Protecting Personhood and Achieving Quality of Life for Older Adults With Dementia in the U.S. Health Care System

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Objective: As the numbers of persons diagnosed with Alzheimer’s disease and related dementias increase, many questions arise pertaining to the quality of life of those diagnosed and the health care system as it relates to the provision of quality care for this population. This article examines the health disparities among older adults with dementia, emphasizing the protection of personhood and quality of life, along with a review of the barriers to health care access and utilization of persons living with dementia. Method: This literature review utilized electronic databases and other documents. Results: The findings suggest that while progress has been realized toward protecting personhood and achieving an improved quality of life among older adults with dementia in the U.S. health care system challenges still exist. Discussion: The implications of current and future public policy, avenues for further research, and strategies by which the health care community may better serve persons with dementia are outlined.

Keywords: older adults; dementia; personhood; quality of life; health disparities

It is now more than 100 years since Alzheimer’s disease (AD) was first described in the medical literature. Increasingly, this disease and related disorders affect the quality of life (QOL) of millions of persons in the United States and the health care system that is designed to serve them. AD and other irreversible dementias (e.g., vascular dementia, mixed dementia, dementia with Lewy bodies and frontotemporal dementia) present a unique set of difficulties for persons diagnosed, their family members, and their caregivers. In addition, these disorders among older adults pose
a significant challenge to a health care system, which by its very design is better suited to the care of those with acute illnesses and conditions. This review explores the current system of health care for persons with dementia (PWDs) and factors that contribute to QOL and shape the experience for the many millions of Americans presently living with dementia and their caregivers. Health care disparities for this vulnerable population are addressed, and the effects of existing public policy are outlined. Finally, strategies to address the issues identified, specifically those that will protect one’s personhood and QOL, are discussed and conclusions are drawn.

It is estimated that the prevalence of AD alone in the United States is 5.1 million. The majority of persons diagnosed are older adults, aged 65 and older, and this population is the primary focus of this review. However, it must be noted that there may be as many as 500,000 persons diagnosed with early-onset AD, aged younger than 65, among these figures (Alzheimer’s Association, 2007). As the incidence of AD increases with age, the rapidly aging population in the United States means that these numbers are set to increase unless an effective treatment or prevention is found. The diagnosis of AD or a related form of irreversible dementia has profound implications and consequences for both the person diagnosed and their informal support system, including family members and friends. These disorders are complex with biological, social, and psychological effects. The effects are further complicated by the ever-changing health and social needs that evolve as the person diagnosed moves from independence to total dependency. To be diagnosed with dementia, individuals cope with deficits in at least two essential cognitive functions: (a) memory, (b) speech and the process of communication, (c) the ability to plan, reason, and perform complex tasks, and (d) the processing and interpretation of visual information (Alzheimer’s Association, 2007). The process of dementia, although often gradual, is progressive and ultimately disabling (Small et al., 1997). Those affected confront not only an ultimately fatal disease but also a progressive deterioration that may follow an uncertain, diverse, and often chronic course. The cognitive decline leads to worsening functional impairment and eventual death for those affected.

Despite some differences between the courses of the various forms of irreversible dementias, all involved face the challenge of balancing the maintenance of autonomy and independence. Many PWDs strive to be independent for as long as they are able while also negotiating and adapting to changes that will eventually lead to total dependency. The care needed by PWDs necessitates the blending of both medical and social care. The struggle of people with dementia to adapt to their diagnosis and increasing losses and retain a sense of purpose and meaning must also be acknowledged.
by the health care community. Indeed, Scholl and Sabat (2008) caution that the manner in which PWDs are treated by others can have powerful effects on their “(a) subjective experience, (b) ability to display cognitive abilities that remain intact, (c) ability to meet the demands of everyday life, and (d) QOL and ability to live meaningfully” (p. 104).

Therefore, PWDs and their caregivers have a complex assignment before them. They must negotiate the often fragmented and complex systems of health care and social and community services while attempting to maintain their QOL. However, there are many challenges involved in this task. First and foremost, older adults with dementia must combat the harmful effects of the societal negative stereotyping of both ageism and the disease itself (Clark, 2005; Scholl & Sabat, 2008). Treatment and care decisions can be complex for the management of the dementia itself, as can be the influence of a dementia diagnosis on the choice of treatments for coexisting pathologies (Sloan, Trogdon, Curtis, & Schulman, 2004). Clark (2005) discussed the dangers of attributing diagnostic labels, such as AD, that can belie the diversity and individuality of older adults and their medical needs. QOL is an important factor throughout the disease for both the persons diagnosed and their caregivers in terms of physical, cognitive, and mental health. Therefore, all these issues must be addressed in combination when considering the current system of health care for older adults with dementia and in maintaining a focus on the personhood of the individual diagnosed.

