

Special Care Units

Living with Dementia in Today's LTC System

"Dementia doesn't rob someone of their dignity, it's our reaction to them that does."

-Teepa Snow

Introduction

Those living with dementia often face a long-term care system that segregates based on diagnoses, and one that is often ill equipped to provide high quality, specialized care. One type of long-term care (LTC) community--special care units (SCUs)--promises to deliver dedicated LTC to those who are living with dementia. SCUs often have 24 hour staffing, dementia specific programming, specialized staff, and additional security such as locks or video monitoring. Typically, people living with dementia are grouped onto one floor or wing.

About 11 percent of residential care communities have a wing, unit, or floor dedicated to dementia care and 6 percent of communities are dementia care only (NCHS Data Brief, 2013). The number of SCUs is likely to grow in the coming years as the number of those living with dementia rises. The growth in SCUs is concerning, however, because it is an expensive form of LTC that takes many forms and raises many questions regarding quality of care and quality of life. This issue brief examines the factors that improve quality of care and quality of life, some of the research findings on SCUs, and alternatives.

Dementia

Dementia affects millions and certain groups are more likely than others to receive a diagnosis. Five million people in the U.S. are living with dementia--Alzheimer's being the most common type. Older adults are more likely to be living with the syndrome although older age is not necessarily the cause (for example, thyroid disease can cause dementia symptoms). Dementia is more likely among those who are female, and among those who are Black or Hispanic (US Department of HHS, 2015). Almost 70 percent of those living in nursing homes are estimated to have some sort of cognitive impairment with 41 percent having moderate to severe impairment (US Department of HHS, 2015).

Dementia is defined by several sets of behaviors and stages. It's a chronic or progressive syndrome characterized by a set of symptoms including problems with memory, reasoning and judgment, focus

and attention, behavioral issues, communication and language, and visual perception. Two or more of the aforementioned symptoms must be present for a diagnosis. Dementia interferes with daily life and can cause problems with things like the ability to pay bills and to live safely alone. Although there is no fixed trajectory and each person's experience will be different, there are 3 stages of the disease—early, middle, and late. Early symptoms include losing track of time, getting lost in a familiar place, and forgetfulness. Middle stage symptoms include short-term memory loss, difficulty communicating, needing help with grooming, repeating questions, and wandering. Late stage symptoms include difficulty recognizing family and friends, a lost sense of time and space, difficulty with mobility, extreme behaviors including aggression, and an inability to care for oneself (Alzheimers.org, 2016).

There is no cure for dementia. Instead, treatment is focused on managing symptoms and safety which often involves segregation, monitoring, and restricting movements in a costly setting.

Current Issues in SCUs

Care in SCUs is costly. The average cost of care in an assisted living SCU is \$60,000 per year compared to \$39,600 per year in a regular Assisted Living Facility (ALF; Genworth, 2012). Most Skilled Nursing Facilities (SNFs) have 24 hour supervised care and are, therefore, better able to care for those living with dementia. Care in SNFs is also expensive with an average of \$82,125 per year for a shared room and \$92,378 for a private room (Genworth, 2016). If someone is living with advanced dementia, they will likely have to pay for a private room as sharing a room might not be an option. Residential care communities with dementia care units are increasingly more common but are less likely to be certified or registered to participate in Medicaid thus requiring the individual to private pay for boarding and services (CDC.gov, 2010).

The high cost of care in SCUs (especially in ALFs) gives cause for concern given that there is little evidence that demonstrates that those living with dementia receive better quality of care or have a better quality of life in SCUs. About half of the states require SCUs to report exactly which additional services that their facilities intend to provide. However, defining itself as an SCU or claiming to provide additional services does not necessarily translate into better outcomes.

Another issue is that of segregation, restricting movement, and monitoring-- effectively denying people access to natural sunlight, the outdoors, and places to wander safely. People living in SCUs are often confined to a floor or wing of a larger complex. Many SCUs are required by states to have certain physical features such as locked doors. Almost 90% of resident care communities

with SCUs had dementia-specific activities and doors with alarms. About 80% had an enclosed courtyard, doors with keypads or electronic keys, or locked exit doors. Thirty-five percent had personal monitoring devices and 19% had TV monitoring. Another type of restraint--the offlabel use of antipsychotic and psychotropic drugs-- occurs in residential communities. Approximately 40 percent of residents with cognitive impairment have been given antipsychotic drugs (Center for Medicare Advocacy, 2010), which is an ethically questionable way to restrict movement. Antipsychotic drugs are also ineffective and potentially dangerous with side effects like delirium, falls, and death.

