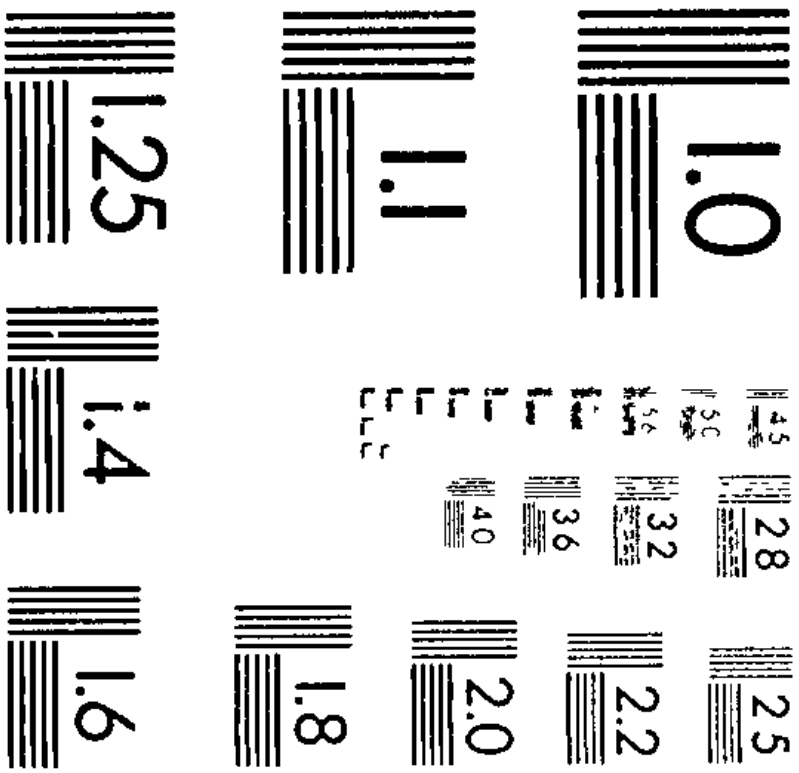

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DOCUMENT RESUME

ED 286 114 CG 020 197

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TITLE Support for Maintaining Independence in the Elderly--Future Requirements and Solutions: Florida's TEACH Demonstration Project--Home-Based, Care Management Services to the Medically Dependent Elderly and Their Caregivers--What We Hope To Learn.
PUB DATE 28 Jan 87
NOTE 24p.; Paper presented at the Caregiving-Support for Maintaining Independence in the Elderly Conference (Tallahassee, FL, January 27-28, 1987).
PUB TYPE Reports - Evaluative/Feasibility (142) -- Speeches/Conference Papers (150)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS Agency Cooperation; Coordination; Cost Effectiveness; Delivery Systems; *Health Programs; *Home Programs; Home Visits; Models; *Older Adults; *Social Support Groups; Veterans
IDENTIFIERS *Caregivers; *Florida

ABSTRACT

This document describes the TEACH (Train the Elderly And their Caregivers at Home) project, a demonstration project developed by Florida's District 12 Veterans Administration and the Florida Department of Health and Rehabilitative Services to reduce Medicaid nursing home expenditures by delaying or avoiding nursing home placement and to provide improved support for informal care by the family and other caregivers. It focuses on the role of the caregiver. The TEACH service delivery model is described, issues for the caregiver now and in the future are considered, and the planned TEACH evaluation project is explained. Past policy options for addressing the issues involved in long-term care are reviewed, the purpose of TEACH services is defined, the conceptual model of TEACH service intervention is presented, and the evaluation of TEACH service hypotheses is discussed. Future requirements of caregivers are projected and three alternatives are identified: (1) purchasing care for the medically dependent through formal services, including home health, nursing home care, and other means; (2) providing requisite care at home through family members, friends, neighbors, or other informal means; or (3) some combination of these mechanisms over the period of time needed. Future caregiver problems are discussed with regard to how the TEACH evaluation effort can offer guidance to possible solutions to some of those problems. (NB)

