

Editorial Board

Amanda Smith Barusch, PhD

David E. Biegel, PhD

Iris Carlton-LaNey, PhD

Namkee G. Choi, PhD

Linda Harootyan, MSW

Nancy Hooyman, PhD

Amy Horowitz, DSW

Rosalie A. Kane, DSW

James E. Lubben, DSW, MPH

Deborah D. Padgett, PhD

Marsha Mailick Seltzer, PhD

Patricia Volland, MSW, MBA

Handbook of Social Work in Health and Aging

Barbara Berkman

EDITOR

Sarah D'Ambruoso

ASSOCIATE EDITOR

OXFORD
UNIVERSITY PRESS
2006

OXFORD
UNIVERSITY PRESS

Oxford University Press, Inc., publishes works that further
Oxford University's objective of excellence
in research, scholarship, and education.

Oxford New York
Auckland Cape Town Dar es Salaam Hong Kong Karachi
Kuala Lumpur Madrid Melbourne Mexico City Nairobi
New Delhi Shanghai Taipei Toronto

With offices in
Argentina Austria Brazil Chile Czech Republic France Greece
Guatemala Hungary Italy Japan Poland Portugal Singapore
South Korea Switzerland Thailand Turkey Ukraine Vietnam

Copyright © 2006 by Oxford University Press, Inc.

Published by Oxford University Press, Inc.
198 Madison Avenue, New York, New York 10016
www.oup.com

Oxford is a registered trademark of Oxford University Press

All rights reserved. No part of this publication may be reproduced,
stored in a retrieval system, or transmitted, in any form or by any means,
electronic, mechanical, photocopying, recording, or otherwise,
without the prior permission of Oxford University Press.

Library of Congress Cataloging-in-Publication Data
Handbook of social work in health and aging / Barbara Berkman, editor;
Sarah D'Ambruoso, associate editor.

p. cm.

Includes bibliographical references and index.

ISBN-13 978-0-19-517372-7

ISBN 0-19-517372-4

1. Social work with older people—Handbooks, manuals, etc. 2. Medical social work—
Handbooks, manuals, etc. I. Berkman, Barbara. II. D'Ambruoso, Sarah.

HV1451.H34 2006

362.1'0425—dc22 2005014223

*We dedicate this book to older adults and their families
worldwide who deserve only the best of social and health
care services, and to those social workers who strive every day
to help them manage their health with quality of life.*

9 8 7 6 5 4 3 2 1

Printed in the United States of America
on acid-free paper

UNIVERSITY OF UTAH LIBRARIES

RONALD W. TOSELAND
MICHAEL PARKER

Older Adults Suffering From Significant Dementia

10

Dementia is very difficult to cope with because it affects both mental and physical functioning progressively, until death. Dementing illnesses have been called “the most feared and devastating disorder of later life” (Zarit & Zarit, 1998, p. 32). The purpose of this chapter is to provide an overview of the social work role in the care of persons with dementia. The social work role is to provide services and support to persons with dementia to help them cope with the disease. These services also extend to family members and to those who care for persons with dementia.

BACKGROUND

Dementia comes from the Latin term *de mens* or “out of mind.” It is used to describe a group of symptoms, a syndrome, characterized by multiple cognitive deficits of sufficient severity to interfere with daily activities and social relationships (American Psychiatric Association, 2000). Typically, the symptoms are insidious at onset, gradually progressing until death as an increasing number of brain cells become impaired. Although progressive, the course of dementia symptoms is variable depending on underlying disease processes.

Because dementia affects many areas of functioning, social workers’ assessments and interventions must be broad, focusing on the whole person. Thus, assessment and intervention should include the emotional, physical, psychological, social, and spiritual aspects of the functioning of persons with dementia and their caregivers. Also, because of the progressive nature of the disease, advance planning is essential. Good social work intervention focuses both on current functioning and planning for the future.

Dementia in the elderly can be grouped into four broad categories by etiology and approximate incidence: (1) primary degenerative dementia (in 50% to 60% of dementia cases, e.g., Alzheimer’s disease, Pick’s disease); (2) multi-infarct dementias (stroke-related, 10% to 20%); (3) partially reversible dementias (20% to 30%, e.g., vascular diseases, infections, metabolic disorders); and (4) other neurological disorders (5% to 10%, Huntington’s and Parkinson’s diseases; Kane, Ouslander, & Abrass, 2004). Alzheimer’s disease is by far the most common cause of dementia, with vascular-related diseases a distant second. Dementia can be caused by a variety of other diseases and conditions, including HIV/AIDS, alcoholism, traumatic brain injury (i.e., head trauma), Creutzfeldt-Jakob’s disease, Down syndrome, and dementia due to other general

medical conditions and etiologies (American Psychiatric Association, 2000; Gauthier, 2003; Kane et al., 2004; Weiner, 1991; Zarit & Zarit, 1998).

The prevalence of dementia increases rapidly with advancing age. For example, it has been estimated that at age 65, only about .06% of males and .8% of females have dementia, whereas by age 85, the rates rise to 21% for males and 25% for females. By age 95, 36% of males and 41% of females are affected with some form of dementia (American Psychiatric Association, 2000). Because of the aging of the population in the United States and other nations, the prevalence of dementia is expected to increase dramatically in the next several decades (e.g., Katzman, 2001). Therefore, social workers can be expected to encounter an increasing number of persons with dementia and their caregivers in future years.