The high cost and reduced quality of life in many SCUs begs the question--what are the factors that could improve dementia care? The next section examines these factors.

Community Characteristics that Improve Quality of Care and Quality of Life for those Living with Dementia

Physical Environment

Thoughtful design can improve quality of life for those living with dementia. Environmental features such as shiny floors, certain patterns, long and winding corridors, hospital like environments, certain sounds or the volume of sounds, improper lighting, things that don't work properly (e.g., a door that won't open) can make symptoms worse. Research shows that the people living with dementia experience a better quality of life in smaller, homelike long-term care settings. Smaller settings, or those with less than 50 beds, have been associated with fewer behavioral problems, a better sense of well-being, greater satisfaction, better relationships, meaningful activities, better functioning, increased privacy, and greater autonomy. Smaller facilities are also more willing to serve those living with dementia (Leroi et al., 2007).

With regard to environment, varied ambience, camouflaged exit doors, control over decor, access to the outdoors, and spaces for wandering and walking are associated with less rhythm disturbance, less agitation, less social isolation, fewer hallucinations, and increased walking (Zisel, 2003; Zhipeng, 2010). An open plan design (as opposed to long corridors), residential flooring and furniture, warm and welcoming decor, and homelike dining areas are associated with increased pleasure, higher caloric and fluid intake, easier navigation, fewer pacing episodes, increased social interaction, engagement in daily activities, less anxiety, and less aggression (Bicket et al., 2010; Sloane, 2005; Tilly and Reed, 2008).

Finally, researchers have found that facilities in general tend to have very high noise levels that are much higher than in residential dwellings or even hospitals. Keeping noise to a minimum is especially important for those living with dementia because a high noise level is associated with increased agitation, aggression, confusion, wandering, and reduced socialization (Hayne and Flemming, 2014). To minimize noise, communities should be cognizant about the noise produced by alarms, intercom systems, medical equipment, televisions, staff talking amongst themselves, and other sources of sound.

Dining

Many improvements in dining can be made for those living with dementia and their care partners. Dining is essential to quality of care and quality of life in LTC. In fact, poor quality food is one of the most cited complaints by residents, many of whom are at a high risk of malnutrition (Bownan, 2010; Pezzana et al., 2015). Dining practices like serving food in a smaller dining room with homelike decor can encourage social interaction, foster relationships, increase caloric intake, and reduce anxiety (Pioneer Network, 2011). The dining experience in most LTC facilities revolves around a rigid schedule with little resident input about mealtimes and the menu. Furthermore, dining is often constrained by what is convenient for staff rather than the diner. This can lead to unnecessary pureed diet orders when eating takes too long or is complicated. However, providing cues like smells, familiar dining spaces, and using tableware that has high contrast color schemes can increase food intake (Pioneer Network, 2011).

Bathing

Bathing that is done in a low stress environment can provide relaxation and stress relief, especially for those living with dementia. Certain practices can encourage this while reducing anxiety and privacy concerns. Improper water and/or air temperature, privacy intrusions including the presence of multiple caregivers, mechanical bathtub devices, and loud noises can lead to confusion and agitation. Caregiver abuse of residents has even been linked to improper water temperature and the presence of multiple caregivers.

Staff

Staff can affect quality of life for those living with dementia. Research shows that agitation, stress, and behavioral problems in those living with dementia is reduced when there is consistent staff assignment and when staff have additional training in caring for those living with dementia including

an understanding of the benefits of personalized music therapy on an ongoing basis (Tilly and Reed, 2008; see Zhang et al., 2017 for a review of music therapy and dementia).

Research on Dementia Care

Ideally, all persons including those living with dementia would live in a safe, homelike environment, in the least restrictive environment, be included in, and make as many decisions about their healthcare and life as possible. As mentioned above, the physical structure, practices, staffing, and dining contribute to this goal. How well, then, do SCUs achieve this goal?

Several studies have compared the setting (e.g., skilled nursing, Assisted Living, the community) in which people living with dementia live in terms of quality of care, quality of life, and ability to age in place. In one study, researchers compared those living with dementia who were receiving home and community based service (HCBS) to those living with dementia in ALFs in Florida and found that those receiving HCBS were more likely to be transferred to a nursing home, implying that Assisted Living allows people with dementia to age in place (Temple et al., 2010). Another study that compared those living with dementia in nursing homes to those living in ALFs found that the setting did not affect quality of life (Zimmerman et al., 2005). A separate study by Sloane and colleagues (2005) also found no difference in quality of life for those living with dementia in nursing homes versus assisted living facilities. Hospitalization rates, however, did differ between the two settings with ALFs having higher rates than nursing homes, a finding that could indicate that ALFs are not as well equipped for those residents living with dementia. One study of ALFs found that dementia was not only underdiagnosed, but also undertreated. An analysis of the characteristics of those with dementia living in ALFs found that those living with moderate or severe cognitive impairment were more likely than those living with mild or no cognitive impairment to live in SCUs (Zimmerman, Sloane, and Reed 2014). In a study of 198 residents living in 2 ALFs in Maryland, Lyketsos et al. (2007) found that dementia was a major predictor of the time to discharge from the ALF. For those diagnosed with dementia, the two most significant factors leading to earlier departure were a lack of dementia treatment and more serious medical co-morbidity.