SUPPORT FOR MAINTAINING INDEPENDENCE IN THE ELDERLY - FUTURE REQUIREMENTS AND SOLUTIONS:

Florida's TEACH Demonstration Project - Home-based, Case Management Services to the Medically Dependent Elderly and their Caregivers - What We Hope to Learn

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Presented by Dr. Bradham
at the conference entitled "Caregiving - Support for Maintaining Independence in the Elderly"
January 27-28, 1987
Florida State Conference Center
Florida State University
Tallahassee, Florida

January 28, 1987
10:15 - 12:15 AM

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Florida's TEACH Demonstration Project - Home-based, Case Management Services to the Medically Dependent Elderly and their Caregivers - What We Hope to Learn

ABSTRACT

The VA in Florida (District 12) and the Florida Department of Health and Rehabilitative Services (HRS) are planning a unique cooperative demonstration for medically dependent elderly and their caregivers under Medicaid waiver. HRS desires to demonstrate the effectiveness of nurse case-managed home services in conjunction with caregiver training. The VA perceives a need to deliver medical case-management services to veterans who currently do not receive home-based services due to the geographic restrictions of the VA's Hospital-Based Home Care Program (HBHC). Consequently, an opportunity exists to develop coordination agreements of cost sharing between the VA and HRS that result in local service delivery to the elderly. The demonstration includes an independent evaluation.

The evaluation project has two major phases: (1) service evaluation and (2) interagency coordination evaluation. The service evaluation will assess three outcomes: service cost-effectiveness, impacts on the care receiver and caregiver, and impacts on health service utilization by the targeted Medicaid population over 65. The inter-agency coordination evaluation will describe the coordination efforts in terms of: domain consensus, goal congruence, and communication. This paper discusses the TEACH Demonstration Project, its conceptualization, development and implementation within the context of caregivers' problems today, and the future. The Evaluation will provide insights to the caregivers' burdens and potential solutions.

TABLES and FIGURES

Florida's TEACH Demonstration Project - Home-based, Case Management Services to the Medically Dependent Elderly and their Caregivers - What We Hope to Learn

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Introduction

The theme of this Conference is the caregiver. Over the past two days we have learned who they are, things that should be considered in designing new programs, and ideas from across the state, the country and abroad. This morning our task is to think about what future requirements will be and what solutions might be suggested.

It was our hope that my coauthors, Innette Chico and Melody Marshall, and I would be able to show you the very early returns from a unique demonstration project for a new service to Florida's elderly and their caregivers. Contract delays have put service delivery behind schedule, so we have no data yet. The good news is that we expect services to begin next month. For those of us who have nurtured this project from its infancy, we are quite pleased to see this progress, and we have grown accustomed to the delays involved in such a complex service demonstration. Given that complexity, it is a credit to three key persons in HRS Aging and Adult Services who have maintained the necessary support and energy since early 1984 to achieve this goal. Margaret Lynn Duggar, June Noel, and Dawn Pollock, the

TEACH State Coordinator, deserve our thanks for seeing that this concept became a reality.

In this paper, we will describe what we see as the future caregiver's problems and how the TEACH Evaluation effort will offer some guidance to possible solutions of some of those challenges.

We must see these problems as challenges, some with easier answers than others. It is a fact that we can solve many logistical and technical problems. But still, there remain some fundamental human challenges that may never be solved. These challenges, like the degenerative conditions that are associated with aging, can be significantly ameliorated by creative responses. As evidence, we have seen dramatic increases in life spans over the past fifty years_ by solving technical problems. Increased longevity and its associated chronicity in concert with other trends have precipitated the elderly's burgeoning demographic imperative -- an imperative that demands humane services at low cost to the recipient and to society.