Dementia causes profound changes in a person's functional abilities. The essential feature of dementia is memory impairment, but at least one of the following cognitive disturbances must also be present: (1) aphasia (vague or empty speech), (2) apraxia (impaired ability to execute motor functioning), (3) agnosia (failure to recognize or identify objects), and (4) disturbance in executive function (ability to think abstractly and to plan, initiate, sequence, monitor, and stop complex behavior; American Psychiatric Association, 2000).

As dementia progresses, memory, judgment, language, and abilities to engage in activities of daily living become increasingly impaired, and behavioral disturbances can arise. Psychiatric symptoms may also occur and cause personality changes, depression, anxiety, delusions, or hallucinations. Gerontological social workers need to be able to recognize and treat these symptoms. They also need to help persons with dementia and their caregivers to cope with the limitations and impairments that arise with continuing declines in physical and mental functioning.

ASSESSMENT

The first step in working with older persons with dementia and their caregivers is to conduct a thorough assessment of the situation. If a diagnosis of dementia has not already been established, the social worker's role is to help people with dementia and their caregivers get an accurate diagnosis. Dementia is diagnosed by ruling out other physical illnesses that may be causing the symptoms and by history taking, which establishes progressive memory loss. Because it affects

many aspects of functioning, a good assessment of dementia is conducted most thoroughly by a multidisciplinary team (Mulligan, Linden, & Juillerat, 2003).

For example, social workers should encourage older persons with suspected dementia and their caregivers to get a comprehensive geriatric assessment that includes a social and medical history, a physical exam, appropriate laboratory work, a mental status exam, environmental assessment, and assessment of functional status (ADLs, IADLs; see Table 10.1; Kane et al., 2004; Toseland, Derico, & Owen, 1984). Such an assessment is necessary to rule out other illnesses and to track the trajectory of the illness and the effects of care. Therefore, it is important to have referral sources of physicians who specialize in dementia (Toseland et al., 1984). This includes geriatric-trained doctors who can lead a team of professionals in conducting and coordinating a comprehensive assessment (Fuller et al., 2003; Kane et al., 2004). Memory clinics and Alzheimer's disease assistance centers, now available in some communities, often employ multidisciplinary, geriatric teams that include the disciplines of medicine, nursing, and social work. If a dementia specialist or geriatric-trained internist or family practitioner is not available, the social worker may need to recommend to the family the involvement of other professionals (neurologists, psychiatrists, nurses, nutritionists, physical and occupational therapists) in the assessment process.

While making an assessment, social workers should consider using one of the instruments available to assess the level of cognitive impairment experienced by the person, such as the Mini Mental Status Exam (Folstein, Folstein, & McHugh, 1975). Social workers may also want to use other instruments, such as the Global Deterioration Scale, to determine the stage of disease progression (Reisberg, Ferris, & deLeon, 1982), or the Life Space Assessment (Parker, Baker, & Allman, 2002) to assess early changes in functional status and to monitor changes in mobility over time.

The assessment of dementia should include determining the current stage of the disease. Many resources are available to identify what stage of dementia a person is currently experiencing. For example, a CD-ROM is available that can be used by both professionals and laypersons to identify the stage of the disease and to address concerns arising during each stage (Health Care Interactive, 2001). There is still some controversy about whether to disclose the diagnosis of dementia to the person with the disease, and some have argued that the best approach is to ask the person at the outset whether he or she would like to know the result of the diagnos-

TABLE 10.1. A Comprehensive Geriatric Assessment

- Social and Medical History
- Physical Exam:
 - vital signs
 - behavior and appearance
 - sensory (ears/eyes)
 - dental
 - skin
 - chest/cardiovascular
 - abdomen/genitourinary
 - extremities
 - neurological
- Laboratory Assessment
- Mental Status Exam
- Spirituality Assessment
- Environmental Assessment
- Functional Assessment
 - ADLs
 - feeding
 - dressing
 - ambulation
 - toileting
 - bathing
 - continence
 - grooming
 - communication
 - IADLs
 - writing
 - reading
 - cooking, cleaning, shopping, climbing stairs, using telephone, managing medication, managing money
- Social Service Assessment
 - family dynamics
 - service needs
 - resource needs
 - benefits
 - legal issues (e.g., power of attorney, health care proxy)
 - advance care planning: functional needs
 - advance care planning: medical and end-of-life preferences

tic process (Downs, 1999). Although we respect the person's right not to know, in the overwhelming majority of situations, our clinical experience suggests that people want to know the diagnosis. Disclosing the diagnosis is also important because it affirms the person's

right to know and because early diagnosis can lead to earlier and better treatment.

Part of the role of the social worker in the early stage of work with persons with dementia and their caregivers is to provide support as they go through the process of accepting the diagnosis and understanding its implications. Social workers provide information to help persons with dementia and their caregivers gradually understand the consequences of the diagnosis to functional abilities. According to Kaplan (1996), caregivers of dementia patients go through the following states of adjustment: (1) denial and making excuses for the person's behavior; (2) overinvolvement and overcompensation for the person's losses; (3) anger over the loss, frustration about the inability to halt the disease progression, and embarrassment caused by the person's behavior; (4) guilt about the inability to accommodate and fully meet the person's behavior and care needs; and (5) grieving and acceptance.

