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ABSTRACT

This demonstration program was designed to impart specific nursing, psychosocial, and community knowledge skills to caregivers, particularly those who themselves were older adults and were caring for a family member at home. Begun in October 1986, this program featured basic home nursing instruction and an orientation to the demands and rewards of caregiving. The Caregiver Education and Training (CET) Project included two components. Two integrated home nursing courses demonstrated basic nursing skills to families who cared for an ill, frail, impaired, or older family member in the home. A companion course focused on the psychosocial aspects of caregiving and provided information about community resources. During its 18-month duration, CET offered 65 classes to the community at no charge. Some 342 individuals representing 221 families and 62 paraprofessionals/professionals participated. Their response was quite favorable. Pretests and posttests demonstrated the acquisition of significant caregiving knowledge and skills. A 60-minute videotape and two teaching guides for the two components of the program were developed. Appendixes include pretests, posttests, and questionnaires. (YLB)

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# THE CAREGIVER EDUCATION AND TRAINING PROJECT:

## A Comprehensive Training Program for Family Caregivers

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March 1988  
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# **THE CAREGIVER EDUCATION AND TRAINING**

## **PROJECT:**

### **A Comprehensive Training Program for Family Caregivers**

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**March 1988**

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# **PRELIMINARY MATERIALS**

**Abstract**

**Executive Summary**

**Policy/Program implications**

**Project Dissemination and Utilization**

## **ABSTRACT**

Grossmont District Hospital developed a comprehensive education and training program for caregivers in the San Diego, California area. Funded in part by a grant from the Administration on Aging, this demonstration project was designed to impart specific nursing, psychosocial and community knowledge skills to caregivers, particularly those who themselves were older adults, and were caring for a family member at home.

Featuring basic home nursing instruction and an orientation to the demands and rewards of caregiving, this unique program began in October 1986. The Caregiver Education and Training (CET) Project included the following two components:

- 1) Two integrated home nursing courses demonstrated basic nursing skills to families who cared for an ill, frail, impaired or older family member in the home. Topics included home safety, skin care, transfers and mobility, personal hygiene, nutrition, record keeping, urinary and bowel management, etc.; and
- 2) A companion course focused on the psychosocial aspects of caregiving and provided information about community resources. The "Becoming a Caregiver" course dealt with such issues as the rewards and pitfalls of caregiving, common emotional reactions to this role, community resources for home care, alternatives to home care, and the decision-making process.

During its eighteen month duration, the Caregiver Education and Training Project offered 65 classes to the community at no charge. Some 342 individuals (representing 221 families and 62 paraprofessionals/professionals) were able to take advantage of the program. Overwhelmingly, their response to the project was quite favorable. Pretests and posttests were utilized to demonstrate the acquisition of significant knowledge and skills which could aid the participant in performing their caregiving responsibilities.

Although this education and training program was oriented towards those who were caring for a family member in the home, the sessions were open to anyone who was currently helping, or anticipated helping, an older person to remain in the home. These home nursing and psychosocial courses were not intended to supplant existing services in the community such as case management, home health, respite or hospital discharge planning services. Instead, they were designed to add to and complement any education and training efforts which may be of assistance to any and all caregivers in the community.

A sixty-minute videotape and two teaching guides for the nursing and psychosocial components of the program were developed. They are now available for purchase and can be utilized in the development and initiation of similar caregiver education and training programs across the country.

**Caregiver Education and Training Project  
Grossmont District Hospital  
La Mesa, CA  
Grant # 90AM0252**

## EXECUTIVE SUMMARY

Caregiver Education and Training Project  
Grossmont District Hospital  
La Mesa, CA  
Grant # 90AM0252

### Introduction

More and more Americans who once might have spent months or years in hospitals or nursing homes are today being cared for at home. They are under the supervision of a relative or friend.

As America's population ages, the need for long term care--and caregivers--increases. According to the 1982 National Long Term Care Survey, over 1.2 million frail and disabled elderly were receiving this so-called informal care, mainly in the home setting. The average older person receiving such care was a 78-year-old, married female living with either her husband or her husband and one of their children.

And who was providing this needed care? As a group, these 2.2 million caregivers were largely female. Their average age was 57. Seventy-five percent lived with the older person, one-third continued to be employed outside the home, and one-fourth also had children under the age of 18 living at home.

That was 1982. And all indications are that this situation continues to be true today. A main reason that more Americans are caring for parents today is that they are living longer--long enough to suffer the debilitating stages of chronic illness and disease. In 1900, the average American lived to the age of 49. Now, we can expect to live to the ripe old age of 75. By the year 2000, over 17 million people in our country will be 75 years of age or older.

While most older people are healthy and fairly independent, about one-fourth of them need some help in coping with the routine activities of daily living such as feeding, dressing, bathing, toileting, meal preparation, household chores and shopping. About 10% are bedfast and homebound and just as functionally impaired as their peers in nursing homes.

But Medicare and other forms of private health insurance do not always pay the costs of out-of-home custodial care. And only the fairly affluent can afford the high fees charged by long term care facilities, often called nursing homes or convalescent hospitals. Thus, more people must themselves become caregivers for their loved ones--often without formal assistance.

It is family members--wives and husbands, daughters and sons, daughters-in-law and other relatives--who provide the great majority of assistance needed by older people to continue living in their own homes and communities. Thus caregiving is indeed a concern to literally millions of Americans.

Up until very recently, the San Diego community has not had any coordinated or comprehensive programs for informing, educating, training or supporting caregivers. Yet the San Diego area faces the nationwide problems of an aging society, spiraling health care costs and ever increasing needs for long term services.

Specific caregiver services in San Diego County are somewhat limited. There are three or four caregiver support groups, Grossmont Hospital's Caregiver Education and Training Project,

an East County volunteer-staffed respite program, a Respite Registry administered by the Area Agency on Aging, and a recently developed state-funded program, the Southern Regional Resource Center for the Brain Impaired, that provides services to family caregivers of the brain impaired.

With the present public policy trends for an expanded informal care network and the health care system demands for decreased hospitalization, Grossmont Hospital has recognized the need to work collaboratively with families and friends who will be caring for the ill, frail, impaired and elderly in the home setting. It was within this framework that Grossmont Hospital developed a comprehensive education and training program for caregivers.

### Project Methodology

The overall mission for the Caregiver Education and Training (CET) Project was to provide for the dissemination of information, education and training to those persons in the community who were engaged in informal caregiving activities with the frail, ill, impaired and elderly. Special emphasis was directed toward caregivers who were themselves older adults.

The Caregiver Education and Training Project included five different service delivery components during its eighteen month duration, October 1986 through February 1988.

#### 1) Home Nursing Courses

Two integrated home nursing courses taught the basic home nursing skills to family members who were functioning as caregivers. Both courses, a basic and an advanced class, were offered at no charge two times a month at the hospital site and two times during the project's duration at selected community sites in the rural, Back Country area of the hospital district. Topics included in these eight- and six-hour class sessions were the home care environment, safety, transfers and mobility, nutrition, personal care, record keeping, etc.

#### 2) Psychosocial Course

This companion course, entitled "Becoming a Caregiver", focused on the psychosocial aspects of caregiving and provided information about community resources available to both caregivers and the ill, frail or older person. These two- or three-hour classes were originally scheduled for two times a month at the hospital site and six times during the project's duration at selected East County sites. After the first few months of the project, the hospital site courses were offered just once a month, and additional sessions were held in the various communities.

#### 3) Research Component

Specific demographic and caregiving related data was collected on each individual who participated in the CET Project. In addition, a research instrument was designed and distributed to 56 individuals who had attended the Nursing Classes and had indicated that they were caring for someone at the time they enrolled in the program. This self-administered questionnaire was also designed

to gather relevant data on the caregiving experiences of project participants with a major focus on quantifying the utilization of caregiving skills and knowledge.

4) Support Group and Respite Feasibility

CET Project personnel explored the need for developing self-help, support groups for caregivers in the East County area. It soon became evident that the existing mutual aid resources were adequately meeting the community's need. It also became quite clear that additional free or low-fee respite resources were desperately needed.

5) Development of Audiovisual and Teaching Materials

Two videotapes and two companion teaching guides were developed. These products are now available for sale at a reasonable price and can be utilized in the development and implementation of similar educational programs for caregivers in other parts of the country.

### Project Results

Over the eighteen month duration of the Caregiver Education and Training Project, several distinct and concrete results were realized.