Elaine Brody has suggested that caring for the elderly has become "a normative experience". We do not disagree, but see this issue through a different disciplinary screen. The public policy issues at all governmental levels appear to distill to "who gets what, when, and how, at what cost and who pays?". Many policy makers know the elderly's plight well. They have parents of their own. They also have several Robson's choices to make daily; and the drive for cost-containment is quite strong with society's competing needs and limited public and private resources. This situation demands that resource scarcity must be considered constantly while seeking to meet the challenge posed by the demographic imperative. So, it would seem that the normative experience of caring for our elderly is a "normative economic one", and we therefore need to find innovative solutions to the challenges that spread the financial burden across the family, the public, industry, and the elderly.

Some believe that nothing new can be proposed - that only variations on old approaches can be offered. Regardless, it is through creative demonstration projects like TEACH that new responses can be evaluated and the best solutions turned into realities. One important role for the service industries and government is to cooperatively fund and implement these demonstrations. The point is, we have little time in some states, like Florida, to meet the challenge.

This discussion will not review the litany of elderly demographics or descriptive data concerning caregivers and their challenges. We will describe the TEACH service delivery model in some detail; issues for the caregiver now and in the future, and the planned TEACH Evaluation Project.

Introduction to the TEACH Demonstration and its Evaluation

Both the Florida Aging and Adult Services Program within HRS and District 12 of the Veterans Administration are engaged in the TEACH demonstration. Obviously, these two agencies have recognized the value of caregivers, and the potential for improved quality of life if the medically dependent elderly are kept at home. The potential public savings to be gained from avoided or delayed nursing home entry has not been lost on the policy makers in these agencies either.

The project has been called "T.E.A.C.H." because it will Train the Elderly And their Caregivers at Home. The primary goals of the TEACH Demonstration are: (a) to reduce Medicaid nursing home expenditures by delaying or avoiding nursing home placement and (b) to provide improved support for informal care by the family and other caregivers. TEACH services can be described as home-based, nurse case-managed service to medically dependent elderly in conjunction with training and support of their informal caregivers by the visiting nurse. That is the key innovation in the delivery concept - the health provider also supports and monitors the caregivers; trains them for their health support tasks: and supports their process of dealing with the various burdens from stress, long hours, physical deterioration and others. Another unique aspect of the project is the cooperative approach between the VA and the state-wide HRS organizations. The Evaluation Project will address both the health impact and the cost-effectiveness of the new service for Medicaid clients, and the process of inter-agency coordination between the two principal organizations involved.

Past Policy Options for Addressing the Issues

Concern over public cost containment and expected growth in long term care needs has lead to three major policy responses in the past. One response has been to design programs to insure the proper use of health care resources thereby limiting costs. Examples include nursing home preadmission screening, certificates of need, and skilled-care reimbursement policy (Lave, 1985). These programs have concentrated on the nursing home where the majority of public funds for the elderly are spent.

A second approach has been to rethink the public/private nature of financing these services. New mechanisms for financing long term care have been proposed, including private LTC insurance (Meiners, 1983 & 1984; Ruchlin, Morris and Eggert, 1982); health trusts (Anlyan and Lipscomb, 1985); social health

maintenance organizations (Greenberg and Leutz, 1984); congregate housing (Howell, 1984); block grants from the Federal government to communities (Hudson, 1981; Merrill and Smith, 1985); and home equity conversion (Jacobs and Weissert, 1984).

New approaches to care delivery, most notably managed care by direct provision or by brokerage of services, have been explored in the hope that institutional care might be avoided or delayed. Many of these methods use community-based health services (Eggert, 1980; Quinn, et al. 1982; Yordi and Waldman, 1985). Other tactics look to the family of the elderly for increased family-centered care (Cantor, 1984), recognizing the extent of informal care delivered by family members or friends. It has been documented that these principal caregivers (PCGs) can play an important role in delaying or deferring nursing home placements in Florida. For example in a 1983 study, changes in the status of the PCG (e.g., deteriorating health, job change, etc.) precipitated 29% of decisions to place someone into a nursing home in Florida (Bradham and Pendergast, 1984).

Purpose of TEACH Services

The planned TEACH services combine these community-based and family-centered methods with nurse case management and PCG training for what is hoped will be more cost-effective community-based service to Florida's medically dependent, Medicaid eligible elderly.

