your family member with banking and financial matters?	NO YES NO YES NO YES	Do Not Write In This Space 1 2 3 4 1 2 3 4 1 2 3 4
42. Assist your family member in completing necessary forms such as taxes, medicare, social security or insurance? 43. Help your family member make major financial decisions? 44. Take your family member to medical appointments?	NO YES NO YES NO YES	1 2 3 4 1 2 3 4 1 2 3 4
45. Take your family member to other places, such as to friends' homes, to church, or to restaurants? 46. Assist with activities to meet your family member's spiritual needs (For example, arranging for a priest/minister/rabbi, arranging to watch religious programs on T.V., or reading religious materials)? 47. Participate in discussions with your family member about the future, the meaning and purpose of life, or how he/she has lived his/her life?	NO YES NO YES NO YES	1 2 3 4 1 2 3 4 1 2 3 4
48. Assist your family member with his/her medications or shots? 49. Have to handle your family member's pain?	NO YES NO YES	1 2 3 4 1 2 3 4

PREP Nurse Name: _____

Caregiver Name: _____

Date: _____

Caregiving Activities Record

DO YOU.....	If NO, go to next question.	How well prepared do you think you are to do that? 4 = VERY WELL PREPARED 3 = PRETTY WELL PREPARED 2 = SOMEWHAT WELL PREPARED 1 = NOT TOO WELL PREPARED
50. Handle or manage medical equipment or machines (For example, oxygen, feeding tube, or intravenous equipment ? 51. Keep other family members informed about your family member and/or his/her condition? 52. Keep the physician informed of your family member's condition?	NO YES NO YES NO YES	Do Not Write In This Space 1 2 3 4 1 2 3 4 1 2 3 4
53. Keep nurses and other health care workers informed of your family member's condition? 54. Have to check on or treat skin conditions in your family member? 55. Have to watch out for and treat infections in your family member?	NO YES NO YES NO YES	1 2 3 4 1 2 3 4 1 2 3 4
56. Have to help your family member with breathing problems? 57. Have to help your family member with bowel problems like constipation or diarrhea? 58. Have to manage your family member's problems with fatigue?	NO YES NO YES NO YES	1 2 3 4 1 2 3 4 1 2 3 4
59. Have to manage your family member's nausea? 60. Have to watch out for problems that your family member has with swelling? 61. Is there anything missing from this list? <i>(please specify)</i> _____ _____ _____	NO YES NO YES NO YES	1 2 3 4 1 2 3 4 1 2 3 4

Appendix P

General Assessment Protocol

General Assessment Protocol

(Complete with both CG and CR unless CR is unable to participate.)

A. Caregiver Demographic Information

1. What name do you preferred to be called? _____
2. How are you related to CR? _____
 - a. (If CG is spouse ask:) What is your anniversary date? _____
 - b. (If CG is not spouse ask:) What is your current marital status?

3. What is your date of birth? _____
4. Are you working outside the home at this time? Yes ___ No ___ (If Yes, ask:)
 - a. How many hours per week? _____
 - b. How flexible is your work schedule? _____
5. What health insurance do you have?
 - ___ Kaiser Permanente - Health Record Number _____
 - ___ Other _____

B. The Caregiving Situation

1. General Situation

I'd like to understand more about your caregiving situation. How have things been going the last few days?

2. History of Caregiving

a. How long have you been caring for CR?

b. How has your situation changed over time?

c. Have you cared for any other people including relatives or friends in the past?

CR Name _____

HR # _____

PID _____

4. Eco-Map

Start Time: _____

Stop Time: _____

I'd like to begin to look at a broader picture of your household and the people with whom you have contact. One way to do this with you is to draw an Eco-map. An Eco-map is used to look at a family and their connections with people and places outside the home. It shows us three things. It shows us what a family's connections are, such as friends, relatives, health care providers, church, etc. It shows whether the connections are considered strong, weak, or stressful. And, it shows for each connection whether energy tends to flow into or away from the family or both ways.

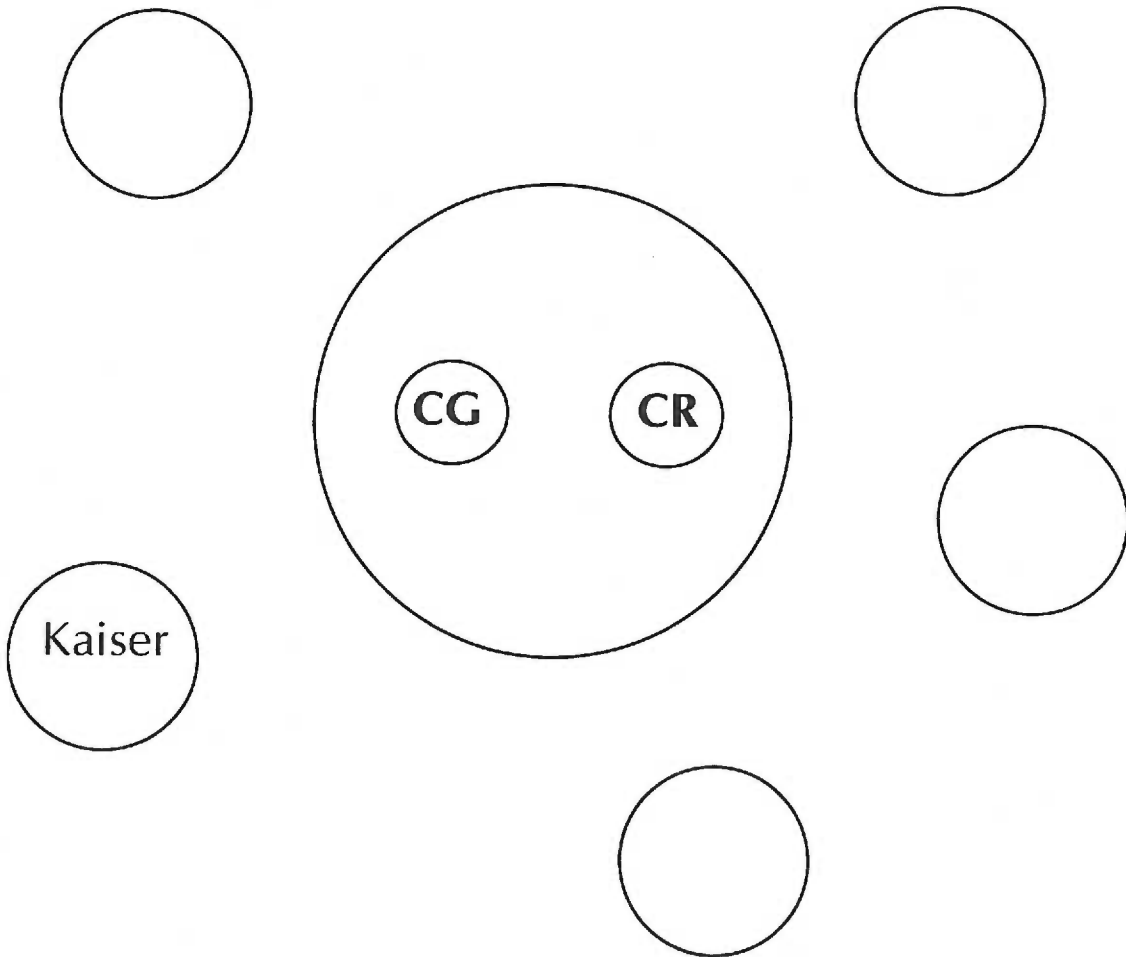
(Clarify if CR/CG live together or live in separate households. If CR and CG live in separate dwellings, draw line down the middle of large circle.)

- a. Who are the important people or organizations in the community that you and CR have a connection with? *(Friends, relatives, church, work, Kaiser)*
- b. Is the connection strong, weak, and /or stressful?
- c. Do you give more than you receive, do you receive more than you give, or is it about equal? *(Draw arrows to and from CG and CR in the direction the energy flows. If energy flow is equal draw arrow in both directions. If CG/CR receive more energy than they give, draw arrow toward center circle. If they give out more energy, draw arrow away from center circle.)*
- d. *(If connection with K-P is weak or stressful, ask:)* What experiences or difficulties have you had getting the help you need from the Kaiser system?

CR Name _____

HR # _____

PID _____



— = strong
- - - = weak
= stressful

CR Name _____

HR # _____

PID _____

b. How is your typical day different now than it was before CR was (*in the hospital, at the clinic, or started PT?*) Tell me about it.

c. Within a given day, what kinds of changes do you see in the CR?

d. When does the CR seem to have the most energy?

e. When does CR rest during the day? How can you tell when the h/she needs to rest?

f. How is CR eating? What kinds of foods does the h/she prefer?

g. Does CR have any problems sleeping at night? (*If yes,*) What are they?

h. What helps him/her go to sleep?

i. How has CR's mood been lately - sad or happy?

CR Name _____
HR # _____
PID _____

j. Have there been any recent changes in his/her mood?

k. What things seem to affect his/her mood?

l. Have you been able to establish a routine of caregiving activities? *(If yes, ask:)* How is that working for you? *(If no, ask:)* What obstacles stand in the way?

7. Enrichment

The next few questions focus on enrichment, or things that you find satisfying, meaningful, and enjoyable.

a. Are there things that you do for CR just because you think that s/he likes it?

b. Are there times of the day that you spend with CR that you look forward to?

c. Are there things that you do with CR that you plan and look forward to?

CR Name _____
HR # _____
PID _____

d. Are there things you used to do together that you enjoyed?

e. Are there things you do by yourself for enjoyment? (*Ask both CR and CG*)

f. In your everyday life, what personal beliefs are important to you?

g. (*Notice an object or previous issue that has come up in the interview or something in or outside the home that appears to have particular meaning - pets, hobbies, memorabilia, collections, plants/flowers/garden.*) Does it have special meaning to you? What is it that you like about your _____?

C. Mutuality

The next questions are about how well you and CR get along.