During the assessment process it is important to identify the primary caregiver. For persons with early-stage dementia, Kuhn (1999) suggests that at least one person who is close to the person with dementia should be helped to step into a leadership role. This person takes overall responsibility for ensuring the well-being of the person with dementia, while not undermining the remaining abilities of the person, and encouraging the active involvement of others interested in the person's well-being. However, because caregiving frequently involves a primary caregiver and secondary caregivers, an important role for social work is to help families define roles, to cooperate in care planning and decision making, and to negotiate and resolve conflicts as they occur.

Once a diagnosis of dementia has been confirmed, the social worker can proceed with the assessment process. A comprehensive assessment of persons with dementia should consider the physical, emotional, psychological, social, practical, and spiritual aspects of their functioning and that of their caregivers.

PHYSICAL FUNCTIONING AND DEMENTIA

Dementia has a profound impact on functional abilities, language and speech, motor ability, judgment and reasoning, and many other areas of functioning. Functional status measures can be used to measure basic activities of daily living skills such as bathing and toileting and also higher-level instrumental activities of daily living skills such as managing money and driving. In early stages of dementia, social workers' role

is often to help the person with dementia and caregivers to make adaptations in their environment to help them compensate for memory loss. In the middle stages of dementia, functional assessments can aid social workers in helping caregivers to learn communication strategies that compensate for impairments in language and speech. Later in the disease process, social workers' role is often focused on assessing informal support services and providing information about formal community supports such as day care and home care. At a minimum, this information can help to reassure caregivers that help is available and that they are able to have some respite from caregiving if needed. Social workers may also help caregivers to obtain needed home care, adult day care, or nursing home services.

PSYCHOLOGICAL AND EMOTIONAL IMPACT OF DEMENTIA

Emotional lability and emotional problems are common among both persons with dementia and their caregivers. Caregivers often struggle emotionally as they reflect on the continual cognitive decline. They face profound changes in their loved one. Social workers can help caregivers in many ways, including providing support and reassurance, developing long-term care plans that address medical care (e.g., locating a geriatrician), addressing legal issues (e.g., completion of a durable power of attorney), understanding family dynamics (coordination of a family meeting to determine who does what), and addressing work and financial issues, spiritual concerns, grief and loss counseling, emotional support, and assistance with practical issues such as obtaining needed health and social services (Parker et al., 2004). Because people cope in many different ways with emotional challenges, a careful assessment of the emotional concerns of persons with dementia and their caregivers can help to guide intervention efforts. Some persons with dementia and their caregivers may, for example, benefit from early-stage dementia support groups (Yale, 1995). Others may benefit from individual or family counseling to alleviate emotional problems.

Psychological impairments can occur in all stages of the disease. In early stages, depression is a common problem, and anxiety may also be present. In later stages of the disease, psychotic symptoms such as hallucinations and delusions may occur, and agitation is common. Pharmacologic treatment may help, but the

use of psychotropic medications is complicated by the underlying disease processes, and some medications, such as the benzodiazepines, may make the dementia worse. Therefore, it is essential for social workers to work closely with psychiatrists who are familiar with the treatment of persons with dementia.

We have observed that behavioral symptoms are often the result of inappropriate environmental stimulation or poor pain management. Therefore, it is important to conduct a careful assessment of the environment and the physical comfort of the person with dementia before assuming that behavioral symptoms are due to psychiatric problems. Because of the adverse effects that psychotropic medications can have on persons with dementia, it is always preferable to use nonpharmacological approaches if these are effective. (For additional information, see Callaway, 1998; Galasko, 1996; Kennedy, 2000; Zarit & Zarit, 1998.)

THE SOCIAL IMPACT OF DEMENTIA

Socially, the person with dementia often becomes isolated. Dementia causes problems in word finding, in sentence structure, and in ability to communicate. As dementia progresses, it becomes increasingly difficult to understand what the person is trying to communicate. Even close family caregivers may become frustrated, and some become angry and short-tempered. Because of these problems, caregivers often feel ashamed to take the person out in public or to have visitors. When visitors do come, they may find it difficult to interact with the person with dementia.

Caregivers also often become socially isolated as they increasingly have to be available around the clock to make sure that the person with dementia is safe. Therefore, it is important for social workers to encourage caregivers to take care of themselves. It is also important to make use of informal and formal services as part of the care plan. Social workers can teach caregivers communication skills and activities that can be used to continue engagement as skills deteriorate and dementia progresses. Some of these skills and activities are briefly described later in this chapter.

PRACTICAL ASPECTS OF CARE

Another important social work assessment and intervention role is to help with the practical aspects of care planning and management. Social workers assess

the capacity of persons with dementia and their caregivers to get practical needs met. As a result of this type of assessment, social workers, for example, frequently become involved in helping the person with dementia and family caregivers to understand the role of Medicaid and Medicare and other health and social service programs, such as home heating assistance and food stamps. This assistance may include helping them with questions about eligibility and with required application procedures. It also may include helping to coordinate or manage services once they are obtained.

Social workers frequently become involved in planning for future care needs. For example, social workers may help persons with mild dementia and their caregivers to develop health care proxies and advance directives regarding medical care wishes if they become incapacitated. They may also encourage caregivers and persons with dementia who are still capable to develop or update wills, powers of attorney, and other legal documents, to review financial arrangements, and to plan for the assistance and support that will be needed during later stages of the disease.

