Living at Home with Dementia Now More Complicated with COVID-19

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Well before the coronavirus disease (COVID-19) pandemic, dementia care posed unique challenges to every health care system. Global estimates for dementia are sobering, with numbers expected to almost double every 20 years, to 65.7 million in 2030 and 115.4 million in 2050 (Prince et al., 2013). This dire prediction is juxtaposed with a woefully inadequate workforce to care for individuals with dementia and support family caregivers. Social work education and practice with the geriatric population has been reported to lack a core set of competencies and expected proficiencies not clearly defined (Kaplan & Andersen, 2013; Keating, 2017). Nevertheless, social workers are playing key roles in dementia care around the world and have become critical components of interprofessional teams (Livingston et al., 2017), a need that is accelerating in the era of COVID-19.

Social Work Dementia Care Pre-COVID-19

Early in the dementia process, social workers can help support optimal function (nutrition, regular exercise, cognitive stimulation, social interactions, and adequate sleep) that can affect dementia progression (George & Reddy, 2019). As dementia progresses, families may need further assistance to develop creative ways to address evolving needs and develop the complex skills needed to keep the relative at home. Family challenges may include coordination of medical appointments and transportation services, assistance with activities of daily living, supervision and reassurance, de-escalation of behavioral issues, and taking over financial responsibilities. These capacities may also challenge caregivers who simultaneously face their own health threats. Caregiver stress is pervasive with dementia care and contributes to twice the rates of substantial financial, emotional, and physical difficulties compared with difficulties of caregivers of people with nondementing illness (Zwerling, Cohen, & Verghese, 2016).

Dementia Dilemmas for Social Workers

Difficulty with information exchange and conflicting interests among family members have been identified as dilemmas often faced by social workers and case managers (Nordh & Nedlund, 2017). Sinclair et al. (2018) concluded that strategies are needed to support productive attempts at joint decision making by couples living with dementia and suggested that post-diagnostic support, educational resources, and proactive dyadic interventions should all be used. Family caregivers report that although resources exist, a clear channel for accessing information and resources is often lacking (Cai & Chung, 2007). Common challenges include geographical barriers to resources, financial shortfalls, premature departure of a caregiver from the workforce, and the physical and emotional strain inherent in caregiving. Providing health care and emotional support for the family caregiver becomes an urgent issue if there is no one else to care for the individual with dementia. Evidence has shown that helping caregivers develop skills and strategies is an essential component of dementia care, yet caregivers may not be able to express their needs explicitly (McCabe, You, & Tatangelo, 2016).

In a preliminary qualitative, descriptive study of social workers providing dementia care in one small rural New England state, three themes within the meta-theme of navigating unpredictability emerged: (1) weaving together insufficient, inadequate, inconsistent, and inequitable resources; (2) cobbling a foundation for an uncertain future; and (3) catalyzing capacity and supporting emotional endurance (Palumbo, McKenna, & Rambur, 2019). These themes are now even more poignant, given that dementia home care is significantly more difficult during a
LESSONS LEARNED DURING THE PANDEMIC

Drawn from our practice experiences during the pandemic and research on dementia care, the following are observations about dementia care during the COVID-19 pandemic. First, unpredictability is heightened as a core experience of caregivers during COVID-19, as illustrated by this spouse’s comments:

I have thoughts of “What else can I/should I do?” “I am not doing enough.” These continual feelings as a carer are even more intense through this pandemic—it’s always too much to do, yet it’s never enough. I need to have more stamina and courage in decision making and feelings of guilt over these daily decisions. “Should the respite caregiver come in? How do I ensure she is following safe practices? Should I go to the store? Should I sanitize the mail? Should I take a walk with my friend? And what about the stupid toilet paper?” I am missing interaction with others and the energy this interjects into our daily life; missing the camaraderie of being understood by others in similar situations; I feel isolated, lonely; missing the physical presence of others makes me less resilient and promotes sorrow. The touchstone of others helped us keep the person and couple we once were more intact and gave me a strong sense of belonging. (personal communication, used with permission)

The grief associated with dementia progression because of relationship changes, loss of emotional support, decreased financial support, increased dependency, and loss of future plans has intensified. Family caregivers whose loved ones are in older adult housing or residential care find themselves cut off, unable to visit, which often causes excruciating sorrow. For those who are sheltering in place with a family member with dementia, community services like personal care attendants and adult day programming have ceased or been dramatically reduced. The absence of activities that normally replenish the family caregiver (friendships, groups, or exercise) leaves them more vulnerable to depression and anxiety.

