

Living with Dementia: Reframing Ideas and Transforming Experience

Introduction

“So, what do you want to do with your life? What are your plans after college?” Doris leaned forward and folded her hands in her lap. “I hope to go to medical school and maybe go into primary care.” “Oh, you want to be a doctor, huh? My father and grandfather were both doctors . . . but it was different for women back then,” her eyes narrowed. “I was a nurse,” a proud smile washed over her face, visible even behind her blue medical mask. “That’s awesome, what was that like? Did you like being a nurse?” “Oh I loved it, it felt so good to help people,” her eyes sparkled with joy, her smile lingering as she paused and seemed to relish the fulfillment nursing brought to her life. “Anyway,” she sat up in her chair, “What do you study? What do you want to do?” My conversations with Doris circled back like this many times, with variations in the words we used and slight digressions to other parts of our lives, but invariably returning to this centerpiece. At first, I was tempted to drive the conversation somewhere else, to learn more about Doris and her life. But I soon realized that talking about her nursing career gave her the most pleasure and satisfaction, her radiant smile and gleaming eyes revealing the contentment she found from reliving this part of her life through each telling. The meaning of this conversation was rooted in these feelings, and the feeling of the conversation is what stays with me.

With people living longer, many of us and our loved ones will face dementia toward the end of our lives. Rather than excluding those of us who experience dementia from the rest of society and pronouncing us having experienced a kind of social death, we have the opportunity to build more inclusive communities, nourish our relationships, affirm dignity, and ensure the highest possible quality of life for those of us living with dementia. Reconceptualizing dementia

as a condition that people can live with, and still experience joy and flourishing relationships, can allow us all to live more meaningful lives. Attending to embodied demonstrations of emotional expression and caring capacity rather than narrowly focusing on cognitive abilities reveals not only personhood, but also opportunities to bring about positive experiences for both the person living with dementia and those entrusted with their care.

Current Cultural Narratives About Dementia

The dominant cultural narrative surrounding dementia is familiar: a tragic and horrific story in which the person receives the devastating diagnosis, loses their memories and the ability to recognize their loved ones, and becomes helpless. Their cognitive decline causes pain for their loved ones and caregivers—spouses lose the person they once loved, children lose their parents, and caregivers face a drastic emotional toll. In a *New York Times* review of the 2001 film “A Song for Martin,” the author writes that the movie “unblinkingly focuses on the special horror of Alzheimer's as Barbara helplessly watches her husband turn into a stranger and disappear before her eyes,” calling Martin’s trajectory an “implacably bleak” kind of “fate” (Holden, 2002, p. 1). Likewise, Behuniak (2011) notes that the trope of the “living dead” abounds in book and journal article titles, such as *Alzheimer's Disease: Coping with a Living Death* (Woods, 1989); *The Living Death: Alzheimer's in America* (Lushin, 1990); and “Beyond appearances: Caring in the land of the living dead” (Dunkle, 1995). Even when the content of these works aims to uphold the humanity of people with dementia, the use of this term reflects and sometimes reinforces the cultural association of dementia with a zombie-like existence. In short, this narrative concludes that dementia leads to social death, hopelessness, and ceaseless suffering.

This narrative is not only *conceptually* dehumanizing and demoralizing for people receiving this diagnosis and their loved ones, but it also negatively affects *experiences* with

dementia for people diagnosed. The cultural association of dementia with violent horror stories or zombie-like scenarios worsens the experience of the disease, as this narrative influences the ways others interact with the person with dementia (Taylor, 2008) or withdraw from their relationships (Powell, 2018). If it is believed that the *person* inside the body has died, people responsible for their care may ignore or dehumanize them, thinking their actions do not harm anyone because “no one is in there.” This framework disregards the inalienable persistence of personhood in people with dementia, as well as the widely varying levels of impairment of dementia (Taylor, 2008).

Challenges of Dementia

Reframing dementia should not invalidate the real challenges of living with dementia or caring for people with cognitive impairment, but rather illuminate the possibilities for these experiences. Therefore, as we reconceptualize dementia, we must also not romanticize it and first acknowledge these challenges.