Financially, this produces a complex project. As TABLE 1 shows, the Robert Wood Johnson Foundation has funded the State Coordinating Office and the Service Impact Evaluation. The VA has developed a cost-sharing agreement with HRS. The VA will barter medical-backup and training to the contracted case managers in return for services to veterans who are geographically beyond their boundaries for Hospital-Based Home Care (HBHC) Program. The VA is also funding an evaluation of the inter-agency coordination experience. Funds have been received from the Office of Human Development Services in DHHS to provide services to the veterans, since Medicaid dollars can not be used for veterans. (This funding is one example of the creative solution to regulatory challenges for such a inter-agency service project.) Florida is the recipient of a Medicaid waiver to allow reimbursement for TEACH services. There are Legislative funds to develop training materials for the caregivers. Additionally, the College of Public Health at the University of South Florida in Tampa has contributed significant support to the Evaluation Team.

These various funding sources suggest a variety of eligibility criteria for the care receiver. They must have a caregiver willing to participate in additional training and the

Evaluation; be Medicaid eligible; over 64; and be certified for for nursing home placement under normal circumstances (i.e., medically dependent). The caregiver can be a family member, friend or neighbor who normally provides at least forty percent of the informal care. These are restated in TABLE 2.

The two demonstration areas for TEACH services geographically include portions of HRS Districts 3 and 11. Both HRS districts, one rural and one urban, are contained within the VA's District 12.

Conceptual Model of TEACH Service Intervention

The TEACH demonstration's service design is unique among alternatives to nursing home care for the frail elderly and their principal caregivers. FIGURE 1 illustrates the intervention and TABLE 3 lists the expected outcomes of TEACH services.

As FIGURE 1 shows, several environmental factors influence the condition of both the PCG and the CR. Low income and assets may reduce access to needed health services (Aday, Anderson & Fleming, 1980). When the PCG and the CR are the only members of a household, and when there are no back-up caregivers, the PCG and the elderly person may suffer additional stress. Other living arrangement factors may exacerbate stressful conditions for both the PCG and the elderly care receiver.

Isolation, with its negative impact on social-emotional and cognitive functioning, is a major source of stress. The long hours and constant attention required of PCGs naturally cause mental and physical fatigue. Additional demands of work and family can "put a squeeze" on a PCG's caregiving time and energy. Declines in the health and physical functioning of either the CR or the PCG increase stress for both parties. These stressors negatively affect both the patient's condition and the PCG's ability to provide care (Rowe, 1985; Satariano et al., 1984). For elderly care receivers and their principal caregivers who are themselves elderly, as many are (Soldo, et al., 1983), age would tends to increase stress while lowering health status (Rowe, 1985).

The interpersonal relationship between the PCG and the CR is even more complex and fragile when the care receiver is medically dependent. TEACH services will intervene in these medically dependent situations by working to counter the negative effects of stress, poor living arrangements, and age using health support training of PCGs and case management services. Thus, improvement in the PCG s physical functioning and the quality of the PCG-CR relationship should occur, enabling PCGs to maintain their caring role longer. Any improvements in the condition of the PCG

should in turn have a positive effect on the CR's condition. TEACH services will, of course, also work to influence directly the patient's condition, both physical and mental, through case management and the provision of needed services.

One significant service from the nurse case-manager will be that of piloting the PCG and care receiver through the system of bureaucratic service programs and negotiating the merging of eligibility guidelines to affect the care needed and for which the care receiver is qualified. This is case management, and it seems critical to the caregiver's retention and effectiveness. Nevertheless, recent research by Day (1985) warns that the family's capacity to carry this burden is tenuous. Recognizing the burden can be too much, TEACH nurse case managers will monitor the health of the PCG.

Potential clients will be referred to HRS from many sources: hospitals, nursing homes, community providers, and existing HRS case workers and preadmission screening analysts. Then, they will be screened for the presence of a willing caregiver, and for medical dependency equivalent to nursing home eligibility[1] by existing Medicaid standards. Finally, they are referred to the contracted home-health provider that will deliver a specific set of services to the client and to the caregiver.