Other studies have focused on quality of care and quality of life for those living in SCUs. A study from the UK (Lou et al., 2010) found that those living in SCUs were more likely to receive specialized behavioral and dementia care. The study also found that SCUs were less likely to use bed rails and catheters but more likely to have falls. Street and colleagues (2009) found that newer model nursing homes compared to ALFs were more likely to admit high-frailty persons and provide specialized services largely due to having specialized licenses. Another study found that quality of

life indicators including depression, behavioral problems, social function, activities of daily living, and social withdrawal didn't differ between SCUs and non-SCUs (Sloane et al., 2005). In a study of 421 residents residing in 35 ALFs and 10 nursing homes, Zimmerman et al. 2005 found that positive change in quality of life was greater in facilities that used a specialized worker approach, trained more staff in more domains central to dementia care, and encouraged activity participation.

Non-SCU Dementia Care Examples

The ideal setting for those living with dementia is one that is safe--but in the least restrictive sense-- and one that has specially trained staff, provides privacy and dignity without segregation, provides a homelike setting and ambience that is not likely to worsen symptoms, and allows for as normal a life as possible. The following are examples of such settings.

The Green House model is one alternative to SCUs. Each Green House provides 10-12 elders their own private bedroom and bathroom. The bedrooms are arranged around a central area, giving both residents and staff a line of sight, thus reducing the need for overhead call systems, alarms, or video monitoring. Green Houses have a hearth area with fireplace, a dining room where residents and staff eat together, and a homelike kitchen that is open to residents. Medical equipment is stored out of sight. Each house provides access to green spaces or gardens, especially important for those living with dementia and those who walk or wander. Residents are treated with respect and dignity-- they make decisions about when they want to get up, what they want to eat and when, and how they want to engage in social interaction. CNAs in Green Houses (called Shahbazim) are able to spend more time with each resident and provide consistent staffing, thus reducing confusion and allowing for a deep connection between residents and Shahbazim.

Those living with dementia and their care partners are often up during the night. One program in New York provides some relief for those with dementia and care partners. The Hebrew Home at Riverdale allows caregivers to drop off their loved ones for care between 7:00pm and 7:00am. Once there, the elders are given meals if they desire, can listen to music and dance, watch plays, walk, or engage in other social activities. This program allows informal caregivers to run errands and get some sleep.

Another promising program developed by the Dutch provides 24-hour care for those with dementia and Alzheimer's disease. "Dementia Villages" look just like real cities complete with gardens, a post office, shopping, and grocery stores. Caretakers dress in plain clothes and residents are monitored by cameras spread throughout the city. Residents are able to wander in the safely

enclosed “city” and conduct business much like they would in a normal city. This reduces agitation and allows wandering in a familiar setting. Similar to Green Houses, residents and their caretakers live in houses that contain several care partners and between 6 and 7 residents per house (Planos, 2014).

Person directed care can be provided in any setting and can alleviate many of the current problems with dementia care. The Eden Alternative provides a framework that focuses on identity, growth, autonomy, security, connectedness, meaning, and joy. The following describes the Eden Alternative domains of well-being: <http://www.edenalt.org/wordpress/wp-content/uploads/2014/02/EdenAltWellBeingWhitePaperv5.pdf>

Finally, Fazio and colleagues (2018) recommend the following based on their literature review on what works in dementia care:

- Know the person living with dementia.
- Recognize and accept the person’s reality.
- Identify and support ongoing opportunities for meaningful engagement.
- Build and nurture authentic, caring relationships.
- Create and maintain a supportive community for individuals, families, and staff.
- Evaluate care practices regularly and make appropriate changes.

Conclusion

As the aging population continues to grow, along with the number of people who are living with dementia, outdated long-term care settings will have to be updated to provide person-centered or person-directed care in a home-like environment. SCUs, as they exist today, are unlikely to provide the environment or care that research shows people living with dementia need and want. The future of care for those living with dementia will be care that is affordable, personalized, allows for privacy, autonomy, and choice in a familiar living environment that is not segregated.

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