Living with Dementia

Difficulties of living with dementia may be either primarily due to symptoms of cognitive impairment within the diagnosed person, or due to culturally shaped personal responses early after diagnosis and social responses to dementia among those charged with caregiving. People may struggle in their everyday lives with difficulties associated with cognitive impairment, such as trouble with forgetting, getting lost, movement, and incontinence. Other aspects of suffering are shaped largely by cultural attitudes and structural policies. Owing no small part to the cultural values of cognition and individualism, people who receive a diagnosis may experience fear and despair as they notice their own cognitive decline and feel a loss of agency (Bartlett, 2017). Additionally, due to the stigma of dementia and discomfort with the diagnosis, family and

friends may increase their distance, causing people with dementia to experience isolation. Keith Oliver reflects, “As time has moved on the nature of suffering has changed it has become more emotional. . . . I’m scared of losing support and that becomes frustrating” (Bartlett, 2017, p. 178).

The stigma against people with dementia and older persons in general is often reflected in understaffed and poorly run for-profit care facilities. Residents with dementia, then, might be mistreated and neglected, and suffer from boredom, excessive indoor restrictions, insufficient pain relief, and malnourishment (Bartlett, 2017). The cultural and structural foundations of the fear of cognitive decline, distress about loss of autonomy, sadness due to social isolation, and suffering in care facilities reinforces the need to attend to people’s distress and respond with social action.

Caring for A Person with Dementia

Carers may struggle with new logistical challenges following the cognitive decline of the person with dementia. They may need to provide extensive support for the person with dementia to keep them safe and fulfill their basic needs—feeding them, dressing them, bathing them, helping them use the toilet, and ensuring they do not get lost. They may face difficulties with managing all the responsibilities of the household and taking care of their own basic needs while looking after the person with dementia (Tolhurst, 2019). With significant time allocated to the caregiving role, carers may feel they lack freedom and cannot express aspects of their identity that do not pertain to caregiving. They too may feel the social isolation of illness: “A crushing sameness prevails: the loneliness of the place where, in O’Connor’s words, nobody can follow. Doctors apart, where is everybody?” (Hadas, 2011, p. 32). In addition, carers, particular spouses, may experience a particular emotional pain stemming from a sense of loss (Førsund, 2015). If their spouse has moved to a care facility, they may struggle with the physical separation from

their partner and miss sharing everyday life with them. When their spouse no longer recalls valued memories or recognizes meaningful places, they may feel a loss of a shared past and, in that sense, a part of their own personhood. As they no longer are able to live out their previously planned vision of the future, they may mourn the loss of a shared life ahead.

The suffering experienced by individuals with dementia and their carers is partly inherent to the disease but substantially exacerbated by cultural stigma and lack of institutional support. As Powell (2018) argues, “it would be wrong to focus only on the family, as if the needs of this vast population could be dismissed as the private obligation of countless individual families. To the contrary, it is the larger community, as well as government entities, that must address the challenge of supporting those with dementia” (p. S73). Changing societal understandings of dementia, implementing programs that support the well-being of people with dementia and their carers, and supporting carers in their efforts have the potential to improve quality of life for everyone affected by dementia. This requires a structural foundation that creates space for caring, including economic and organizational structures that prioritize care over profit; resources to support sufficient staffing and supplies; removal of stigma in attitudes, language, and policies in care settings; and leadership that mentors carers to center affect and relationships in their practice (Kontos et al., 2021; Mitchell et al., 2020). Given the complexities of structural change, this paper will focus on the *cultural* change to which readers can contribute through everyday interactions. To change cultural attitudes toward dementia and those of us living with it, we must start by recognizing the personhood of individuals with dementia.

Inherent Persistence of Personhood

Embodied Memory

Despite Euro-American notions of personhood centering on rational cognitive abilities, what makes someone a person is more complex and varied than their ability to think logically or recall discrete memories. Personhood can be “embodied”—meaning it can be expressed through the physical body. Memory itself is not limited to remembering information but can be embodied in the form of skills. Sociocultural background can be embodied in dress, physical manner, etiquette, gestures, and intonations. Personality can be embodied in the actions aligning with an individual’s will and habits. For example, one woman does not remember that she knows how to sew, but with encouragement, she demonstrates her exceptional sewing skill and the undeniable presence of her embodied memory (Kontos, 2006). Another woman, while being fed at the dining room table, carefully places a napkin in her lap, gently pulls her pearl necklace over her bib, and acknowledges each person seated around her by making eye contact, revealing her attention to neatness, elegance, and etiquette. Another woman, on the eighth day of Hanukkah, refuses to return to her room by shaking her head and grasping the aide’s arm, then wheels herself to the menorah, places a napkin on her head, prays with her hands covering her eyes, cries, and smiles, then willingly lets the aide take her to her room, demonstrating an individual will and a deep spirituality. These embodied manifestations of what is and has been meaningful to these people in their lives—sewing, sophistication, and piety—exemplifies an inherent personhood left out by limited definitions based on cognition.