Increasing the complexity of this discussion is the question as to the appropriateness of including persons diagnosed with mild cognitive impairment (MCI) under the category of PWDs. Unquestionably, the diagnosis of MCI has profound implications for both the person diagnosed and the health care community. Discussions pertaining to the labeling of persons with this diagnosis leads to many ethical considerations as to the value of early diagnosis, the value of the labeling of persons within this category for themselves and the medical community, and the effects of this diagnosis on the person diagnosed (Whitehouse & Moody, 2006). Therefore, for the purposes of this article, although the focus is older adults diagnosed with an irreversible form of dementia, it is recognized that this categorization is complex and must consider several factors: (a) the length of time a person has experienced symptoms, (b) the level of cognitive impairment, and (c) the presence of comorbid conditions.

Health Disparities

Health disparities have been defined as differences in health, or in the factors that can influence health, among disadvantaged social groups who
consequently experience poorer health than those who belong to groups with more social advantages. Disparities can occur within groups of varying levels of social advantage as well as between these groups (Braveman, 2006). In the context of health disparities, PWDs often belong to other groups that have been traditionally viewed as socially disadvantaged, most commonly older adult status. Older adults have been shown to exhibit patterns of cumulative disadvantage whereby patterns of systematic disadvantage and lack of opportunity throughout their lives accumulate to shape their experience in later life (Quadagno, 2008).

A theoretical explanation of this disadvantage that can be applied to health status in later life is known as multiple jeopardy. That is, older adults who belong to more than one group at risk of lower social status in later life such as women, minority groups, and those of lower socioeconomic status also are at increased risk of illness and disadvantage in later life (Novak, 2006). Although, the evidence surrounding this concept is controversial (Moody, 2006), there is evidence that inequality in health status in later life can be influenced by race and socioeconomic status (House et al., 1994; Kelley-Moore & Ferraro, 2004) and that older women are often placed among the least advantaged older adults (Moody, 2006). Existing or newly developed chronic diseases have also been shown to have a significant impact on the financial well-being of older adults (Lee & Kim, 2003).

In addition, the presence of multiple pathologies may blur the distinctions between symptomatology and the cognitive decline, associated with dementia, may make it difficult for the PWDs to identify and report symptoms. Indeed, McCormick et al. (1994) found that their sample of 154 PWDs were less likely to report common symptomatology, unrelated to cognitive impairment, than their counterparts without cognitive loss. Concurrent medical conditions may even serve to worsen the symptomatology of dementia. Thus, it is important that a holistic approach to the care of PWDs be undertaken (Kitwood, 1997). The dementia itself may occur in association with other diseases that have increased prevalence in later life such as dementia associated with Parkinson’s disease or vascular disease (Small et al., 1994). When considering disease management programs for frail older adults, Levine et al. (2006) emphasize that disease management in the frail elderly population is more than the sum of the programs targeting the diseases that affect their lives, thus illustrating the complexity of health care needs. The importance of multidisciplinary care, care management, acknowledgement of the contribution of informal caregivers, the heterogeneous nature of health and social needs, and mental and cognitive health needs was also highlighted by the authors. Prior studies have recognized the need for improved medical,
long-term, and social care for those with dementia (Chodosh et al., 2007; Schubert et al., 2006; Sloan et al., 2004; Warchol, 2004).

As outlined in a consensus statement by the American Association of Geriatric Psychiatry, the Alzheimer’s Association, and the American Geriatrics Society, many PWDs receive inadequate care and persons with AD often fall through the gaps between psychiatric and medical services. The authors concluded that the precise role of these services in the management of AD has not been defined (Small et al., 1997). A recent study by Laditka, Laditka, and Cornman (2005) reported that men with AD have a higher risk of mortality on hospitalization than males without AD, for several conditions including acute myocardial infarction, congestive heart failure, pneumonia, and gastrointestinal hemorrhage. However, the women in the study with AD generally demonstrated lower mortality risks than their male counterparts. Conversely, PWDs admitted to nursing homes had lower rates of both mortality and infections than their peers without a dementia diagnosis (Magaziner et al., 2005). In the light of this finding, the authors suggested further research is needed to explore the optimum setting for the provision of the most cost-effective care for PWDs.

In their exploration of quality of care among 387 caregiver–PWD pairs in three different health care systems, Chodosh et al. (2007) reported that the majority of health care providers in their study did not adhere to existing recommended guidelines for practice and that the care provided could be considerably improved. The authors stated that cognition and language skills, decreased life expectancy, and the fact that PWDs are often excluded from randomized clinical trials of therapies (not specifically targeted at dementia and therefore unforeseen effects of treatments are possible) should all be considered when treating comorbid illnesses in PWDs. Therefore, when dementia occurs in combination with other physical or mental health disease processes, the impact of additional health disparities that develop as a result of co-occurring diseases is great. It must also be remembered that quality care for PWDs cannot involve curative measures for the dementia at this present time, and so the framework for health care decisions is developed in this context. At different stages of the dementia disease process, the focus on dementia-specific care may change (i.e., it may take priority over other health concerns in the severe stage of the diseases; Chodosh et al., 2007).