THE ROLE OF RELIGION AND SPIRITUALITY

Many families confronted with the effects of dementia find strength in their spiritual beliefs and the support they receive from their communities of faith (Myers, Roff, Klemmack, & Parker, 2004; Parker et al., 2004; Roff & Parker, 2003). Religious beliefs are particularly strong in North America among elderly women and members of some minority groups (Koenig, McCullough, & Larson, 2001; McInnis-Dittrich, 2002; Roff, Klemmack, Parker, Baker, & Allman, 2005; Tobin 1999).

The early stage of a dementing illness is a good time to help persons express what type of religious or spiritual support, if any, they would like as their symptoms progress. For some individuals, this may include continued or renewed contact with clerics or with formal religious organizations such as churches or synagogues. For others, it may mean help in coming to terms with the illness and its course, the meaning of their lives and making peace with family, friends, and those with whom they may have had conflictual relationships. Social workers can help older persons with mild dementia to incorporate spirituality and religion in life review, reminiscence, and legacy work that helps to make sense of and give

meaning to life (Roff & Parker, 2003). It can also mean helping persons with dementia to articulate and record preferences for medical care and funeral arrangements at the end of their life that reflect their religious and spiritual values.

ATTENDING TO THE NEEDS OF CAREGIVERS

Although we have already mentioned the importance of including the primary caregiver in the assessment process, a comprehensive biopsychosocial and environmental assessment should always consider the needs of all family members and other concerned persons who are involved with the person with dementia. In some families, for example, a diagnosis of dementia can rekindle or exacerbate long-standing family conflicts. In others, it can bring family members closer together. One or more family meetings are often helpful to assess the strengths and weaknesses of the family system in planning for the future, in problem solving, and in resolving conflicts and differences of opinion about care options and roles (Toseland, Smith, & McCallion, 1995).

Cummings (1996) points out that it is essential for social workers to recognize that understanding, accepting, and coming to terms with the dementing illnesses of a family member may be a long and slow process and that this process varies significantly by individual family member. Family caregivers are faced not only with the prospect of providing care over the long term, but also with the emotional challenge of coming to grips with the gradual loss of their loved one and changing expectations about the relationship they will have with the person as disease processes progress (Cummings, 1996). Social workers have an important role to play in helping individual family members and the entire family system to cope with these emotional adjustments and to work together to plan for and manage the care of the person with dementia as symptoms progress.

INTERVENTION ROLES

Social workers can be called on to play a variety of roles when working with persons with dementia. These roles can include consultant, coordinator, care manager, and interdisciplinary care team member (Toseland, Smith, & McCallion, 2001; Toseland, Smith, & Zinoman, 2004). In consulting roles, social

workers utilize the competencies, expertise, and skills of persons with dementia and their family care systems to the maximum extent possible. They rely heavily on the input of persons with dementia and their caregivers during both assessment and care planning. Social workers assume that caregivers and persons with dementia will take primary responsibility for the day-to-day implementation and monitoring of the care plan.

After an intensive period of consultation during which the assessment is conducted and a care plan is made, social workers in the consulting role reduce contact, occasionally checking that the care plan is being implemented properly and responding to problems or issues as they arise. Frequently occurring problems often include emotional lability, agitation, and behavioral disturbances such as aggressiveness and apathy. They may also include adjustments in living status (such as when a person with dementia moves in with a caregiver or moves to supportive housing or a nursing home), resistance to some forms of care such as bathing, or safety issues arising from the declining judgment and reasoning of the person with dementia. The consultant role is often used by private social work care managers and agency-based social workers in outpatient memory clinics, housing projects, family service agencies, and senior centers in the early stages of dementing illnesses and when strong family supports are available.

In the care coordinator role, social workers take greater responsibility for implementing the care plan they have developed with family members and persons with dementia. Social workers help to link persons with dementia and their informal caregivers to needed community resources and services and help to ensure that these services are received in a timely and consistent fashion by resolving any ongoing care plan implementation issues. In the care coordinator role, social workers are frequently called on to help with applications for medical, social service, and housing assistance and may serve as an advocate to help obtain them. As care coordinators, they may also provide education about the disease and limited individual, family, or group counseling. The social worker plays a broker role linking the person with dementia and family members to more extensive counseling services if needed.

Once services are in place, the care coordinator's role is to ensure that services continue to meet ongoing needs and that they are responsive to changing circumstances as the dementia progresses. The care coordinator role is frequently used by social workers

who are called on to work with persons with moderate dementia. Care coordination is also frequently needed in situations where informal caregivers can't assume these responsibilities or where they are unable or unwilling to provide day-to-day monitoring of care plans.

The care management role is assumed by social workers when their comprehensive assessments reveal that persons with dementia are severely impaired or when informal caregivers are unavailable or unwilling to provide the type of around-the-clock monitoring of the situation and the extensive day-to-day care that is often needed. In this role, social workers involve informal caregivers in the care planning and implementation process. In general, however, care managers help caregivers by putting services in place that remove some or all of the responsibility for day-to-day care of persons with dementia.