1) Nursing Classes

Forty-one (41) nursing skills class sessions were held during an eleven month period, December 1986 through November 1987. These class sessions were attended by 185 persons representing 103 families and 52 'paraprofessionals'/'professionals'. In an effort to quantify learning, participants were asked to complete both a pretest and a posttest. The average score on the pretest was 3.11 incorrect responses; this average dropped to .67 incorrect responses on the posttest. Participants were also asked to evaluate their learning experiences; overwhelmingly, their responses to the educational and training project were extremely positive.

2) Psychosocial Classes

Twenty-four (24) psychosocial classes were held during this same time period. The sessions were attended by 157 persons representing 118 families and 9 'paraprofessionals'/'professionals'. Ten of the 24 classes were offered away from the hospital site and out in the community. Similar attempts were made to evaluate the educational impact of the course. Participants averaged 3.28 incorrect responses on the pretest and 2.17 incorrect responses on the posttest. Attendees also responded positively to this class and rated the instructors, course material and class content quite high.

3) Research Component

A 54-item, self-administered survey instrument was developed. The

questionnaire was sent to 56 eligible subjects; after a two-month period and a reminder letter, the response rate was 41% (23 returned surveys). Due to the small size of both the eligible sample and the completed questionnaires, only frequency distributions were completed. The following results seemed to be most relevant:

- 96% of the caregivers were female.
- They ranged in age from 19 to 80, with an average age of 54.8.
- 35% were caring for their husband, 26% for their parents, and another 26% for their grandparents, aunts, uncles, etc.
- 39% lived with the person that they were caring for.
- They had been caring for their family member from less than three months to 10 years; 43% had been providing care for one year or less.
- 83% provided emotional support and encouragement; 78%, shopping and errands; 74%, meal preparation; 70%, transportation; 65%, personal care; 57%, paying bills, etc.; and 52%, household chores.
- Caregivers found that they learned certain skills in the class that had helped them in their role: a) use of specific equipment like quad cane, gait belt, etc.; b) learning techniques such as taking a pulse, diapering, bathing, transfers; and c) several felt that what they had learned made them feel much more confident in everything that they did.
- 63% stated that they were moderately to extremely stressed by their caregiving responsibilities.

### Discussion and Implications

The Caregiver Education and Training Project was able to demonstrate the following positive outcomes at the duration of the project:

- 1) an improved caregiving experience for caregivers--both physically and emotionally;
- 2) an increased knowledge regarding the process of caregiving; and
- 3) the development and marketing of videotapes and teaching guides for use in expanding caregiver education and training services throughout the country.

Review of participant course evaluation forms and the 23 completed questionnaires documented that the training classes had enhanced their caregiving experiences--increased self-confidence; provided reassurance of capabilities; realization they were not alone; and discovery of answers, understanding, compassion and experience. Course participants also shared that certain skills they learned from the training program had been helpful in their caregiving roles--for example, the use of specific equipment, the acquisition of specific nursing techniques, etc. The acquisition of caregiver knowledge and skills was further validated by review of the pre- and posttests in both nursing skills and psychosocial courses.

The major problem area that surfaced during the eighteen month project was the need for

continual and comprehensive publicity and community outreach about these caregiver classes. Reaching the people who needed the services was a continuing dilemma.

Caregiver education and training services such as the model utilized in the CET Project appear to be beneficial to both the caregiver and the care recipient. This type of program is easily duplicated. Personnel costs can be minimized; and applicable and transferable instructional materials can be purchased at an extremely reasonable price. All of the participants--the ill, frail, impaired and elderly; family, friends and employees in caregiving roles; senior service providers; and acute care hospitals--can benefit from the training, educating and supporting of caregivers.

### Project Summary

Health and human service practitioners, administrators, policy-makers and planners can utilize the results of this demonstration project. The graying of the American population, with its dramatic increase in sheer numbers of older persons, will undoubtedly result in an even greater need for both informal and formal health and human care services.

With these trends in mind, Grossmont Hospital recognized the need to work collaboratively with family, friends and 'paraprofessionals' who care for the ill, frail, impaired and elderly in the home setting. With the financial assistance of the Administration on Aging, the Caregiver Education and Training project was designed and implemented in the San Diego community. Over 340 individuals participated in 65 free classes which imparted specific nursing, psychosocial and community knowledge skills to caregivers who were providing assistance to a family member or friend. The CET Project was able to enhance the caregiving experiences of program participants and increase their knowledge about the caregiving process. In addition, an affordable instructional package was produced. It is now available for purchase and can be used in the development and implementation of similar caregiver training programs across the country.

Although this federally-funded demonstration project was completed on February 28, 1988, Grossmont Hospital plans to continue to offer this caregiver education and training program through the collaborative efforts of the Department of Senior Programs and the Hospital and Community Education Center.

## POLICY/PROGRAM IMPLICATIONS

Increasing attention is being paid to the needs of persons providing care to family members or friends. The demands placed on a caregiver can greatly impact their own emotional and financial situation. Many caregivers have to leave their jobs or reduce their working hours, rearrange their daily schedules and often take time off without pay due to caregiving responsibilities. The caregiver is often unprepared and untrained for their new role. While adjusting to the emotional aspects of providing care to someone who is ill, frail, impaired or elderly, the caregiver is also coping with learning new home nursing skills.

Caregiver education and training services such as the model utilized in the CET Project appear to be beneficial to both the caregiver and the care recipient. This type of program is easily duplicated. Personnel costs can be minimized; and applicable and transferrable instructional materials can be purchased at an extremely reasonable price. All of the participants-- the ill, frail, disabled and elderly; family, friends and employees in caregiving roles; senior service providers; and acute care hospitals-- can benefit from the training, educating and supporting of caregivers.

With a greater percentage of the population living to older age and developing chronic impairments and with the ever increasing costs of formal health care, legislators and policy makers are looking to the family to take greater responsibility for the care of the frail, ill, impaired and elderly. And, to assume a greater share of the financial liability. Thus, more and more families will be providing care to their older members and will be faced with varying degrees of strain on their personal, physical and financial resources.

No doubt, the sheer aging of the American population will result in an even greater need for informal care services. And there is a concomitant recognition that as a society we need to be more proficient in meeting the needs of caregivers, as well as assisting, educating, and supporting them in their efforts.

Caregiver education is a necessity in addressing the needs of both the older population and its caregivers. Support must be given to the caregiver and attention to their physical and mental health. Through education, caregivers not only acquire essential caregiving skills, but they are also given permission to care for themselves. Thus, caregiver education ensures quality care for both the older person and the caregiver.

**Caregiver Education and Training Project  
Grossmont District Hospital  
La Mesa, CA  
Grant # 90AM0252**

## PROJECT DISSEMINATION AND UTILIZATION

The dissemination and utilization activities related to the Caregiver Education and Training (CET) Project throughout its eighteen month duration were vast and are summarized in the following three sections.

### 1) Local Outreach Efforts

Throughout the CET Project, it became evident that continual publicity about the caregiver training program was essential to its success.

Efforts were made to reach caregivers themselves--through articles in community newsletters, items in various newsletters sponsored by community groups, public service announcements on radio and television stations, as well as program brochures and fliers which were displayed in prominent locations throughout the community. Certain community groups were more likely to include current or future caregivers--caregiver and disease-specific support groups, Older Women's League, church groups, senior organizations, etc.

It was also valuable to inform and educate local agencies and programs that served seniors about the caregiver education and training classes. Many of these senior providers were able to identify caregivers in need of assistance and to enable the caregiver to 'care' for themselves as well by attending the training sessions.

The following summarizes local dissemination activities during the project.

- Program announcement letter and postable flier sent to over 300 community agencies and senior groups.
- Specialized follow-up letters and postable fliers sent to 15 local senior complex managers, 43 senior clubs, and 75 mobile home park managers.
- Specialized follow-up letters also sent to all East County branch libraries (25), hospital chaplains (35) and home health agencies (15).
- Revised and expanded program brochure sent to all of the above.
- Articles in local newspapers: 3 feature articles; 9 meeting announcements.
- One feature article in a local magazine for seniors.
- Twenty-one articles in senior agency/senior group newsletters.
- Five articles in the hospital's 'in-house' publications.
- Meeting announcement included in two monthly community calendars
- Two participants--one a special guest; the second, a professional audience guest--in a local Public Broadcasting Service television show for seniors focusing on the needs of seniors who are caregivers.