Following a thorough assessment, the nurse case managers will tailor a program of services for the care receiver (CR) and training for the PCG which fits both the patient's medical needs, and the age and abilities of the principal caregiver. The nurse case managers will also provide visible social support to the principal caregiver by monitoring the caregiver's health, the competence of their health support activities, and their impacts.

1

TEACH Medicaid Waiver (Section 2176) Eligibility

TEACH clients must be 65 or older and have:

(a) Medicaid qualification for at least intermediate level care in nursing homes,

(b) a principal caregiver -- either family or other -- willing to be trained and to assist the client, and

(c) a condition for which the PCG can be trained to monitor and provide care.

TEACH Service Hypotheses and their Evaluation

HRS and the VA are vitally interested in retaining the PCG, not causing them to become the next public supported patient. TEACH services have been designed to respond to the caregiving problems that have been visible in past research and to prepare them for adapting to future problems in their role.

TEACH's service hypotheses fall into five major, multidimensional areas. When the experience of demonstration clients is compared to a similar group of elderly people with PCGs, but who are not receiving demonstration services, several outcomes are expected, delineated in TABLE 3.

TEACH clients' long-run use of community services and institutional health services will be- lower, for the same case-mix severity. Clients' use of institutional health services (e.g, ambulatory, hospital, and nursing home care) will be delayed longer and perhaps avoided. TEACH clients' lengths of stay when hospitalized or placed in nursing homes will be shorter. TEACH clients' rates of deterioration and mortality, within case-severity groups, will be slower and lower, respectively. PCGs will be retained in care giving roles longer. The implicatior is that the TEACH project should reduce overall expenses for the state Medicaid program.

The services are detailed in TABLE 4. Notice the specific services directed toward the PCG. In anticipation of additional stress being shifted to the caregivers, the project has consciously attempted to provide for the PCG personal support, caregiving task training and health status monitoring by health providers.

Confirming or rejecting expenditure reductions through evaluation of TEACH service impacts is critical prior to any statewide replication by HRS. But our comprehensive Evaluation will not stop there. We will also be analyzing the health and economic impacts of the project on the PCG. The evaluation will be monitoring the coordination of the two major bureaucracies involved in the VA-HRS coordination evaluation. The objectives of this companion inter-agency evaluation are presented in TABLE 5 and their conceptual relationship to the project's success in FIGURE 2.

Future Requirements of Caregivers

What are some of these future requirements of caregivers? Caregiving choices seem to be limited now, and may be broader in the future, but essentially can be summarized by three alternatives:

a. Purchasing care for the medically dependent through formal (paid) services, including home health, nursing home care, and others; or

b. Providing the requisite care at home through family members, friends, neighbors, or other informal means; or

c. Some combination of these mechanisms over the period of time needed.

In the future, there are several issues for the caregiver. Caregivers and care receivers should be adequately prepared for their tasks. This preventive strategy must be consistent with the anticipated problem. First, and most fundamental, general information about the aging processes, service needs, their expense and source agencies should be more readily available to individuals at ages when the information can be most effective. Some information should be incorporated into high school education concerning human growth and development. Other information must await the later years when the means for solutions are available. Community education programs for the adult learner should be routine, and might target these same topics--caregiving tasks, service -integration and case management. There are several researchable issues that must be investigated to facilitate these potential solutions. What are the topics of aging and caregiving that can be well internalized by various age groups? What age groups are most receptive? What is the best learning format? Are these training methods cost-effective to the recipient, or to society? How are they best marketed?

Caregiving training for caregivers must be widely available, cost-effective and profitable. Training modules must be efficiently packaged and economically delivered to have the largest possible impact. These educational systems must be developed with the concept of marketability, so that the private sector can disseminate the product. The efficacy of this training must be understood and documented. The planned TEACH evaluation will address this issue to the extent that standardized PCG-training modules are used. Encouraging the use of these training programs might be enhanced by tax credits for the expense, or insurance reimbursement. Issues of caregiver training efficacy, marketability, and financing must be researched now in order to properly shape future policy.

