

INTRODUCTION

PURPOSE

This document reports findings from three related studies that extended the initial evaluation of the ADDGS program to obtain additional information about the patterns of use and delivery of respite services. The studies focused on (1) factors related to client satisfaction with special attention to differences in cultural beliefs; (2) patterns of respite use over time; and (3) strategies used by providers to develop appropriate and successful respite services. Findings from the studies are potentially useful for providers and policy makers responsible for the allocation of limited resources and the development of respite programs.

ALZHEIMER'S DEMONSTRATION PROGRAM

The Alzheimer's Demonstration Grant to States (ADDGS) Program was authorized through Sections 398, 399, and 399A of the Public Health Service (PHS) Act (P.L. 78-410), as amended by Public Law 101-157, Home Health Care and Alzheimer's Disease Amendments of 1990 and by Public Law 105-379, the Health Professions Education Partnerships Act of 1998. *The goal of this legislation was to expand support services for person's with Alzheimer's Disease and their caregivers.* Special attention has been given to reaching hard-to-serve and underserved populations. The demonstration was intended to assist grantees in planning, establishing, and operating demonstration programs in the following areas: (1) program development, (2) services delivery, and (3) information dissemination.

Fifteen grantees were selected through two rounds of competitive requests for proposals. In September of 1992, eleven states (*California, District of Columbia, Florida, Maine, Maryland, Michigan, Montana, Ohio, Oregon, Puerto Rico, South Carolina*) received a three-year Alzheimer's Demonstration Project grant award. In July of 1993, four additional states received a demonstration grant (*Georgia, Hawaii, North Carolina, and Washington*). The state demonstration projects were all extended through July 2000.

Unlike many federal programs, the Alzheimer's Demonstration has been characterized by great local diversity in design and implementation. Although every grantee has been responsible for the creation of respite services and outreach to hard-to-reach populations, each state (or territory) has developed and implemented a program of outreach and support services that is specific to the unique needs and resources of their citizens. A second hallmark of the project has been the development of cooperative partnerships among public and private organizations to integrate the new programs and services effectively into existing service environments.

WHAT IS RESPITE?

Respite is a term used to refer to a wide range of services intended to give temporary relief to families caring for disabled members. This concept of care developed in the United States as a corollary of the early 1970s deinstitutionalization movement for developmentally disabled children and adults (Cohen, 1982). As families assumed the primary responsibility for the developmentally disabled, the need for temporary relief from their caregiving responsibilities created a demand for respite services.

Recognition, in the United States, of the parallel need for relief of family members caring for frail and disabled elderly did not emerge until the mid 1980s when formal respite services were initially developed as demonstration projects.

While there is general consensus that respite means "an interval of temporary relief," there is almost no agreement as to the composition of the services that are to provide this relief. Respite programs have ranged from volunteers providing short periods of companionship to short stays in institutions. Services can be provided in a client's home (in-home services), in a group or institutional setting (out-of-home service), or in multiple settings (combination programs). Out-of-home services include foster homes, adult day-care centers, respite facilities, nursing homes, and hospitals. The only element common to these services is the intent to provide a period of relief for caregivers.

Within the three general types of respite settings, there are a number of possible variations depending upon the level of care, the types of activities available to participants, and the duration and frequency of respite episodes. Programs may vary along a continuum from low to high levels of care, and respite episodes may range from

short periods of a few hours to long stays of up to six weeks. Clients may be able to use services as frequently as once or twice a week or as infrequently as once or twice a year.

In-home Care

The most frequently requested and utilized form of respite service is in-home respite care provided for short periods, usually by a home health aide (Montgomery and Kosloski, 1994; Feinberg and Whitlach, 1998). A sitter/companion, homemaker, home health aide, or a nurse can provide in-home respite care. Some programs provide all of these levels of service while others may offer only companion or sitter services. Several public and private initiatives have encouraged the development of volunteer respite programs. These volunteer programs are usually confined to the companion level of care (Montgomery and Hatch, 1987). Most in-home programs provide services for a period of three to four hours, although some programs do offer more extended overnight or weekend services.

Out-of-home Community Care

The most common form of out-of-home respite is provided through adult day-care centers (Weissert et al., 1990; Montgomery, 1995). Usually respite care is offered in adult day-care centers on a regularly scheduled basis providing about four to six hours of care on each visit. Adult day care centers are best able to serve clients who need minimal assistance and, when they were initially developed, often did not enroll clients who were incontinent or who wandered (Montgomery and Kosloski, 1995). Additionally, some programs have been specifically developed for persons with Alzheimer's Disease or other related disorders (Lyman et al., 1993, Lindeman et al., 1991; Zawadski and Van Behren, 1990).

POTENTIAL BENEFITS OF RESPITE SERVICES

Currently there is overwhelming consensus among families and service providers that respite services are the most desired and needed support for families caring for persons with Alzheimer's disease or other dementias. Many researchers suggest that respite care can relieve the burden of the caregiving situation and, perhaps, even allow families to continue to care for relatives who otherwise might have been institutionalized (Deimling, 1991; Van Werkhoven, 1991; Montgomery and Williams, *in press*).