1. How well would you say the two of you get along?

CR Name _____

HR # _____

PID _____

2. How well did you get along in the past?

3. Has his/her illness changed how the two of you get along?

D. Caregiver Health/Health Behavior

(Talk to CG alone) These last questions are about your health.

1. Do you have any health problems? *(Include sensory impairments)*

a. Do any of these problems interfere with your ability to care for CR?

b. Are any of these problems made worse by caring for CR?

2. What medications are you taking?

CR Name _____

HR # _____

PID _____

3. Is there anything you do on a regular basis to take care of your health?

4. We know that caregiving can be stressful. How much stress do you feel in your life at this time?

5. *(Nurse observations of physical and/or emotional health.)*

(At the conclusion of the interview, review the "follow-up" list.) Now I would like to show you what I've written on the follow-up list to make sure that I really understand the issues that are most important to you. Is there anything else that is important that you would like to add to the list at this time, and we can add things later at other visits too. *(The follow-up list becomes the basis for mutual negotiation.)*

We have quite a few things on this list. Which are the most important for us to talk about first? *(CG and CR identify the high priority items.)* I'd like you to think about this because you really know your situation well, and I'm going to think about it too.

(Nurse writes on the page: Think about the following issues, and we will talk about them at our next visit; if you'd like to write anything down about any of them, you can do it on this page, but you do not have to.)

Appendix Q
The Caregiving Profile

	20	30	40	50	60	70	80
	Very Low		Low	Average	High	Very High	
Nature of Caregiving Role							
Personal Care							
Housekeeping							
Protection							
Transportation							
Financial/Legal							
Behavior Problems							
Medical Care							
Little Extras							
Total Direct Care							
Strain from Direct Care							
Personal Care							
Housekeeping							
Protection							
Transportation							
Financial/Legal							
Behavior Problems							
Medical Care							
Little Extras							
Total Direct Care							

NATURE OF THE CAREGIVING ROLE PROFILE

Caregiving Activities

The concept of the amount of direct care refers to the number of caregiving tasks performed by the Caregiver for the Care Receiver. The direct Care Scale contains 50 items. Caregivers receiving high scores on this scale report that they do a great many caregiving tasks for the care receiver. Caregivers receiving low scores on this scale report that they do few caregiving tasks for the Care Receiver.

This scale contains eight subscales which measure whether or not the caregiver performs specific tasks within eight categories of caregiving tasks. The eight categories of caregiving tasks are: Personal Care (11 items); Housekeeping (3 items); Protection (4 items); Transportation (4 items); Financial, Legal & Health Decision-making (6 items); Handling Behavior Problems (6 items); Management of Medically-related Problems (13 items); and Little Extras (3 items). Norms are based on an average of the Time One and Time Three data from the PREP study.

Strain from Direct Care

The concept of caregiver role strain related to direct care refers to the caregiver's felt difficulty in performing specific caregiving tasks. Specifically, it measures overall how hard the caregiving tasks are to do. This scale is composed of 50 items corresponding to the items on the Direct Care scale. Caregivers receiving high scores on this scale report that the caregiving tasks that they do are very hard. Caregivers receiving low scores on this scale report that the caregiving tasks that they do are very easy. Norms are based on an average of the Time One and Time Three data from the PREP study.

CAREGIVER ROLE STRAIN PROFILE

Global Strain

The concept of Global Role Strain refers to the caregiver's overall felt difficulty in fulfilling the caregiver role. This scale is composed of four items. Caregivers receiving high scores on this scale report that they experience a great deal of stress and strain related to the overall caregiving situation. Caregivers receiving low scores on this scale report that they experience little or no stress or strain related to the overall caregiving situation. Norms are based on an average of the Time One and Time Three data from the PREP study.

Strain from Worry

The concept of Caregiver Role Strain from Worry refers to the caregiver's felt difficulty in fulfilling the caregiver role because of worry about the Care Receiver, his/her future, aspects of caregiving per se, or the caregiver's future. This concept is future-oriented; that is, it relates to things that may happen in the future. This scale is composed of ten items. Caregivers receiving high scores on this scale report that they worry a lot about things related to caregiving. Caregivers receiving low scores on this scale report that they do not worry at all, or worry very little about things related to caregiving. Norms are based on an average of the Time One and Time Three data from the PREP study.

Lack of Resources

The concept of caregiver role strain from lack of resources refers to the caregiver's felt difficulty in fulfilling the caregiver role because of inadequate resources. The resources included in this scale are emotional, physical, help from other people, time, and enough sleep. This scale is composed of six items. Caregivers receiving high scores on this scale report that they have a big problem with lack of resources. Caregivers receiving low scores on this scale report that they do not have a problem with lack of resources, or that they have a small problem. Norms are based on an average of the Time One and Time Three data from the PREP study.

Tension in Relationship

The concept of Caregiver Role Strain from Tension in the Relationship refers to the caregiver's felt difficulty in fulfilling the caregiver role because of tension, stress, depression and anxiety in the Caregiver/Care Receiver relationship. This scale was borrowed from Montgomery & Borgatta (undated). It contains four items. Caregivers receiving high scores on this scale report that their relationship with the Care Receiver creates a great deal of stress, tension, nervousness, and anxiety for them. Caregivers receiving low scores on this scale report that their relationship with the Care Receiver creates little or no tension, stress, anxiety or nervousness for them. Norms are based on an average of the Time One and Time Three data from the PREP study.

Manipulation

The concept of Caregiver Role Strain from Manipulation refers to the caregiver's felt difficulty in fulfilling the caregiver role because of feeling manipulated or taken advantage of as a caregiver. This scale was borrowed from Montgomery & Borgatta (undated). It contains four items. Caregivers receiving high scores on this scale report that they feel manipulated a great deal because of their caregiving situation. Caregivers receiving low scores on this scale report that feel little or no manipulation because of their caregiving situation. Norms are based on an average of the Time One and Time Three data from the PREP study.

Negative Lifestyle Changes

The concept of Caregiver Role Strain from Negative Lifestyle Changes refers to the caregiver's felt difficulty in fulfilling the caregiver role because of negative changes in the caregiver's lifestyle. This scale was borrowed from Montgomery & Borgatta (undated). It contains four items. Caregivers receiving high scores on this scale report that their caregiving situation has created a great deal of negative lifestyle changes such as decreased privacy, or reduced vacation. Caregivers receiving low scores on this scale report that their caregiving situation has created little or no negative lifestyle changes. Norms are based on an average of the Time One and Time Three data from the PREP study.

Role Conflict

The concept of Caregiver Role Strain from Role Conflict refers to the caregiver's felt difficulty in fulfilling the caregiver role because of conflicting demands caused by role expectations. This scale is composed of 13 items. Caregivers receiving high scores on this scale report that caregiving interferes a lot with other roles, and that other roles interfere a lot with caregiving. Caregivers receiving low scores on this scale report that caregiving does not interfere with other roles and other roles do not interfere with caregiving. Norms are based on an average of the Time One and Time Three data from the PREP study.

Economic Burden

The concept of Caregiver Role Strain from Economic Burden refers to the caregiver's felt difficulty in fulfilling the caregiver role because its financial costs. This scale is composed of four items. Caregivers receiving high scores on this scale report that they experience high levels of economic strain from caregiving. Caregivers receiving low scores on this scale report little or no economic strain from caregiving. Norms are based on an average of the Time One and Time Three data from the PREP study.

CAREGIVER STRENGTH'S PROFILE

Mutuality

The concept of Mutuality refers to the quality of the caregiver/care receiver relationship, based on reciprocity, love, shared pleasurable activities, and shared values. This scale is composed of 15 items.

Caregivers receiving high scores on this scale report that their relationship with the care receiver is characterized by a lot or a great deal of reciprocity, love, pleasurable activities, and shared values. Caregivers receiving low scores on this scale report that their relationship with the care receiver is not characterized by these qualities. Norms are based on an average of the Time One and Time Three data from the PREP study.

Rewards of Meaning

The concept of Caregiver Rewards of Meaning refers to the positive meaning the caregiver finds in fulfilling the caregiver role. This scale is composed of four items. Caregivers receiving high scores on this scale report that caregiving is very rewarding and meaningful to them.

Caregivers receiving low scores on this scale report that caregiving is not at all or only a little rewarding or meaningful to them. Norms are based on an average of the Time One and Time Three data from the PREP study.

Cognitive Rewards

The concept of Caregiver Cognitive Rewards refers to beneficial learning that has occurred for the Caregiver because he/she fulfills the caregiver role. This scale is composed of three items. Caregivers receiving high scores on this scale report that caregiving has taught them a lot about their own aging, about older people, and has enabled them to show others the importance of caregiving. Caregivers receiving low scores on this scale report that caregiving has not helped them understand their own aging or about older people, and has not helped them show others the importance of caregiving. Norms are based on an average of the Time One and Time Three data from the PREP study.

Preparedness

The concept of Caregiver Preparedness refers to the caregiver's perception of how well-prepared he/she is for the tasks and stress of the caregiving role. This scale is composed of eight items. Caregivers receiving high scores on this scale report that they think they are very well-prepared for the caregiving role. Caregivers receiving low scores on this scale report that they think they are not too well-prepared for the caregiving role. Norms are based on an average of the Time One and Time Three data from the PREP study.

CAREGIVER HEALTH PROFILE

Health Problem in Systems

The concept of Health Problems in Systems refers to whether or not a caregiver has a problem in one or more of twelve body parts: back, eyes, feet or legs, hands, hearing, heart, lungs or breathing, memory, skin, stomach or bowel, headaches and urinary tract. The Health Problems in Systems scale is composed of 12 dichotomous items. Caregivers receiving high scores on this scale report that they have health problems in many systems. Caregivers receiving low scores on this scale report that they have few or no health problems in any system. Norms are based on the Time One data from the Caregiver Relief Study.