There are more specific requirements for future caregivers. For instance, whether from publicly or privately funded, family-centered caregivers will face severe economic strain in the future. Governmental funding will be more scarce. Personal funds have not been adequately invested in the past to generate enough capital to handle even current LTC expenses. Predicted health expenses (Arnett, et al., 1984) suggest a 9% average annual increase until 1990. This economic information should be provided early enough to permit investment suggesting the economic information is needed at mid-life or before to affect adequate investment. It is apparent that long term care insurance should be a part of corporate retirement and fringe packages. Some employers are beginning to see this. Such a program should be comprehensive and not just additional catastrophic insurance for Medicare recipients, as the current administration would suggest. This is an economic and policy issue of individual as well as public responsibility. On the public side, revision of tax regulations at state and federal levels should encourage this type of investment. Conversion of home equity must be explored more carefully, and creatively, since most elderly have this asset, if no others. Again there are researchable issues. What forms of private LTC insurance can be marke d successfully? What tax incentives will encourage the proper ivate investment and be deficit reducing as well? How much of the general public will prepare for their own care needs in this way? What barriers have prevented the use of home equity conversions?

If individuals want to protect their options for the future, they must recognize that care giving services, whether formal or informal, have direct and indirect costs associated with them. Even in the case of spousal caregiving, there may be significant indirect costs which reduce the care receiver's and caregiver's actual purchasing power. Among these opportunity costs is the foregone income of lower workforce participation, or the elimination of income if the caregiver leaves the workforce. (Additionally, we recognize the psychological, health and social costs of caregiving roles that were described earlier.) Researchable questions in this area can also be specified. What are the PCG's indirect costs? How do these costs differ across levels of medical dependency? What decisions are being made by caregivers? Are those decisions economically rational,given both direct and indirect costs estimates? The Evaluation of Florida's TEACH Demonstration will estimate these costs are for the caregiver.

Direct costs associated with informal care will no doubt include in-home medical equipment and training of caregivers. These will be available in most geographic markets in the future. However, some rural areas may be underserved. How can this classic maldistribution be avoided? Formal service expenses have

been well documented and they lead to another PCG task that has implications for the future.

One new aspect of the caregiver's role will be managing the financial support for care. This may be more important than actually delivering care if services can be purchased more economically than produced by the caregiver. For many potential caregivers, it may be a more rewarding experience to stay in their employment scene and pay for the services that are needed. What information is useful to these informal case managers? How can businesses and agencies reach and train these care-purchasers?

Logically, in order for formal caregiving services themselves to be available, effective, financially accessible, and economical they must be profitable to the producer. Reimbursement through Medicare and other insurance schemes will help to assure service availability, since the market will respond to demand. How can insurers design their coverage to encourage the market, but to discourage over- or needless utilization? How can public and private policy be used to encourage cost-reducing technologies and services?

This raises additional issues of assuring quality and limiting fraud -- issues that have plagued all service provision to a dependent, often frail population. What protections are necessary? Which are too cumbersome?

The choices are more limited when considering non-family caregiving. Given the reduction in intact families, fewer spouses and fewer children will be available to serve as caregivers. The stereotypical "older daughter", who is now more career oriented, may especially be less available. This scenario suggests that many single elderly will rely on friends and neighbors as potential caregivers, or seek paid caregivers. The result will be a substantial market for caregiving services, beyond home health. Again, the normative experience of caregiving obtains economic consequences that must be anticipated and financed, privately or publicly.

Finally, governments will begin planning for more limited assistance programs, with severe means testing for eligibility. Evidence of this orientation exists in the Veterans Administration's recent adoption of such cost-containment policy. At a time when more services are required, the limiting of public services availability seems incongruent. The answer is a larger tax base and the trade-off of other public services or incentives for informal cargiving. Analysts could provide assistance to policy makers through studies of tax credits, creative tax structures, categorical taxation for additional services to the elderly, and mechanisms to encourage private spending in the areas mentioned above.