Kaplan (1996) points out that there are several different forms of care management. Medical care management was originally developed by health maintenance organizations and insurance companies to contain medical costs. Typically, medical care management emphasizes the provision of quality care at the lowest possible cost, coordination of care between providers and informal caregivers, and the utilization of benefit coverage to provide preventive services, health care maintenance services, and the management of chronic diseases. Social care management services typically help persons with dementia and their caregivers obtain needed social services such as Meals on Wheels and day care. Social care management may also include limited or extensive medical care management. Kaplan also mentions that there are mental health care management services that provide supportive care or rehabilitation and private geriatric care management provided to persons with dementia and their family members on a fee-for-service basis. These latter services are particularly useful for long-distance caregivers who have sufficient resources to pay for these services but who are not in a position to relocate to provide the necessary ongoing monitoring and day-to-day assistance that may be needed by the person with dementia.

Typically, in the care management role the social worker (1) completes a comprehensive assessment of the situation, (2) develops a care plan, (3) implements the plan by coordinating health and social service delivery from different providers and by providing services directly to both the caregiver and informal caregivers, (4) maintains regular and frequent contact with the person with dementia and informal care-

givers to ensure that appropriate care is delivered in a timely fashion and that adjustments to changing circumstances are made on an ongoing basis, and (5) advocates to close gaps and fill in needs that are not being fully met by the care plan. Overall, the focus of care management is to keep the person living at home for as long as possible in a safe and comfortable setting. When needs become too great, the care manager's role includes helping to place the person with dementia in a more sheltered environment such as assisted living or a special care unit in a nursing home that may better meet his or her needs.

Social workers' roles may include being members of interdisciplinary teams in outpatient and inpatient organizations designed to help persons with dementia. These include outpatient programs such as memory clinics designed to provide multidisciplinary assessment and care plans (often a geriatrician, nurse, and social worker team) to help caregivers maintain persons with dementia in community settings (see, e.g., Freed, Elder, Lauderdale, & Carter, 1999). These may also include social workers in home care agencies, adult day care centers, and other community agencies designed to support caregivers and persons with dementia. Social workers play vital roles in sheltered housing programs and nursing homes where they work with other team members to provide high-quality care to persons with advanced dementia. In their role as interdisciplinary team members, social workers frequently serve as care coordinators but may also take on consultation or care management roles.

INTERVENTION STRATEGIES

There are a wide variety of intervention strategies that can be used to help persons with dementia and their caregivers cope with the disease. These can be classified into strategies focused on prevention, remediation, and support. Although an extensive discussion of each of these types of intervention strategies is beyond the scope of this chapter, brief overviews are presented with references to more comprehensive resources for further reading.

The label "prevention" is not meant to imply that there are intervention strategies that can prevent or reverse the course of dementing illnesses. At this time, there are no such strategies. There are, however, intervention strategies that can slow the course of dementia and mitigate some of its harmful side effects.

There are now several drugs on the market that are helpful in slowing the course of the dementia in some

persons. For an overview of pharmacological treatment from a social work perspective, see Callaway (1998), but for up-to-date information about the latest medications to reach the market, a review of the results of recent clinical drug trials is necessary. Some reviews of the recent literature are written in language easily understood by practicing social workers and include medications not only to treat cognitive loss but also to treat depression, agitation, delusions, and hallucinations (e.g., Kawas, 2003). The social work role in pharmacology management is to help persons with dementia and their caregivers to obtain appointments with geriatricians, neurologists, and psychiatrists who can help them determine whether they are good candidates for medications useful in the treatment of symptoms of dementia. In general, it is thought that pharmacological agents to treat cognitive loss are most effective if they are administered in early dementia. Therefore, social workers can play an important role in urging persons with dementia and their caregivers to have medication reviews as early as possible. Social workers can also play an important role by helping persons with dementia to consistently take medications as prescribed.

Another type of preventive intervention consists of cognitive stimulation programs. Early attempts at cognitive stimulation include reality orientation, reminiscence, and remotivation therapy. The efficacy of these approaches for persons with dementia is limited (the evidence is discussed in several reviews; e.g., Beck, 1998; Kasl-Godley & Gatz, 2000; Miller & Morris, 1993; Spector, Davies, Woods & Orrell, 2000; Spector, Orrell, Davies, & Woods, 1998a, 1998b, & 2001; Van der Linden, Juillerat, & Adam, 2003; Zarit & Zarit, 1998). More recent cognitive stimulation and training programs that have focused on cognitive deficits in episodic memory, language, and numerical skills have also been attempted (for a review, see Van der Linden et al., 2003).

Although social workers sometimes become involved in cognitive training programs, most of their involvement has been limited to cognitive stimulation programs, such as reality orientation and reminiscence programs, and to efforts designed to structure the environment of persons with dementia by providing external cognitive aides to enhance memory. These interventions include suggesting specific places to store keys and other items used daily, medication organizers, the use of labels and color coding, and similar memory aides.

Apathy and lack of engagement are major problems for persons with dementia, particularly during

middle and late stages of the disease, problems that can be vexing to family caregivers. Programs to maintain communication and to stimulate interaction have been developed (e.g., Toseland & McCallion, 1998). Table 10.2 presents some general strategies for maintaining communication. Other strategies for maintaining communication with persons with dementia at early, moderate, and severe stages of the disease can be found in Toseland and McCallion.