Fear of contracting the virus has exacerbated stress for single, largely homebound family caregivers. Elderly individuals with underlying health issues are the most vulnerable to the virus, and family members who provided respite care before spring 2020 may be sidelined with concerns that they are unwitting disease vectors. This is particularly poignant for caregivers who do not have alternatives for the care recipient if they should become ill. Caregivers have expressed the need for help updating end-of-life medical and financial directives in the event that they become ill and may not meet the care needs of their loved one. Anxiety about future plans increases sleep disturbances, irritability, and ability to determine what is within—or outside—the family caregiver’s control. It seems inevitable that mental health crises will increase.

The person with dementia may have poor understanding of safety protocols necessary during the pandemic, which increases the need for fresh approaches to problem solving and caregiver decision making. The caregiver may have limited capacity to address this challenge, however, and lack support resources. Anticipating and mitigating the behaviors of the person with dementia (poor hand hygiene, refusing to wear a mask) to prevent virus exposure puts the family caregiver at increased risk for burnout. Sadly, all this converges on the caregiver at a time when fewer services and informal helpers are available to support them. The ability to move a person to an assisted-living or a nursing home facility has all but vanished for the time being. COVID-19 has stressed an already overburdened system of care, resulting in fewer support services, decreased respite, increased stressors, and uncertainty about the future. The following case illustrates how social workers can engage the family caregiver to address increased obstacles exacerbated by limited community supports during the COVID-19 pandemic:

Caregiver Joe and spouse Millie (diagnosed with midstage Alzheimer’s disease) were vacationing from home when quarantining became mandated (significantly extending their holiday). Millie became increasingly anxious without her usual day program supports and routine to manage her behaviors. Her symptoms of anxiety and disinhibition intensified, causing Joe to become overwhelmed. As
days turned into weeks, Joe’s ability to manage Millie’s increasing behavioral symptoms intensified his own despair and his thoughts of self-harm ensued. Using telemedicine, the social worker relied on problem-solving skills to strengthen Joe’s coping mechanisms and support him to regain his previous level of functioning. This intervention enabled Joe to successfully address Millie’s behavioral symptoms and plan a return home.

IMPLICATIONS FOR SOCIAL WORK PRACTICE
Social workers are a vital part of any health care team involved in dementia care of individuals and their families. Ideally, social work interaction begins at the time of diagnosis and lays a foundation for support that becomes necessary as the disease progresses. Providing emotional support and fostering the self-management capacity of individuals and families are essential and ongoing roles of the social worker. Challenges will arise in all cases, and social workers can provide the needed help to weave together resources that are often lacking. Financial means can make a family’s path easier to navigate; however, in our experience, financial resources pale in comparison with cultural, systematic, and social barriers. The social worker’s ability to appreciate the family culture and capacity and inform team members is essential, especially regarding end-of-life care. Given that the COVID-19 pandemic will likely not resolve quickly, weaving together resources that are available and developing new telehealth options for communication and counseling will be necessary.

Social workers act to enhance family’s capacity for self-management and provide emotional support during the caregiver trajectory. The social worker’s ability to identify strengths and address challenges is key to optimal dementia care. Resourcefulness and creativity are among foundational social work skills that have been more crucial during the pandemic; however, dementia’s devastating effects on individuals and family will outlast this virus, and the lessons learned can serve society going forward. Toward that aim, contemporary essential social work competencies for dementia care are detailed in the following list:

• Knowledge of ethical and appropriate care for the individual experiencing the disease
• Ability to provide individual and group support for caregivers
• Knowledge of stages of dementia of all types
• Competence in assisting families to prepare with advance directives
• Understanding of behavioral and environmental interventions to diffuse agitated behaviors
• Awareness of local resources for caregiving respite, support, and health, including those available through telehealth and other virtual and emerging modalities
• Familiarly with levels of care, payment models, and state and national financial regulations for payment.

These skills, in combination with the unique abilities of social workers, offer essential contributions to an interprofessional dementia care team and are needed to improve the quality of life for the growing number of individuals and families experiencing dementia. COVID-19 has illuminated the need for compassionate and creative approaches to meet these pressing needs.

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