

Dementia is a common neurodegenerative disease that primarily affects aging individuals. Dementia, specifically Alzheimer's disease—the most common type of dementia—negatively affects the mental and physical processes that are necessary for the motor, memory, decision-making, and communication skills that people frequently take for granted. The adverse effects on communication include difficulty recalling words, understanding semantics, and comprehending others (Miller-Ott, 2020; Nickbakht et al., 2023). Additionally, the general decline in critical abilities frequently causes individuals to become gradually more dependent on family members for anything from simple daily tasks to making important medical decisions. These challenges affect communication and change preexisting roles within the interpersonal relationships between individuals with dementia and their family members. For these reasons, dementia is a communication-debilitating illness that affects how the individual with dementia and family members perceive their communication and relationship, as well as their approaches to health care.

Dementia is communication-debilitating illness (CDI), meaning that it affects the individual's ability to communicate as effortlessly as they did before they started to experience symptoms. Those who experience CDIs report experiencing a decrease in the amount of people they communicate and hold interpersonal relationships with because of these changes (Bute et al., 2007). Similarly, in a study on perceived communication changes from dementia among those with the disease and a family member, the respondents with dementia discussed that their communication within their close interpersonal relationships has been negatively impacted, both in quantity and quality of conversations. Further, the researchers found that dementia patients openly expressed that communication has become difficult due to losing the skills associated with word retrieval and understanding meaning. The patients described the frustrations they feel

at not being able to communicate as they used to and with feeling judged by others. They know that sometimes how they behave or communicate may not make sense to those around them, which makes it easy for them to feel misunderstood, embarrassed, and even disrespected. They found that disclosing their dementia to others helps mitigate these feelings (Nickbakht et al., 2023). Therefore, dementia patients understand that this type of CDI is limiting their communication abilities, thus impacting their relationships.

Studies on family perspectives indicate a similar belief that family communication and relationship with the dementia patient have changed since the onset of symptoms. In the same study by Nickbakht et al. (2023), caregivers of individuals with dementia noted that the patient will sometimes use the wrong words or be otherwise incoherent. They also noticed a connection between decreased memory and communication abilities whereby the patient will repeat the same questions or stories. In another study focused on adult children of Alzheimer's patients, researchers found common perceptions of communication changes. The adult child expressed that even though it technically is still their parent, the topics and manner of communication are different than what they were before the illness. They felt that they essentially became a parent to their own parent while remaining their child, especially when they must correct their parent's behavior or speak on their behalf in a public setting. These changes are often frustrating and overwhelming for adult children of Alzheimer's patients (Miller-Ott, 2020). However, Bute et al. (2007) explained that while many participants in their study on CDIs expressed the same feelings of frustration and stress explained in Miller-Ott's research, some found helping the individual with the CDI rewarding and were able to appreciate the new relationship they established. In other words, despite participants' agreement that there are at least some changes in their

communication and relationship after onset of a CDI, there are some differing experiences and opinions about if the changes are positive or negative.

Importantly, Bute et al. (2007) and Nickbakht et al.'s (2023) research highlights several strategies of engaging in this changed communication. Remaining patient and kindly prompting the individual helps patients feel more comfortable and improves their confidence in their communication abilities. Participants also found that they should speak more slowly to give the patient more time to process the meaning of what they are saying, and they are able to gauge understanding through verbal and nonverbal cues by the patient. Many participants expressed that they even use written communication to provide important reminders or to help fill in the cognitive gaps that may be harder to fill through verbal communication. When communicating with the patient in a larger group, family members also explained that they control the topic to ensure that it is something the individual with the CDI can understand and participate in. These strategies demonstrate a conscious effort to maintain some level of communication with the dementia patient, even though it may be completely different than their prior methods.

These demonstrated changes in communication ability and the increased dependence on family members have clear manifestations within health care. Adult children of Alzheimer's patients explained that they gained control over their parent's personal information and decisions (Miller-Ott, 2020). In this way, family members are almost thrust into a caregiver role naturally. In a study focused on the amount of verbal communication during routine primary care visits by the practitioner, patient, and family caregiver, researchers found that 53% of verbal communication during the appointment was by the provider, 31% was by the caregiver, and only 16% was by the Alzheimer's patient. Patients with lower reported cognitive abilities spoke even less frequently during the appointment, while caregivers competed with the provider for

speaking time at various points in the monitored appointments (Schmidt et al., 2009). Karnieli-Miller et al. (2012) also looked at the communication between providers, patients, and caregivers. The appointments primarily consisted of dyadic communication between the provider and either the patient or the caregiver; the patient and caregiver rarely engaged in conversation with each other. The provider maintained control over communication by redirecting attention at various points during the appointment because the patient and caregiver have different informational needs and interests. Therefore, a major change associated with dementia care is the shift from the typical dyad of patient-provider communication to a triad of patient-provider-caregiver communication.

Dementia and Alzheimer's disease inherently affect communication through the biological processes that affect general cognition. This change in communication abilities prevents dementia patients from maintaining their typical communication habits with family members, which in turn affects their relationships. Family members frequently take on new roles as caregivers, parental figures, and managers of personal information. However, research has shown that it is possible to find somewhat of a new-normal in which the individual with dementia and their family members accept and adapt to the communication and relationship changes. The mental and physical changes that dementia patients face can be drastic, but family support can be key to maintaining some level of communication ability and strong, albeit different, interpersonal relationships.

References

- Bute, J. J., Donovan-Kicken, E., & Martins, N. (2007). Effects of Communication-Debilitating Illnesses and Injuries on Close Relationships: A Relational Maintenance Perspective. *Health Communication, 21*(3), 235–246. <https://doi.org/10.1080/10410230701307675>
- Karnieli-Miller, Orit, Werner, P., Neufeld-Kroszynski, G., & Eidelman, S. (2012). Are you talking to me?! An exploration of the triadic physician–patient–companion communication within memory clinics encounters. *Patient Education and Counseling, 88*(3), 381–390. <https://doi.org/10.1016/j.pec.2012.06.014>
- Miller-Ott, A. E. (2020). “Just a Heads Up, My Father Has Alzheimer’s”: Changes in Communication and Identity of Adult Children of Parents With Alzheimer’s Disease. *Health Communication, 35*(1), 119–126. <https://doi.org/10.1080/10410236.2018.1547676>
- Nickbakht, M., Angwin, A. J., Cheng, B. B. Y., Liddle, J., Worthy, P., Wiles, J. H., Angus, D., & Wallace, S. J. (2023). Putting “the broken bits together”: A qualitative exploration of the impact of communication changes in dementia. *Journal of Communication Disorders, 101*, 106294–106294. <https://doi.org/10.1016/j.jcomdis.2022.106294>
- Schmidt, K. L., Lingler, J. H., & Schulz, R. (2009). Verbal communication among Alzheimer’s disease patients, their caregivers, and primary care physicians during their primary care office visits. *Patient Education and Counseling, 77*(2), 197–201. <https://doi.org/10.1016/j.pec.2009.03.023>