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Nancy S. Jecker

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Commentary
What Stories of Dementia Teach

Nancy S. Jecker[*†]

[*] University of Washington School of Medicine

[†]Correspondence concerning this article should be addressed to Nancy S. Jecker, Ph.D. University of Washington School of Medicine, Department of Bioethics & Humanities, 1959 NE Pacific Street, Box 357120, Seattle, Washington 98195–7120

Email: nsjecker@uw.edu

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Abstract. This commentary focuses on 12 narratives written by caregivers of people living with Alzheimer's Disease and other types of dementia. While each narrative is distinctive and particular telling, common themes woven throughout the narratives include: embarking on a journey; I changed and they changed; feelings elicited; the hardest and best parts; understandings and acceptance; intersections; and what the future holds. This commentary shares these common themes and how they play out in the lives of people caring for loved ones with dementia. The last section connects the narrative themes to bioethical inquiry, with a focus on discerning moral boundaries. The boundaries touched on relate to justice within families, caregiver self-respect, and the persistence of persons and personal relationships over time.

Keywords. Caregiving, Dementia, Alzheimer Disease, Justice, Respect, Self-Respect, Empathy, Emotions, Narrative, Families, Personal Relationships, Gratitude, Filial Duty,

With advances in public health and modern medicine, the narratives of old age have changed. Gawande notes that in the not too distant past, later life was typically like a roll of the dice, with a person puttering along and then the bottom would drop out (Gawande, 2014). Today, by contrast, an aging person's descent more often resembles a long journey down a hilly mountain, a journey that involves living for extended periods with chronic conditions such as heart disease, cancer, respiratory illness, stroke, or dementia. Along the way, although "we may not be able to stave off the damage . . . we can stave off the death . . . ," making it possible for an older adult to make it home—weaker and more impaired though (Gawande, 2014, p. 27).

When individuals live well into their seventies and eighties, they are more likely to suffer from chronic disease and spend their last stage of life dependent on family members for help with activities of daily living. Longevity has resulted in family relationships that are not only stretched to new lengths but transformed. Parents and children, spouses, and others who are navigating this experience are charting new terrain.

For many grown children, parents once stood out as larger-than-life figures. Fonts of some of our strongest early emotions, parents can evoke feelings

that range from safety and refuge to angst, from love to loathing. Parents can be the most important people in our lives or the bane of our existence. Strong feelings often linger well into adulthood, gradually diminishing only as adult children witness parents grow old. When a parent develops dementia, this can knock a parent off the pedestal a child might have placed them on. Whether a parent was loved or loathed, they are toppled. Any lingering perception of a parent as commanding and authoritative is laid to waste. A parent is no longer larger-than-life, but human, like me.

A different course unfolds when the caregiver of a person with dementia is a spouse. While a parent with dementia might be knocked off their pedestal, a spouse's dementia can feel too close for comfort. A spouse is typically not older or other, but a peer, perhaps perceived as part of one's self or, as the adage puts it, "one's better half." Reckoning with a dementia diagnosis for a partner can bring home a deeply personal realization. A debilitated spouse is a blunt reminder that we are all creatures that decay and die. With a spouse's decline closeup and personal, our usual defense mechanisms to avoid dwelling on decline and death break down.

Common Themes

Sharing stories of dementia can teach many lessons about what might be in store for us as individuals, offspring, and spouses. From the twelve NIB narratives of dementia, we learn about individuals moving from a mostly intellectual comprehension that a person close to them has dementia to a fuller appreciation of what this means. For some, the narrative includes a wish for a loved one's death; for others, the narrative is a love story. All the narratives express an effort to find meaning or something redemptive, yet for some, there is neither.

Embarking on the journey

Of course, an adult *knows*, intellectually, that a parent is just human. Yet in some salient ways, they don't really *know*. Some ways of knowing are gained only from living through experiences, such as the experience of a parent's decline or death. For some sons and daughters, the first sign that their parent is not invincible comes with noticing signs, such as wrinkles and gray hair, a stooped gait, a walker. For others, it is a parent's diagnosis of cancer. For the narrators of these stories, the path is marked by a fading mental state and an eventual dementia diagnosis. With dementia, signs and symptoms can arise as a dawning awareness that things are not right, or suddenly, like a jolt. Witnessing a parent's decline enacted forces a person's hand. It cannot be contested.