Memory albums and memory charts can be used to stimulate reminiscence and life review and to engage persons with dementia whose language abilities may be quite limited. Memory albums are small photo albums with pictures of important people, places, and events from the distant past that are particularly meaningful to the person with dementia. Simple words describing each picture are placed underneath the picture or on the opposite page of the photo album. Memory charts are larger boards that contain photographs and simple words in different panels that can be placed where a person with dementia spends a considerable amount of time. Memory albums and memory charts are particularly effective for engaging persons with moderate and severe dementia (for more information, see Toseland & McCallion, 1998).

Remedial intervention strategies include those that are focused on emotional and psychological problems and personality changes that are frequently

observed in early- and middle-stage dementia as well as agitation and behavior problems that are commonly encountered in moderate to severe stages of dementia. Emotional and psychological problems such as depression, anxiety, delusions, and hallucinations (more common in later-stage dementia) can be treated effectively with psychotropic medications, but support and reassurance also play an important role.

A useful theoretical framework to reduce emotional and psychological problems is the Progressively Lowered Stress Threshold (PLST) model originally developed by Hall and Buckwalter (1987). Adapted from stress adaptation and coping models, the PLST model identifies clinical triggers such as fatigue, change in routine, inappropriate stimulation, and internal and external demands that exceed the capacities of the person with dementia. According to PLST, these triggers can lead to a sudden decline in functional ability. The PLST model recommends establishing daily routines, making environmental modifications, minimizing fatigue, managing inappropriate stimuli, minimizing affective responses, decreasing excessive demands, limiting physical triggers, and improving communication and behavior management strategies (Buckwalter et al., 1999; Gerdner, Hall, & Buckwalter, 1996; Hall & Laloudakis, 1999; Toseland & McCallion, 1998).

Most remedial approaches to agitation and behavior problems rely on some form of behavioral

analysis, with caregivers becoming behavior detectives identifying when problems occur and the antecedents and consequences of behavior. The idea is to find out precisely when behaviors occur and to try to determine the underlying needs that are not being met. Caregivers can be encouraged to identify antecedents that may stimulate the behavior and consequences that maintain the behavior. Based on these data, the environment can often be modified so that the comfort of the person with dementia is restored. Simple strategies such as making the room cooler or warmer, engaging the person in an activity, reducing noise or other stimulation, and reassurance and attention to positive behaviors often help reduce behavior problems.

Some agitated behaviors and behavior problems may be the result of poor pain management. Therefore, a careful review of physical causes (e.g., arthritis pain) for such behavior problems should be undertaken before behavioral intervention programs are initiated. A number of helpful books give directions for how to handle a variety of specific behavior problems, including but not limited to apathy, combativeness, food refusal, insomnia, resistance to care, and wandering (e.g., Hoffman & Platt, 1991; Mahoney, Volicer, & Hurley, 2000; Rau, 1993). There are also many excellent articles and book chapters that address apathy as well as behavioral and sleep problems (e.g., Cohen-Mansfield, 2000; Engelman, Altus, & Mathews, 1999; McCurry, Logsdon, Vitiello, & Teri, 1998). Recently, a CD has been created to help social workers and allied professionals to address problem behaviors and promote positive behaviors (McCallion, Lacey, & Toseland, 2003).

In our haste to address agitation and behavior problems and to prevent further declines in memory and communication, support strategies are sometimes neglected. Social workers, however, have a vital role to play in supporting persons with dementia and caregivers through the inevitable decline to death that is the ultimate result of dementia. In the early stages of dementia, support may take the form of affirming the coping abilities of persons with dementia and their caregivers. In later stages, reassurance and gentle touch can be used, and strategies to continue verbal and nonverbal engagement can be implemented by continuing to engage and stimulate whatever aspects of long-term memories and language abilities remain intact. Supportive interventions also include keeping caregivers and persons with dementia educated about the stages of the disorder new developments in care, helping caregivers and persons with

dementia to obtain needed services and resources, and helping them plan for the future. For family members and other caregivers, supportive interventions may include family care planning and problem-solving meetings, supportive counseling and reassurance, and assistance with community and institutional options for care as dementia advances.

CONCLUSIONS

Because it affects many different aspects of emotional, physical, mental, social, and spiritual functioning, dementia is a very challenging disease to cope with both for the person afflicted and for family caregivers. Social workers are called on to play a vital role in supporting and assisting persons with dementia and their family caregivers in many different community and institutional settings. During assessment and intervention, it is essential for social workers to take a broad view of the whole person, considering the impact of dementia on the biopsychosocial and environmental functioning of the person with dementia and their informal caregivers. The social work profession is ideally suited for this role, working alone and in conjunction with other disciplines to help persons with dementia and their family caregivers cope with the devastating impact of this disease.