Although the focus of medical and social interventions for PWDs must be based on realistic expectations, members of the medical community must also be aware of their own prejudices and misconceptions to provide care that is responsive to the holistic needs of the person diagnosed
For instance, recent research from Europe has shown that the stigma associated with dementia leads to discrepancies between accepted and actual levels of timely diagnosis and clinical practice because of physicians’ perception of the effects of disclosing diagnosis and of having little to offer patients with such diagnosis (van Hout, Vernooij-Dassen, Bakker, Blom, & Grol, 2000; Vernooij-Dassen et al., 2005). However, if there is a call for early diagnosis, this must be supported by the health care community. For instance, Pratt, Clare, and Kirchner (2006), in their study of 30 health care professionals’ perceptions of services for persons with early-stage dementia in the United Kingdom, found that the participants identified many factors necessary to meet needs of these persons. They identified the need for more information and support in regard to coming to terms with the diagnosis, access to medical support and services to enable the preservation of independence and to prevent crisis situations, and services appropriate for ethnic minorities and persons living alone. Although no comparative studies conducted in the United States were found, it is clear that practitioner attitudes can greatly affect the quality of care and QOL of PWDs.

Therefore, older adults with dementia are at risk of health disparities because of their generational membership and their diagnosis. The aging process itself may further compound health disparities experienced by persons with other disease processes as they age, such as cardiovascular disease and diabetes (Ai & Carrigan, 2007; Black, 2002) and lead to poorer health outcomes. A diagnosis of dementia for an older adult often means higher out-of-pocket health care expenses and a greater need for long-term care services and informal care than needed for older adults without a dementia diagnosis and older adults with other chronic illnesses (Alzheimer’s Association, 2007). In addition, coexisting medical conditions may contribute to a higher mortality rate in those with dementia. The number of deaths attributable to AD is increasing; it is acknowledged that this number may be underreported and not entirely reflective of the real impact of the disease. Deaths from AD increased by 32.8% between 2000 and 2004, whereas deaths from the other common diseases of later life such as heart disease, some forms of cancer, and stroke declined during the same period (Alzheimer’s Association, 2007). The Alzheimer’s Association (2006) reported that the majority of dementia-related deaths (67%) occur in nursing homes and few of these persons (11%) are referred to hospice care. In addition, nonpalliative care interventions such as feeding tubes and restraints are common among nursing home residents with dementia. Recent literature illustrates that a diagnosis of dementia may occur not in isolation but
in relation to other health conditions. It is increasingly common for PWDs to develop, or have preexisting, co-occurring morbidities, and many older adults with dementia also have a high level of comorbidities (Schubert et al., 2006).

Routine medical care for those with dementia can be complicated by the person’s ability, or inability, to make decisions, to comply with treatment regimes, and to report symptomatology and adverse effects (Brauner, Muir, & Sachs, 2000). In their study of Medicare recipients with a diagnosis of AD, Bynum et al. (2004) found that 60% had hypertension, 30% had coronary artery disease, 28% had congestive heart failure, 26% had osteoarthritis, 21% had diabetes, and 18% were depressed. The analysis of Schubert et al. (2006) concluded that PWDs, cared for by primary care physicians, have a rate of comorbidities that is high and not significantly different from that of their peers without dementia. The authors stated that the coexisting dementia diagnosis can lead to an increased complexity in the medical management of these persons and that it is important that comprehensive, appropriate models of care, which as yet do not fully exist, be developed. They concluded that such models will serve to improve the quality of health care received by PWDs in the primary care setting.

A much neglected facet of the discussion of quality of health care, and indeed QOL for PWDs, is the voice of the PWDs themselves. Prior research has tended to focus mainly on the needs of the health care practitioner or the informal caregiver. It is encouraging that more recent research has begun to explore this discussion from the perspective of the PWDs (Cahill et al., 2004; Steeman, Godderis, Grypdonck, De Bal, & Dierckx de Casterlé, 2007) and even use the client perspective to evaluate services, such as adult day care, for PWDs (Murphy, 2002). For example, Murphy (2002) found that among clients participating in an adult day care and befriending service in Scotland, PWDs can communicate their wishes as to their need for support. They wished not just to be passive recipients of their care but also to actively contribute and participate for as long as they were able. Although this was a very situation-specific, qualitative study with a small number of participants (n = 6) this work gives us an insight into the benefits of including PWDs in the earlier stages of the disease in evaluations of both services and factors that affect their QOL.

**QOL and PWDs**

As Warchol (2004) stated, the focus of the management of dementia and care of persons diagnosed must be interdisciplinary, and the primary focus
will often be the maintenance and enhancement of remaining capabilities rather than rehabilitation. This is in contrast to the traditional medical model of care, where QOL may be a low priority as the system focuses on medical needs. Engel (1982) described the traditional biomedical model of care as one that is disease orientated and separates the body from the soul. Clearly, the care of PWDs concerns far more than the physical aspects of the disease. Consideration of biopsychosocial factors and an emphasis on QOL are essential. PWDs have been shown to rate their health status and overall well-being in terms of concepts such as happiness and enjoyment of life and their health in positive terms (Smith et al., 2005). However, the existing body of knowledge as to the QOL of PWDs highlights the difficulties in accurately defining and measuring this concept among this population and identifies discrepancies between informant reports of QOL of PWDs and the their own assessment (Ettema et al., 2005; Ready, Ott, & Grace, 2004; Scocco, Fantoni, & Caon, 2006; Steeman et al., 2007).