Medical Problems

The concept of Medical Problems refers to the number of medical problems the caregiver has in the following categories: arthritis, cancer, circulation, diabetes, dizziness, fainting spells, colds or flu, headaches, high blood pressure, pain, amputation, and/or stroke. The Medical Problems scale is composed of 11 dichotomous items. Caregivers receiving high scores on this scale report having many medical problems. Caregivers receiving low scores on this scale report that they have few medical problems. Norms are based on the Time One data from the Caregiver Relief Study.

Health Problems from Accidents

The concept of Health Problems from Accidents refers to whether or not a caregiver has experienced a fall or a fracture/injury. The Health Problems from Accidents scale is composed of two dichotomous items. Caregivers receiving high scores on this scale report that they have fallen or sustained a fracture or injury. Caregivers receiving low scores on this scale report that they have not fallen or sustained a fracture or injury. Norms are based on the Time One data from the Caregiver Relief Study.

Bothered by System Health Problems

The concept of Bothered by System Health Problems refers to how much a caregiver is bothered by problems with his/her back, eyes, feet or legs, hands, hearing, heart, lungs or breathing, memory, skin, stomach or bowel, headaches and urinary tract. The Bothered by System Health Problems scale is composed of 12 items. Caregivers receiving high scores on this scale report that they experience a lot of bother from the problems with their body parts. Caregivers receiving low scores on this scale report that they either do not have or are not bothered by problems with their body parts. Norms are based on the Time One data from the Caregiver Relief Study.

Bothered by Medical Problems

The concept of Bothered by Medical Problems refers to how much a caregiver is bothered by problems in the following categories: arthritis, cancer, circulation, diabetes, dizziness, fainting spells, colds or flu, headaches, high blood pressure, pain, amputation, and/or stroke. The Bothered by Medical Problems scale is composed of 11 items. Caregivers receiving high scores on this scale report that they experience a lot of bother from medical problems. Caregivers receiving low scores on this scale report that they either do not have or are not bothered by medical problems. Norms are based on the Time One data from the Caregiver Relief Study.

Bothered by Accident Problems

The concept of Bothered by Accidents refers to how much a caregiver is bothered by falls or fractures or injuries. The Bothered from Accidents scale is composed of two items. Caregivers receiving high scores on this scale report that they are bothered a lot by both falls and fractures or injuries. Caregivers receiving low scores on this scale report that they have not been bothered by falls or fractures/injuries. Norms are based on the Time One data from the Caregiver Relief Study.

Depression

The concept of Depression was measured by the Center for Epidemiologic Studies Depression Scale (CES-D). The CES-D is composed of 20 items designed to measure current levels of depressive symptomatology, with emphasis on the affective component. Caregivers receiving high scores on this scale report that they experience depressive symptomatology all or most of the time. Caregivers receiving low scores on this scale report that they experience depressive symptomatology rarely or none of the time. A clinical cut-off for probable or possible depression has been established at 36. It is suggested that caregiver's scoring at or above 36 should be assessed further for depression by a professional in mental health.

Appendix R

**Standardized List of Conceptually and Clinically
Derived Caregiving Issues**

PREP Problem List

I. Unpreparedness

A. Personal Care

1. Lift/transfer
2. Assist bathing
3. Clean urinary incontinence
4. Clean bowel incontinence
5. Brush teeth
6. Assist with dressing
7. Help at night
8. Check skin
9. Help toilet
10. Assist with hair care
11. Trim fingernails/toenails

B. Housekeeping

1. Prepare meals
2. Change linens
3. Do light housekeeping

C. Protection

1. Assist with walking
2. Keep one eye on
3. Protect from falls
4. Check in on

D. Transportation

1. Do shopping
2. Accompany shopping
3. Take to medical appointments
4. Take other places

E. Financial, Legal and Health Decisions

1. Decide major health decisions
2. Help with legal matters
3. Assist with banking
4. Fix things and do odd jobs
5. Assist with forms
6. Help decide finances

F. Handle Behavior Problems

1. Handle crying
2. Handle paranoia
3. Handle aggression
4. Listen to repetitive questions
5. Handle wandering
6. Remind who and where is
7. Handle yelling

G. Medically Related

1. Assist with medications
2. Handle pain
3. Check on/treat skin conditions
4. Infections
5. Get right amount of liquids
6. Eat right foods
7. Help with breathing problems
8. Constipation/diarrhea
9. Fatigue
10. Nausea
12. Problems with swelling
13. Emotional ups and downs
14. Medical equipment or machines (Includes catheter, O²)
15. Temp
16. Cough
17. Blood in urine
18. Catheter pulled out

H. Little Extras

1. Sit and spend time with
2. Participate in leisure activities
3. Hold hands, rub back

I. Access to KP System

II. Unpredictable caregiving routine

1. New or changing disease symptoms
2. Change in CR health status
3. New treatment regimen, regimen has unpredictable aspects
4. Change in CG health or ability to provide care
5. Change in available caregiving help, either formal or informal
6. Ineffective prescribed treatment

III. Low enrichment

1. Either individual or for the dyad

IV. Caregiver Health Problems

V. Worry, Strain and/or Other Affective Response to Caregiving

1. Strain from direct care
2. Worry
3. Manipulation
4. Role Conflict
5. Lack of resources
6. Stress in the CG/CR relationship

VI. Low mutuality

VII. Knowledge deficit

Appendix S

Keep-in-Touch Assessment Form

Keep-In-Touch Charting Form

Date: _____ Time: _____ HR #: _____

Name of Caregiver: _____

Aspects of Caregiving Situation to be Monitored: _____

ASSESSMENT re: TRANSITIONS

a. CR Health/Health Behaviors (*probe active protocols*) _____

b. CG Health & Health Behaviors: _____

c. CG Role Strain: _____

d. Changes in Household or Family: _____

ASSESSMENT re: PRINCIPLES

a. Preparation: _____

b. Predictability: _____

c. Enrichment: _____

Intervention: _____

Next K-I-T Contact Scheduled for: _____

Aspects of Situation to be Monitored Next Contact: _____

Time Contact Completed: _____ Length of Contact (*in minutes*): _____

Action Codes	Nature of K-I-T Contact	Protocol(s) Being Monitored		
1 = Referred to MD	1 = Phone	0 = None	10 = Decision	20 = Sleep
2 = Referred to KP System	2 = Home Visit	1 = Incon.	11 =	21 = Worry
3 = Resolved Over Phone	3 = Other	2 = Bowel	12 =	22 =
4 = Planned Home Visit		3 = Beh. Mgmt.	13 =	23 =
5 = Other _____		4 = Medications	14 =	24 =
		5 = Mobility	15 =	25 =
		6 = Comm. Probs.	16 =	26 =
		7 = Feeding	17 =	27 =
		8 = Skin Care	18 =	28 =
		9 = Grooming	19 =	29 =

(circle all that apply)

Appendix T

List of Caregiving Issues, Interventions, Home Visits by Dyad

Subject 303

Component 1

First home visit - July 18, 1991
4 home visits made in Component 1
Transferred to KIT on August 9, 1991

Component 2

8/9/91 - 12/31/91
2 KIT calls

Problem List

1. Unpreparedness - Personal Care
 - A. Clean urinary incontinence (10.03)
2. Low enrichment (40.00)

INTERVENTIONS BY PROBLEM

1. Unprepared - Personal Care - Clean (manage) urinary incontinence
 - A. Get from HH chart
 - B. Brief assessment (not adequate), problem of dribbling noted
 - C. Advised on incontinence products 8/8
 - D. Gave name of ET nurse 8/8

Unprepared - Financial/Legal and Health Decisions (14)

 - A. Noted as a major difficulty by the CG - no interventions

Unprepared - Medically Related - High BUN, lower extremity edema (16)

 - A. No interventions

Unprepared - Transportation (13.04) Take other places: difficulty in managing the wheelchair

 - A. Discussed 8/8
 - B. Recommended bike rack 8/8
2. Low enrichment
 - A. Discussed ways that the couple could find more enriching activities 8/8
 - B. Supported enrichment for the caregiver - daily walks with another caregiver
3. Worry, Strain, other affective response--worried about emergency situations (60.02).

No assessment, minimal discussion 8/8

4. Lack of resources (60.05). Mentioned, no interventions

KIT Call Interventions

1. 9/5/92
 - A. KIT assessment
 - B. Reassurance
2. 10/22/92
 - A. Kit assessment
 - B. Reassurance

Subject 305

Component 1

First home visit 7/30/91
6 home visits made in component 1
Transferred to component 2 on 9/20/91

Component 2 -- KIT

Date - 12/31/91
6 KIT calls made

1 Termination visit

Problem List

1. Unpreparedness - Housekeeping
 - A. laundry (11.04)
2. Unpreparedness - Protection
 - A. fear about falling at night when getting up to BR (12.03)
3. Unpreparedness - Medical management
 - A. abdominal fullness due to gas, esp. at night (16.21)
 - B. nocturia (16.22)
 - C. constipation (16.08)
 - D. health parameters - BP and weight (16.20)
 - E. eat right foods (16.06)
4. Unpreparedness in dealing with KP system (18.00)
5. Role strain (60.00)
 - a. tension in relationship regarding CR resuming previous household chores and duties and CG giving these up. The CG wants to give them up, and CR does not want them back as fast.
 - b. worry about prognosis, future
6. CG health - angina, BP (50.00)

