Dementia and the Problem of Loneliness: How Faith Communities Can Help

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Abstract

Considerable recent research has focused on loneliness and its effects on the mental and physical health of persons of all ages. This paper addresses the emotional experience of loneliness among people living with dementia and those who love and care for them. Loneliness can have many causes, but a notable one is the way dementia stigma negatively affects relationships. This paper asserts that faith communities can address dementia stigma and the problem of friends drifting away by adopting a new culture of congregational care and becoming what is commonly called "dementia friendly." Examples of obstacles to such care are offered as well as descriptions of vital programs that serve as models for dementia-friendly faith communities. Faith communities have resources in their sacred texts, theology, and the regularity of social interaction in worship which can help to ameliorate the loneliness and social isolation that often accompany the condition of dementia.

Keywords: loneliness, dementia, dementia-friendly faith communities

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Loneliness has become a hot topic among researchers, public policy experts, healthcare professionals, and the public since the Covid-19 pandemic forced everyone to endure physical distancing to avoid catching or spreading the virus. Of course, physical distancing, whether via footstep images on the floors of shops or through the windows of long-term care communities, did not necessarily produce the emotional pain of loneliness if people had meaningful and effective ways to overcome social distancing. However, the enforced isolation of the pandemic and the inability of many people to access 21st century face-to-face communication tools like Facebook Live and Zoom increased awareness of the effects of loneliness on mental and physical health. Even before the World Health Organization declared Covid-19 to be a pandemic, researchers and public policy experts were recognizing the harmful effects of loneliness, leading the United Kingdom in early 2018 to appoint a Minister for Loneliness (Yeginsu, 2018).

For those living with some type of dementia and their care partners, both social and physical distancing added new challenges. Many already knew the emotional pain of loneliness produced when others withdrew from them, too often offering hurtful excuses like "I want to remember the person before the dementia symptoms appeared." Several years prior to the onset

of the pandemic, researchers began to document the problems of loneliness among people living with dementia (e.g., Burholt, Windle, & Morgan, 2017), with some work even suggesting that loneliness is a risk factor for the development of dementia (Sundström et al., 2020; Sutin et al., 2020).

Although he was not the first to make this claim, Vivek Murthy (2020), Surgeon General of the United States, famously compared the health risks of loneliness to smoking 15 cigarettes a day. Since the turn of the 21st century, these health risks have been widely documented by researchers (e.g., Cacioppo, Hawkley, & Bernston, 2003; Hawkley & Cacioppo, 2007; Holt-Lunstad et al., 2015). These efforts to determine the effects of loneliness on morbidity and mortality emerged at the same time that psychologists were embracing what has come to be called social neuroscience, an interdisciplinary field boosted by the development of imaging techniques that enabled scientists to observe brain changes associated with chronic emotions like loneliness (Cacioppo et al., 2007). However, it should be noted that psychologists were rather late in identifying the deleterious effects of loneliness compared to concerns about loneliness raised by sociologists since the middle of the 20th century, most notably with David Riesman's book *The Lonely Crowd*, first published in 1950 (Riesman, 1961) and Philip Slater's book *The Pursuit of Loneliness: American Culture at the Breaking Point* which appeared in 1970 (Slater, 1976).

As a result of more recent research by psychologists, sociologists, neuroscientists, physicians, and others examining the complex relationship between human beings and their social environments, healthcare professionals now measure and evaluate structural and social determinants of health, often abbreviated as SSDoH (Charles et al., 2021). Anyone who has had a recent medical appointment probably recognizes the SSDoH questions about issues like food security, safety, social isolation, and loneliness. In 2022, an international group of fourteen researchers working in Alzheimer's Disease Research Centers defined SSDoH as "environmental conditions in which individuals are born, live, learn, work, play, worship, and age that affect health, functioning, and quality-of-life outcomes across the life course" (Stites et al., 2022, p. 694). The National Institutes of Health (NIH) in the US is now referring to these domains of life as the "exposome". A recent call for proposals for research on the exposome's effects on dementia risk stated that "exposures in the environments where people live, work, pray, and play across their lives shape health outcomes" (NIH, 2022) including outcomes for people with Alzheimer's Disease and Alzheimer's Disease Related Dementias (AD/ADRD).

It is notable that these two recent publications about social factors that influence health and disease include public religious participation and private religious activities. Nevertheless, the possibility that worship and prayer might contribute to health by ameliorating loneliness received scant attention from Surgeon General Murthy (2020) who only mentioned religion on two pages of his book about the damaging effects of loneliness in the 21st century. He argued correctly that "service plays an elemental role in every major religion" (p. 164) and that regular practices of kindness toward others produce the kinds of meaningful relationships that help to ward off loneliness. However, this minimal attention to faith traditions in a book that has generated so much interest in loneliness is surprising in light of the fact that religion has been examined in "population-based research studies by epidemiologists and physicians [that] date to the nineteenth century" with programmatic research emerging in the 1950s and NIH funding beginning in 1990 (Levin, 2017, p. 32). Notable examples of research focused on religion and

health in particular among older persons include the work of Ellen Idler (e.g., Idler, 1987), Neal Krause (e.g., Krause, 2008) and Harold Koenig (e.g., Koenig, VanderWeele, & Peteet, 2023).