Yarbrough's journey bears this out. It began with a physician's pronouncement during a routine visit that "veered unexpectedly onto the caregiver path . . . I learned that Mom's cognitive changes were more than normal aging; they were the early stages of dementia."

For Chittooran, witnessing a parent's decline was like watching someone fall from a cliff. "My mother's symptoms devolved at an alarming rate into confusion, hallucinations, and delusions. She reverted to her days as a high-ranking government official's wife in India, with an army of servants at her disposal—she began to order people around, constantly asked who was coming to visit, and reminded me to 'tidy the house' and 'cook enough food for all our guests.'"

The lived experience was unmistakable for Pearson too, who describes an adventure his entire family embarked on several years into his dad's long course of Parkinson's Disease, "We set out to see the giraffe . . . he was starting to hallucinate but, in our stubbornness, we thought we could convince him the visions were not real." It was not that the family did not know; they did. But after the giraffe adventure, it could no longer be denied, tucked away for later consumption.

I changed and they changed

Each narrative depicts not just the arrival of something new, but the process of coming to terms with a life-changing truth. A common theme throughout was that a change was occurring not just in a loved

one but in themselves. Ferguson muses, "Watching someone you love, someone who was so beautiful, intelligent, witty, and loving lose piece after piece of herself changed me; changed all of us who loved her. You don't come out of something like that the same as when you went into it."

Personal change sometimes grew out of sacrifice. Zerrenner relates career and lifestyle adjustments, which began when "I had to shut down my consulting business, as I could not travel . . . I had just landed a very lucrative consulting engagement with a large healthcare system and had to turn it down."

Referring to serving as her mother's caregiver, Thew asserts that "what had changed her eventually changed me. I came to accept it all and accept her without embarrassment or explanation to others. This was an important transformation of heart and spirit and one I wished I had reached sooner."

Feelings elicited

Accompanying the change were often a range of intense feelings. Binning recounts the "battle with anger" after living for over fifty years in a loving marriage and watching Alzheimer's drive "a sharp jagged wedge" into the life he had built with his wife.

Guilt and resentment loom large too. Chittooran describes the feeling that "as hard as I try, my caregiving goes unappreciated by my mother." For example, "When people tell my mother she's lucky to have me as a daughter, she rolls her eyes and smirks behind their backs. Recently, she commented, 'What exactly *are* you doing for me? I don't need you . . . '"

Worrying is the hallmark of Chittooran's caregiving experience, especially the incessant worry about "what will happen to her if something should happen to me . . . She'd have to move to an assisted living facility, something we wouldn't do unless it was the last resort because it would be a somewhat shameful thing to do in our Indian community."

The pain of others making comments that hurt was pronounced for Ferguson, who describes being on the receiving end of remarks such as, "'I'd never expect my kids to take care of me. I will go to a nursing home,'" with "[t]he subliminal message being 'your mother expected *you* to take care of her?'"

Feeling overwhelmed is also emblematic of dementia stories. Chittoran advises all caregivers "not to lose themselves in the act of caregiving, even though it is difficult to remember a life BC (Before Caregiving)."

The hardest and best parts

For many, the hardest part of caregiving involved a decision to place a family member in a nursing home. Pearson confesses, "I did not want to admit to myself that he probably was never coming back home. He would live in the nursing home . . ." For Binning, the nursing home was a trial of separation and a painful letting go of his life partner. The pain grew to new heights when nursing home staff directed him to come only two times a week in order to help his wife "adjust to her 'new home.'" This was followed by a moratorium on phone calls, because "Talking by phone only connected us together and made our separation worse." Scoring his visits on a scale of one to ten, Binning surmised, "There will never be a number 10; there will never be a perfect visit." It was torturous simply to hear his wife recite questions like, "'Are we ever going to be together again?'"

Some of the best parts were simple things. Pearson writes, "I began to appreciate the small but profound moments" and "these ancillary personnel . . . the assistants who gently turn him, change his wet diaper pad; the woman who tidies up the room." In a particularly poignant depiction of ancillary staff, Pearson says, "I watched the person who empties the trash can as she tied up the bags. When finished, she motioned toward my father, 'May I?' 'Sure,' I said, uncertain of her intentions. She walked over, spoke to him, kissed him on the forehead, and walked out to the next room. She did this every day." Pearson recounts daily scenes five or more caregivers who, embraced his dad. Some cried, others smiled. Pearson thinks, "We should all be so lucky."