### 2) Linkage With Other Service Providers

Linkages with other senior care providers, both locally and nationally, were viewed as an integral part of the dissemination activities. Formalized relationships were developed with the local Area Agency on Aging (its Information and Referral Component and its Respite Registry Service), the state-funded Southern Regional Resource Center for the Brain Impaired, the In-Home Supportive Services Section of the Department of Social Services, the county's contracted homemaker program, and the Alzheimer's Family Center, which operates three day care programs for victims of Alzheimer's and other related disorders.

Just as important, inquiries about the project were received from fifteen diverse areas and/or organizations: several from the Hawaiian Islands; Baltimore, Maryland; Sacramento, California; the state of Illinois; the University of Missouri at Kansas City; the Medical College of Ohio; the Sisters of St. Francis of Philadelphia; as well as a Veterans Administration Hospital and a local San Diego acute care facility. There has been communication with the above throughout the project. A massive promotional mailing to programs, agencies, etc. across the country is planned to inform them of the educational training package ( a sixty-minute videotape and two companion teaching guides) which is now available for purchase.

### 3) Professional Presentations, Papers and Dissemination of Project Results

Two CET Project staff presented project results in an Idea Exchange session at the recent national meeting of the American Society on Aging held in San Diego, California. In addition, 50 copies of the Final Project Report are available for distribution to interested parties.

**Caregiver Education and Training Project  
Grossmont District Hospital  
La Mesa, California  
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# **FINAL REPORT**

**Introduction**

**Project Methodology**

**Project Results**

**Discussion and Implications**

**Project Summary**

## INTRODUCTION

The graying of America, and how to provide services to that older, aging portion of society, is fast becoming one of the most important personal and public policy issues of the 1980's and beyond.

In 1984, 12% of the United States population, or some 28 million people, were over 65 years of age. In the last decade alone, the over-65 age group has increased by 23.5% as contrasted to a 6.3% increase in those under 65. What's more, experts estimate continued growth. By the year 2030, over 65 million people in the United States will be 65 years of age and older, with some 8.6 million being 85 years or older. By that date, the elderly in this country will represent one-fifth of our population--that is one out of every five persons. At the same time, we find that Americans are also living longer. Today, American life expectancy is 75 years; in 1900, one could expect to live only an average of 49 years.

Not surprisingly, as a greater percentage of the population is living to older ages, they are developing many of the chronic conditions that are associated with advanced age--coronary artery disease, hypertension, arthritis, hearing and visual impairments, diabetes, etc. And with chronic illness and disease one often finds both limitations in activities of daily living and varying degrees of disability.

Data from the 1979 Home Care Supplement to the National Health Survey showed that a significant minority of the 65+ population reported some kind of limitation of activity due to chronic conditions. Over half of the 'old-old' (85+) are limited to some extent. Not surprisingly, the need for assistance in personal care and home management increases in the upper age ranges. Only slightly over 5% of community residing adults aged 65-74 need the help of another person in one or more of the seven basic physical activities of daily living. Yet this percentage doubles for those 75-84 years, and increases to over 33% for those over 85 years of age. Another study, the 1985 National Long Term Care Survey, shows similar, yet slightly higher, needs for personal care and household management assistance.

Nonetheless, the majority of older people with physical, social or mental functioning limitations live at home and receive care from a relative or friend. Only five percent of the elderly live outside the home in a variety of institutional settings.

The sheer aging of the American population over the next forty years will increase--some experts say at least by double--the number of older persons with activity limitations. This dramatic increase in numbers will more than likely result in an even greater need for both informal and formal care services to this particular population group.

Despite the possible need for an expanded formal care system, much more emphasis will need to be directed toward the informal care system. Aging experts assert that some 80-90% of all medically-related care--case management, chore service, nursing, housework, and supportive/effective care--is provided by families. Brody estimates that well over five million people are involved in some form of family or parent care at any given time.

This phenomenon known as caregiving is not new. Research on the care of the older person over the past 30 years has shown that families care for and provide care for their older members. More importantly, the use of caregivers is seen as a major deterrent for early institutionalization and is unquestionably a much lesser cost to society.

Eighty-five percent or more of caregivers are women. It is women who provide the

primary caregiving to babies and young children, and as society ages, to the elderly and impaired. Today, primary caregivers in family settings are overwhelmingly spouses and daughters, followed by sisters, daughters-in-law, nieces and friends. Many of those adult children who are helpers are themselves in their 50's and 60's. It is not uncommon for a 90-year-old widowed mother to be cared for by a 65-year-old adult daughter.

Caregiving responsibilities can range from minimal assistance with one or more tasks such as transportation and financial management to around-the-clock assistance and supervision. Caregiving also differs in the degrees of physical, financial and emotional demands made by the impaired person.

Often caregivers are unprepared for their new roles. They have little or no skills or expertise to handle the various needs of a frail or impaired older person. Providing care to a family member may affect the caregivers physical and mental health, their social and recreational activities and their financial resources. The rigors of care can be physically exhausting and the need to provide constant care without relief has been associated with the development or exacerbation of health problems. Loss of personal freedom, lack of time for social and recreational activities and changes in family roles and functioning can all lead to lowered life satisfaction for the caregiver. The financial impact of providing care to an older person can also be devastating.

It follows that there is no one single pattern of response to caregiving. Families reach many different solutions to the task of providing care. A families response depends to some degree on their family organization--size, geographic proximity, differentiation of roles, past history of caregiving, emotional closeness, values, etc. Also important is the degree to which an elder's illness has disrupted the family system and how the family constellation is able to marshal resources and coping strategies to deal with their new responsibilities.

Policy makers in the field of aging continue to urge collaboration between agencies and families in the care of the elderly and impaired. More attention has been focused on care in the community--home health, adult day care, nutrition programs, etc.--due to the advent of Diagnostically Related Groups (DRG's) with its alterations in the reimbursement and service delivery systems in acute care hospitals.

A recent national study of Area Agencies on Aging conducted by the Southwest Long Term Care Gerontology Center has quantitatively documented the impact of DRG's upon the community-based long term care system. A major shift in service delivery patterns has been identified since DRG implementation. Community case management service units increased 365% with an accompanying increase of 196% in in-home skilled nursing. Housekeeping and personal care units also showed substantial increases of 69.2% and 63% respectively. These same community-based long term care agencies reported an increase in both length of service and number of units per client. For many of these agencies, the result was a forced reduction in the number of service units per client in order to provide services for a longer period of time.

Yet we can not avoid the inevitable. With a greater percentage of the population living to older age and developing chronic impairments and with the ever increasing costs of health care, legislators and policy makers are looking to the family to take greater responsibility for the care of the frail and impaired elderly and to assume a larger share of the financial liability. Thus, more and more families will be providing care to their older members and will be faced with varying degrees of strain on their personal, physical and financial resources.

There is a growing consensus that as a society we need to do a better job in meeting the needs of caregivers even though there is disagreement about the mix of services and supports that would be best. Efforts to aid caregivers have been boosted by the recent allocation of federal, state and private foundation monies for the development of a variety of caregiver and respite care programs across the country. Case management services, caregiver support groups, education and information projects and respite programs are increasingly viewed as positive approaches to aiding caregivers. Programs such as the Mentally Impaired Caregiver Project at the Philadelphia Geriatric Center, the Family Survival Project in San Francisco, and the Texas Project for Elders in Houston, Texas provide excellent models for expanding services of this type.

### The San Diego Community

Up until recently, the San Diego community has not had a coordinated or comprehensive program for informing, educating, training or supporting caregivers. Yet the San Diego area faces the same problems of an aging society, spiraling health care costs and ever increasing needs for long term care services.

Demographically, San Diego County encompasses 4255 square miles in the south-west corner of the United States with a 1985 population of close to 2,100,000 persons. This is a 12.7% increase from the 1980 population figures. The over 60 population itself has increased 22.5% over the past five years, and now numbers some 330,000. Not surprisingly, the 65+ and 75+ population figures have also expanded since 1980--23.1% and 38.4% respectively.

The eastern portion of San Diego County, known as the East County, had a 1987 population census of over 600,000 people; of this total, some 67,000, or 19%, were 65 years of age or older.

Grossmont District Hospital, located in San Diego's East County, has also been impacted by this large senior population. As a district hospital both financed and governed by taxpayers, it experienced some 6731 Medicare admissions in FY 1985-86. That year Medicare patients accounted for 33% of all hospitalized patients and 48% of all patient days. The average length of stay for Medicare patients was 8.1 days as compared to the overall hospital LOS of 5.4 days. From 1986-87, Medicare patients comprised 49.3% of the hospital's payor composition. The projected patient days figure for Medicare patients for fiscal year 1988-89 is some 53,987 patient days, or 45.7% of the projected total usage.