INTERVENTIONS BY PROBLEM

1. Unprepared - Housekeeping - Laundry
No interventions
2. Unprepared - Protection - Protect from falls
 - A. Evaluated local knowledge 7/30
 - B. Reinforced CG's measures to date 7/30
 - C. Discussed AMBU-Alarm 7/30
 - D. Assessed current status, change since last visit 8/1
 - E. Assessed - no longer much of a problem 9/20
 - F. Supported CG's plan to let CR be 70% independent, and make decisions himself for the other 30% 9/20
- 3a. Unprepared - Medically Related - Abdominal gas, fullness
 - A. Taught:
 1. Factors that may contribute - fatty foods 7/30
 2. Factors related to slowed GI motility - decreased ambulation and S/P abdominal surgery 7/30
 - B. Involved niece in discussion 7/30
 - C. Assessed current status 8/1, 8/13
 - D. Assessed if using information taught at last visit 8/1
 - E. Provided commercial handout for ways to reduce gas 8/1
 - F. Supported doctor's advice to sleep with head elevated, and eating smaller, more frequent meals 8/13
 - G. Provided information to CG that CT's weight gain was appropriate and that larger meals weren't necessary 8/13
 - H. Discussed meal schedule with CR 8/22
 - I. Helped set realistic goals for weight gain 8/22
- 3b. Unprepared - Medically related - Nocturia
 - A. Assessment 8/22
 - B. Report to MD 8/22
- 3c. Unprepared - Medically Related - Constipation
 - A. Explained relationship between narcotics and constipation 8/22
 - B. Encouraged CR not to take old medications, but to discard them 8/22
 - C. Assessed - problem resolved 8/28
- 3d. Unprepared - Medically Related - Health parameters - BP, weight, medication
 - A. Took BP 8/1, 8/22, 8/28
 - B. Took weight 8/1
 - C. Encouraged CR to call MD about medication
 - D. Called doctor re: Dilantin dose 8/28
 - E. Supported CR related to Dilantin dose 9/20
 - F. Assessed Dilantin dose and schedule 9/20
 - G. Reviewed all medications 9/20

4. Unprepared - Access to KP system (primarily a CR problem, did not intervene with CG (done during KIT call on 10/11)
 - A. Assisted in identifying the appropriate telephone numbers
 - B. Role played interactions
 - C. Contingency planning if MD does not call back
 - D. Direct assistance in contacts
 - E. Follow-up to check on success of strategies

5. Role Strain - tension in relationship, worry
 - A. Discussed what CG found out at doctor appointment since last visit 8/1
 - B. Assessed 7/30, 8/1
 - C. Discussed most recent visit to doctor, test results, what the doctor told them 8/13
 - D. Let CR vent about this problem 8/22
 - E. Assessed niece's caregiving role 8/22
 - F. Facilitated discussion CR with CG 8/22
 - G. Explored possibility of increasing activity and resumption of previous activities - going outside, going out to dinner 8/22
 - H. Lead discussion about what CR can do for herself and what CG still should help with

6. Caregiver health
 - A. Took BP 8/1, 8/28
 - B. Assessed angina 8/28, 9/20
 - C. Assessed medication 9/20

KIT Calls and Interventions (Most KIT calls with CR, not CG)

1. 10/1/91
 - A. Assessed CR's depression
 - B. Gave positive feedback to CG for discussing with PREP nurse
 - C. Told CG about KP cancer counseling services and asked him to support CR if she wanted to use them
 - D. Assessed CAD symptoms

2. 10/11/91
 - A. Assessed CR's mood
 - B. Assessed CAD symptoms
 - C. Assessed nocturia
 - D. Advised to call MD about nocturia
 - E. Advised decrease caffeine, continue with cranberry juice
 - F. Assisted CR with content of call to MD about nocturia

3. 10/23/91
 - A. Discussed advice from advice nurse re: nocturia
 - B. Assessed CR's mood
 - C. Discussed recent yearly physical
 - D. Discussed possibility of changing physicians

4. 11/2/91
 - A. Assessed urinary symptoms
 - B. Instructed re: side effects of antidepressant, when to call doctor
 - C. Advice on how to circumvent problem getting prompt help at KP

5. 11/14/91
 - A. Assessed symptoms of renal infection, drug treatment, and episodes of nocturia
 - B. Reinforced need for adequate fluid intake, completing course of antibiotics

6. 12/2/91
 - A. Assessed previous side effects of antidepressant
 - B. Assessed mood
 - C. Explored what CR is doing on days when she is not so depressed
 - D. Individualized intervention to prevent a.m. dysphoria
 - E. Assessed number of episodes of nocturia, other urinary symptoms
 - F. Reviewed s/s of urinary problems to report to doctor
 - G. Discussed events of previous doctor visit
 - H. Verbal support for voicing opinion with doctor

12/17/91 Termination Visit

- A. Reviewed events of last doctor visit
- B. Gave positive feedback to CR for asking for what she wanted from doctor, for taking a list of questions in to him
- C. Discussed alternate treatments for stomach distress other than taking Valium as doctor suggested, which CR did not want to do
- D. Discussed treatments which were effective that CR is using and encouraged continuing

Subject 308

Component 1

First home visit - 8/6/91

20 plus 1 (by the HH nurse) visits in Component 1

Not transferred to KIT because CR was hospitalized, recurring lung infections, ER use

Problem List

1. Unprepared - Protection
 - A. protect from falls (12.03)
 - B. keep one eye on (so he wouldn't pull out catheter) (12.02)
2. Unprepared - Behavior Problems
 - A. listen to repetitive questions (15.04)
 - B. handle agitation/restlessness
3. Unprepared - Medically Related
 - A. medical equipment (catheter) (16.14)
 - B. constipation (16.08)
 - C. check on and treat skin conditions (16.03)
4. Unpredictability - Disease Process/Symptoms (recurring lung infections, hospitalizations, ER visits) (30.02)
5. High Strain (60.00)
 - A. Manipulation
6. Caregiver Health Problems (50.00)
7. Unprepared - Personal Care
 - A. Assist bathing (10.02)
8. Access to KP system

INTERVENTIONS BY PROBLEM

- 1a. Unprepared - Protection - Protect from falls
 - A. Involve informal support in assisting with ambulating CR 8/14
 - B. Assessed CR strength, activity 8/14, 10/2, 10/15, 10/29
 - C. Assessed safety of mobility 8/27
 - D. Rearranged furniture for safety 8/29
 - E. Assessed CGs knowledge of what to do in case of a fall 9/5
 - F. Assessed carpet, equipment 8/29
 - G. Discussed visual barriers to keep CR from getting out of bed or chair unassisted 8/29
 - H. Incorporated enrichment into ambulation task 8/22
- 1b. No interventions
- 2. Unprepared - Behavior Problem
 - A. Assessed CGs interaction with CR 8/14
 - B. Had CG keep record of out-of-hand behavior for one week 9/10
 - C. Assessment of behavior - when it occurs, etc. 9/10, 10/2
 - D. Assessed strategies CG has used in past 9/10
 - E. Assessed CGs ability to identify triggers to behavior 9/10
 - F. Specific strategies to decrease agitation/restlessness - wrote in health diary
 - 1. "Go along with" CR, assume role of security guard and check outside of house 9/17
 - 2. Don't argue with CR, but try to do what he wants if possible 9/17
 - 3. Use distraction 9/25
 - 4. Use comfort measures 9/25
 - 5. Assessing increased agitation with need to have BM 10/10
 - 6. Change tone of voice when responding to behavior problems - no date
 - 7. Increase physical activity - no date
 - G. Encouraged CG to share strategies with other family members 9/17
 - H. Assessed effectiveness of strategies 10/2, 10/15, 10/29
 - I. Demonstration of strategies 10/10
 - J. Discussed distraction options when a change in seasons precluded going outside 10/2
 - K. Suggested delaying repeated request (Wait for bath aide) 10/10
 - L. Suggested exploring other meanings of behavior (was he cold?) 10/10
 - M. Consulted with expert in behavior management in dementia 9/11
 - N. Used examples to help CG see that there may be emotions underlying behavior problems - no date

- 3a. Unprepared - Medically Related - Medical equipment (catheter)
 - A. Assessed ability to manage 9/10
 - B. Discussed contingency plans for catheter emergencies 8/22
- 3b. Unprepared - Medically Related - Constipation
 - A. Keep record of BMs on calendar 9/25
 - B. Evaluation of BM pattern 9/25
- 3c. Unprepared - Medically Related - Check on and treat skin conditions (16.03)
 - A. Assessed (HH nurse), Janet 8/22, 9/25, 12/17
 - B. Demonstrated propping CR with pillows to prevent rolling over 9/25
 - C. Taught:
 - 1. Turn CR to get off back (HH nurse) Janet 9/25
 - 2. Rub back with lotion 9/25
 - D. Incorporate enrichment - give backrub 9/25
- 4. Unpredictability - Disease Process/symptoms
 - A. Assessed for new symptoms 8/14
 - B. Discussed confusion as sign of illness 8/27
 - C. Assessed CGs ability to detect subtle changes in CR's condition 9/10
 - D. Physical assessment (lungs, cough, urine) 8/22, 9/10, 9/17, 12/3, 12/17
 - E. Keep record of urinary symptoms on calendar 9/25
 - F. Gave flu shots 10/24
 - G. Assessed CGs knowledge of urinary symptoms 11/13
 - H. Taught:
 - 1. Propping with pillows to change position 8/22
 - I. Discussed CPR status, family's commitment to continue caring for CR 8/22
 - J. Got report from CG about visit to MD - MD's opinion about CR status, no change in Rx 3/22
- 5. High Strain
 - A. Assessed 8/14, 8/22, 9/10, 9/17, 10/29, 11/13
 - B. Assessed informal support 8/22
- 6. Caregiver Health Problems
 - A. Assessed for health problems 8/14, 8/27, 9/25
 - B. Assessed health promotion 9/10
 - C. Encouraged CG to see her own MD 9/25
 - D. Involved CG's daughter in care planning 8/22
- 7a. Unprepared - Personal Care - Assist bathing
 - A. HHA begun 3/14
 - B. Tried to arrange HHA visits on predictable schedule 8/14, 8/27

8. Unprepared - Access to KP system

A. Reviewed MD clinic visit with CG, evaluated CG's understanding of what she was told 8/22, 9/25

Subject 309

Component 1

First home visit - 8/19/91
9 home visits in component 1
Transferred to KIT on 10/11/91