Understandings and acceptance

Appreciation and gratitude for what remained was one path to understanding and acceptance for many family caregivers. For example, Pearson describes the value of mundane things, which matter because they are not mundane to the person with dementia: "[a] smile, a hand placed in another's," "presence," and "the dose of kindness."

Reaching acceptance for others meant mustering the ability to laugh. For Pearson, a surgeon, it was the fact that "Years later, we could finally laugh about my botched job of a shave." Yarbrough also recounts "Making a commitment to laughter" and to "Creating good memories." Pearson's good memories came from creating "a ritual beyond words. When I visited, I would cut his fingernails."

Binning found acceptance in the clarity of belief that he was doing the right thing even when there was stigma associated with those decisions. Referring to the stigma of having a spouse in a nursing home, Binning declares, "Let it be known and understood, we who are left will ask: 'Have we abandoned our life's partner?' The truthful answer is: It's imagined abandonment." Binning states that with his wife in a nursing home, he is "more than comfortable with the care my Soulmate is getting."

For others, such as We, there was little comfort. Instead, an acceptance of sorts came with the realization that the father who abused her and now suffered Alzheimer's would eventually die, but the death would not heal, just end, the narrative of their relationship. She writes, "closure is not a requirement of caregiving. When we can accept that not all stories from caregivers are caring, nor should they have to be, caregivers can finally begin to heal and speak their truth." Perhaps, We's best hope for closure is to finally be permitted to give testimony to her truth and to have it affirmed and accepted by listeners.

Intersections

The twelve narratives make clear that dementia does not take place in a vacuum, but in tandem with the rest of life. For example, Pearson's father broke his hip. So did Zerrenner's wife. Tumosa describes her father's ten-year battle with dementia coinciding with "the deaths of two wives and his oldest son, a serious tractor accident, hypertension, several transient ischemic attacks (ITAs), and cancer." Yarbrough reports life changed with "two small but utterly terrifying words, *breast cancer* . . ." Her mom "could not fully process the diagnosis and treatment options, so the decision-making was up to me."

For We, "the rest of life" included the ever-present history of domestic violence perpetrated by the father she cared for. Haunted by a history of "Pop Pop's" violence toward her, there was constant tension from the incongruity of the dual identities her father epitomized, as both a perpetrator of violence and an individual with Alzheimer's. Describing others' attempts to reconcile the tension in unkind ways, We describes their "chortles and phrases like, 'Well, he *was* your father . . . you must have loved him deep inside," or, "'You don't mean that. He *is* your father, after all.'" Repeated insistence that this duality was, indeed, her truth, were inevitably resisted. As she puts it, "each narrative of suffering repelled the other like two magnets of the same poll . . . no crossovers allowed." As a result, the complexities and contradictions that constituted her story was a truth she was forbidden to share.

What the future holds

The future for many caregivers did not look rosy. Anonymous cautions, "What's coming next is cognitive decline, choking, aspirating, maybe pneumonia, incontinence. Already social gatherings cause distress, and what's coming is harder . . ." Pearson warns that "families need to realize that further decline is inevitable" and advises those with loved ones in nursing homes to go on outings, bring them home, visit, celebrate holidays," a lesson he learned only after the window closed: "Perhaps this should have been obvious, but we really never gathered as a family in the nursing home until he was dying"

Chittooran confesses she does not know what to think: "I don't know whether to hope that the end is swift and merciful or that she will live many more years, even as her light gradually dims." She adds, "I pray for patience and understanding, for strength

and courage, so that we can handle whatever the days ahead may bring."

Thinking about the future, some caregivers wish that their family member would die or that they themselves would. Anonymous, who has a life-threatening illness, states starkly, "[m]y advance directive is on file, but that is not enough. I need to finish my own end-of-life plan: get the 'No Code' tattoo, set aside money for a ticket to Amsterdam, and, just in case, order a copy of *Final Exit*."

Chittooran worries about what comes after her parent's death. "I worry about my own future if I too, should develop dementia. I tell my children that if I do, they're to walk me to the lake in our neighborhood and simply push me in. They think I'm joking."