Specific caregiver services in San Diego are somewhat limited. There are three or four caregiver support groups, Grossmont Hospital's Caregiver Education and Training Project, an East County volunteer-staffed repite program, a Respite Registry run by the Area Agency on Aging, and a recently developed state funded program, the Southern Regional Resource Center for the Brain Impaired, that provides support services to family caregivers.

With the present public policy trend of an expanded informal care network and the health care system demands of increased community based services and decreased hospital utilization, Grossmont Hospital has recognized the need to work collaboratively with families and friends who will be caring for the ill, frail, disabled and elderly in the home setting. It was within this framework that Grossmont Hospital developed a comprehensive education and training program for caregivers.

## PROJECT METHODOLOGY

The overall mission for the Caregiver Education and Training (CET) Project was to provide for the dissemination of information, education and training to those persons in the community who were engaged in informal caregiving activities with the frail, ill, impaired and elderly. Special emphasis was directed toward caregivers who were themselves older adults.

The Caregiver Education and Training Project included five different service delivery components during its eighteen month duration, October 1986 through February 1988.

### 1) Home Nursing Courses

Two integrated home nursing courses taught the basic home nursing skills to families who were caring for an ill, frail, impaired or older family member in the home setting. Both courses were offered two times a month at the hospital site and two times during the project's duration at selected community sites in the rural, Back Country area of the hospital district.

The Basic Home Nursing Course included eight hours of instruction given in two four-hour sessions. Course content was organized into six modules or units, each of which covered a topic of essential consideration in home nursing care. Teaching modules included the following topics: planning the home care environment and safety features; mobility and transfers; personal care; nutrition; reporting signs and symptoms and record keeping; and community resources.

The Advanced Home Nursing Course was a six-hour session focusing on the care of the helpless patient and the increased caregiving responsibilities when a person has very limited ability to assist in their own care. Learning areas such as increased personal care needs, bed turning and positioning, dependent transfers, feeding, skin care, and bedpan, urinal and bedside commode management were highlighted.

To aid them in their caregiving roles, course participants had continued access to the Clinical Nursing Coordinator for both consultation and follow-up. The Clinical Nursing Coordinator made an effort to contact each caregiver by phone at least one time after the completion of the courses. Together they were able to assess the specific caregiving situation and make recommendations and/or community referrals as appropriate.

Both courses were primarily developed and implemented by Susan Schenk, R.N., P.H.N., a Nurse Educator in the Hospital and Community Education Department. She was assisted in this task by Doris Hareh, R.N., C., also of the Hospital and Community Education Department, and Ruth Brawdy, R.N., P.H.N., Discharge Coordinator in the hospital's Patient and Family Services Department.

### 2) Psychosocial Course

This companion course, entitled "Becoming a Caregiver", focused on the psychosocial aspects of caregiving and provided information about community resources available to both caregivers and the ill, frail or older person. These two- to three-hour sessions were originally scheduled for two times a month at the hospital setting and six times during the project's existence at selected East

County sites in the communities of Campo, Dulzura, El Cajon, Lemon Grove, Santee and Spring Valley. After the first few months of the project, the hospital site courses were offered just once a month, and additional sessions were held in various communities.

The psychosocial course dealt with such issues as the rewards and pitfalls of caregiving, common emotional reactions to this role, community resources for home care, alternatives to home care and the decision-making process. The film "Where Do I Go From Here?" was used to facilitate group discussion and involvement. Course participants also received selected agency brochures and a handout that summarized the content areas discussed in the class session.

The "Becoming A Caregiver" Course was designed and presented by Ruth Brawdy, R.N., P.H.N., a discharge coordinator, and Deborah Yiss, L.C.S.W., a social worker, both staff of the hospital's Patient and Family Services Department.

### 3) Research Component

Specific demographic and caregiving-related data was collected on each individual who attended either the nursing or the psychosocial classes. In addition, a research instrument was designed and distributed to 56 individuals who had attended the nursing courses and had indicated that they were currently involved in caregiving. The survey questionnaire was designed to gather relevant data on the caregiving experiences of program participant with a major focus on quantifying the utilization of caregiving skills and knowledge.

### 4) Support Group and Respite Feasibility Study

CET Project personnel explored the need for developing self-help support groups for caregivers in the East County area. It soon became evident that the current resources, a support group run through staff at the Community Mental Health Center and an Alzheimer's support group, were adequately meeting the community's need. However, despite the existence of an excellent volunteer-staffed respite program, more services of this type were desired and needed by local caregivers.

### 5) Development of Audiovisual and Teaching Materials

Two videotapes and two companion teaching guides were developed and produced. These products are now available for sale and can be used in the development and implementation of similar educational programs for caregivers in other parts of the country.

## PROJECT RESULTS

Over the eighteen month duration of the Caregiver Education and Training Project several distinct and concrete outcomes became evident. For the purposes of this Final Report, project results were organized and presented using the following five service delivery components--- Nursing Classes, Psychosocial Classes, Research Endeavour, Support Group/Respite Need Evaluation, and Development of Audiovisual and Teaching Guide Materials.

### 1) Nursing Classes

Thirty-nine (39) nursing skills classes were held at the hospital site from December 1986 through November 1987. These hospital classes were attended by 172 persons representing 95 families and 49 'paraprofessionals'/'professionals'. Two (2) class sessions were held at community sites during the same period-- in Campo and in Dulzura. These classes were attended by 13 persons representing 3 families and 3 'paraprofessionals'/'professionals'. In total, forty-one (41) class sessions were held, they were attended by 185 persons representing 103 families and 52 'paraprofessionals'/'professionals'.

In an effort to quantify learning, these course participants were asked to take both a pretest and a posttest that attempted to measure basic knowledge of home nursing skills and caregiver techniques (see Appendix A and B). Pretests and posttests were completed by 145 of the 185 course participants. On a ten- item instrument, these individuals averaged 3.11 incorrect responses on the pretest and only .67 incorrect responses on the posttest.

Course participants were also asked to evaluate their learning experiences; one hundred and forty-five individuals completed the evaluation forms. Utilizing a four-point scale (4=superior; 3=good; 2=average; 1=poor), respondents rated the following six areas. Respondents also suggested that the classroom facilities could be improved by remodeling and painting (which is now being done) and recommended other such educational programs on CPR, Alzheimer's Disease, death and dying, etc.

Class Objectives Met	3.66
Instructor's Mastery of Subject	3.80
Usefulness of Information	3.75
Appropriateness of Teaching Methods	3.73
Questions Answered	3.81
Room and Facilities	3.27

Further indication of the positive reaction to these caregiver courses are the following excerpts from the 'comments' section of the evaluation forms.

- "Learned a lot. Will recommend this class to friends and relatives."
- "Excellent program. I learned a great deal of information."
- "Very impressed and very thankful something like this is available for caregivers. I felt inferior and incompetent...(now) have more self-confidence in helping my parents."
- "Enjoyed class; was very helpful. Feel prepared to care for Mom."
- "Like finding friends with answers, understanding, compassion and experience."
- "I feel that the class is excellent for a person caring for a loved one. It has enlightened me greatly."
- "This class is a blessing to people who have someone to care for. I only wish I had this two years ago."

- "Super class. Enjoyed hearing of others' situations and how they were handling them."
- "I'm very, very pleased with the program. The experience has made me more confident in my profession; for which I am very grateful because now I am more comfortable handling clients with medical problems and severe handicaps."
- "Thank you. You've reassured me that I'm capable of this care."

Data on the caregiving participants was also gathered. Fifty-nine (59) individuals provided complete information as follows:

- 33 were "old" or "continuing" caregivers; 26 were "new".
- 20 were caring for their mother, 18 for their husband, and 14 were paid employees. Five were caring for their grandmother, 5 for a friend, 2 caring for their parents, and another 2 for their father. There was also one person caring for each of the following: father-in-law; wife; sister; great aunt-in-law; and grandfather.
- The length of time that they had been providing care also varied.
 

Less than 3 months	17
Less than 1 year	7
1 Year	10
2 Years	2
3 Years	3
5 Years	3
6 Years	1
- Some were receiving help with their caregiving responsibilities.
 

From friends	3
From family	25
From hired help	3

## 2) Psychosocial Classes

Fourteen (14) "Becoming a Caregiver" classes were held at the hospital site over the 18 month project. They were attended by 64 persons representing 49 families and 5 'professionals'/'paraprofessionals'. An additional ten (10) class sessions were held at community sites and were attended by 93 persons representing 69 families and 4 'professionals'/'paraprofessionals'. In all, 157 persons (representing 118 families and 9 'professionals'/'paraprofessionals') attended the 24 psychosocial classes.