Component 2 -- Keep-in-Touch

10/11/91 - 12/31/91
5 KIT calls
1 KIT home visit with PT consultant
1 Termination home visit

Problem List

1. Unpreparedness - Personal Care - Trim fingernails/toenails (10.11)
2. Unpreparedness - Protection - mobility, help with walking (12.01)
3. Unpreparedness - Medical management
 - a. pain (16.02)
 - b. blood pressure (16.2)
 - c. check on/treat skin conditions (under breasts) (16.03)
 - d. medication management (16.01)
4. Role strain (60.00)
 - a. Lack of resources - CG needed respite
 - b. worry about recovery, trajectory of RA, ability of CG to continue caring for CR
5. Unpredictability (30.01)
 - a. daughter assisted for about 2 weeks and then went home--CG was worried about managing all care alone.
 - b. Formal support stopped - PT and HHA

INTERVENTIONS BY PROBLEM

1. Unprepared - Personal Care - Trim fingernails/toenails
 - A. Demonstrated foot care 9/6
 - B. Return demonstration of foot care 9/6
 - C. Asked how foot care is going, how it is worked into daily schedule 9/11

2. Unprepared - Protection - Mobility, help with walking
 - A. Helped CR plan a program of progressive increase in ambulation 10/11
 - B. Took CR out to garden for first time since surgery (Combined care activity - walking - with enriching activity - going into the garden) 10/11

- 3a. Unprepared - Medically Related - pain management (Interventions done with both CG and CR)
 - A. Asked CR to keep a pain management diary to document when the pain occurred, how severe it was, when she took pills, and the effectiveness of analgesic 9/6
 - B. Evaluated pain log 9/11
 - C. Suggested changing pain medication schedule 9/11
 - D. Evaluated effectiveness of pain relief with new medication schedule 9/18, 9/26, 10/3, 10/11
 - E. Discussed seeing a rheumatoid specialist so that CR could get better pain relief 9/26
 - F. Discussion of side effects of pain medication 10/11
 - G. Suggested that CR see a rheumatoid specialist and wrote in diary the reasons why 10/11

- 3b. Unprepared - Medically Related - blood pressure
 - A. Took BP 8/19, 8/22, 8/27, 9/6, 9/18, 9/26, 10/11
 - B. Taught about BP medication, need to take it every day, and not let it run out 9/18

- 3c. Unprepared - Medically Related - check on/treat skin conditions
 - A. Wrote 4 instructions about caring for skin rash in health diary 10/3
 - B. Assessed skin 10/11
 - C. Assessed skin care protocol which was written in health diary 10/11
 - D. Changed soap 10/7

- 3d. Unprepared - Medically Related - Medication management
 - A. Taught about relationship of analgesics to constipation 9/6
 - B. Developed steps to manage bowels while on analgesics, and wrote in diary 9/6
 - C. Assessed. Problem resolved. 9/11

4. Role Strain

- A. Assessed 8/22, 8/27, 9/11, 9/18, 10/3
- B. Supported CG's need to relax sometime during the day, get some respite 8/27
- C. Facilitated discussion about how CG could get some respite, how to fit it into daily routine 8/27, 9/6
- D. Taught:
 - 1. need for CG to get some respite 8/27
- E. Listen to CG's fears, worries about recovery, chance of falling 9/6 (Resolved 10/3)
- F. Initiated discussion of potential changes in caregiving routine if CG became sick 10/11
- G. Helped problem-solve about what they would do if CG became temporarily ill 10/11

5. Unpredictability with Caregiving Routine

- A. Assessed resources available to help 8/22, 9/6
- B. Assessed CGs and CRs assessment of the problem 8/22
- C. Assessed CG's adjustment to performing caregiving without help of daughter 9/6
- D. Assessed caregiving routine 9/26

KIT Interventions

10/17/91

KIT assessment

- 1. Assessed how skin was doing
- 2. Assessed how much pain medication CR was taking, how much pain she was having
- 3. Asked if appointment made with specialist
- 4. Assessed exercise program, asked if CR was following up on what she said she would do

10/23/91 KIT Call

KIT assessment

- 1. Assessed skin (clear)
- 2. Discussed prevention of further problems with skin rash
- 3. Assessed how CR was following exercise program
- 4. Discussed ways to alter exercise

10/31\91 KIT Call

KIT assessment

- 1. Asked if referral made with specialist
- 2. Assessed skin condition
- 3. Discussed exercise program, return of CR to spa for swimming

11/6/91 Home Visit

Problem 2

1. PT consult and home visit to prescribe daily exercise routine, adaptive equipment

Problem 3a

1. Assessed effectiveness of new pain medication
2. Changed medication schedule to cover 24-hour period, instead of only during the day
3. Gave information about when and how to refill medication

Problem 3b

1. Took BP
2. Gave information about use of whirlpool at spa related to warning at spa not to use whirlpool in hypertensive

Problem 3c

1. Assessed skin
2. Assessed skin care protocol

11/14/91 KIT Call

KIT assessment

1. Assessed if CR was following up on the recommendations of PT from previous week
2. Reviewed effectiveness of incorporating new exercises
3. Asked if CR made appointment with specialist
4. Assessed effect of new medication

11/26\91 KIT Call

KIT assessment

1. Assessed if CR continuing with exercise program
2. Gave reinforcement about continuing exercise program
3. Assessed use of pain medication
4. Assessed amount of pain

12/17/91 Termination Visit

1. Discussed Dr. appointment with rheumatoid specialist, new medications, stopping BP medication, lab work, how she liked the DR., etc.
2. Teaching about effect of new medications
3. Gave advice about scheduling one medication and about discontinuing a medication taken previously

Subject 310

Component 1

First home visit - August 20, 1991

21 home visits in Component 1

Discharged in Component 1 at end of project, 12/31/91

Stayed in Component 1 because CR continued to have severe behavior problems and nurse was in frequent contact with CG about behavior and medication changes.

Component 2

None

Problem List

1. Unprepared - Protection
 - A. Walking (12.01)
 - B. Keep one eye on (12.02)
 - C. Protect from falls (12.03)
2. Unprepared - Transportation
 - A. Shopping and errands (13.01)
 - B. Take to medical appointments (13.03)
3. Unprepared - Handle behavior problems
 - A. Aggressive (15.03)
 - B. Yelling (15.07)
 - C. Agitation (15.08)
4. Unprepared Medically Related
 - A. Get right amount of liquids (16.05)
 - B. General physical health
 - C. Constipation (16.08)
5. Role Strain (60)
 - A. Strain from direct care
 - B. Lack of resources
6. Unprepared - Access to KP system

Problems identified, but not addressed in any depth or not at all by PREP nurse:

1. Unprepared - Transportation
 - A. Do shopping and errands
2. Unprepared - Personal Care - Lift or transfer
3. Unprepared - Medically Related - Handle pain

INTERVENTIONS BY PROBLEM

1. Unprepared - Protection
 - A. Checked BP for hypotension 10/4
 - B. Assessed balance, ambulating ability 10/4, 10/14, 10/29, 11/7, 11/14
 - C. Observed CG while assisting CR to ambulate 10/14
 - D. Observed CR in shower given by HHA 10/29
 - E. W/C tray to prevent CR from getting out of W/C unassisted 10/29
 - F. Assisted CG to ambulate CR 11/7
2. Unprepared - Transportation
 - A. Tri-Met Lift card 11/14
3. Unprepared - Handle Behavior Problems
 - A. Generic protocol - indepth assessment 8/29, 9/5
 - B. Assessment of patterns of agitation 8/27, 9/13, 9/19, 9/24, 9/27, 10/4, 10/7, 10/14, 11/7, 12/4, 12/9
 - C. Assessment of medication to manage behavior 8/27, 9/13, 9/24, 10/4, 10/7, 10/14, 12/4
 - D. Assessment of what CG has tried, what works, what does not 9/19,
 - E. Taught CG
 1. Give more tactile stimulation (9/19)
 - F. Frequent phone calls for support, assess behavior and effect of medications
 - H. Tried different strategies:
 1. Treat pain with Ibuprofen 9/19
 2. Give warm blanket for comfort 9/24
 3. Put CR on floor when agitated to unrestrain him 9/24
 4. Give CR something to occupy hands 9/24
 5. Explore methods of relaxation, comfort and security
 6. Kushball 10/29
 - I. Assess effect of strategies 9/24, 10/4, 10/14
 - J. Had CG chart behavior on calendar 10/4, 10/7
 - K. Taught adverse reactions to Mellaril 8/27
- 4a. Unprepared - Medically Related - Get the right amount of liquids
 - A. Assessment of fluid intake 9/13, 9/19, 10/4, 10/7, 10/23
- 4b. Unprepared Medically Related - General physical health
 - A. Physical assessment - BP, lungs, abdomen, skin 10/4, 10/23, 11/7, 11/14
 - B. Got UA 10/23
 - C. Assessment of skin rash, 10/29, 11/7, 11/14
 - D. Assessment bloody stool 10/29, 11/14, 12/19
 - E. Assessment ankle edema 11/14

- 4c. Unprepared Medically Related - Constipation/diarrhea
 - A. Documented BMS on calendar for one month and evaluated pattern 11/7

- 5. Role strain
 - A. Frequent phone calls for support
 - B. Assessment of informal support 8/27, 10/7
 - C. Assessment of strain 8/27, 9/13, 9/24, 10/4, 10/29, 11/7, 11/14
 - D. Gave information:
 - 1. Adult Day Care 10/4
 - 2. Good Samaritan Respite Program 10/4
 - E. Encouraged use of MAP program 11/7, 12/9

- 6. Unprepared - Access to KP system
 - A. Assisted CG to make list of concerns to take to Dr. 11/14

