

PREFACE

The incidence of Alzheimer's disease appears to increase with each newly published research report. Similarly, the programs and services available to caregivers and patients with Alzheimer's disease and other dementias are expanding. The role of speech-language pathologists has widened to include not only their traditional diagnostic role, but also the rehabilitation and management of individuals with dementia and the counseling and training of their families. Increasingly speech-language pathologists are joining forces with professionals in other disciplines to provide a full range of services to individuals with a dementia and their families. Because the potential success of therapeutic and life-enhancing programming with patients having Alzheimer's disease is directly related to caregiver involvement, the focus of this issue, and that of the subsequent issue, of *Seminars in Speech and Language* is on caregivers. Although most caregivers are eager to acquire information and many may be appropriate intervention agents, a myriad of caregiver psychosocial, emotional, and cultural issues can raise barriers to effective service utilization and intervention implementation. Speech-language pathologists need to understand the full range of factors that impact on caregivers, and accordingly on their patients, in order to design successful intervention strategies. The purpose of this two-issue series on Caregiving in Dementia is threefold: (1) to provide information on the characteristics of family caregivers of dementia patients, including discussions of their needs and changing roles, (2) to describe the range of interventions and treatment programs for caregivers (including skills training, support groups, respite/daycare, counseling, etc.), and (3) to discuss the continuum of community

resources available to caregivers, including in-home, center-based, and nursing home services.

This issue begins with Schulz and O'Brien's overview of the prevalence of Alzheimer's disease and other dementias and the demand for family caregiving. With current estimates of 2–3 million caregivers expected to increase as the elderly become an increasingly larger segment of the U.S. population, researchers are particularly interested in identifying the physical and emotional burdens of caregiving and in finding ways to reduce the negative impact of providing care to a relative having dementia. The article by Haley, Wadley, West, and Vetzal addresses a major source of caregiving stress—the severity of a patient's cognitive and behavioral impairments. They evaluate various dementia rating scales and provide useful clinical data from a large sample of patients to document the progression of specific behavioral and self-care impairments. The clinical implications of different familial caregiving relationships are explored in Morycz's article. It should be apparent that researchers are just beginning to sort out the complex psychosocial variables that may affect caregiving burdens as a function of being the patient's spouse, child, sibling, or other relative. Clinicians may recognize that many of our past clinical assumptions about caregivers have been overly simplistic in describing the realities of the caregiving experience for diverse individuals. Similarly, clinicians may not be aware of the ethnic and cultural differences in identifying and managing the problem behaviors associated with dementia that affect ethnic minority caregivers' perception of burden. As Henderson points out in his article, understanding the cultural health beliefs of caregivers

is crucial to effective intervention; the case histories of three culturally different Hispanic families are used to illustrate some of the more common cultural obstacles to obtaining effective health care services.

Kosloski and Montgomery's article on service utilization by family caregivers of patients with dementia is an excellent example of how researchers develop theories and models to explain clinical and social phenomena. As these authors point out, it is important to understand and predict patterns of service use by caregivers for economic as well as social policy reasons. Currently available services, while designed to reduce costs and delay nursing home placement, may not be accessible or attractive to caregivers due to a multitude of behavioral and cultural factors. Mapping the interrelationships among such factors is the first step towards understanding and predicting service use by caregivers of patients with dementia.

This issue concludes with an article by Santo Pietro that outlines the impact of different communication styles on the interactions between caregivers and patients with dementia. A patient's lack of communication and caregivers' dissatisfaction with

communicative interactions with the patient are often perceived by caregivers to be a major contributor to caregiving burden and stress. Santo Pietro has included several questionnaires that may be particularly useful for clinicians in designing effective interventions for promoting satisfying communicative interactions between caregivers and patients.

In summary, this collection of articles by well-known and widely respected health care professionals currently engaged in caregiving research represents the most up-to-date research and knowledge about the characteristics of caregivers of patients who have a dementia. It is intended to be a useful resource for clinicians who are trying to provide socially, emotionally, and culturally appropriate services to a wide range of caregivers. The next issue of *Seminars in Speech and Language*, "Caregiving in Dementia II: Interventions," will focus on the range of specific interventions that have been designed to reduce caregiver burden by improving caregiver coping and management strategies.

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