Knowing that caregiving will one day end, Chittooran advises caregivers "to remember who they were before they became caregivers, and how important it is to maintain ties to the people they once were and to the lives they once had . . ."

Zerrenner speaks of opportunities that come with loss: "[t]here was no more chance to learn about the past since there were few memories of it to share, but there was still time to share the present and to experience the warmth of a mother's love."

Setting Moral Boundaries

Family caregiving raises bioethical questions related to moral boundaries in family relationships, which are often sidelined in scholarly literature. These questions emerge differently for adult offspring caring for aging parents compared to spouses caring for partners. A salient ethical concern for some offspring concerns the fair division of caregiving between them and their siblings. For both offspring and spouses, issues of self-respect, and the persistence of persons and relationships are central.

The fair division of caregiving within families

An issue Chittooran flags early on is the gendered division of caregiving. She wonders about "[h]ow it's all on me, not my dear brothers?" Chittooran is right to question the assumption that caregiving must fall only on her shoulders. Her experience points to the larger, gendered pattern of caregiving that has taken place since time immemorial.

Although longstanding prejudices about who ought to care can be difficult to budge, a just society ought to make reasonable efforts to support a fair division of caregiving not just within families but between families and the wider society. This includes protecting family caregivers against threats to their central life opportunities. A good place to start is by asking, do caregivers retain or lose the capability to create their own life narratives; be healthy; maintain bodily integrity; use senses, imagination and thought; express a range of human emotions; make and carryout life plans; affiliate with others; relate to nature; play and recreate; and regulate their environments (Jecker, 2020).

Absent minimal supports, family caregivers may find themselves in an uneasy place, where moral limits to what is asked of them fall to the wayside. Chittoran describes caregiving for her mother as teetering on the edges of moral boundaries when she refers to, "The most challenging aspect of being a caregiver . . . how it has consumed every minute of my time." Having cared for her husband before caring for her mother, she felt her life's time was not her own.

Culture is also interwoven into stories of filial duty. Thus, Chittooran explains that in "an Asian family . . . respect for, and obedience towards, one's elders is expected." Yet, at the same time, she steps back and reflects on the moral code she inherits, acknowledging "how important it is" for caregivers "to be kind to, and take care of, themselves, to accept support when it's offered and to ask for it when it's not."

Self-respect

The perception of a responsibility to care for a family member arises differently for children versus marriage partners. For adult offspring (Baxter, Bogdan-Lovis, Chittooran, Ferguson, We, Tumosa, Yarbrough, and Driver), the decision to care may be informed by a sense of moral responsibility that

springs from gratitude for life or for being raised by a parent (Jecker, 1989). Yet it is widely held in moral philosophy that certain conditions must obtain for a debt of gratitude to arise, although the exact nature of these conditions is disputed.

One widely accepted precondition for gratitude is that the acts for which one is grateful were not performed in ways that violate the rights and dignity of the recipient. When they were, any assertion that one should be grateful is morally dubious. For example, We's childhood included violence perpetrated against her by the parent she now cares for. Since childhoods vary, a gratitude-based duty must be modulated by the nature of the acts for which one is grateful (Manela, 2019). In some instances, family history renders caregiving harmful and these harms are sufficiently weighty to establish that a person should forego caregiving. For example, if a person perceives caregiving to be tantamount to denying their own worth and dignity, a self-respecting person does not take on caregiving.

For some adult offspring of formerly abusive parents, a path forward arises out of the belief that a person with dementia is not the same person as the individual who perpetrated violence years before. Another path forward is the belief that the prior act of abuse does not entail that a person forfeits their dignity. Analogously, someone convicted of an egregious crime and sentenced to prison still retains a right to be fed, sheltered, and live under humane conditions. Similarly, a parent who was abusive to their child in the past does not forfeit all claims to help with activities of daily living, such as being toileted, bathed, and fed. Yet it might be argued that the duty to provide this cannot fall on an abused child, but instead rests with the wider society.

The persistence of personal relationships over time

For spouses (Binning, Anonymous, Pearson, and Zerrenner), the perception of a duty to care takes a different form. In contrast to a sense of moral responsibility based on gratitude, a sense of spousal responsibility may relate to the voluntary decision and commitment that initiates the relationship. Perhaps the most obvious basis for this perceived responsibility is the promise undertaken during marriage, which traditionally commits a person 'for better, for worse, for richer, for poorer, in sickness and in health, till death do us part.' Based on this, someone might reasonably expect that if a party to a relationship becomes the victim of a devastating disease, the other will stay by their side and care for them.