Subject 312

Component 1

First home visit -
12 home visits in Component 1
Not transferred to KIT

Problem List

1. Unpreparedness - Transportation (13.03)
2. Unpreparedness - Medically Related
 - A. medical equipment, machines - catheter (16.14)
 - B. constipation (16.08)
 - C. check on/treat skin conditions (16.03)
 - D. emotional ups and downs (16.13)
 - E. pain
 - F. fatigue
3. Unpreparedness - access to KP system (18.00)
4. High Strain - lack of resources (sleep, informal support), worry, strain from direct care
5. Low Enrichment (40.00)
6. CG Health - prolapsed bladder, depression
7. Unprepared - Protection - Assist with walking (12.01)
8. Unprepared - Personal Care - Help at night

INTERVENTIONS BY PROBLEM

1. Unprepared - Transportation
 - A. Tri-Met Lift application filled out and sent in 9/10
- 2a. Unprepared - Medically Related - Medical equipment (catheter)
- 2b. Unprepared - Medically Related - Constipation
 - A. Keep track of BMs on calendar, to see pattern 9/10
 - B. Evaluated bowel pattern on calendar 9/17, 9/24
 - C. Planned laxative administration based on pattern 9/17
 - D. Assessed CG knowledge of diet, liquids, exercise 9/17
 - E. Encouraged less use of harsh laxative and more use of Metamucil 9/24
 - F. Evaluated CG management of this problem 10/24
- 2c. Unprepared - Medically Related - Check on/treat skin conditions
 - A. Gave foot bath, foot care 9/17
 - B. Assessed foot skin 9/17, 10/7 12/5
 - C. Created bed cradle to protect feet from bedding 10/7
 - D. Assessed methods used by CG to treat skin 10/7, 12/5
 - E. Taught:
 1. S/sx to report to MD 10/7
 - F. Assessed sources of pressure on feet, including shoes 10/15
 - G. Advised CG to continue with foot baths, foot cradle 10/15
 - H. Observed wound care 12/5
 - I. Provided rubber donut to use on commode 12/17
- 2d. Unprepared - Medically Related - Emotional ups and downs
 - A. Suggested adding humor to caregiving task of doing exercises 9/17
 - B. Suggested concentrating on benefits of having done exercises 9/17
 - C. Assessed emotional ups and downs 10/24
- 2e. Unprepared - Medically Related - Pain
 - A. Assessed current medications used for pain 10/24
- 2f. Unprepared - Medically Related - Fatigue
 - A. Assessment of status 10/24
3. Unprepared - access to KP system
 - A. Assessed CG's knowledge of who to call for what 9/10
 - B. Assessed nature of difficulty 9/10, 10/24
 - C. Discussed things to talk to MD about at next appointment 9/17
4. High Strain
 - A. Suggested relaxation exercises at bedtime 9/10

- B. Suggested imagery (for relaxation) 9/10
 - C. Asked CR to support CG efforts at relaxation 9/10
 - D. Discussed getting children, grandchildren to help with some tasks 9/17
 - E. Let CG talk about feelings of frustration with caregiving 9/17
 - F. Explored with CG feelings about getting more informal help 9/24
 - G. Assessed strain 9/10, 9/15
 - H. Assessed use of informal support 10/15, 10/24
 - I. Explored use of AAA benefits 10/24
 - J. Encouraged CG to build in time for socializing
5. Low Enrichment
- A. Use commercial time on TV to do exercises 9/17
 - B. Assessed enrichment
 - C. Reinforced use of humor 9/17
 - D. Encouraged gardening
 - E. Encouraged CG to get another family member to take CR to the library 9/24
 - F. Encouraged dyad to incorporate going out to lunch with going to doctor's office 10/7
 - G. Explored possibility of massage to give skin care and also as an enriching activity 10/7
6. CG Health
- A. Assessed constipation problem 9/17, 9/24
 - B. Recommended use of Metamucil 9/17
 - C. Discussed ways to provide care that minimized lifting 9/24
 - D. Encouraged CG to teach other family members some aspects of care in event she is unable to provide all care 9/24
 - E. Explored possibility of planning needed bladder surgery and not waiting until it was crisis 10/15
 - F. Assessed amount of lifting CG is doing 10/24
 - G. Discussed use of adaptive equipment 10/24
7. Unprepared - Protection - Assist with walking
- A. Assisted CG to get CR out of bed, dressed, and into living room when CR experienced increased weakness - assessed care needs by doing care 12/10
 - B. Taught:
 - 1. How to get CR out of a chair 12/10
 - C. Suggested modifications in environment that would help in mobilizing CR (ramp, carpets, reorganization of bedroom) 12/10
 - D. Assessed increased weakness 12/10
8. Unprepared - Personal Care - Help at night
- A. Assessment of night time routine 10/24

10/16/92 - Finished
Subject 314

Component 1

First home visit -
6 home visits in component 1
Transferred to KIT on 10/3

Component 2 - Keep-in-Touch

10/3/91 - 12/31/91
5 KIT Calls

Problem List

1. Unpreparedness - Handle Behavior Problems
 - A. Aggression (15.03)
2. Unpreparedness - Medical Management
 - A. Diabetic management (16.25)
3. Unpreparedness - Protection - Protect from Falls (12.03)
4. High strain (60)
Strain from communication problems
Tension in the relationship
5. Caregiver health (5)
6. Unprepared - Financial, Legal, Health Decisions - Help with
legal matters (14.02)

INTERVENTIONS BY PROBLEM

1. Unprepared - Handle Behavior Problems - Aggression
 - A. Assessment of context in which aggressive behavior occurs 9/10
 - B. Asked what strategies CG used to manage behavior 9/10
 - C. Consult with mental health nurse
 - D. Suggested checking blood sugar when aggressive behavior occurs 9/17
 - E. Assessment of problem 9/26 (Resolved)
2. Unprepared - Medically Related - Diabetic management
 - A. Assessment of blood sugar, s/sx hyper/hypoglycemia, diet 9/5, 9/10, 9/17, 9/27, 10/3
 - B. Assisted dyad to register for diabetic classes 9/5
 - C. Taught:
 1. Check BS same time in afternoon 9/17
 2. What to do if BS above 250 10/3
 3. Foot care 10/3
 - D. Changed caloric intake according to BS reading 9/17
3. Unprepared - Protection
 - A. Discussed PT visits, reinforced PT instructions 9/5
 - B. Discussed need for assist with ambulation 9/5
 - C. Assessed vertigo 9/5, 9/10
 - D. Assisted dyad to make a contract about safety - they mutually agreed on the activities that CR could do alone and those for which he needed assistance 9/26
 - E. Assessed effectiveness of contract 10/3
4. High Strain
 - A. Assessment of strain, including tension in relationship and communication 9/3, 9/10, 9/17, 9/26, 10/3
 - B. Taught:
 1. Effective communication with hearing impaired 9/5
 - Look at hearing-impaired person
 - Talk slowly, enunciate clearly
 - Lower voice pitch
 - Relax
 - C. Suggested enrichment strategy of incorporating reminiscence to practice communication 9/5
5. CG Health
 - A. Assessment of arthritic pain 9/10
 - B. Assessment of smoking behavior 9/10
 - C. Assisted CG to set up schedule for taking Prednisone 9/17
 - D. Had CG take first dose of Prednisone at home visit 9/17
 - E. Assessment of rash 9/17, 9/26, 10/3
 - F. Made recommendations about use of cortisone cream 9/26
 - G. Explained what to do if rash got worse 9/26
 - H. Obtained history of seeing a doctor 10/3
6. Help with Legal Matters

- A. Discussed the need for help in making major decisions

KIT Interventions

1. 10/10/91
 - A. KIT Assessment
 - B. Assessed diabetic management, BS
 - C. Discussed diet - sugar content in Gator Aid
2. 10/17/91
 - A. KIT Assessment
 - B. Assessed blood sugar
 - C. Suggested strategies to CG for CR impulsiveness
3. 11/1/91
 - A. KIT Assessment
 - B. Assessed diabetic management
 - C. Advised to call Dr. if dizziness recurs
4. 11/12/91
 - A. KIT Assessment
 - B. Assessed dizzy episodes
 - C. Devised action plan for dizziness episodes - Check BP and blood sugar
 - D. Encouraged CR to take driving test before resuming driving
5. 11/26/91
 - A. KIT Assessment
 - B. Assessed blood sugar
 - C. Reviewed s/sx hyperglycemia
 - D. Encouraged pt to write down reasons for high blood sugar when they occurred

Subject 317

Component 1

First home visit -

11 home visits

Did not transfer to KIT because of new health problems, symptoms, hospitalization

Discharged from Home Health on ??? because he was no longer home bound and catheter changes could be done in OP clinic

Problem List

1. Unprepared - Medically Related
 - A. breathing problems (16.07) (also involved swallowing) (HH problem)
 - B. medical equipment - catheter (16.14) (HH problem)
 - C. check on/treat skin conditions (16.03) (HH problem)
2. Unprepared - Protection - Assist with walking (12.01)
3. Unpredictability Caregiving Routine - change in formal caregiving help, DIL and son moved out of CG's home (30.01)

INTERVENTIONS BY PROBLEM

- 1a. Unprepared - Medically Related - Breathing Problems, swallowing
 - A. Arranged for same-day appointment to see MD re problem with lung sounds 10/14
 - B. Assessed oral intake in relation to aspiration 10/14
 - C. Assessed cough, lung sounds, sputum 9/27, 10/23
 - D. Taught:
 1. Aspiration precautions 10/4
 2. Choking assistance 10/4
 3. s/sx respiratory infection/pneumonia 10/4

- 1b. Unprepared - Medically Related - Medical equipment, catheter
 - A. Assessed CGs and CRs acceptance of, concerns about catheter 10/29
 - B. Assessed CGs assessment and management of new symptoms 11/7
 - C. Assessed urine 9/27, 10/4, 10/23, 12/10
 - D. Assessed access and quality of assistance from KP for urinary related problems 12/10
 - E. Taught:
 1. How to evaluate for dislodgement of catheter 10/4, 10/23
 2. s/sx urinary infection 9/27, 10/4
 3. How to evaluate clotting, blockage 9/27

