Succcessful management of dementia in the community extends beyond the person who has been diagnosed with the condition. Management focuses around two key people: the patient with dementia and the caregiver. Maintaining the person with dementia at home means optimizing potential while minimizing the debilitation normally associated with a progressive neurological condition. The challenge and responsibility for this burden falls to the caregiver in community-based dementia care. The goal of maintaining and sustaining a healthy, successful caregiver is essential to achieve quality health outcomes for the community-dwelling patient with dementia. The purpose of this article is to provide an overview of evidence upon which reasoned practice strategies and decisions can be based to address caregiver burden incurred in the management of a patient with dementia in the home.

The State of Dementia Care in the U.S. Population
Dementia is a general term for a decline in mental ability that causes difficulties in carrying out normal activities. Alzheimer’s disease (AD), the most common type of dementia, is a condition characterized by progressive deterioration in memory, behavior, and thinking (Alzheimer’s Association, 2014a). Although no definitive cure for dementia has been found, preservation of cognition and memory while delaying continued loss of function has been the goal of caregiving.

Hebert et al. (2013) estimated there are 4.7 million cases of AD in persons 65 years old.
and above. Of these, 0.7 million are between the ages of 65 to 74, 2.3 million between the ages of 75 to 84, and 1.8 million are 85 years and older. It is projected that by 2050, these numbers will almost triple. The benefits of medical and health innovation are allowing us to manage disease, which can delay death, but which has resulted in increased numbers of the “old-old.” With this increased longevity comes the risk of acquiring age-related health problems such as dementia.

Cost of care has become an important issue as the population of dementia patients grows and economic conditions become more fragile. The complexity of care for patients with dementia along with the progressive nature of the disease means caregiver burden tends to grow over time. The demands of caregiving often compromise the financial stability of the family and place an additional burden on the caregiver. In 2013, the cost of care provided by 15.5 million unpaid caregivers was estimated to be valued at more than $220 billion (Alzheimer’s Association, 2014a). The cost of healthcare for the caregivers is an additional $9.3 billion. It is clear that managing AD will be financially challenging for the next 25 years.

The National Alliance for Caregiving (NAC) reported that it is usually a family member who acts as caregiver. Two out of three caregivers are women, with an average age of 51 years, and having been in the caregiving role for an average
Female caregivers have been found to experience more burden, poorer mental and physical health, increased depressive symptoms, and decreased participation in health promoting activities.

of 4 years. The average total number of years of caring for a spouse with dementia is 8.7. Caregivers often suffer from worsening health and less time with family and friends (NAC, 2009).

Both men and women are faced with physical and emotional challenges when they undertake caregiving a person with dementia. Female caregivers have been found to experience more burden, poorer mental and physical health, increased depressive symptoms, and decreased participation in health promoting activities (Gibbons et al., 2014). Men tend to use fewer opportunities to seek and use social support strategies when compared with women caregivers (Baker et al. 2010). Ethnicity may also play a role in caregiver responses. Whites have reported more depression symptoms than Blacks when studied over 4 years (Skarupski et al., 2009).

The health of the caregiver may impact ability and confidence to manage the patient with dementia. Medical conditions most frequently reported by caregivers included arthritis, back problems, diabetes, heart conditions, high cholesterol hypertension, anxiety, and osteoporosis (Gibbons et al., 2014). Self-efficacy refers to one’s ability and confidence to achieve an outcome or goal, and it is a good measure of a person’s current and future status. Caregivers who exhibit self-efficacy in symptom management tend to have less burden and depression (Gallagher et al., 2011).