Selai and Trimble (1999) discussed that QOL is becoming increasingly important as an outcome measure in the evaluation of new treatments and that the assessment of such a concept in a person with cognitive deficits is complex and difficult. Self-reported QOL of PWDs is difficult to assess because of factors such as inaccurate evaluations, inaccurate understanding, or a distortion of reality (Ettema et al., 2005). Several factors have been identified that can influence both proxy and self-assessed QOL in PWDs. Factors influencing caregiver proxy reports of QOL include caregiver depression, the caregiver’s assessment of the mental status of the PWD, the relationship between the caregiver and the PWD, levels of stress in the domains of perception of disturbance to routines and social functioning, and whether the PWD lives with the caregiver (Burgener & Twigg, 2002; Frank et al., 2006; Logsdon, Gibbons, McCurry, & Teri, 2002; Ready et al., 2004, Scocco et al., 2006). However, among the PWD factors identified as influencing their perception of QOL and of living with dementia were depressive symptomatology, frequency of pleasant events, physical functioning, and adaptive abilities (Ettema et al., 2005; Logsdon et al., 2002). Perhaps it is surprising that several studies found that PWDs seemed to rate their QOL as good as, or even better, than that of the control groups (Ready et al., 2004; Scocco et al., 2006). Ettema et al. (2005) found that proxies may underestimate the adaptive capabilities of the PWDs and postulated that this adaptive ability may allow PWDs to rate their QOL as high even in the face of cognitive and functional losses. Thus, it appears that functional ability and the ability to remain socially active are important factors contributing to the QOL of PWDs. It seems appropriate, therefore, that
health care interventions support and maximize the abilities of the PWDs within the realms of safety.

Ettema et al. (2005) acknowledged the adaptive capabilities of those with chronic diseases that can often affect their perception of QOL. They recommended that this be considered when assessing this concept among this population at all stages of the disease. The domains identified as common features utilized in assessing QOL of PWDs are social relations and interactions, self-esteem, and affect. A definition of dementia-specific QOL that reflects the importance of this adaptive function was offered: “The multidimensional evaluation of the person-environment system of the individual, in terms of adaptation to the perceived consequences of the dementia” (Ettema et al., 2005, p. 366). Therefore, it is apparent that QOL in PWDs is a complex phenomenon, inclusive of social, physical, and cognitive components. Care that focuses on isolated domains of this concept may be less than optimal for the person diagnosed.

Therefore, social contacts play an important role in determining QOL for both PWDs and their caregivers (Burgener & Twigg, 2002; Ettema et al., 2005). It is often difficult for PWDs to maintain their social roles and social interactions as the disease progresses, and they often need assistance from others to achieve this balance. For instance, Burgener and Twigg (2002) found that the number of social contacts PWDs had and their frequency of participation in positive experiences were both protective against depression and predictive of QOL. They found that the caregivers’ perception of disturbance to routine and social functions could negatively affect the behavior and functional abilities of the PWDs. Thus, it is important that PWDs have support in maintaining their social contacts as they are able. This support might be practical in nature (i.e., transportation or companionship) or might be in the form of assistance to find or maintain activities that allow them to use their remaining abilities or adapt activities that are becoming difficult or stressful.

In summary, QOL in PWDs has been identified as an important concept that may affect individuals’ ability to focus on their remaining functional abilities and to maintain prior interests (Logsdon, 2002). PWDs are faced with the task of having realistic expectations for the future and maintaining a sense of self and continuity. The importance of maintaining a sense of self and personhood among PWDs has been highlighted by the work of Sabat (2002). The author described how a sense of selfhood is maintained by persons with AD in their communication of their personal identity (Self 1), attributes (Self 2), and their socially presented selves (Self 3). To maintain our socially presented self, the cooperation of others must be enlisted. Therefore, it is clear that interactions with others can positively or negative...
affect the ability of PWDs to maintain and communicate their sense of self. Indeed, Sabat, Fath, Moghaddam, and Harré (1999) identified the importance of support in maintaining this sense of Self 3 to the self-esteem of persons with AD. Loss of self-esteem can be perpetuated by the failure to recognize the social self of PWDs and result in a focus on lost abilities and defects. Therefore, the authors concluded that the maintenance of self-esteem, decreasing perceptions of being a burden of others, and decreasing anxiety can be facilitated by others in allowing PWDs to express and maintain their sense of self and personhood. Ultimately, their voice will be heard with respect to their health care needs and expectation.