- 1c. Unprepared - Medically Related - Check on/treat skin conditions
 - A. Assess skin, breakdown 9/27, 10/4
 - B. Recommended Desinex cream applied to site 9/27

2. Unprepared - Protection
 - A. Assessed exercise regimen 9/27, 10/23
 - B. Assessed mobility ability 9/27 10/4, 10/23, 10/29, 11/7
 - C. Assessed safety 10/4, 10/23

3. Unpredictability with caregiving routine
 - A. Discussed worst case scenario with CG and DIL related to son and DIL moving out of CG/CRs home and into their own 10/23
 - B. Planned trial with CG giving all care for a day before DIL move out 10/23
 - C. Reviewed typical day with CG 10/29
 - D. Evaluated trial 10/29
 - E. Reviewed progress in organizing caregiving tasks 11/7

Subject 322

Component 1

First home visit - 1/30/92

10 home visits in Component 1

Not transferred to KIT because problems not resolved, and CR in NH from 2/26 to 3/30

Problem List

1. Unpredictability Caregiving Routine - (30.01) CR home from ICF, new Foley catheter, change in CG health (knee pain), new formal help (HHA)
2. Unpreparedness - Behavior Problems
 - A. Handle yelling (15.07)
3. High strain (60.00)
 - A. Strain from direct care
 - B. Manipulation
 - C. Lack of resources (sleep, respite, informal help)
 - D. Stress in relationship
4. Unpreparedness - Medically Related
 - A. Medical equipment/machines (16.14)
5. Caregiver Health
6. Unprepared - Bathing

INTERVENTIONS BY PROBLEM

1. Unpredictable caregiving routine
 - A. Reviewed caregiving routine 1/30
 - B. Facilitated discussion of how CG could change caregiving routine 2/10
 - C. Advised less time between feedings 3/31
 - D. Advised CG to spread tasks out over the day and take more rest periods 3/2
 - E. Advised do mouth care with meals 3/31
 - F. Do only necessary bathing as indicated 3/31
 - G. Give pain medication before activities like bathing 3/31
 - H. Give up some tasks to others, i.e., HHA 3/2
2. Unprepared - Behavior Problem - Yelling
 - A. Discussed briefly 1/30
 - B. Indepth assessment using generic protocol 2/5
 - C. Specific strategies:
 1. Provide explanations to CR about leaving him alone in the evening and CG's need for rest 2/10
 2. Anticipate needs in the evening so that the CR does not have to call out 1/18
 3. Check the CR every 30 minutes 2/18
 4. Changed schedule of sleeping medication 2/18
 - D. Keep record on calendar of calling out 2/5
 - E. Discussed pain as possible cause of hollering, and giving pain medication prophylactically 3/19
3. High Strain
 - A. Assessed strain 1/30, 2/10, 2/18, 3/19, 3/31
 - B. Validated good caregiving practices 1/30
 - C. Observed communication between CG and CR using communication board 2/10
 - D. Role played enrichment strategies to incorporate into physical caregiving tasks 2/10
 - E. Provided care to CR while CG slept for several hours 2/18
 - F. Called Advice Nurse about medication for diarrhea 2/18
 - G. Assessed CR adjustment to nursing home 3/2
 - H. Participated in care conference at nursing home 3/5
 - I. Assisted with discharge plans from nursing home 3/2, 3/5
 - J. Referral to inhome respite 3/3
 - K. Discussed AFC, nursing home as respite alternative 3/5
 - L. Encouraged CG to talk about difficulties 3/19, 3/31
 - M. Encouraged CG to use planned respite 3/31
 - N. Facilitated transfer back to Home Health 3/31
4. Unprepared - Medically Related - Medical equipment/machines (catheter care)
 - A. Taught:
 1. Catheter irrigation, purpose of procedure 2/10
 2. What to do if catheter came out 2/10

3. Return demonstration of catheter irrigation 3/31
4. Monitor amount of sediment with irrigation 3/31
5. Caregiver Health
 - A. Assessed knee pain, medication for pain 2/10
6. Unprepared - Bathing
 - A. Completed home health aide assignment with caregiver 1/20
 - B. Home health aide supervision 2/10

Subject 323

Component 1

First home visit - January 21, 1992

13 home visits in Component 1

Discharged in Component 1 at end of project - 3/31/92

Component 2 - Keep-in-Touch

None

Problem List

1. Unpreparedness - Protection
 - A. Protect from falls (12.03)
2. Unpreparedness - Medically Related
 - A. Reportable signs and symptoms (16.19)
3. Unpreparedness - Handle Behavior Problems
 - A. Listen to repetitive questions (15.04)
 - B. Handle crying (15.01)
 - C. Handle paranoia (15.02)
 - D. Handle yelling (15.07)
4. Caregiver Health Problems - BP, (50.00)
5. Low enrichment for dyad - Curtailment of previously enjoyable activities, i.e., bowling, dancing (40.00)
6. Unpreparedness - Personal Care
 - A. Trim fingernails/toenails (10.11)
7. High strain - feeling exasperated, hyper (?), worry (60.00)
8. Unprepared to access KP system (Discussed only in summary at the termination visit. (18.00)

Problems identified, but not actively worked on by PREP nurse

1. Unprepared Personal Care - Clean bowel incontinence
2. Unprepared Personal Care - Help at night
3. Caregiver depression (This problem was probably worked on as CG strain

INTERVENTIONS BY PROBLEM

1A. Unpreparedness - Protection - Protect from falls

- A. Identified the problem at home visit 2/3
- B. Assessed CG knowledge about CR's risk of falls 2/3
- C. Taught
 - 1. Increased risk of falls with dementia, stroke, Parkinson's 2/3, 3/4
 - 2. CR needs to be accompanied any time he is outside, especially on uneven ground 3/4, 3/18
 - 3. Call Fire Dept to help CR up after fall if CG unable to get him up by herself 3/4
- D. Suggested involving visitors in accompanying CR on walks 2/3
- E. Reviewed "Home Safety Guide" with CG 2/14
- F. Expressed concern about a fall outside 3/4
- G. Assisted in problem solving in regard to walking outside
 - 1. Asked CG how she could help prevent falls outside 3/4
 - 2. Explored reasons why CG or CR should need to walk on the slippery slope area in the yard 3/4
 - 3. Move garbage from slippery slope to yard so that neither CG nor CR need to go to slippery slope 3/4
- H. Provided safety cover for door knob /11
- I. Involve nearby niece in accompanying CR on exercise walks 3/18
- J. Niece will take out trash every week 3/18

2A. Unpreparedness - Medically Related - reportable signs and symptoms

- A. Reviewed recent episodes warranting informing MD or nurse 2/3, 2/10
- B. Assessed CG knowledge about disease processes in MI, CVA, TIA 2/3
- C. Taught
 - 1. Signs and symptoms to report - wrote in Health Diary 2/3
 - 2. How to take pulse 2/3, 2/7
 - 3. Heimlich maneuver 3/18
 - 4. Purpose of Lanoxin and when to give and not give 3/18
 - 5. Contact Advice Nurse if CG has any questions 3/18
- D. Assess if any reportable s/sx had been noted during the week 2/14
- E. Assist CG to write s/sx down to report to MD at next clinic visit 3/18

- 3A,B,C,D Unpreparedness - Handle Behavior Problem - repetitive questions, yelling, crying, paranoia
- A. Assessed nature of problem 2/3
 - B. Taught
 - 1. Behaviors associated with dementia 2/3
 - 2. Behaviors as symptoms, not under control of CR 2/17
 - 3. How CR reacts to nonverbals 2/21
 - 4. Plant suggestion to CR of not discussing going to work 2/26
 - 5. "Helping Memory Impaired Elders: A Guide for Caregivers" 2/26
 - C. Reviewed with CG how she handled problem 2/3
 - D. Strategies to address specific behavior problems - written in health diary 2/7, 2/10
 - 1. Remember CR is not doing the behavior on purpose, he can't control it because of the disease
 - 2. Don't argue with CR or try to reason with him
 - 3. Say "We'll talk about it later - it's no use arguing about it, neither of us know enough about it anyway"
 - 4. Ignore the repeated questions. Reassure him when he is worried if the bills are being paid - change the subject
 - 5. Relax, take a few deep breaths, leave the room, saying, "I'm going to let you sit there and think about it awhile".
 - 6. Tell him step by step what to do when he can't remember
 - 7. When CR loses something, look for it and then give it to him without explaining
 - 8. When CR cries because he is afraid something is going to happen to him - reassure him by telling him, touching him, and holding him
 - 9. For bedtime management - 1) make sure CR gets exercise during the day, 2) go into bedroom and instruct CR on what to do or assist him with undressing, 3) sit on edge of the bed and talk to him, sometimes lie down on the bed next to him, 4) give Tylenol, 5) offer cup of warm milk or tea, 6) give diphenhydramine
 - 10. Use humor and joke with CR
 - 11. When CR wants to go to work, say "You can go to work tomorrow, today is your day off".
 - 12. If you find yourself arguing with CR, STOP and think of something he is saying you CAN AGREE WITH 2/26.
 - E. Evaluated effectiveness of strategies with CG 2/14, 3/19
 - F. Suggested Caregiver Support Groups 2/17
 - G. Gave examples of other patients with similar problems 2/21
 - H. Explore CG's affection, basis for empathy 2/26