Attempts were also made to evaluate and quantify the educational impact of the course. Pretests and posttests (see Appendix C) were completed by 92 participants. They averaged 3.28 incorrect responses out of ten items on the pretest and 2.17 incorrect on the posttest.

Course evaluations were also completed by 123 attendees using the same four-point scale (4=superior, 3=good, 2=average, 1=poor). Major suggestions were to increase the time allocated for the presentation to allow for more group discussion, sharing of ideas and solutions, and to focus more on problem-solving.

Class objectives met	3.54
Instructor's Mastery of Subject	3.7
Usefulness of Information	3.62

Appropriate Teaching methods	3.5
Questions answered satisfactorily	3.55
Room and facilities	3.25

The following statements were included on the 'comments' section of the course evaluation form.

- "This type of program is very helpful to us. We need all the help and information we can obtain."
- "Information given was complete and to the point. Phone numbers and names of agencies should be helpful in the future."
- "Excellent. Shows extensive preparation."
- "Do wish more caregivers could have taken advantage of this course. There are so many of them 'out there' in need of assistance."
- "An excellent opportunity to learn essential matters. With many thanks and compliments; well done."
- "Enjoyed the class. Learned a great deal. Very helpful and informative."
- "Thank you. I feel oriented now."
- "Much appreciated. A good service to the community."

Similar to the nursing skills classes, efforts were made to gather relevant data on their caregiving experiences. Of the 157 attendees, 70 indicated that they were currently functioning as caregivers.

- a) Who were they caring for?
  - mother 20 (28.6%)
  - husband 18 (25.7%)
  - in-laws 7 (10%)
  - friend 6 (8.6%)
  - father, children, employer 4 (5.7%)
- b) How long caring for that person?
  - Ranged from less than 3 months to 25 years to "years"
  - Less than 3 months 16 (23.5%)
  - Less than 1 year 12 (17.6%)
- c) Where does the person receiving care live?
  - In own home 65.7%
  - In caregiver's home 27.1%
  - in a facility of some sort 7.1%
- d) Who helps?
  - In only 40% of these respondents, did family or friends help with the caregiving.
  - Family members 85.7%
  - Friends 14.3%
- e) Other community agencies involved?
  - Homemaker services 20%
  - Home health agency 12.9%
  - Adult day care 11.4%
  - Meals-on-wheels 7.1%
  - Other 7.1%
  - Church 5.7%

- f) What are they not receiving?
  - Seven persons identified respite services as something they needed.
  - Others mentioned day care, barber, and more help in general.
- g) Caregiver's age, sex and educational attainment
  - 57 females, 13 males
  - age range was 19 to 79 years; average age, 57 years.
  - 66.1% had attended college; 30.5% had attended high school.
- h) Care Recipients age and sex
  - 35 females, 35 males
  - age range was 32 to 97 years; average age, 73.7 years

### 3) Research Component

A 54-item, self-administered survey instrument was developed in an attempt to meet the following objectives: a) gather data on the caregiving experiences of program participants; b) quantify the utilization of specific home nursing skills and techniques; c) assess the utilization of other health care resources in the form of phone contact with physicians, physician office visits, Emergency Room visits, hospital admissions, and other long term care services available in the community.

The questionnaire (refer to Appendix D and E) was sent to 56 individuals who had attended one or both of the nursing skills courses during an eleven month period of the project, December 1986 through October 1987, and had indicated that they were caring for a family member in the home at the time that they attended the classes. Twenty-three participants, or 41%, returned a completed survey in a self-addressed, stamped envelope by the end of the project, February 28, 1988.

Due to the small size of both the selected sample and the completed surveys, the only appropriate form of data analysis was a frequency distribution. In addition to the small numbers, some surveys were returned with minimal data. Because of these two factors, only the most pertinent and reasonable valid findings are reported in the following 12 areas.

1. Most of the 23 respondents attended both the basic and advanced Courses ( 17 or 74%).
2. Twenty-two of the respondents/caregivers (96%) were female.
3. The age of these caregivers ranged from 19 to 80, with an average age of 54.8 years.
4. Eight caregivers (35%) were caring for their husband, six (26%) for their parents, two for their daughters, one for their friend, while the remaining six respondents (26%) cared for grandparents, aunts, uncles, etc.
5. Thirty-nine percent of the caregivers lived with the person that they were caring for. Only two of the individuals receiving some type of family care were currently living in some form of residential or institutional housing.

6. The duration of the caregiving responsibilities ranged from less than three months to 10 years. Forty-three percent had been providing care for one year or less, while only 3 respondents (13%) had provided care for five years or more.
7. Caregivers were asked to be specific about the types of care they were providing to family members. The most frequently cited type of assistance provided was emotional support and encouragement; it was mentioned by 19 of 23 respondents, or 83%. A close second, at 78%, was shopping and errands. They were followed by meal preparation (74%), transportation (70%), dispensing medications (70%), personal care such as bathing, hair care, etc. (65%), responsibilities such as correspondence and bill paying (57%), and household chores such as vacuuming and dusting (52%).
8. Caregivers mentioned certain skills that they learned which had been helpful to them in their caregiving roles-- use of specific equipment like a transfer or gait belt, quad cane, etc.; learning how to perform specific tasks like taking a pulse, diapering, bathing, transfers, etc.; while several mentioned that they now felt much more confident in their caregiving.
9. Sixty-one percent of the respondents felt that the number of necessary physician visits either remained the same or decreased due to their course participation and new acquisition of new skills. Similarly, 52% felt that the number of needed phone contacts with the doctor had either decreased or remained the same since their participation in the training program.
10. The utilization of community resources by caregivers was a revealing item on the questionnaire. Not surprisingly, the most common resource utilized by caregivers (57%) was financial assistance such as Medicare, Medi-Cal, Social Security, etc., all seemingly related to reimbursement of health care costs and everyday living expenses. A close second was medical equipment and supplies, used by 48% of the respondents; followed by home-maker (35%), and home health agency services (30%).
11. An attempt was made to measure caregiver burden utilizing the Burden Scale formulated by Steven and Judy Zarit. The caregiver was asked to respond to a series of statements which reflected how people sometimes feel when they are taking care of another person. The responses to these 21 items were quite difficult to analyze due to the very small number of respondents and the fact that each item had anywhere from 3 to 9 missing responses. It was apparent, though, that three areas were significant for caregivers. Ten of 15 caregivers, or 67%, stated that they felt that the person they are caring for is quite frequently or always dependent upon them. Likewise, 73% of the caregivers indicated that they often have little time for themselves because of the person they care for and that they feel stressed between their caregiving and other family and work responsibilities. Despite the inability to do indepth analysis of caregiver burden, 63% indicated that they were moderately to extremely stressed by their caregiving responsibilities.

12. Caregivers were also asked if they feel differently about their caregiving responsibilities since attending the training classes. The following comments were written on some of the completed surveys.

-- "I feel a responsibility for the patient...but I also have a responsibility to myself. Meeting needs rather than all wants is enough...Giving 100% is enough. I do not have to give 300%"

-- "I knew others were going through what I was and that there was help. I was encouraged"

-- "I understand the caregiver's role better and realize I'm but one among many experiencing a similar responsibility...I feel more comfortable knowing about community resources I may need in the future."

-- "I have more confidence and apply positive thinking."

-- "More confident in handling auntie. I won't break her or cause her death."

-- "I would have been marking fives (on the burden scale=very stressed) if the questionnaire was given to me (before I took the class)...more confident with doctor and family."

-- "I feel more confident in my actions and in knowing how to deal with him."

#### 4) Support Group and Respite Feasibility Study

As was mentioned in the Project Methodology Section, it soon became evident to CET staff that the existing support groups in the community were adequately meeting the community's needs. However, more respite care resources of a free or reduced fee nature were desperately needed. This area continues to be explored and it is hoped that alternatives can be developed within the next six to twelve months.

#### 5) Development of Audiovisual and Teaching Materials

As part of the grant requirements, the Caregiver Education and Training Project developed a sixty-minute audiovisual tape and two companion teaching guides. The materials covered in the basic and advanced nursing skills courses are summarized in a 45-minute section of the tape and a 57-page teaching guide entitled "Teaching Basic Caregiver Skills". The "Becoming a Caregiver Course" is essentially synthesized in a 15-minute section of the tape and a 63-page teaching guide entitled "Labors of Love: Realities and Solutions. A Comprehensive Guide to Family Caregiving". The one-hour tape and both teaching guides are available for purchase for \$89.95. Marketing materials have been developed and will aid in the franchising of these materials.