Benefits for Families

Respite care is assumed to benefit both caregivers and the older persons for whom they provide care. The temporary relief from care tasks that respite services provide may reduce the level of stress that caregivers experience as a consequence of their care responsibilities. Indeed, adult day care has been seen to reduce care-related stress and increase psychological well-being of caregivers significantly (Zarit et al., 1998). Elders benefit indirectly from respite when the reduction in caregivers' stress and burden leads to enhanced quality of interactions between the caregiver and the care recipient. Elders attending day care centers also benefit directly from increased opportunities for socialization and stimulation.

Reduced Long-term Care Costs

Although, the belief that individual families benefit from respite programs has been one of the catalysts for the development of respite programs throughout the country, the major force driving the development of respite has been the general belief that respite programs may reduce the costs of long term care by reducing or delaying the need for more costly forms of care. Indirect support for this belief has been found in the fact that frail elders, who have in-home caregivers, are more likely to remain in the community than are those without such support, regardless of the elder's medical condition (Berman et al., 1987; Feinberg and Whitlach, 1998). In addition, there is mounting evidence that the caregiver's capacities and health may be as important in predicting institutionalization as is the physical condition of the person receiving the care (McFall and Miller, 1992; Pruchno, Michaels, and Potashnik, 1990; Haug et al., 1999; Whitlatch et al., 1997). Direct support for the notion that respite may save long-term care costs has been relatively sparse. In fact, findings from early studies of respite programs failed to confirm delays in nursing home placement (Lawton et al., 1989; Montgomery and Borgatta, 1989). More recently, investigations that have used more appropriate methodologies for field studies of respite programs operating in communities have affirmed an empirical link between respite care and delayed placement (Montgomery and Kosloski, 1995; Zarit et al., 1998).

LIMITATIONS OF PREVIOUS RESEARCH

To a large extent, any empirical evidence to demonstrate the psychological and monetary benefits of respite remains sparse and uneven because respite remains an

amorphous notion that has not been systematically studied. Previous studies have defined respite in different ways and focused on programs that offer very different services. In fact, some of the definitions of respite that have been used, ironically, did not even involve actual use of the service. Instead, respite was defined as merely having knowledge of, or access to, a particular service. For the most part, little attention has been given to the basic issues of dosage and timing of respite services. Most often, past evaluations have treated respite use as a dichotomous variable reflecting "use" versus "non-use" or even more problematic, "eligibility for use" versus "non-eligibility of use" (e.g. Lawton, Brody, and Saperstein, 1989; Montgomery and Borgatta, 1989).

Unlike pharmaceutical studies, which use rigid protocols to control the content and quantity of a treatment, respite as a treatment has varied widely in composition and quantity both among studies and within single studies. Insufficient attention has been given to describing service interventions or patterns of service use over time (Lawton, Brody and Saperstein, 1989; Montgomery and Borgatta, 1989). In the end, the relevance of past studies to real-life settings (i.e., their external validity) remains dubious. The question as to whether respite services ultimately reduce the cost of long-term care remains an important policy issue. Yet the question remains largely unanswered because little is truly known about how caregivers opt to use respite services when they are available. Despite growing evidence that respite services, indeed, do help families continue in their caregiving role for a longer period of time (see Montgomery and Kosloski, 1995), there is little systematic knowledge about long-term patterns of respite service use *in situ*.

It is also the case that the failure of researchers to make a definitive pronouncement about the efficacy of respite has done little to discourage practitioners and users of respite services. Respite programs have continued to proliferate. Practitioners have gone forward without waiting for explicit or even tacit approval from researchers. And, as a practical matter, answering the question of cost effectiveness does little to help community-based service providers to plan and implement their programs. They have a need for even more basic information about patterns of respite use. For example, in a real life setting, how much respite will a family use? Over what period of time do families use respite and at what level of intensity?

PROJECT GOALS

These lingering questions about utilization patterns and the benefits of respite programs prompted the extended analyses of data from the AOA Alzheimer's Disease Demonstration Grant to States (ADDGS) program that are reported here. Specifically three studies were undertaken that capitalize on the unique qualities of the data that were gathered over a seven year period from September 1992 to October 1999.

The focus of Study One was to explore the links between clients' cultural characteristics and client satisfaction with respite services. The central purpose of the study was to identify differences among cultural groups in their beliefs about long term care and to determine whether these beliefs were linked with views about services offered through the ADDGS program. Data were gathered through interviews conducted with current caregivers. The underlying assumption of this study was that clients would be more likely to use those services that they deem appropriate and with which they were most satisfied. Knowledge of these factors could then be utilized by service providers to fine-tune their programs and maximize efficiency.

The primary purpose of Study Two was to identify and document long-term profiles of respite use among a diverse sample of families caring for elders with dementia. These profiles are potentially useful planning tools for policy makers and service providers responsible for implementing effective and efficient respite programs.

Study Three used a qualitative design to explore more fully the ethnic, geographic and familial contexts of service from the perspective of service providers. Data were gathered through interviews with key service delivery staff to identify successful strategies for addressing cultural and/or structural barriers to service use. The purpose was to provide a more detailed understanding of the issues confronting providers as they attempted to successfully develop and implement culturally appropriate support services for diverse populations.