Evidence to Support Caregiving Strategies

Caregiver burden is the response of the caregiver to the stresses of providing care. Caregivers are faced with physical, emotional, psychological, and financial burdens of caregiving (Asiret & Kapucu, 2012). Razani et al. (2014) found that anxiety, depression, and hostility of caregivers were significantly related to the level of caregiver burden. Treatment of depression and anxiety to support the caregiver is imperative. Rockwood et al. (2013) found that the most common events that triggered the transfer from home to a nursing home or assisted living facility were illness, absence, or death of a caregiver. Transfers were necessitated by impaired instrumental activities of daily living (especially meal preparation), which was the single most common reason for a move to a nursing home or assisted living.

Behavior Problems

Another of the major reasons for patients with dementia to be transferred to an institution is behavioral issues (Nichols et al., 2009). When the caregiver feels unable to deal with the changing behavioral issues of the care recipient, the only alternative is often institutionalization. These behaviors include apathy, aggressiveness, depression, and restlessness (Aminzadeh et al., 2006; Fauth & Gibbons, 2014). Sometimes these behavior problems occur in the late afternoon to early evening, a condition known as sundowning. Nowak and Davis (2007) described sundowning as a group of symptoms exhibiting physical aggression, resistance, and disconcerted vocalizations. Identifying and treating unmet needs such as pain, constipation, lack of sleep, and fatigue may help manage the behavior. Minimizing activities in the evening and providing nap times may also help. A consult to an occupational therapist may be made for assessment and utilization of interventions such as aromatherapy, music therapy, and environmental modification to minimize agitation (Padilla, 2011).

Safety Issues

Caregivers show increasing concern about the safety of the person with dementia for whom they care (Lach & Chang, 2007; Samia et al. 2012). In these studies, modifying the home by using baby monitors, alarms, and monitoring systems were safety initiatives utilized by caregivers. Some caregivers considered moving to a more supportive living environment such as a smaller house, an apartment, or assisted living. Caregivers need guidance on disease progression, monitoring devices, and housing options to make informed decisions about equipment acquisition or relocation.
media, traffic signs, radio and telephone stations, and law enforcement agencies to inform the public of missing elderly. Silver Alert also uses variable-message signs on roadways to alert motorists to be on the lookout for missing persons. The home care clinician is in a pivotal position to prevent the person with dementia from getting lost by encouraging early registration where technology is available.

In a study by Rowe et al. (2012) most persons with dementia, who were lost, were found driving a car. Asking a person with dementia to stop driving may be a source of guilt and anxiety for caregivers. The decision to restrict the patient’s driving privileges should be made with the collaboration of family, healthcare providers, and law enforcement. The American Association of Retired Persons [AARP] (2014) has a publication available on its Web site about “10 Signs That It’s Time to Limit or Stop Driving.” The “We Need to Talk Program” available in the AARP Web site is an educational program to help the caregiver approach people with dementia about driving restrictions.

**Functional Challenges**

Functional limitations of people with dementia and dependence on the caregiver for daily tasks have been correlated to burden (Abdollahpour et al., 2011; Razani et al., 2014). Problem behaviors and the demands of assisting with activities of daily living have been documented as the greatest cause of caregiver depression and anxiety (Pioli, 2010). Promoting optimal function of patients with dementia is the goal of intervention; however, due to disease progression, function may be limited. The caregiver then has to perform additional tasks for the care recipient. Improving mastery in performing caregiver tasks may help reduce the burden of caregiving. Referral to physical therapy services may help establish routine activity and an exercise program that maximizes functional skills. A 30-minute exercise program performed several times a week that includes walking may also have a positive impact on mood (Eggermont & Scherder, 2006) and may improve stability and decrease the potential for fall and injury.

**Falls**

An intervention that may be used at home to prevent falls is an early warning device available in the market ranging from $100 to $200. The device

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**Wandering**

Patients may engage in episodes of walking about without a goal or destination at any time during the night or day resulting in inadequate rest for the patient and caregiver, as well as presenting safety concerns. Houston et al. (2011) found that although information was available to prevent the patient with dementia from wandering, some caregivers had not adopted any of them. Most caregivers do not utilize an identification bracelet and have not made any physical alterations to their homes to prevent wandering. It is evident that some caregivers fail to recognize wandering as a problem, until the person with dementia gets lost.