#### 6) Evaluation Activities

Due to the demonstration nature of the Caregiver Education and Training Project, staff were quite sensitive to any and all forms of program evaluation. Class participants were strongly urged to fill out class evaluations and their comments were taken seriously.

Two cases in point. A large percentage of the project participants who attended the psychosocial class felt that the initial two-hour time frame was too short. They requested additional time in which to have group discussion about common caregiver concerns and to

provide a forum for sharing and problem-solving. As a result, the psychosocial courses are now two-and-a-half to three-hours in duration, and attempt to meet this very important need. Secondly, nursing skills participants had felt that the room and facilities available to them during their class sessions was inadequate. Although the staff certainly agreed with them, it was the input on paper of these class participants that encouraged administration to remodel and upgrade the classroom facilities.

Other issues pertinent to the actual classroom instruction became evident. Caregivers in the nursing skills classes benefitted most when they could enact the role of both patient and caregiver. It was quite helpful for the caregiver to 'step into the care recipient's shoes', so to speak, as it provided them with an additional perspective in which to view their caregiving tasks. Caregiver participants also found it helpful to have an extensive outline of the material covered in the psychosocial class so that they could focus on the information presented rather than frantically writing copious notes and missing important concepts and issues. The need for continual publicity and community outreach became quite apparent and is discussed in greater depth in the succeeding section, "Discussion and Implications of Project Results".

It was important to validate the educational/instructional approach to basic caregiver skills and expertise. Thus, a method of testing class participants before and after their educational involvement was seen as a way to measure effectiveness. The experiences of both the nursing skills and the psychosocial classes demonstrate effective learning--3.11 to .67 incorrect responses respectively on the pre- and posttests in the nursing skills classes and 3.28 to 2.17 incorrect responses respectively on the psychosocial pre- and posttests.

Although federal funding for the CET Project ended on February 28, 1988, this educational and training program for San Diego caregivers will be continued through a joint effort of two hospital departments-- Senior Programs and Hospital and Community Education.

## DISCUSSION AND IMPLICATIONS

### Discussion

Throughout the development and the implementation of the Caregiver Education and Training Project, it was anticipated that the following outcomes would occur:

- 1) an improved caregiving experience-- physically and emotionally-- for both caregivers and recipients of care;
- 2) increased utilization of appropriate community-based long term care services;
- 3) increased knowledge regarding the process of caregiving;
- 4) reduced utilization of acute care hospital resources with a resultant cost savings; and
- 5) the development and marketing of videotapes and teaching guides for use in expanding caregiver education and training services throughout the country.

At the conclusion of the eighteen month demonstration project, it had been possible to accomplish and/or validate three of the five items listed above and to partially validate a fourth item.

Review of the participant course evaluation forms and the 23 completed questionnaires appears to document that participation in the training project had enhanced their caregiving experiences-- both physically and emotionally. Comments such as:

- "I felt inferior and incompetent... (now) have more self-confidence in helping my parents."
- "(now) feel prepared to care for Mom."
- "Like finding friends with answers, understanding, compassion and experience."
- "This class is a blessing to people who have someone to care for. I only wish I had this two years ago."
- "You've reassured me that I'm capable of this care."
- "I feel a responsibility for the patient..but I also have a responsibility to myself...I do not have to give 300%."
- "I knew others were going through what I was and that there was help. I was encouraged."
- "I would have been marking five's (on the burden scale=very stressed) if the questionnaire was given to me (before I took the class)..."

Course participants further documented in the completed surveys that certain skills they learned from the training program had been helpful in their caregiving roles-- for example, the use of specific equipment like a transfer or gait belt, quad cane, etc., and learning certain nursing techniques such as taking a pulse, bathing, diapering, transfers, etc. Although we found no direct documentation of enhanced experiences for the care recipient, it logically follows that the care they were receiving was improved in all aspects.

The acquisition of knowledge about the caregiving process was also validated. A review of

the pre- and posttests in both the nursing skills and psychosocial classes revealed a dramatic decrease in the number of incorrect responses--from 3.11 to .67 in the nursing sessions, and 3.28 to 2.11 in the psychosocial.

An excellent educational package was produced--a sixty-minute videotape and two companion teaching guides--and is now available for purchase. These materials can be utilized in the development and implementation of similar caregiving training programs across the country.

The completed questionnaires revealed that caregivers do utilize community long term care resources, yet the small number of eligible respondents, as well as the small numbers of returned and totally completed surveys, makes further validation impossible. We were not able to explore the utilization of acute care hospital services for this very same reason. Further evaluation and research in these two areas might yield more fruitful and enlightening results.

The Caregiver Education and Training Project was designed to impart specific nursing, psychosocial and community knowledge and skills to those who were caring for a family member at home. Although not anticipated, these caregiver education and training classes also attracted other groups--identified senior or indigenous leaders who often helped neighbors and friends in a variety of ways; persons who recognized that they soon may be in a caregiver role; and individuals ('paraprofessionals'/'professionals') who care for older, frail, impaired or ill persons in the home setting for a fee. All of these groups were welcomed in the program as their education and training could also directly benefit the older person who was being cared for in the home setting.

#### Problems During the Project

The major problem area that surfaced during the eighteen month demonstration project was the need for continual and comprehensive publicity about these caregiver classes. Reaching the people who needed the services was a continuing dilemma. Monthly press releases with specific information on upcoming class dates and times were sent to local newspapers and to senior groups and organizations that published monthly, bi-monthly or quarterly newsletters. Promotional materials such as program brochures and fliers were periodically sent to a variety of potential referres--senior service agencies, senior clubs or groups, mobile home park managers, senior complex managers, community chaplains, local librarians, home health agencies, etc.

Initially, two psychosocial classes were offered each month at the hospital site--one in the afternoon, one in the early evening. The evening session was planned primarily for caregivers who might also be employed, or who could find respite only during the evening hours from other family members or friends. After several months, attendance at the evening session was determined to be quite poor. The evening session at the hospital site was eliminated, and additional classes at various community sites were added. These community offerings became quite popular and were well attended.

## Implications

Increasing attention is being paid to the needs of persons providing care to family members or friends. The demands placed on a caregiver can greatly impact their own emotional and financial situation. Many caregivers have to leave their jobs or reduce their working hours, rearrange their daily schedules and often take time off without pay due to caregiving responsibilities. The caregiver is often unprepared and untrained for their new role. While adjusting to the emotional aspects of providing care to someone who is ill, frail, impaired or elderly, the caregiver is also coping with learning new home nursing skills.

Caregiver education and training services such as the model utilized in the CET Project appear to be beneficial to both the caregiver and the care recipient. This type of program is easily duplicated. Personnel costs can be minimized; and applicable and transferrable instructional materials can be purchased at an extremely reasonable price. All of the participants--the ill, frail, disabled and elderly; family, friends and employees in caregiving roles; senior service providers; and acute care hospitals--can benefit from the training, educating and supporting of caregivers.

No doubt, the sheer aging of the American population will result in an even greater need for informal care services. And there is a concomitant recognition that as a society we need to be more proficient in meeting the needs of caregivers, as well as assisting, educating, and supporting them in their efforts.

Caregiver education is a necessity in addressing the needs of both the older population and its caregivers. Support must be given to the caregiver and attention to their physical and mental health. Through education, caregivers not only acquire essential caregiving skills, but they are also given permission to care for themselves. Thus, caregiver education ensures quality care for both the older person and the caregiver.

## PROJECT SUMMARY

Health and human service practitioners, administrators, policy-makers and planners can utilize the results of this demonstration project. The graying of the American population, with its dramatic increase in numbers of older persons, will undoubtedly result in an even greater need for informal and formal health and human care services.

With a greater percentage of the population living to older age and developing chronic impairments and with the ever increasing costs of health care, legislators and policy makers are looking to the family to take greater responsibility for the care of the frail, ill and impaired elderly. And, to assume a larger share of the financial liability. Thus, more and more families will be providing care to their older members and will be faced with varying degrees of strain on their personal, physical and financial resources.

Despite the possible need for an expanded formal care system, much more emphasis will be directed toward the informal care system. The overburdened health care system with its new reimbursement limitations will continue to push toward increased long term, community-based and informal care services.