Barriers to Health Care Access and Utilization

Barriers to health care access and utilization can further promote health disparities for vulnerable or at-risk populations. Barriers to health care utilization among PWDs are multiple and varied and include social and cultural factors. Prior research has identified many factors that may influence health care received by PWDs that range from policy issues and reimbursement systems to end-of-life and nursing home care (Brauner et al., 2000; Luchins & Hanrahan, 1993; Newcomer, Fox, & Harrington, 2001; Sloan et al., 2004). People with dementia need services and support from the health care community during all stages of the disease and this care must be provided in a variety of settings. The research of Steeman et al. (2007) yielded an in-depth insight into the challenges that PWDs face in living with the disease. This work revealed the complexities that PWDs face as they begin to adapt to their diagnosis and changing abilities and their struggle to balance self-value and feelings of worthlessness. Therefore, it is the responsibility of the health care community to assist persons diagnosed in this adaptation, to facilitate their access to the appropriate level of care and support necessary at each stage or challenge of the disease, and to assist them in maintaining their optimal QOL in the face of an incurable and debilitating disease. These tasks do not always fit well into the existing medical structure. Three barriers to health care access and utilization are highlighted: (a) the structure of the current health care systems, (b) learning needs of health care professionals, and (c) the perceived social stigma of dementia.

The Structure of the Current Health Care Systems

As the Alzheimer’s Association (2006) highlighted, “Alzheimer’s disease is the most expensive uninsured illness older Americans are likely to
face” (p. 12). In comparison to older adults without a dementia diagnosis, the costs of care are higher (Chodosh et al., 2007). In 2005, the financial costs to Medicare for those with AD and other dementias were $91 billion and Medicaid costs for nursing home care were $21 billion. In addition, persons diagnosed and their families bear many out-of-pocket expenditures, in addition to caregiver costs from lost productivity (Alzheimer’s Association, 2007). Therefore, policies and programs that determine reimbursement systems for care of PWDs can greatly affect options for care for diagnosed individuals, dependent on their socioeconomic status. The majority of PWDs are Medicare beneficiaries, and Medicaid is available for eligible individuals to meet some long-term care needs. However, there are many identified limitations in these two systems that jeopardize the health care utilization of older adults with dementia, such as the fact that much of the long-term care and drug costs for PWDs are not covered by Medicare (Alzheimer’s Association, 2001). The work of Fox, Maslow, and Zhang (1999) highlighted the fact that eligibility criteria such as assessment of activities of daily living (ADLs), behavioral issues, and mini-mental status cutoff points decrease the numbers of PWDs who are eligible for publicly funded long-term care benefits. The authors postulated that the care needed by a PWDs who needs assistance with one less ADL requirement than the eligibility criteria will probably not be any less or present any less stress to the caregiver and yet that person would not be eligible for publicly funded assistance. Therefore, although these two programs are very costly to society, it is still families who pay for a much of the costs of care for PWDs (Alzheimer’s Association, 2001).

The Alzheimer’s Association (2006) acknowledged that much exciting research has been undertaken by the scientific community but that little has yielded results that can be translated into improved QOL, care, or medical interventions for those with dementia. Timely investment in AD research will be extremely cost-effective from a long-term perspective. End-of-life care, access to Medicare for those with dementia younger than 65, and innovations to meet long-term care needs were all also proposed (Alzheimer’s Association, 2006). Indeed, caregivers’ reports of unmet needs of PWDs in the realms of ADLs have been shown to be predictive of earlier nursing home placement or even mortality of the PWDs in comparison with those whose caregiver did not report unmet needs (Gaugler, Kane, Kane, & Newcomer, 2005). Many of these needs for assistance with ADLs cannot be met by the current structure of health care provision under Medicare and Medicaid.
Learning Needs of Health Care Professionals

Physicians and other health care professions must have adequate knowledge of dementia and the biological, social, and psychological challenges that may arise from this disease. The importance of dementia education for a wide group of health care professionals, because of the complexity of the disease, has been acknowledged (Iliffe & Manthorpe, 2004). Studies have shown that health care professionals often identify learning needs in relation to the prevalence, diagnosis, evaluation, and treatment of dementia. They also lack knowledge in the areas of community-based care, especially adult day health care and residential care alternatives and the role of nutrition in AD (Damron-Rodriguez et al., 1998; Goins, Gainor, Pollard, & Spencer, 2003; Robinson, Barry, Renick, Bergen, & Stratos, 2001; Rust & See, 2007; Smith, 2007). The need for physician education has also been identified in the context of the recognition and diagnosis of dementia and strategies to prevent undercoding of diagnoses, which may translate into poorer quality of care for PWDs (Fillit, Geldmacher, Welter, Maslow, & Fraser, 2002). Health care professions are also experiencing difficulties in preparing for an aging population; a shortage among geriatric-trained nurses and nursing faculty currently exists (Hollinger-Smith, 2003). It is important that the quality of the relationship between the health care provider and the family caregiver can also be crucial to the provision of care for PWDs and has been shown to assume great importance in situations such as the considerations of end-of-life decision making in the long-term care setting (Caron, Griffith, & Arcand, 2005). Thus, a holistic and interdisciplinary approach to the learning needs of health care professions is necessary to meet the needs to the increasing population of older adults with dementia.