There is strong evidence indicating the need for a tracking system for patients who wander to benefit both patients and caregivers (Landau et al., 2009). Although tracking device technology is available, it has not been widely studied due to ethical implications of privacy and autonomy. Environmental changes to prevent exit-seeking behaviors have been identified in research but were mostly conducted in institutions. To prevent door-exiting behaviors, Kincaid and Peacock (2003) found this behavior was minimized by painting murals on exit doors. Further testing in the home setting is needed.

Project Lifesaver International (Alzheimer’s Foundation of America, 2014) is a rapid response system that locates patients who wander through a radio technology connected to specially trained rescue and response teams. Persons who are enrolled wear a bracelet or an anklet that transmits signals within a mile radius from the ground and 5 miles from the air. When a person is missing, the caregiver notifies the Project Lifesaver International local county office, and an emergency response team is activated.

The Safe Return Program (Alzheimer’s Association, 2014b) uses a network of local association chapters of the Alzheimer’s Association and law enforcement agencies to help locate missing people with dementia. The cost of enrolling in the Safe Return Program is $55, which includes the cost of the identification jewelry. It also includes a wallet card, a 24-hour response service, personal record, and a safe tips magnet. When the person is missing, an emergency response number can be notified to alert law enforcement agencies.

The Silver Alert program (American Silver Alert Coalition, 2014) is another emergency response system, which integrates the use of...
The decision to restrict the patient’s driving privileges should be made with the collaboration of family, healthcare providers, and law enforcement.

comes wired or wireless with a chair or bed pad connected to an alarm on-site or in an adjacent room. When the person attempts to get up, weight is lifted from the pad, which causes an alarm to sound. A variation of this alarm is available as a sensor with an infrared light. The device senses obstruction to the light beam and sends off an alarm when the person crosses the light beam while trying to get out of bed. There have been conflicting reports on the effectiveness of the alarm in institutional settings (Kosse et al., 2013) due to increased number of false alarms and the nursing staff’s lack of response. However, a reduction in falls and fall-related injuries has resulted from the use of bed exit alarms. Falls can be averted with the use of these devices and may provide the caregiver the much-needed peace of mind.

Communication Disruptions
People with dementia often experience speech deficits in the form of inability to name objects, incoherent conversations, and progressive deterioration of communication (Egan et al., 2010) and may eventually cease speaking due to the frustration of not being understood. This leads to further distress, depression, and anxieties in both care recipient and caregiver. Effective strategies of communication need to be learned and utilized by the caregiver to meet the needs of people with dementia. Mason-Baughman and Lander (2012) trained caregivers on 11 techniques in communication. At the end of the study, they found that eliminating distractions and utilization of picture books were most helpful to the caregivers. The training session positively affected the caregiver’s knowledge and willingness to implement the methods.

Education of Caregivers
Most caregivers entering into the role of providing care to a person with dementia have little or no formal preparation or in-depth understanding of the care required. Many caregivers express frustration about their lack of knowledge and inability to find resources when needed (Samia et al., 2012). In a systematic review, Thines and Padilla (2011) proposed that caregivers and families be provided with information needed to understand the expected decline to prepare them for making modifications in lifestyle and activities. Meeting the educational needs of caregivers can improve their self-efficacy and decrease feelings of depression and anxiety in their new role.

Caregivers identified the following topics as the most important for caregivers of people with dementia: combativeness, confusion, and communication (Nichols et al., 2009). Managing these challenges should be the focus of teaching. The top three stress and coping topics identified by the caregivers were on healthy lifestyle, grief, and relaxation. Caregivers recognized the necessity of maintaining their own health in order to be prepared for the job ahead of them.