If we are successful in demonstrating and evaluating Florida's TEACH project, we will have some answers to the many questions we have raised, and we will probably uncover new issues as well.

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FIGURE 1

Expected Impact of TEACH Intervention

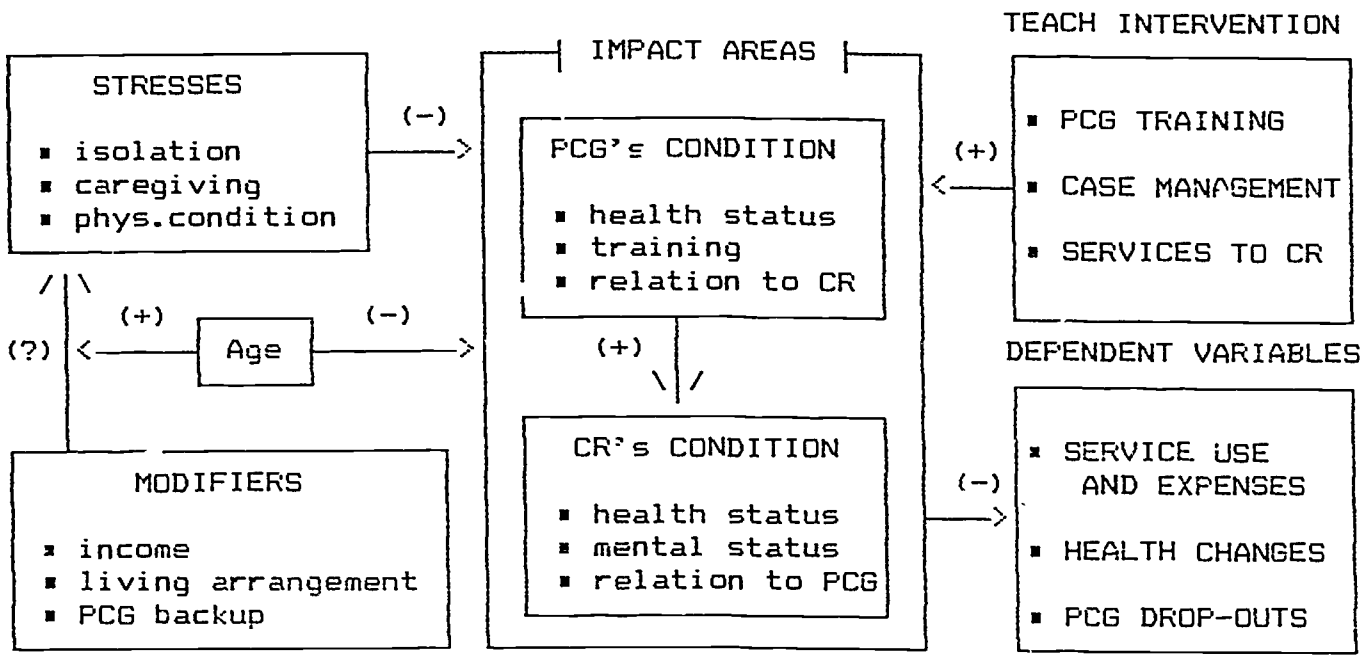

FIGURE 2

Inter-Agency Coordination Influences Under Study

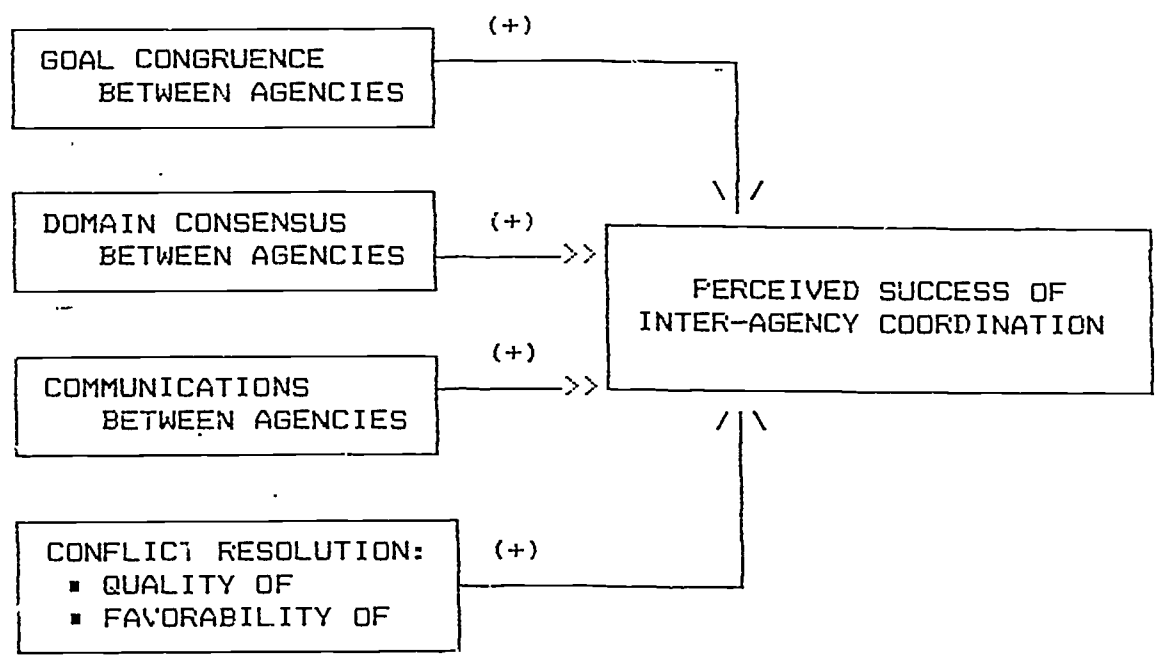

TABLE 1

TEACH Funding Sources

SOURCE:	OBJECT OF FUNDING:
1. RWJ Foundation	▪ State-level Administration ▪ Service Impact Evaluation
2. Veterans Administration	▪ In-Kind Cost-Sharing for services to Veterans ▪ Inter-Agency Coordination Evaluation
3. Office of Human Development Services, DHHS	▪ Services to eligible Veterans
4. Medicaid Waiver Funds (State and Federal)	▪ Services to Medicaid eligibles
5. Florida General Revenue	▪ Principal Caregiver training

TABLE 2

TEACH Eligibility

Clients must be:

1. 65 year old or older, and

2. Medicaid certified for minimum of intermediate (ICF) nursing home care, or more severe - or be a veteran.

Clients must have:

3. a Principal Caregiver (PCG) - a family member, neighbor or friend, willing to be trained to monitor and assist Client at home 40% or more of the time.

TABLE 3

Expected TEACH Outcomes

Clients will demonstrate:

1. Lower service use and expense for same illness severity;
2. Delayed or avoided institutional placements;
3. Shorter lengths of stay when institionalized;
4. Slower deterioration rates and lower mortality rates over time in project; and
5. Principal Caregivers will stay in caregiving role longer.

TABLE 4

TEACH Services

FOR CARE RECEIVER (CR)	FOR CAREGIVER (PCG)
1. Assessment of medical & social service needs	1. Assessment of caregiving skills & training needs
2. Health status monitoring	2. Health status monitoring
3. Provision of in-home services	3. Training for PCG tasks
4. Brokerage of other services	4. Visible support for PCG
5. Social & medical case management	5. Assist in case management

TABLE 5

VA-HRS Inter-Agency Coordination

EVALUATION OBJECTIVES

1. How similar or divergent were the goals and objectives of TEACH among the staff involved in implementing the project? [Goal Congruence]

2. How similar or divergent were the roles and responsibilities of each agency understood? [Domain Consensus]

3. What communication patterns were required, among which staff? [Communication]

4. What issues became sources of conflict? How well were they resolved? [Conflict and Resolution]