With these trends in mind, Grossmont Hospital recognized the need to work collaboratively with family, friends and 'paraprofessionals' who care for the ill, frail, impaired and elderly in the home setting. With the financial assistance of the Administration on Aging, the Caregiver Education and Training Project was designed and implemented in the San Diego community. Over 340 individuals participated in 65 free classes which imparted specific nursing, psychosocial and community knowledge skills to caregivers who were providing assistance to a family member or friend. The CET Project was successful in three specific areas:

- 1) enhanced the caregiving experiences for those providing care to a family member or friend--both physically and emotionally;
- 2) increased knowledge about the process of caregiving and added to the skills and expertise of those in a caregiver role; and
- 3) produced an affordable instructional package which can be used to develop and implement similar caregiver education and training programs in other parts of the country.

Although the federal financing of the CET Project has been completed, Grossmont Hospital remains committed to providing caregiver education and training services to the community. The CET Project will continue through the joint efforts of two hospital departments--the Department of Senior Programs and the Hospital and Community Education Center.

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## APPENDICES

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APPENDIX A

PRETEST

HOME NURSING COURSE - BASIC

Mark the one best answer to each question.

1. When arranging a bedroom for home nursing care, it's best to place the bed:
  - a. facing a sunny window
  - b. with one long side against a wall
  - c. head of bed to wall, both sides clear
  - d. in the center of the room
  
2. A walker should be used only by a person who has had a stroke.  
TRUE            FALSE
  
3. Changes caused by aging include:
  - a. Drying of the skin
  - b. Loss of memory
  - c. Defects in judgement
  - d. Loss of bowel and bladder control
  
4. The primary caregiver should always be present with the patient so there is consistency of care.  
TRUE            FALSE
  
5. Urine is normally
  - a. sterile/clean
  - b. contaminated/dirty
  
6. Elderly people need a daily bath to maintain health and a sense of well-being.  
TRUE            FALSE
  
7. Bedsores, or pressure areas, can develop into life-threatening conditions.  
TRUE            FALSE
  
8. The basic four food groups include: . (Circle 4 groups)
  - a. breads & cereals
  - b. milk & milk products
  - c. sugar & substitutes
  - d. meat & meat alternatives
  - e. fats & oils
  - f. vegetables & fruit

9. Caregivers should do for the patient even things they can do for themselves - this communicates caring.

TRUE                      FALSE .

10. When consulting with a physician about a health care quest. ons, you should be prepared to describe:

- a. when the problem began
- b. how it is different from normal
- c. what helps it or makes it worse
- d. all of the above
- e. none of the above - the doctor would prefer to draw his own conclusions from examination.

NAME: \_\_\_\_\_

DATE: \_\_\_\_\_

Please answer these questions to help us in developing other services for caregivers.

1. Have you been caring for this patient before taking this course?    YES    NO

a. If yes, for how long? \_\_\_\_\_

2. What do you want to learn from this course?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

3. Will any other family members be helping with care of this patient?    YES    NO

a. If so, who and how much? \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_



APPENDIX B

PRETEST

HOME NURSING COURSE - ADVANCED

Circle T (true) or F (false) for each question.

- T F 1. The best position for feeding a patient in bed is to raise the head of the bed 30°.
- T F 2. If a person chokes and is coughing a lot, you should apply the Heimlich maneuver immediately.
- T F 3. When feeding a patient, be sure they have swallowed their food before offering more.
- T F 4. A bedpan is placed by lifting the patient's hips and sliding the pan under.
- T F 5. To prevent pressure sores, keep the bottom bedding smooth and dry.
- T F 6. To prevent pressure sores, turn the helpless patient every 4 to 6 hours.
- T F 7. Immobility, or lack of movement, can lead to problems with circulation, breathing, bowel elimination, or skin breakdown.
- T F 8. Patients confined to bed need the lights left on at night to avoid confusion.
- T F 9. When moving a person using a mechanical lift device, (like a Hoyer lift), always roll the lift sideways to avoid tips.
- T F 10. When a gait belt is used, it should be fastened loosely around the patient's waist.

NAME \_\_\_\_\_

DATE \_\_\_\_\_

APPENDIX C

BECOMING A CAREGIVER

Circle either True or False for each statement

- TRUE  
FALSE
1. Medicare usually pays for care given in skilled nursing facilities.
- TRUE  
FALSE
2. Residential care facilities do not provide nursing care.
- TRUE  
FALSE
3. Finances do not need to be considered when making care plans for the elderly or disabled.
- TRUE  
FALSE
4. The stresses of caregiving seldom cause increased health problems for the caregiver.
- TRUE  
FALSE
5. It is usually best to make decisions for older dependent family members by consulting them.
- TRUE  
FALSE
6. A person is not eligible for Medi-Cal if he has Medicare insurance.
- TRUE  
FALSE
7. Private medical insurance in addition to Medicare will cover all medical expenses.
- TRUE  
FALSE
8. Medicare does not cover 24-hour nursing care in the home.
- TRUE  
FALSE
9. A caregiver should not try to find time for himself/herself if the older family member seems to need constant attention.
- TRUE  
FALSE
10. Anyone can make a referral to a home health agency.
- TRUE  
FALSE
11. It is common for caregivers to feel guilty when caring for a family member.
- TRUE  
FALSE
12. A family member can be a conservator of person and/or finances.
- TRUE  
FALSE
13. Family members should assume all needed caregiving responsibilities.
- TRUE  
FALSE
14. Caregivers may feel guilty when transferring some caregiving responsibilities to agency personnel.
- TRUE  
FALSE
15. When skilled nursing facility care is needed, the family always has a choice of facilities.



Grossmont  
District Hospital

East San Diego County  
Regional Medical Center

P.O. Box 158  
La Mesa, California 92041-0300  
(619) 465-0711

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September 28, 1987

Dear Caregiver Program Participant:

We are very pleased that you were able to participate in Grossmont District Hospital's Caregiver Education and Training Project. We hope that the classes you attended have been helpful to you and have assisted you in your caregiving activities.

As part of our Caregiver Program, we would like to validate the effects of our training efforts. Thus, we would like to know more about your caregiving responsibilities and how they may have changed since participating in our nursing skills classes.

Please take a few minutes in the next week to complete the attached Caregiver Survey. All responses are confidential and can not be linked to any particular participant. When you have completed the survey, please return it in the enclosed addressed and stamped envelope.

We thank you in advance for your efforts in this evaluation process. If you have any questions about the survey or about our Caregiver Program, please do not hesitate to contact me at Grossmont Hospital's Senior Programs Office, 465-2582.

Sincerely,

Nancy B. Bryant, DrPH  
Manager, Senior Programs

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APPENDIX E  
CAREGIVER SURVEY

The purpose of this survey is to find out more about your caregiving responsibilities and to determine if they have changed in any way since your participation in Grossmont Hospital's Caregiver Program. It should not take longer than twenty minutes to complete the questionnaire. Please try to answer all questions as completely as possible. Specific instructions for completing the survey will be in CAPITAL LETTERS or in boxes for easier recognition. The column on the right-hand side of the questionnaire is designed for coding purposes only.

1. When did you attend the Caregiver Training classes? (PLEASE SPECIFY THE MONTH THAT YOU ATTENDED) \_\_\_\_\_
  
2. Which Nursing Skills Classes did you attend? (CIRCLE RESPONSE)  
Basic            1  
Advanced       2  
Both             3
  
3. Were you a caregiver when you attended the classes? (CIRCLE RESPONSE)  
Yes              1  
No                2
  
4. Are you a caregiver now? (CIRCLE RESPONSE)  
Yes              1  
No                2
  
5. What is your sex? (CIRCLE RESPONSE)  
Female          1  
Male             2
  
6. What is your age in years? \_\_\_\_\_
  
7. What is your relationship to the person you are or were caring for? (CIRCLE RESPONSE)  
Wife             1  
Husband        2  
Daughter       3  
Son              4  
Parent          5  
Friend          6  
Employee       7  
Other            8 (BE SPECIFIC) \_\_\_\_\_  
                  -35-

8. Where does the person you are caring for live? (CIRCLE RESPONSE)

- Lives with me 1
- Lives Alone 2
- Lives with family 3
- Lives in board and care  
or residential facility 4
- Other 5 (BE SPECIFIC) \_\_\_\_\_

9. How long have you been a caregiver for the person specified in Question 7? (IN YEARS)

\_\_\_\_\_

10. Are you the only caregiver for the person specified in Question 7? (CIRCLE RESPONSE)

- Yes 1
- No 2

(IF YES, SKIP TO QUESTION 12.  
IF NO, ANSWER QUESTION 11.)