Caregiver Need for Support
Caregiving requires a considerable amount of time. Most caregivers would like to obtain extra help from paid caregivers to attend to personal needs. Aminzadeh et al. (2006) identified a relationship between caregiver burden and provision of assistance with personal tasks, dissatisfaction with received help, and patient dysfunctional behavior. Although the authors predicted that education and management strategies would improve caregiver quality of life, caregivers felt that their greatest need was for relief from hours of caregiving. More hours in respite care were needed to improve quality of life. Support services should be individualized depending on the needs of the care recipient, the social support available to the caregiver, and the overall physical and emotional health of both. The role of the social worker in identifying groups that provide intervention and advocacy is vital to improve caregiver knowledge and decrease caregiver burden (Pinson et al., 2010). Promoting support groups in existing organizational settings, such as faith-based settings, provides an avenue for identifying caregivers who otherwise may not seek help. With most of the caregivers being elderly spouses, referral to a
The use of palliative services toward the end-of-life is inevitable as the health of the person with dementia deteriorates. Emotional support and management of pain and other end-of-life symptoms are valuable services offered. Constant communication, emotional support, and a trusting relationship with the hospice team is vital in assisting caregivers in making end-of-life choices for the patients with dementia, such as artificial feeding, hospitalizations, and other treatment options (Davies et al., 2014).

**Positive Caregiving: Finding Meaning**

Positive effects of caregiving through finding meaning and developing a closer relationship with the care recipient have been reported (Shim et al., 2013). Finding meaning for caregivers is a matter of choice and requires acceptance of the changes in both the caregiver and the person with dementia (Shim et al., 2012). Quinn et al. (2012) concluded that lessening the feelings of feeling “trapped” is predictive of higher meaning on the part of caregivers. Respite care, through substitute family caregivers and adult day care utilization can help minimize these feelings. The relationships between spouses before the onset of dementia have also been documented in the literature as a determinant of how much caregiver burden is experienced and how the problematic behaviors of the care recipient are perceived (Shim et al., 2012). A spousal caregiver who has had a negative relationship with the person with dementia before illness will often experience greater burden than the caregiver who has had a positive relationship. Promoting positive relationship strategies such as negotiation, empathy, and compassion and minimizing negative relationships such as confrontation, ignoring, or criticism can lessen feelings of burden (Shim et al., 2012).

**Further Research Needs**

Caregiving is complex and requires interplay between the care recipient and the caregiver, the extended family, various healthcare providers, and the community. Each one plays a different role with one common goal, to provide the best possible care and keep the person with dementia at home without sacrificing the quality of life of the caregiver. Multiple interventions have been enumerated, most of which improve the care recipient’s quality of life but not necessarily the caregiver’s.

Further research should focus on the best way to find safe alternatives for daily care available to working persons responsible for the care of dementia patients as well as respite care for full-time caregivers. Most sources agree that home-based care is the most effective, humane, and cost-effective way to provide dementia care. Research is needed to define, describe, and design optimal care alternatives to ease caregiver burden and optimize health outcomes.

In the area of communication, training of caregivers was found to improve the quality of life of community-dwelling people with dementia. However, there is insufficient evidence that it decreases challenging behaviors of the care recipient and, thus, perceived caregiving burden. Research should be directed to the use of meaningful communication to handle difficult situations such as aggression and restlessness.

Caring for persons with dementia is a challenge, which forces many unexpected actions and decisions upon a person who is usually unprepared for the experience. Caregivers are in communities doing their best to provide a safe and loving environment for people with dementia while maintaining health, sanity, and an optimal quality of life for both the caregiver and the care receiver. Home care clinicians are often on the front lines of identifying caregiver fatigue and burden and have the knowledge, skills, and resources that can ease the burden and prolong the time that the person with dementia can remain in the home. It is vital for home care clinicians to be knowledgeable about the resources for patients with dementia and their caregivers as we plan for the growing numbers of elderly, many of whom will be on one end or the other of the dementia caregiving spectrum.

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