Yet, it is reasonable to ask if there are any moral boundaries to such a promise. Even if it is reasonable to expect a measure of spousal support, it might not be reasonable to expect that a partner will be there no matter what. A judicious interpretation of marriage might include that the literal vows spoken are not the same as the underlying commitment the vows speak to. One reasonable interpretation of marriage someone might hold is that the actual commitment made is to support and nurture a certain kind of valued relationship (Jecker, 1995). The question then becomes, when dementia advances to the point that a person no longer recognizes their spouse, and nothing is left of the former relationship, what, if anything, is left of the former obligation?

Another way to think about the relationship between husbands and wives is what carries it through tumultuous times are continuing bonds of love. Schoeman (1980) characterizes the ethics that love sustains as having its source in virtues, rather than duties. Virtues of loyalty reflect the fact that "We share ourselves with those with whom we are intimate and are aware that they do the same with us." It follows that "traditional moral boundaries, which give rigid shape to the self," do not apply, and that "talk about rights of others, respect for others, and even welfare of others is to a certain extent irrelevant" (p. 8). For Schoeman, what matters most in marriage is not that one vowed to stay by the other's side, but that, despite illness, love persists.

However, it could be argued that Schoeman's analysis does not preclude the possibility that moral limits remain in force between loving partners, and that these are properly expressed as rights and claims based on justice. The moral responsibilities that love can license are limited,

first, because love does not warrant self-injury. For example, if a spouse with dementia endangers a caregiver's health or grows violent, it may violate the caregiver's self-regarding duties to remain in harm's way. Second, even if a caregiver feels love unconditionally, this does not show that they are morally bound under any and all conditions. Instead, relationships are circumscribed by moral considerations outside themselves (Jecker, 1993). Rather than exempting relationships from moral criticism or holding certain loyalties and allegiances unconditionally, we should instead impose constraints that ensure that each party is regarded as an ends, and each person's moral claims are upheld.

A guiding ethical idea should be the Kantian insight that persons have an ultimate value and worth, in contrast to mere tools, which possess a purely instrumental value (Kant, 1785). Admittedly, moral boundaries can be murky and challenging to set in dementia care. After all, the person with dementia cannot be held responsible for their present actions. When they lose their filter, bully, or behave aggressively, caregivers may feel (and be) trapped. In these instances, it can be morally incumbent upon the caregiver to protect themselves by exiting the caregiver role.

For both offspring and spouses, the test of doing caregiving well is variously described. According to Pearson, the challenge was "to listen and not discredit . . . no matter what." For Ferguson, it was recognizing "although sometimes it's difficult . . . there is still a person inside. A person who deserves the best of ourselves." Yet another test is respecting and caring not only for the care recipient but for oneself. When deciding to treat her mother's breast cancer or not, Yarbrough displays self-respect and a sense of her own moral worth when she affirms a commitment to live without regret, manifest as "the genesis of my central care question: 'what would she want; what do you want?'"

Yet, it is a genuine and difficult moral problem for many family caregivers to know their limits and to reach a decision to cease caregiving. Zerrenner says he knew, "It was time" to move his wife to a memory café (a living facility for older adults with dementia) when it "reached the point where I was stressed out, not sleeping well, and my own health was at risk . . . She was hallucinating at night and causing me to have sleepless nights."

For others, ending a caregiving relationship is not a live option because they perceive no viable alternatives. When this occurs, society has a positive duty to intercede. The alternative is morally tragic: refusing to care is tantamount to abandoning a loved one, yet continuing to care is self-injurious. A just state does not compel such choices; it does not leave families with care-dependent members in the lurch. Instead, it mitigates the financial, social, and emotional costs of caregiving by lending a hand (Brake, 2017).

Conclusion

In conclusion, this collection of narratives depicts humanity on the brink. It reveals human frailties and interdependencies, moral limits, and linkages between personal identity and relationships with others. As old age is stretched and family relationships last longer, these stories offer insights, if not always solace. By showing us how they gathered the wherewithal and courage to care, we can better understand our own stories and our shared human predicament.

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