The Perceived Social Stigma

The perceived stigma associated with AD and dementia is among, and underlies, many of the many barriers for health care access among PWDs. Findings from the work of European researchers (Vernooij-Dassen et al., 2005) highlight how the perceived stigma associated with dementia among persons affected and their caregivers can lead to delayed diagnosis and treatment. Clark (2005) also asserted that negative stereotypes and ageism, leading to the belief that cognitive decline is a normal part of aging, can lead to older adults being more reluctant to express their needs. In the United States, the need to destigmatize dementia is emerging as a serious public health concern (Chapman, Williams, Strine, Anda, & Moore, 2006). The authors acknowledged that it is important that these diseases are recognized
and interventions are put in place as early as possible to optimize the care that the person receives. The discussion by Chapman et al. (2006) of the perceived social stigma surrounding dementia-type illnesses might also shed light on this issue of QOL among PWDs. If there is a perceived social stigma associated with dementia-type illnesses, there might also be an associated risk of social withdrawal by the PWDs and their caregivers. This process or perception, in turn, might be a threat to perceived QOL.

There are, however, many factors that must be considered when exploring the perception of AD and dementia within the community. In contrast to Europe, much of the research relating to negative stereotypes and the stigma associated with dementia in the United States relates to differences between persons of different racial and ethnic groups. The older adult population in the United States is becoming increasingly diverse, and the Federal Interagency Forum on Aging Related Statistics (2004) predicted that by the middle of the century non-Hispanic White older Americans will compose 61% of the older adult population; also, 18% will be Hispanic, 12% African American, and 8% Asian. Thus, cultural and ethnic beliefs and attitudes toward dementia are an important consideration in the provision of appropriate care. Although this is an important focus, the totality of the perceived stigma associated with dementia and its implications for care provision are much-neglected areas of research.

As the majority of PWDs (70%) live at home and receive care from family members and friends (Alzheimer’s Association, 2007), it is vital that all affected by the disease be considered when managing the disease. Thus, in the context of the family and community, it becomes necessary that health care providers practice in both a person-centered and a culturally competent manner. Culturally competent care has been identified as an important strategy to combat health disparities (Betancourt, Green, Carrillo, & Ananeh-Firempong, 2003). The authors describe how this approach emphasizes patient–provider interactions and encompasses “cultural sensitivity, responsiveness, effectiveness, and humility” (Text section, par. 5). The philosophy of person-centered care for persons with cognitive loss was first proposed by Kitwood (1997) and reconceptualized dementia as a process dependent on not only the pathological process but also the social psychology of the person affected (Kitwood, 1993). This perspective clearly illustrates how the interactions of PWDs with health care providers can positively or negatively affect the well-being of PWDs.

Perceptions of dementia, the use of formal services, and family caregiving can be diverse depending on the ethnocultural background of the person diagnosed and his or her family members (Kane & Houston-Vega, 2004).
A review of the literature (Kane & Houston-Vega, 2004) outlining the themes that arise among ethnic/racial groups in the United States found that in all the groups discussed it was identified that dementia may well be viewed as normative aging. This view of dementia as part of the normal aging process provides a barrier to the timely diagnosis of dementia or the access to needed health care and social services for both the PWDs and their caregivers. Indeed, for all the minority ethnic groups identified in their literature review, the authors report an underutilization of services for a variety of reasons. These reasons include the stigma and shame associated with the disease, a lack of knowledge about dementia and available services, economic factors, and preference for traditional services. Structural factors such as language barriers are also identified as being of great importance. In addition, a mistrust of health care providers may also be an influencing factor. Therefore, culture/ethnicity, the stigma associated with dementia-type illnesses, and an individual’s and family’s understanding and knowledge about dementia play very important roles in the access to health care and the utilization of such services.

Public Policy

Public policy also plays a crucial role in determining the QOL of persons diagnosed with dementia and their caregivers in the United States. In response to the increased awareness of the needs of PWDs, policies must address larger social environmental concerns and the importance of social support for PWDs and their caregivers. For example, current federal-level policy does not pay for companion services for PWDs. If such services are covered, they are reimbursed at a very limited scale. Often, they will be provided under the Medicaid waiver program. Therefore, policies currently in place that govern these two important programs often do not fully take into account the unique needs of this population.

For example, Mitchell (2003) described how both Medicare and Medicaid reimbursements may actually provide financial incentives for placing feeding tubes with persons with advanced dementia in the nursing home environment. The author stated that it is unknown whether this fee structure actually influences the clinical decision to place feeding tubes. However, as the author pointed out, this discussion does serve to highlight that the focus of these systems on acute medical needs as alternatives, such as skilled hand feeding, is neglected. Conversely, research exploring end-of-life care for PWDs (Luchins & Hanrahan, 1993) has shown that the majority of those involved
(i.e., physicians and families) prefer the use of less aggressive care for persons with end-stage dementia (which does not include feeding tubes), and the majority viewed hospice care as appropriate. However, the authors also found that the majority of the respondents where unaware of the available hospice programs for PWDs, illustrating learning needs in the context of policy and services available for PWDs and their families.