Widening the Definition of Recognition

The cultural focus on cognitive ability not only obscures embodied forms of memory, but also predicates social and political recognition of a person on their ability to verbally recognize people and things. As a result, social death occurs when one lacks the ability to verbally recognize others. Of course, the idea that forgetting someone close to you is unethical and means

you have stopped caring about that person is invalid for making ethical judgments about people living with dementia (Taylor, 2008). Furthermore, this narrow definition of recognition as the identification of people and things obscures a more important form of recognition, that of intention and behavior (Walrath, 2013). Janelle Taylor writes, “My mother would certainly fail a pop quiz about my name, but she lights up when she sees me. . . . She may not ‘recognize’ me in a narrowly cognitive sense, but my Mom does ‘recognize’ me as someone who is there with her, someone familiar perhaps, and she does not need to have all the details sorted out in order to ‘care’ for me” (Taylor, 2008, pp. 326-329). Taylor’s mother’s recognition of her as a familiar positive presence supports a caring relationship that does not require comprehension of Taylor’s name or exact social role.

Reframing Dementia

As foregrounding overlooked forms of memory and recognition allows us to uphold the inalienable personhood of individuals with dementia, reframing dementia allows us to realize all the possibilities for living with this illness, including the abilities to experience pleasure, to feel greater appreciation, to care for others, to display creativity, and to strengthen relationships.

Pleasure and Appreciation

When we recognize people’s capacity for pleasure and ability to experience the world through their senses without necessarily using speech, we can logistically adjust conditions to invite people to experience joy. At a care home, carers arranged the conditions of dancing, bathing, and other activities of daily living to open space for pleasure (Driessen, 2018). To create space for pleasure in dance, the carers adjusted the environment of the room, their own bodies, and their ideas of what dancing is.

Instead of taking a classical dancing pose, care professionals and residents hold one another's lower arms for stability. Steps are smaller and slower; chairs are always nearby. Those unable to walk dance while standing in front of their chairs. Those unable to stand dance while seated, by moving their arms, legs or feet. With these adjustments, residents do not lack abilities. Instead, they have potentials that can be realized if the right conditions are in place. (Driessen, 2018, p. 28)

Modifying their preconceptions about how dancing should happen and who can dance, and making adjustments accordingly, allowed both the carers and the people with dementia to experience pleasure and enjoy each other's company in a new way.

Mr Richard takes the wheelchair and turns Ms Steiner as well as he can within the circle that we have formed. Both laugh. Then we all do. Ms Steiner drums the beat of the music on the armrests of her chair and she smiles with her eyes wide open now that she is included in our dance. Ms Rose suddenly says, radiating with joy, 'I *like* it!' (Driessen, 2018, p. 28).

The combination of music, movement, and inclusion opens space for joy, expressed not only in words, but also in smiles and laughter.

In addition to the ability to experience pleasure, a fuller appreciation of the moment is a possibility for people with dementia. Taylor writes, "The loosening of memory that leaves [my mom] stranded in the present moment also allows her to inhabit it more fully than I am able to, caught up as I always am in the rush of my days, so full of schedules, deadlines, plans and arrangements" (Taylor, 2008, p. 327). When Taylor is with her mother, she sometimes becomes able to share this new appreciation of the present, demonstrating the possibilities for new ways of engaging with the world when we reframe the experience of dementia. Thus, individuals with

dementia can find pleasure and appreciation in moments, either when conditions are carefully arranged like the dance or when being present is more spontaneous like Taylor's mom gazing out the window. When individuals without dementia attune to these possible feelings, the experience of pleasure and appreciation can be shared together.

Relationships

Cherishing Caring and Creativity

Just as attunement to pleasure and appreciation of the present moment can enhance the interactions between carers and people with dementia, understanding the ways in which the person with dementia enacts caring or displays creativity can strengthen the dyad's relationship. In my conversation with Doris, her sharing of the joy she found in nursing and her curiosity about my path felt like caring, as she took care to relate her experience to a young woman finding her own sense of direction. We might value this caring capacity of people with dementia over their cognitive capacity. Taylor demonstrates this in her experience with her mother's affection for a doll. She reflects, "The fact that my mother was holding a doll, and that she likely could not clearly distinguish it from a real live baby is, to me, less important than the revelation that this moment offered, of the persistence within her of the procedural knowledge of how to care, and the desire and need to do so" (Taylor, 2008, p. 329). The motivation and embodied inclination to care is cherished over a cognitive ability. Recognizing her mother's display of caring is one way Taylor continues to care for her mother, and this recognition reinforces their relationship.

