The Even Path: Maintaining Family Continuity in Modern Alzheimer’s and Dementia Caregiving

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Abstract

At present time, nearly 6 million Americans have been diagnosed with Alzheimer’s. According to the Alzheimer’s Association, every 65 seconds someone develops the disease. With the increasing dependent population, much of the focus has been on care innovations, new drug therapies, and technological advancements. While fresh ideas are always welcome, there is evidence that maintaining some level of normalcy in older adult’s life plays a role in successful aging. Continuity theory, loosely defined by others, but formally name by Robert Atchley in 1971, states “that in making adaptive choices, older adults attempt to preserve and maintain existing internal and external structures using strategies tied to their past experiences of themselves and their social world”. By Atchley’s theory then, it could be argued that many aspects of dementia caregiving paradigm must reflect this behavior. Perhaps the most important thread of continuity lies in maintaining family relationships. With technology and “Googling” dominating modern culture, how can those with Alzheimer’s expect to have real interactions with children and grandchildren? What does it truly mean to maintain family in this era? This article attempts to answer these questions and looks to develop best practices for family continuity for those with Alzheimer’s disease.

Keywords: Alzheimer’s; Dementia; Continuity theory; Family caregiving

Introduction

Dementia and Alzheimer’s disease

Dementia is an umbrella term commonly used to refer to a group of brain disorders which affect memory, language, visual/spatial understanding, and/or executive functions [1,2]. All types of dementia are characterized by declines in mental capacity that interferes with the ability of the diagnosed to effectively execute normal activities and daily life [3]. Personality and behavioral changes are also common symptoms of those with dementia. These symptoms should not be able to be explained by delirium- which is a short term and/or reversible form of impairment—or by the presence of a major psychiatric illness [4]. Alzheimer’s disease is the most common form dementia, accounting for 60% to 80% of all cases. Alzheimer’s is normally characterized by several stages, with symptoms changing and progressing through the stages. In the early-to-mid stages, symptoms typically include short term memory loss, depression, and apathy. In the later stages, symptoms include communication impairments, changes in judgment, confusion, disorientation, and gait changes [4].

Literature Review

Theories of aging

In order to understand the impact of Alzheimer’s and Dementia on caregivers, those with the disease, and their relationships, it’s important to understand a bit about aging. The three functional theories in aging look at the way older adults choose interact with the world around them. Disengagement theory was proposed by Elaine Cumming and William E. Henry in 1961. They argued that is natural for older adults to withdraw from society. Their theory focused on the fact that distancing oneself allowed one more freedom as he or she prepared for death [5]. Activity Theory was proposed by Robert Havighurst in 1961 as counter theory to disengagement theory. Havighurst argued that older adults obtain the highest level of satisfaction by remaining active and trying new things. The theory stated that there was a direct correlation between life satisfaction and levels of activity [6]. Much like Goldilocks and Three Bears, the first two theories assume a change in older adult’s behavior and interactions. The final theory, Robert Atchley’s continuity theory of aging, states that older adults will usually maintain the same activities, behaviors, personality traits, and relationships as they did in their earlier years of life. It places emphasis on an individual’s patterns and preconceived parameters [6].

Continuity theory has four pieces that define the greater whole – internal structure, external structure, goal setting, and maintaining adaptive capacity [7,8]. Internal structure is made up of the preexisting worldview, attitudes, moral framework, belief systems, knowledge-base, and coping strategies. External structure is made up of social roles, relationships, living environments, and activities. Goal setting is rather straightforward as it assumes that adults have used their own internal structures and assessed the external structures limitations and opportunities in order to intentionally evolve [7,8]. The current elderly generation, characterized by their experiences with the Great Depression and World War II, focus less on materialism and more on hard work and self-reliance. They are also prone to having rigid opinions about race, gender, and sexuality [9]. If they have Alzheimer’s or Dementia they may look at technology with fear or disdain and they have no concept of political correctness. For example, they be racist or misogynist by nature because that was the standard where and when they grew up. They expect in-person engagement with family and caregivers. Upcoming elders, who experienced racial violence, the woman’s rights movement, Woodstock, the advent of television and computers, and terrorism, focus heavily on materialistic opportunities, political correctness, and activism [9]. There is a degree of self-reliance, but many focus more the whole than the individual and access to entitlements. For example, they believe heavily in the Social Security and 401K systems. They are just now reaching retirement age, so

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their expectations and ideas for Alzheimer’s care are yet to be fully understood.