Several policies in the United States are currently under legislative review that would serve to increase the focus on the chronic health care needs of PWDs such as the Geriatric Assessment and Chronic Care Coordination Act of 2007. This bill proposes amendments to the Social Security Act that would entitle Medicare (Part B) recipients to geriatric assessments that encompass physical, social, and cognitive health and chronic care coordination services, which include medication management, patient counseling, and caregiver education and support. This act also calls for a 3-year follow-up assessment of the impact of these services on the well-being of persons with chronic diseases, including dementia. This assessment would utilize preventable hospital admissions, appropriate use of pharmaceuticals, and the reduction of unnecessary medical tests as evaluation criteria. Thus, it appears that legislators are addressing the complex needs of PWDs but the benefits of this act, if passed, will only be available to Medicare Part B recipients.

Other U.S. policies, if passed into law, that will have an impact beyond Medicare recipients that are also currently under legislative review include amendments to the Public Health Service Act in the form of the Alzheimer’s Treatment and Caregiver Support Act of 2007. This bill proposes changes that would provide grants to agencies providing support services for persons with AD and their families. In addition, the need for further education in dementia care is recognized in the proposed Nurse Faculty and Physical Therapist Education Act of 2007, which among its proposals for geriatric faculty fellowships includes a grant for a medical school geriatric department capable of managing multiple chronic conditions, dementia being one condition.

**Implications for Future Research**

The field of research into AD and dementia is rapidly growing and broadening beyond the biomedical focus; it is clear that issues of QOL, especially emphasizing the personhood of PWDs, and quality of care are becoming of increased importance. As diagnostic tools improve, public awareness grows, and treatment options broaden, systems and ethics-orientated questions will
arise as to the care of persons diagnosed. Should older adults be routinely screened for cognitive impairment? How do we provide appropriate care and social support for those with a diagnosis of early stage AD? What is appropriate care? What of those diagnosed with MCI? What effects would there be on the health care systems of routine screening and a broadening of the definition of dementia to include MCI? These are all issues beyond the scope of this review but worthy of debate and further research.

However, the educational need of health care professionals is an area of research that is an immediate area of concern and warrants prompt action. Although several studies exist that highlight the learning needs of health care professionals in the context of dementia care management (Goins et al., 2003; Iliffe & Manthorpe, 2004; Robinson et al., 2001), the impact of existing continuing education practice on the knowledge level of qualified practitioners would be a logical expansion of this research. The diversity of PWDs in terms of age, gender, race/ethnicity, cultural background, and disease of diagnosis must also be acknowledged and emphasized. Conventional, single-discipline approaches to continuing education may not be as appropriate in the case of dementia where the approach to care is often multidisciplinary and inclusive of social and community services.

Traditional lecture formats and single-patient case studies may not be able to adequately capture all the facets of these complex diseases. Research that evaluates educational opportunities that include experiential learning such as the inclusion of the voices of PWDs, their families, and interdisciplinary service providers is warranted. Would interdisciplinary educational opportunities be more beneficial than single-discipline models? How may health care providers be best informed of the support services offered by other professionals and agencies that might assist them in their task of providing quality care for PWD? How might they best be exposed to the true experience of living with such diseases for all involved? In addition, more must be known about the perspective and wishes of the persons diagnosed themselves.

Studies utilizing mixed methodologies and longitudinal perspectives might be warranted to give a clear picture of the experience of dementia and QOL for persons diagnosed and their caregivers in all stages of the disease. This review also highlights the need for further research that is representative of the total population of PWDs and their caregivers (i.e., represents the growing diversity of this population). Research that explores the influence of culture and ethnicity on perceptions of QOL for both PWDs and their caregivers is very much warranted as the older adult population and population of PWDs becomes increasingly diverse. It has also been acknowledged
that QOL and quality of care need to assume greater importance in research and also in the provision of services for persons diagnosed and their caregivers (Logsdon et al., 2002; Steeman et al., 2007). In diseases for which currently there are no curative treatments available, QOL and quality of care must assume priority. This lack of understanding of the experience of the PWDs highlights the limited voices of the PWDs themselves who have until recently been neglected in the research literature. A model of care that encompasses these principles that has been found to be useful in changing the culture of care within mental health services is the “recovery-based” care model. The principles of the recovery model are based on (a) partnership and collaboration through person-centered care planning, (b) empowerment, choice, and personal responsibility, (c) respect, dignity, and compassion, (d) hope and optimism, (e) self-acceptance, personal growth, and healing, and (f) support (Mecklenburg’s PROMISE, n.d.).

The key values of recovery-based programs were identified by Farkas, Gagne, Anthony, and Chamberlin (2005) as person orientation, personal involvement in health care planning, self-determination, and growth potential. Unfortunately, care programs for those with irreversible dementia such as AD cannot presently aim toward recovery. However, recovery-based care emphasizes a personalized, individualized growth that occurs along a continuum that offers choice, utilizes a strengths-based approach, and attends holistically to the health and wellness of the individual (Gagne, White, & Anthony, 2007). Therefore, the guiding principles of this model may be adapted and applied to the care and support of PWDs and their caregivers and should be a focus of future research. QOL and quality of care for persons facing complex and ultimately fatal irreversible dementias must be the current focus of models of care.