Attending to the impressive creative potential of people with dementia can also nourish appreciation for them. This creative potential may manifest in multiple ways, including a departure from standard rules. In such a case, Dana Walrath exemplifies sustained appreciation

by valuing the creative new words and definitions her mother Alice formulates during Scrabble games: “mladz (mə-lădz’) *n.* Term of address for a group of young men; pissquilch (pīs’-skwēlch) *n.* Small bird native to S. America; drends (drëndz) *n., pl.* Sweepings that don’t make it into the dustpan. Challenge her? Never. I just wish I had photographed some of those boards” (Walrath, 2013, p. 19). Walrath refuses to argue with her mother or get frustrated with her use of these new words. Rather, she appreciates Alice’s creative expression and values these words as something to hold dear. When carers treasure the expressions of care and creativity by individuals with dementia—even as these articulations might manifest in unconventional ways—their relationships benefit.

Valuing Affect

Matching the power of cherishing *caring* and *creative expressions*, centering *affective experiences* rather than cognition can cultivate new possibilities for the relationships among the people involved. Recognizing affect theory’s proposition that “human beings are as much feeling creatures as they are thinking ones” (Skoggard & Waterston, 2015), we might foreground the feelings brought about through interactions and let them guide our efforts. This requires that we give up preconceived expectations for how people *should* experience the world. For example, consider two daughters’ reactions to their mother’s attachment to a doll or robotic animal. One daughter hates to see or talk with her mother about the doll, thinking that her mother, if she did not have cognitive impairment, would be “ashamed to see herself now, clutching the doll” (Powell, 2018, S73). Another daughter gives up assumptions about how her mother should find happiness. By accepting that the plush cat makes her mother happy, she increases the joy of her mother, who even becomes more sociable with other people as a result. This shift in perspective may be particularly challenging—the second daughter found her mother’s experience with the

cat “heartbreaking” as well as “wonderful” (S73). Though a visceral feeling of loss may make it emotionally difficult to value the ways people with cognitive impairment may experience the world, this effort is often necessary to promote the well-being of the person with dementia as well as the relationship.

Sources of conflict may be diverse, and the person without dementia often holds agency to react in a way that escalates or resolves the tension. When they prioritize affective experience, it can be easier to move forward from conflict. “I figured him out,” one friend says, “I know when he is frustrated that we change directions and I don’t press him—I just learned what works and what doesn’t, and so we just have a fun time together” (Taylor, 2017, p. 293). This person’s ability to accept their friend with dementia and move on from points of conflict allow the pair to experience positive affect and enjoy each other’s company.

In line with this value of “what works” and the prioritization of the affective experience, Taylor notes that her conversations with her mother “go nowhere, but it hardly matters what we say, really, or whether we said it before, or whether it is accurate or interesting or even comprehensible. The exchange itself is the point” (Taylor, 2008, p. 327). With this understanding in mind, Taylor learns to only ask questions that do not require specific information to answer or make statements that do not require a specific response: ““Sure are a lot of people out walking around today!’ ‘That guy's hair is really curly.’ With each exchange Mom smiles at me, beaming affectionately in that familiar, slightly conspiratorial way, as if we are both in on the same joke” (p. 326). Like my interaction with Doris, the meaning lies in the exchange itself and the affect experienced.

When positive affect is centered, enjoyable ways of engaging together can diffuse the hierarchy between those with and without dementia in their relationship. Through dancing with

residents, carers could more clearly see the personhood of the residents and felt they became “more equal” to them. One carer said, “The way I see it is that I am making contact which is somehow more real. And with ‘more real’ I mean, there is a person sitting in front of you, not only a patient or a resident. There is a person!” (Driessen, 2018, p. 29). Dancing shifts the roles of the carers and residents to become partners, and the way they move and enjoy the experience together powerfully shapes the carer’s understanding of the resident as a person. By centering *feelings* in our understanding of what is most important, we can create space for more joy, strengthen connections, and even equalize relationships.

Engaging Empathetically

In addition to valuing affect in interactions with people with dementia, approaching them with empathy and kindness can help deepen relationships. Part of showing empathy involves acknowledging when the person with dementia has good intentions, particularly when it is less obvious. Dana Walrath, remembering that Alice requested, “Promise me you will do something else when it gets too hard”—meaning move Alice out of their home when caring for her becomes too difficult—assumes and acknowledges good intentions when Alice later hits Dana’s husband with a broom and throws things at him. She “knew it wasn’t meanness”, and understands that Alice “was simply telling [them] it was time for something else” (Walrath, 2013, p. 63). Walrath recognizes that her mother cares about her and her husband; therefore, she can appreciate her mother’s good intentions even when her actions appear to contradict her intentions.