- I. Discuss attribution of behavior - align with CG's interpretation 2/26 ???
 - J. Telephone support every 2-3 days for ongoing processing of behavior strategies for incidents that arise 2/26
 - K. Review with CG her changes in response to CR 3/4
 - L. Support CG's new insights 3/11
 - M. Strategize ways to manage CR's behaviors in environments outside the home 3/11
 - N. Role play strategies 3/11
4. Caregiver Health Problems - BP
- A. Monitor BP at every home visit 1/31, 2/3, 2/7, 2/10, 2/14, 2/17, 2/21, 3/2, 3/4, 3/11, 3/13, 3/19
 - B. Strongly recommended CG to see MD 1/27
 - C. Contact Dr.'s nurse re: B/P f/u appointments 2/10
 - D. Express concern re: CG's health 2/17
 - E. Taught:
 - 1. New Rx (diuretic) - purpose, side effects, incorporating into daily schedule 2/21
 - F. Assess CG's use of Rx 2/26
 - G. Review new symptoms 3/13
 - H. Advised calling Advice Nurse about new symptoms 3/13
 - I. Assess effectiveness of Quinine 3/18
 - J. Reviewed steps the CG made toward addressing her own health needs 3/18
5. Low Enrichment - Curtailment of previous activities
- A. Helped CG to resume previously enriching activities - bowling, contact with friends at Eagles 2/7
 - B. Develop strategies to manage behavior problems at enriching activities (dancing, going to church) 3/11
 - C. CG to discuss with nearby nieces the benefit of outings - i.e., eating out 2/21
 - D. Assessed resumption of previously enriching activities, i.e., was the CG able to resume some activities, what problems was she encountering 3/11, 3/18
 - E. Suggested going out for activity, but staying for shorter periods of time, so that CR would not get restless 3/11
 - F. Encouraged CG to go on outings with CR 3/11
 - G. Explained positive benefits of going for CR even though he is demented 3/11
 - H. Suggested niece go to bowling alley to watch CR rather than stay at home with him 2/7
6. Unpreparedness - Personal Care - trim toenails
- A. Identified CG's preference not to do care herself 2/10
 - B. Trimmed CR's toenails 2/10
 - C. Taught
 - 1. Need to check toenails with each bath 2/10
 - D. Referred to foot clinic nurse 2/10

7. High strain

- A. Explored community services that could assist CG 2/17
- B. Gave written materials re: caring for memory-impaired older person 2/26
- C. Explored with CG activities that nurtured her well-being 2/26
- D. Assisted CG to identify feelings - distress, worry, frustration 3/4
- E. Institute worry protocol
 - 1. CG to have a 10-15 minute worry period each morning at 10:30, to limit worry 3/4
- F. Initiated strategies for short- and long-term respite
 - 1. Nieces to provide 2-3 hours of respite 3 times per week 2/26
- G. Explored with CG what would make her situation better 2/21
- H. Explored pros and cons of moving back to midwest to live near children 2/21
- I. Encouraged CG to use extensive informal support system to provide some respite 2/26
- J. Gave written material on dealing with emotions 3/4
- K. Discussed what to do about the problem that the CG worried about most 3/4
- L. Encouraged CG to get some respite, to get out of house alone 3/11
- M. Explored respite options 3/11

8. Unprepared to access KP system (Information obtained only from notes on the termination visit, not in regular visit notes

- A. Encouraged CG to use the system
- B. Assisted CG to formulate information to give to KP staff, questions to ask.
- C. Supported CGs efforts to use the system

Subject 324

Component 1

First home visit - January 24, 1992

Discharged March 31, 1992 at end of project (CR died on March 22)

9 home visits

Problem List

1. Unpreparedness - Personal Care
 - A. toileting (10.09)
 - B. managing urinary incontinence (10.03)
2. Unpreparedness - Protection
 - A. prevention of falls (12.03)
3. Unpreparedness - Handling Behavior Problems & Medically Related
 - A. Restlessness, calling out (15.07)
 - B. Emotional ups and downs (16.13)
4. Unpreparedness - Medically Related
 - A. reportable signs and symptoms (16.19)
5. Caregiver strain - role conflict (60)
6. Unpredictable caregiving routine (evening, bedtime) (30.01)
7. Low Enrichment (40)
8. Caregiver Health (50)

Interventions

1A. Unpreparedness - Personal Care - toileting

- A. Observed/evaluated toileting in BR, (CG and CR) 1/31, 2/14, 2/28
- B. Taught CG
 - 1. take more time in toileting, 1/31
 - 2. explain what she (CG) is doing, 1/31
 - 3. lower voice, 1/31
 - 4. be gentle 1/31
- C. Recommended safety bar for bathroom 1/31
- D. Assessed toileting 2/7, 2/21
- D. Discuss, report, consult with OT 2/14
- E. Observed/evaluated CR transferring from bed to commode 2/14

Resolved 2/28

1B. Unpreparedness - Personal Care - managing urinary incontinence

- A. Had CG record urination pattern for 5 days 2/14
- C. Assisted CG to establish toileting routine, based on voiding pattern 2/7
- C. Assessed voiding frequency 2/7, 2/14, 2/21, 2/28, 3/6, 3/13
- D. Treated loose stool problem with Metamucil 2/21
- E. Teach CG -
 - 1. Patterned toileting concept 1/31
 - 2. foods which cause loose stools 2/14
 - 3. CR hand washing after toileting 2/14
 - 4. How to use Metamucil 2/28
 - 5. BRAT diet 2/21
 - 6. use of incontinence products 2/21
 - 7. how to obtain incontinence products 2/21
- F. Recommended change in incontinence product 2/21

2. Unprepared - Protection (Preventing falls)

- A. Taught CG
 - 1. Use of safety belt 1/31
 - 2. Use specific directions when ambulating with CR 1/31
 - 3. Effect of stroke on higher risk of falls 2/7
- B. Assessed use of safety belt 2/7
- C. "Blind" simulation 2/7
- D. Reduce physical barriers - fixing doorway, adjusting carpeting to be level, clear walkways of clutter and throwrugs 2/14
- E. Evaluated environmental changes 2/14
- F. Gave positive feedback re: hand rails in bathroom 3/6
- G. Explored options to prevent CR from falling out of bed 3/13

3. Unprepared - Handling Behavior Problems, Emotional Ups and Downs
 - A. Asked CG to keep track of problem behavior on grid and evaluated pattern of behavior 2/7, 2/21
 - B. Assessed CG's knowledge/observation of behavior and her interpretation of behavior 2/14
 - C. Asked CG what CG could do to help CR with problem 2/14
 - D. Suggested CG try to express CR's feelings for her 2/14
 - E. Suggested to CG that sensory deprivation from blindness contributed to withdrawal and to increase CR's sensory input 2/14, 3/13
 - F. Suggested increasing physical activity for CR 2/21, 3/13
 - G. Encouraged CG to report depressed mood to MD 2/21
 - H. Assessed effectiveness of antidepressant with CG 2/28
 - I. Reviewed side effects of antidepressant and their potential effects on caring for CR 2/28

4. Unprepared - Medically Related - Reportable signs and symptoms
 - A. Reassured CG about ability to note changes, new S/Sx 2/28, 3/6
 - B. Taught:
 1. S/Sx of CVA (brochure from Am Heart Assoc) 2/28
 - C. Assessed new symptoms 3/6, 3/13
 - D. Wrote down information CG to report to MD 3/6
 - E. Assisted CG with phone call to MD 3/6
 - F. Prescribed increasing fluid intake, vaporizer 3/13

5. Caregiver Strain - Primarily role conflict, also lack of resources
 - A. Simulated blind experience with CG 2/7
 - B. Referral to Commission for Blind 2/7
 - C. Explored additional respite 2/7, 2/14, 2/28
 - D. Observed CG/CR interaction at lunch time 2/7
 - E. Contacted COHO re: services 2/10
 - F. Discussed services of COHO and COPES, encouraged CG to use services 3/6
 - G. Explored having CG's friends come to visit her on regular in order to get some socialization 3/13
 - H. Explored with CG signs of too much strain and what she could do about it 3/13

6. Unpredictable caregiving routine (evening, bedtime)
 - A. Assess nature of problem 2/7
 - B. Asked CG to describe a recent positive bedtime routine and what was different that night 2/7
 - C. Suggested different routine 2/7
 - D. Incorporated enrichment into routine (rubbing lotion on legs) 2/7
 - E. Suggested that CG's spouse help at night 2/7

- F. Suggested CR use exercycle during the day 2/7
7. Low enrichment
- A. Suggested CG play piano as source of enjoyment for CR 2/14
 - B. Explored ways to increase sensory stimulation through all senses for CR and encouraged CG to do same 2/14
 - C. Took CR for walk outside 2/21
 - D. Discussed and supported additional CG strategies to increase enjoyment through sensory stimulation 2/28
 - E. Supported plans for CG and her spouse to eat out 3/6
8. Caregiver Health
- A. Assessed CG health 2/21, 3/13
 - B. Assessed how current health problem interfered with caregiving 2/21, 3/13
 - C. Explored with CG self-management of migraine headaches 2/28
 - D. Discussed relationship between caregiving demands, fatigue and illness 3/13

CONTROL GROUP

Subject 301

Length of stay in home health--16 days on first admission, 1 day on second admission. Second admission for PT only.
Number of nursing visits--3
Nursing problems
 Knowledge deficit, IDDM

Subject 302

PT Only
Length of stay in home health--24 days

Subject 306

Length of stay in home health--14 days
PT Only

Subject 307

Length of stay in home health--1
PT Only

Subject 311

Length of stay in home health--130
Number of Nursing Visits--9
Nursing Problems
 Self care deficit
 Potential for injury secondary to pernicious anemia

Subject 315

Length of stay in home health--57
Number of nursing visits--14
Nursing problems
 Alteration in nutrition
 Self care deficit
 Impaired home maintenance
 Pain

Subject 316

Length of stay in home health--35 days
Number of nursing visits--6
Nursing problems
 Potential for injury, need for methotrexate

Subject 318

Length of stay in home health--1 day
Number of nursing visits--1, for evaluation only

Subject 319

Length of stay in home health--1 day
Number of nursing visits--1, for evaluation only

Subject 320

Length of stay in home health--19 days

No RN charting

PT Only??

Subject 321

Length of stay in home health--20

Number of nursing visits--2

Nursing problems

 Impaired skin integrity