REFERENCES

- American Psychiatric Association. (2000). *Diagnostic and statistical manual of medical disorders* (4th ed., text rev.). Washington, DC: Author.
- Beck, C. K. (1998). Psychosocial and behavioral interventions for Alzheimer's disease patients and their families. *American Journal of Geriatric Psychiatry*, 6(2), S41-S48.
- Buckwalter, K. C., Gerdner, L., Kohout, F., Hall, G. R., Kelly, A., Richards, B., et al. (1999). A nursing intervention to decrease depression in family caregivers of persons with dementia. *Archives of Psychiatric Nursing*, 13(2), 80-88.
- Callaway, J. (1998). Psychopharmacological treatment of dementia. *Research on Social Work*, 8(4), 452-474.
- Cohen-Mansfield, J. (2000). Nonpharmacological management of behavioral problems in persons with dementia: The TREA model. *Alzheimer's Care Quarterly*, 1(4), 22-33.
- Cummings, S. (1996). Spousal caregivers of early stage Alzheimer's patients: A psychoeducational support

TABLE 10.2. General Communication Guidelines

1. Begin all communications by first ensuring that you are relaxed and are conveying that you are relaxed. One technique to get rid of stress has been called deep breathing. This is a method of breathing for relaxation. This technique should not take more than approximately two minutes.
 - Concentrate on one spot in your stomach.
 - Concentrate on the flow of your breath as you inhale.
 - Concentrate on the flow of your breath as you exhale.
 - Focus on your breathing as you repeat this procedure several times slowly.
 - Visualize your breath going in through your nose, into the center of your body, and out again.
2. Reduce background noise and other distractions and stimuli.
3. Ensure that there is adequate lighting for the person with dementia or move to a brighter location.
4. If the person with dementia usually wears glasses or a hearing aid, try to have the person with dementia use them. However, do not argue if the person with dementia does not want to wear them.
5. Speak in a slow, calm, respectful manner and keep the pitch of your voice low.
6. Avoid speaking to the person with dementia as if he or she is a child.
7. Even when the person with dementia has severe language problems, never assume that he or she does not understand you. Always assume that he or she will understand at least some of the information you are attempting to convey.
8. Do not talk about the person with dementia with others as if the person with dementia is not there.
9. Sit at the same eye level as the person with dementia to show that your attention is focused on him or her.