Another way of showing kindness and empathy involves being open to relating to the person with dementia and acknowledging common ground that may be found. When Janelle Taylor’s mother states that she wants to “go home,” Taylor eventually finds out that her mother

means her childhood home, where she believes her parents, Janelle's grandparents, still live. The author reacts to her mother's belief and wish not with ridicule but with empathy:

You could use that evidence to draw a clear line between us: place me here, on the side of reality, competence, and personhood, and put her over there, on the side of delusion, incapacity, and the not quite (or no longer) fully human.

What I took from that moment, however, was something different. I realized that what she was longing for was not *my* childhood home, but *hers*. She missed her Mom and Dad. She was trying, in her own way, to hold on to them—just as I was trying, against the odds, to hold on to her. Our predicament is exactly the same. (Taylor, 2008, p. 332)

If we empathetically recognize the deepest human feelings and desires we all share, our common humanity is upheld and our relationships are strengthened.

Appreciating people as they are, perceiving good intentions, and finding points of connection may nurture continued relationships and friendships. People without dementia may find meaning in maintaining relationships with their friends and loved ones with dementia. One friend comments, "I want to see them as long as I can. . . . I do it for me. I do it for them too, but I really—it's really important to me. Friendship has always been such an important part of my life" (Taylor, 2017, p. 291). Though stigma causes some to distance themselves from friends with dementia, those that stay may find meaning and benefit in the continued relationship.

Not only can close friends and loved ones sustain their connections with the person with dementia, but acquaintances or mutual friends might also develop relationships with the person during this stage. The woman who learned to move on from conflict, Janet, met Kurt, the person with dementia, after reaching out to his wife, with whom Janet played tennis.

I could tell that she seemed like she needed some help; and so I said, “What do you need?” And I realized that she was the primary caregiver for him, without any type of help or experience at all. And then so I just said, “How about if I come over for a few hours a week and visit?” . . . And she kind of broke out into tears and just said, “I’ve never had anyone offer to do that before.” And so over the last year or so I’ve been doing that at least once a week for three or four hours. (Taylor, 2017, p. 292)

This type of situation in which acquaintances become more involved in the life of a person with dementia also happened for another woman, Jacqueline. Her social network of both friends and acquaintances from church, a hiking club, and her workplace collaboratively cared for her—organizing her finances, hiring a trusted attorney, recruiting a caregiver, arranging her medical appointments, accompanying her on social outings, and coordinating their care through an online calendar and over email (Taylor, 2017, pp. 297-298). When acquaintances, friends, and loved ones empathetically engage, people with dementia can live with flourishing relationships and strong social support, and those in relationships with them can continue to treasure the presence of the person in their lives.

Hope for Healing

In more troubled relationships, reactions to dementia can open the possibility for reconciliation and growth. For Walrath, the time spent with her mother introduced the opportunity for them to heal their relationship. She admits, “We were never close until Alzheimer’s,” reflecting that “it was our unfinished business of finding a good ‘close’” (Walrath, 2013, p. 39). She calls her experience with Alzheimer’s “a time of healing and magic”, adding, “Of course, there is loss with dementia, but what matters is how we approach our losses and our gains” (p. 4). As dementia helped Alice share her inner thoughts, Alice began to apologize for

the past: “I wasn’t very good to you. I’m sorry”, she says, words that Dana “never imagined” she would hear “stated so simply” (p. 43). With these sentiments out in the open, Dana could finally tell her mother that she forgave her. This mother and daughter’s experience demonstrates that shifts in communication and increasing time spent together due to dementia can facilitate the healing of relationships and even spark some “magic” in people’s lives.

Conclusion

While the dominant cultural narrative surrounding dementia exacerbates suffering, a reframed narrative can enact positive changes in people’s experiences of emotions and relationships. Reframing dementia does not mean disregarding its challenges but being open to all the possibilities. This reframed stance requires being open to experiencing the world in new ways: prioritizing the affective experience and creating space for pleasure, valuing people’s caring and creative abilities (as they perhaps manifest in new ways), and empathetically finding ways to connect. The examples in this paper of possibilities for living with or caring for someone with dementia aim to provide hope for newly diagnosed individuals and their loved ones. While we push for structural change to support both carers at home and those in care facilities, we can also start creating cultural change through our attitudes and behaviors.

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