11. Who else helps you with the caregiving responsibilities? (BE SPECIFIC)

\_\_\_\_\_  
\_\_\_\_\_

12. In which of the following ways are you caring for the person specified in Question 7?  
(CIRCLE RESPONSE)

- Personal care (bathing, hair care, etc.) 1
- Transfers and walking 2
- Meal preparation 3
- Household chores (vacuuming, dusting, etc.) 4
- Shopping and errands 5
- Correspondence, banking, bill paying, etc. 6
- Emotional support, encouragement, etc. 7
- Transportation 8
- Dispensing medications 9
- Other 10 (BE SPECIFIC)

\_\_\_\_\_  
\_\_\_\_\_

13. When you attended the Caregiver Classes did you learn any specific nursing skills that have helped you in your caregiver role? (CIRCLE RESPONSE)

Yes 1  
No 2

(IF YES, ANSWER QUESTION 14 and 15.  
IF NO, SKIP TO QUESTION 16)

14. Which of the following nursing skills have helped you in your caregiving responsibilities? (CIRCLE RESPONSE)

Bathing 1  
Assistive transfers 2  
Walking 3  
Skin care 4  
Medication management 5  
Grooming 6  
Toileting 7  
Nutrition 8  
Vital signs (temperature,  
blood pressure, pulse, etc.) 9  
Other 10 (BE SPECIFIC) \_\_\_\_\_  
\_\_\_\_\_

15. Please be specific about the ways in which these nursing skills have helped you in your caregiving role. \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

16. Since your attendance at the Caregiver Classes has the person you are caring for visited a doctor? (CIRCLE RESPONSE)

Yes 1  
No 2

(IF YES, ANSWER QUESTIONS 17 AND 18.  
IF NO, SKIP TO QUESTION 19)

17. How many visits to the doctor? (BE SPECIFIC) \_\_\_\_\_

18. In your opinion, how did attendance at the caregiver classes affect the need to visit the doctor? (CIRCLE RESPONSE)

More visits were needed 1

Less visits were needed 2

Same number visits needed 3

19. Since your attendance at the Caregiver Classes have you needed to make phone contact with the doctor regarding the person you are caring for? (CIRCLE RESPONSE)

Yes 1

No 2

(IF YES, ANSWER QUESTIONS 20 AND 21.

IF NO, SKIP TO QUESTION 22)

20. How many times have you needed to make phone contact with the doctor? \_\_\_\_\_

21. In your opinion, how did attendance at the Caregiver Classes affect the need to make phone contact with the doctor? (CIRCLE RESPONSE)

More phone calls needed 1

Less phone calls needed 2

Same number calls needed 3

22. Since your attendance at the Caregiver Classes did you need to take the person you are caring for to the Emergency Room? (CIRCLE RESPONSE)

Yes 1

No 2

(IF YES, ANSWER QUESTIONS 23 AND 24.

IF NO, SKIP TO QUESTION 25)

23. How many visits to the Emergency Room were made? \_\_\_\_\_

24. In your opinion, how has your participation in the Caregiver Classes affected the need for visits to the Emergency Room? (CIRCLE RESPONSE)

More visits were needed 1

Less visits were needed 2

Same number visits needed 3

25. Since your participation in the Caregiver Classes has the person you are caring for been hospitalized? (CIRCLE RESPONSE)

Yes 1  
No 2

(IF YES, ANSWER QUESTIONS 26 AND 27.  
IF NO, SKIP TO QUESTION 28)

26. How many hospitalizations? \_\_\_\_\_

27. In your opinion, has your participation in the Caregiver Classes affected the need for hospitalizations? (CIRCLE RESPONSE)

Less hospitalizations needed 1  
More hospitalizations needed 2  
Same number hospitalizations needed 3

28. Since your attendance at the Caregiver classes, have you used any of the following community resources? (CIRCLE RESPONSE)

a. Home health agency

Yes 1  
No 2

(If yes, how often \_\_\_\_\_  
and what type of help \_\_\_\_\_  
\_\_\_\_\_)

b. Adult day health care

Yes 1  
No 2

(If yes, how many days a week? \_\_\_\_\_)

c. Homemaker services

Yes 1  
No 2

(If yes, how often? \_\_\_\_\_  
and what type of help? \_\_\_\_\_  
\_\_\_\_\_)

d. Meals-on-Wheels

Yes 1  
No 2

e. Caregiver Support Group

Yes 1

No 2

(If yes, how often do you attend? \_\_\_\_\_  
\_\_\_\_\_)

f. Medical Equipment and Supplies

Yes 1

No 2

(If yes, what equipment or supplies did you use? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_)

g. Financial (Medicare, Medi-Cal, Social Security, SSI, etc.)

Yes 1

No 2

(If yes, which type of financial assistance? \_\_\_\_\_  
\_\_\_\_\_)

h. Other (BE SPECIFIC) \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

29. Were you aware of any of the above community resources prior to attending the Caregiver Classes? (CIRCLE RESPONSE)

Yes 1

No 2

(If yes, which community resources? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_)

30. Did your participation in the Caregiver Classes make it easier to utilize any of the community resources? (CIRCLE RESPONSE)

Yes 1

No 2

Not applicable 9

INSTRUCTIONS: The following is a list of statements which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way by circling the appropriate response.

- | Never | Rarely   | Sometimes | Quite<br>Frequently | Nearly<br>Always | Not<br>Applicable |       |       |
|-------|--|-----------|---------------------|------------------|-------------------|-------|-------|
| 1     | 2  | 3         | 4                   | 5                | 9                 |       |       |
| 31.   | The person I care for asks for more help than he/she needs.  |           |                     |                  |                   | _____ | _____ |
| 32.   | I don't have enough time for myself because of the person I care for.  |           |                     |                  |                   | _____ | _____ |
| 33.   | I feel stressed between caregiving and my other family and work responsibilities.  |           |                     |                  |                   | _____ | _____ |
| 34.   | I feel embarrassed by the behavior of the person I am caring for.  |           |                     |                  |                   | _____ | _____ |
| 35.   | I feel angry when I am around the person I am caring for.  |           |                     |                  |                   | _____ | _____ |
| 36.   | I feel that my caregiving responsibilities affect my relationship with other family members and friends in a negative way. |           |                     |                  |                   | _____ | _____ |
| 37.   | I am afraid of what the future holds for the person I am caring for.   |           |                     |                  |                   | _____ | _____ |
| 38.   | I feel the person I am caring for is dependent upon me.  |           |                     |                  |                   | _____ | _____ |
| 39.   | I feel strained when I am around the person I am caring for.   |           |                     |                  |                   | _____ | _____ |
| 40.   | I feel my health has suffered because of my caregiving responsibilities.   |           |                     |                  |                   | _____ | _____ |
| 41.   | I feel I don't have as much privacy as I would like because of my caregiving role.   |           |                     |                  |                   | _____ | _____ |
| 42.   | I feel my social life has suffered because of my caregiving responsibilities.  |           |                     |                  |                   | _____ | _____ |

- 43. I feel uncomfortable about having friends over because of the person I am caring for. \_\_\_\_\_
- 44. I feel that the person I am caring for seems to expect me to take care of him/her as if I was the only one he/she could depend on. \_\_\_\_\_
- 45. I feel that I do not have enough money to support the person I am caring for in addition to the rest of my expenses. \_\_\_\_\_
- 46. I feel I will be unable to continue to be the caregiver for much longer. \_\_\_\_\_
- 47. I feel I have lost control of my life since my caregiving responsibilities. \_\_\_\_\_
- 48. I wish that I could leave the caregiving role to someone else. \_\_\_\_\_
- 49. I feel uncertain about what to do about the person I am caring for. \_\_\_\_\_
- 50. I feel I should be doing more for the person I am caring for. \_\_\_\_\_
- 51. I feel that I could do a better job in providing care. \_\_\_\_\_

52. Overall, how burdened do you feel in your caregiving responsibilities? (CIRCLE RESPONSE)

- Not at all 1
- A Little 2
- Moderately 3
- Quite a bit 4
- Extremely 5

53. Since your attendance at the Caregiver Classes have your caregiving responsibilities changed in any way?

- Yes 1
- No 2

(If yes, please specify how they have changed? \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_)



54. Since your attendance at the Caregiver Classes do you feel differently about your caregiving responsibilities?

Yes 1

No 2

(If yes, please specify how you feel differently? \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_)

Thank you for your willingness to participate in this survey. If you have any additional comments you would like to make about your caregiving role, our Caregiver Education Courses, or this questionnaire itself please use the space below.

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

# END

U.S. Dept. of Education

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