- group model. *Journal of Gerontological Social Work*, 26(3/4), 83–98.
- Downs, M. (1999). How to tell? Disclosing a diagnosis of dementia. *Journal of the American Society on Aging*, 23(3), 30–34.
- Engleman, K., Altus, D., & Mathews, R. M. (1999). Increasing engagement in daily activities by older adults with dementia. *Journal of Applied Behavior Analysis*, 32, 107–110.
- Folstein, M., Folstein, S., & McHugh, P. (1975). Minimal state: A practical method for grading the cognitive state of patients for the clinicians. *Journal of Psychiatric Research*, 12, 189.
- Freed, D., Elder, W., Lauderdale, S., & Carter, S. (1999). An integrated program for dementia evaluation and care management. *The Gerontologist*, 39(3), 356–361.
- Fuller, G., Baker, P., Larimore, W., Allman, R., Martin, J., & Parker, M. W. (2003). Helping military families establish a medical care plan for an elderly parent. *Geriatric Care Management*, 13(1), 16–22.
- Galasko, D. (1996). Pharmacological approaches to behavioral symptoms in Alzheimer's disease. In Z. Khachaturian & T. Radebaugh (Eds.), *Alzheimer's disease cause(s), diagnosis, treatment, and care* (pp. 249–255). Boca Raton, FL: CRC Press.
- Gauthier, S. (2003). Clinical aspects. In R. Mulligan, M. Van der Linden, & A. Juillerat (Eds.), *The clinical management of early Alzheimer's disease: A handbook* (pp. 21–34). Mahwah, NJ: Lawrence Erlbaum.
- Gerdner, I. A., Hall, G. R., & Buckwalter, K. C. (1996). Caregiver training for people with Alzheimer's based on a stress threshold model. *IMAGE: Journal of Nursing Scholarship*, 28(3), 241–246.
- Hall, G. R., & Buckwalter, K. C. (1987). Progressively lowered stress threshold: A conceptual model for care of adults with Alzheimer's disease. *Archives of Psychiatric Nursing*, 1(16), 399–406.
- Hall, G. R., & Laloudakis, D. (1999). A behavioral approach to Alzheimer's disease: The progressively lowered stress threshold model. *Advance for Nurse Practitioners*, 7(7), 39–44, 81.
- Health Care Interactive. (2001). *Alzheimer's caregiving strategies* [CD-ROM]. Washington, DC: Department of Veteran's Affairs. Global Multimedia.
- Hoffman, S., & Platt, C. (1991). *Comforting the confused: Strategies for managing dementia*. New York: Springer.
- Kane, R., Ouslander, J., & Abrass, I. (2004). *Essentials of clinical geriatrics* (5th ed.). New York: McGraw-Hill.
- Kaplan, M. (1996). *Clinical practice with caregivers of dementia patients*. Washington, DC: Taylor & Francis.
- Kasl-Godley, J., & Gatz, M. (2000). Psychosocial interventions for individuals with dementia: An integration of theory, therapy, and a clinical understanding of dementia. *Clinical Psychological Review*, 20, 755–782.
- Katzman, R. (2001). Epidemiology of Alzheimer's disease and dementia: Advances and challenges. In K. Iqbal, S. Sisodia, & B. Winblad (Eds.), *Alzheimer's disease: Advances in etiology, pathogenesis and therapeutics* (pp. 11–21). Chichester, England: Wiley.
- Kawas, C. (2003). Early Alzheimer's disease. *New England Journal of Medicine*, 349(11), 1056–1063.
- Kennedy, G. (2000). *Geriatric mental health care: A treatment guide for health professionals*. New York: Guilford Press.
- Koenig, H., McCullough, M., & Larson, D. (2001). *Handbook of religion and health*. New York: Oxford University Press.
- Kuhn, D. (1999). *Alzheimer's early stages: First steps in caring and treatment*. Alameda, CA: Hunter House.
- Mahoney, E., Volicer, L., & Hurley, A. (2000). *Management of challenging behaviors in dementia*. Baltimore, MD: Health Professions Press.
- McCallion, P., Lacey, D., & Toseland, R. (2003). *Promoting positive behaviors. Excellence in Aging Services* [CD-ROM]. Albany: University at Albany, State University of New York.
- McCurry, S., Logsdon, R., Vitiello, M., & Teri, L. (1998). Successful behavioral treatment for reported sleep problems in elderly caregivers of dementia patients: A controlled study. *Journal of Gerontology: Psychological Sciences*, 53B(2), 122–129.
- McInnis-Dittrich, K. (2002). *Social work with elders: A biopsychosocial approach to assessment and intervention*. Boston: Allyn & Bacon.
- Miller, E., & Morris, R. (1993). *The psychology of dementia*. Chichester, England: Wiley.
- Mulligan, R., Van der Linden, M., & Juillerat, A.-C. (2003). *The clinical management of early Alzheimer's disease*. Mahwah, NJ: Lawrence Erlbaum.
- Myers, D., Harris, H., Klemmack, D., & Parker, M. (2004). A feasibility study of a parent care planning model with two faith-based communities. *Journal of Religion, Spirituality, and Aging* 17(1/2), 39–53.
- Parker, M. W., Baker, P., & Allman, R. (2002). A life space approach to the functional assessment of the elderly. *Journal of Gerontological Social Work*, 35(4), 35–55.
- Parker, M. W., Roff, L., Myers, D., Martin, J., Toseland, R., Fine, C., et al. (2004). Parent care and religion: A faith-based intervention model for caregiving readiness of congregational members. *Journal of Family Ministry*, 17(4), 51–69.
- Rau, M. (1993). *Coping with communication challenges in Alzheimer's disease*. San Diego: Singular.
- Reisberg, B., Ferris, S., & deLeon, M. (1982). The global deterioration scale for assessment of primary degenerative dementia. *American Journal of Psychiatry*, 139, 1136.
- Roff, L., Klemmack, D. L., Parker, M. W., Baker, P., & Allman, R. (2005). Spirituality and depression in African American and White elders. *Journal of Human Behavior and the Social Environment*, 10(1), 175–211.
- Roff, L. L. & Parker, M. W. (2003). Spirituality and Alzheimer's disease care. *Alzheimer's Care Quarterly*, 4(4), 267–270.
- Spector, A., Davies, S., Woods, B., & Orrell, M. (2000). Reality orientation for dementia: A systematic review of the evidence of effectiveness from randomized controlled trials. *The Gerontologist*, 40, 206–212.
- Spector, A., Orrell, M., Davies, S., & Woods, B. (1998a). *Reality orientation for dementia: A review of the evidence for its effectiveness* [Cochrane Library 4]. Oxford: Update Software.
- Spector, A., Orrell, M., Davies, S., & Woods, B. (1998b). *Reminiscence therapy for dementia: A review of the evidence for its effectiveness* [Cochrane Library 4]. Oxford: Update Software.
- Spector, A., Orrell, M., Davies, S., & Woods, B. (2001). Can reality orientation be rehabilitated? Development and piloting of an evidence-based programme of cognition-based therapies for people with dementia. *Neuropsychological Rehabilitation*, 11, 377–397.
- Tobin, S. (1999). *Preservation of the self in the oldest years*. New York: Springer.
- Toseland, R., Derico, A., & Owen, M. (1984). Alzheimer's disease and related disorders: Assessment and intervention. *Health and Social Work*, 9(3), 212–228.
- Toseland, R., & McCallion, P. (1998). *Maintaining communication with persons with dementia*. New York: Springer.
- Toseland, R., Smith, G., & McCallion, P. (1995). Supporting the family in elder care. In G. C. Smith, S. S. Tobin, E. A. Robertson-Tchabo, & P. W. Power (Eds.), *Strengthening aging families: Diversity in practice and policy* (pp. 3–24). Newbury Park, CA: Sage.
- Toseland, R., Smith, G., & McCallion, P. (2001). Helping family caregivers. In A. Gitterman (Ed.), *Handbook of social work practice with vulnerable and resilient populations* (2nd ed.; pp. 548–581). New York: Columbia University Press.
- Toseland, R., Smith, T., & Zinoman, M. (in press). Social work practice with family caregivers for frail older persons. In M. J. Holosko & P. A. Taylor (Eds.), *Social work practice in health care settings* (2nd ed., pp. 229–252). Toronto: Canadian Scholars Press.
- Van der Linden, M., Juillerat, A., & Adam, S. (2003). Cognitive intervention. In R. Mulligan, M. Van der Linden, & A. Juillerat (Eds.), *The clinical management of early Alzheimer's disease* (pp. 169–233). Mahwah, NJ: Lawrence Erlbaum.
- Weiner, W. (1991). *The dementias: Diagnosis and management*. Washington, DC: American Psychiatric Press.
- Yale, R. (1995). *Developing support groups for individuals with early-stage Alzheimer's disease: Planning, implementation, and evaluation*. Baltimore: Health Professions Press.
- Zarit, S., & Zarit, J. (1998). *Mental disorders in older adults: Fundamentals of assessment and treatment*. New York: Guilford Press.