Generations, communication and technology

When Dementia or Alzheimer’s disease is part of the caregiving experience, the general rule of thumb is to return to the basics, that is, what is familiar and comfortable [5]. This truly supports continuity theory. Whether it be adult daycare where the interior is set up to look like a neighborhood, reminiscence therapy which emphasizes generational movies and music, or arts and crafts which create shadowboxes or picture frames with treasured memories, within facilities there needs to be a balance of self-empowerment and realistic expectations. Family interactions need also follow the same framework. Family caregiving consists of assisting with household tasks, assisting with personal care, providing social and emotional support, providing or assisting with health care access, advocating for needs, coordinating care, and helping making decisions [10].

Family interactions also involves multiple generations. As mentioned previously, the Silent Generation from 1925-1945 represents the current elderly. They are technologically challenged and very traditional in their thinking. Baby Boomers from 1946-1964 are the generation that is currently retiring. They have a unique perspective as they have witnessed the birth of technology and activism [9]. Generation X from 1965-1980, Millennials from 1981-1997, and Generation Z from 1998+, have all grown up with the development of technology and digital solutions like the Internet, Google, Alexa, Siri, and cellphones [9]. Fast communication with text message and instant messengers seems second nature. The generations they care for, however, remember newspapers, handwritten messages, rotary phones, records, and taking trips to see distant friends and relatives. There is little, if any, desire to learn how to use modern technology. Bridging that gap requires the younger generations to adapt to “old” ways using creative means.

According to Parenting.com, there are certain components to a happy family. Creating family traditions, laughing together, playing together, and actively expressing affection all create bonding opportunities. Regardless of time and distance, strong families ensure these components endure [11]. When Alzheimer’s and Dementias are present in families, maintaining family relationships become more complicated. Family caregivers experience a myriad of emotions including happiness, sadness, anger, frustration, and fear as they deal with unfamiliar situations. Those with Alzheimer’s and related Dementias have the same emotions mixed with the disease symptoms. Maintaining the best family relationships requires charting an even path that balances needs, desires, and resources. For many families, connections begin with frequent communication with healthcare staff, but communication within the family is equally, if not more, essential. Presently there is a plethora of new technologies that are cropping up to that serve one of two purposes-connecting caregivers to seniors or providing seniors technologies that make life easier [12].

Discussion

Three of the most popular technologies are GrandPad. CareZone, and MyCelery. GrandPad offers a senior-friendly tablet with basic software for communication and family interaction. GrandPad partners with Consumer Cellular to provide cell phone service and inter-device compatibility [13]. CareZone is a phone application that allows a caregiver create a patient profile, establish a network of family helpers, create a shareable journal/log to track behavioral and appearance changes, catalog medications and pharmacy information, and the ability to broadcast messages to the whole care team [14]. MyCelery, a fax to email system, allows the elderly to hand-write notes and letters then use a fax machine to convert it to a PDF email attachment. Family caregivers can then send emails to the fax machine which prints the note out on paper [15]. Each of these technologies, their competitors, and the additional technologies in development are designed to be easy to use with prompts that caregivers, and even those with Alzheimer’s and Dementia, could understand. By integrating active facility communication with technology, families can maintain the happy relationships that have existed for years.

Conclusion

Maintaining active family relationships with those who have Alzheimer’s and related Dementias begins with an active understanding of the diseases. From there, an understanding of the different theories of aging creates perspective. Robert Atchley’s continuity theory best supports best practices for Alzheimer’s and Dementia care. Generational differences and expectations factor into family communication and caregiving outcomes. Technology allows families and those with Alzheimer’s and Dementia to improve communications. Through continued technological development, family relationships will continue to thrive.

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