It is clear that AD and related dementias provide a complex challenge to the health care system and increasingly a life-course approach is being applied to the etiology, management, and treatment of these diseases in older adults (Whalley, Dick, & McNeill, 2006). In their application of the life course perspective to the etiology of late onset dementias, Whalley et al. (2006) described the approach as one that takes into consideration the factors that influence development and aging in each individual. In addition, this perspective of exploration of dementia seeks to identify dementia risk factors the individual may be exposed to, when these exposures may have a detrimental effect, and if the effects of the exposures have an accumulative effect. Weih, Wiltfang, and Kornhuber (2007) explored the recent literature on factors that may play a preventative role in AD and concluded that, as yet, evidence that suggests lifestyle risk factors has been mainly
obtained from observational studies. They stated that the majority of the risks are described as modest associations only and described recent studies that have explored into the role of lifestyle factors such as physical and cognitive exercise and diet in the increased risk of AD. Thus, factors that may be present throughout life are beginning to be explored in their relationship to the development of dementia in later life. This is a new and developing area of research that highlights the need for holistic and lifespan approaches to health practices and access to health care for PWDs. As more is known about the causes of AD and related disorders and the effects of lifestyle factors, further risk factors and health disparities may also be uncovered.

Conclusions and Recommendations

From this review of the literature, it is clear that there are many areas of health care provision that could be targeted for interventions to enhance systems of health care provision and the social determinants of health for PWDs. Many rely on fundamental changes in the culture of care for these persons from a medically focused model to one that incorporates social care and an emphasis on QOL. However, strategies that are timely and manageable and will provide long-term gains for health care providers, PWDs, and their caregivers are educational opportunities for primary care physicians. These physicians often take on the role of gatekeeper or point of access to other services by PWDs and their caregivers. Therefore, knowledge of the medical, social, and psychological aspects of the disease is necessary to provide comprehensive, holistic, quality health care for PWDs. A standardized program of education on dementia and its implications should be implemented in medical schools, in family practice and internal medicine residency programs, and for practicing primary care physicians. This education will facilitate the physicians in their task of caring for this population, providing them with the resources they need to meet the health and social needs of this diverse and growing population.

Chronic care management programs, programs to ensure earlier diagnosis and treatment, physician reimbursement systems that encourage coordinated care and consultations outside of the office environment, a uniform interpretation policy that allows for caregiver training and home health training, and a broadening of access to rehabilitation services and mental health services are all strategies proposed by the Alzheimer’s Association (2006) in its national public policy program to improve access to health
care for PWDs. Small et al. (1997) highlighted that access to health care for PWDs is a growing concern, and prior studies have called for increased adherence to existing recommended guidelines for care of PWDs (Chodosh et al., 2007). An evaluation of a dementia guideline management program illustrated that the program had a beneficial impact on the health-related QOL and improved caregiver outcomes (Vickery et al., 2006).

The Alzheimer’s Association (2006) focused much of its policy recommendations on Medicare and Medicaid, pointing out that the presence of coexisting chronic diseases among PWDs makes chronic care management benefits for Medicare recipients a much needed benefit. This added benefit would lead to a coordinated system of care for PWDs and Medicare reimbursement for physicians who counsel family caregivers. The Alzheimer’s Association also requested that PWDs be given additional considerations during their application for Medicaid-funded programs by requiring additional protection via the Deficit Reduction Act and also called for a preservation of Medicaid in the light of the limited funding options available for long-term care for PWDs. Thus, these recommendations clearly illustrate the many barriers that currently exist to quality health care utilization by older individuals with dementia.

The Institute of Medicine (2001) report on health care for the 21st century described how the current health care system targets acute, episodic needs to the detriment of services for persons with chronic health care needs. The report called for equitable patient-centered care based on customized, continuous systems in which the patient has control and needs are anticipated. In the context of the population of PWDs, it would be necessary to include in these recommendations an acknowledgement of the important role informal caregivers play in ensuring access to health care for persons who may not possess the required level of competency to do so for themselves. There must be recognition that PWDs will need proxy decision makers as the disease progresses. Levels of competency and the ability to understand the implications of treatment will change, and medical care and social care must often be utilized in combination to provide adequate care for this population. However, it also appears that the voice of the PWD is an important and previously neglected one in the exploration of the provision of health care and the assessment of QOL in PWDs. The more that is known about their perspective and needs, the better care providers will be able to provide appropriate, quality care in the face of a disease for which no curative treatments are as yet available. Therefore, it is apparent that the exploration of the current system of health care for PWDs can lead to questions of equity in health care access and utilization.


Cahill, S., Begley, E., Topo, P., Saarikalle, K., Macijauskiene, J., Budraitiene, A., et al. (2004). “I know where this is going and I know it won’t go back”: Hearing the individual’s voice in dementia quality of life assessments. *Dementia, 3*, 313-330.