The demographics of aging and dementia in the 21st century combined with decades of research on how social support in religious organizations affects older adults' mental and physical health have contributed to interest in how faith communities can meaningfully include and support persons living with dementia and their care partners, people who too often experience loneliness and social isolation. The following sections of this paper reflect the ideal of congregations as "schools for friendship" (McFadden & McFadden, 2011, p. 132), beginning with a discussion of how faith communities are creating a new culture of congregational care with and for persons with dementia. Faith communities can do this because they "are often the glue of their local communities in the United States, especially for the elderly, and are well-situated to invite people into communities of friendship and mutual support" that "aid in mitigating feelings of loneliness" (Upenieks, 2023, p. 313). The work of creating these communities is not without obstacles as noted in the next section. The paper concludes by describing opportunities for spreading a new culture of care beyond the walls of religious organizations to the wider community.

Creating a "New Culture" of Congregational Care

The British psychologist, Tom Kitwood, introduced the idea of a "new culture" of care for persons with dementia in his ground-breaking book, *Dementia Reconsidered: The Person Comes First* (Kitwood, 1997). This book inspired the development of what are now called "dementia-friendly communities," a movement that began in England when people living with this condition described what they wanted from their communities; from there it has spread to many other countries (Buckner et al., 2019; Local Government Association, 2012; McFadden, 2021). In the first chapter of his book, titled "On being a person," Kitwood discussed Martin Buber's notion of "I-thou" relationships. Buber and Kitwood both grounded personhood in relationships with Kitwood quoting one of Buber's most famous sayings: "All real living is meeting" (Kitwood, 1997, p. 11). He continued by writing that this form of meeting has in its essence grace. Using words familiar to many Christians, Kitwood stated: "Grace implies something not sought or bought, not earned or deserved. It is simply that life has mysteriously revealed itself in the manner of a gift" (p. 11).

Kitwood titled the last chapter of his book "The task of transformation." He was talking about transforming the old cultures of care that viewed persons with dementia as lacking dignity because of their cognitive deficits. The old cultures considered medical professionals and researchers to have the only valid knowledge about dementia and they focused on states and stages of decline rather than individual "abilities, tastes, interests, values, forms of spirituality." (Kitwood, 1997, p. 135). In this last chapter, Kitwood wrote:

> The new culture…reinstates the emotions as the well-spring of human life, and enjoys the fact that we are embodied beings. It emphasizes the fact that our existence is essentially social. (p. 135)

Kitwood focused his ideas about the "new culture of care" primarily on the care provided by staff for people with dementia living in some type of long-term care. However, one can apply his ideas to an inquiry into what a new culture of congregational care for persons with dementia would look like. It would be very different from the kinds of comments sometimes heard from clergy who hold the prejudice that people with dementia will not remember their visits, cannot

understand their sermons, and have nothing to contribute to the life of the faith community. That old version of congregational care meant dropping off Sunday's flowers to people labelled "shut-ins". It was laden with ageism and assumptions that elders and especially those with dementia had no interest in nor capacity for spiritual growth. It also failed to recognize the progressive nature of dementia given how many people with various dementia diagnoses continue to offer service to their faith communities, enjoy the fellowship of weekly worship services, sing in the choir, and participate in the rituals that have bound their communities together for millennia.

Importantly, the new culture of congregational care takes seriously the demographics of aging and dementia. Methodist Bishop Kenneth Carder recently offered a good example of this: "A typical mainline congregation with a membership of two hundred will include seventy who are sixty-five or older. Of that number, seven will have Alzheimer's disease" (Carder, 2019, p. 101). Many more persons in this congregation will have relatives or friends living with some kind of dementia.

The new culture of congregational care affirms that it is not the sole responsibility of the faith community's leadership to provide this care, but rather it encourages all persons of all ages to engage in "I-Thou" meetings, whether at a coffee hour after a service, or in a visit in someone's home. The new culture of congregational care also understands that the rewards of being of service to others should be shared by all, including people living with dementia. This includes residents of residential care communities who can be enlisted in doing good for others. As noted by Surgeon General Murthy, this commitment to service is found in every religion.

Faith communities that embrace a new culture of congregational care do something that is all too rare today: they hold opposites in creative tension for good. Yes, there is plenty of loss and suffering with the progression of dementia for people with the condition and those who love them. However, family members and friends also tell stories of gains in expressions of love and gratitude, in playfulness, in living joyfully in the moment, in participating in religious rituals. All of this assumes that people with dementia live in an environment that treats them as a "Thou" and supports their carers as "Thou" also.

These expressions of a new culture of congregational care can be found in the many resources available to help congregations become dementia-friendly faith communities. (See the Appendix for an annotated list of guides for faith communities.) As more faith communities endeavor to recognize the needs and capabilities of people living with dementia, researchers have begun to document outcomes of their efforts such as an increase in knowledge about dementia and comfort with persons having dementia (Kevern & Primrose, 2020). Researchers have also documented various challenges to these efforts such as physical infrastructure that excludes some persons and lack of transportation to worship and social events offered by the faith community (Plunkett & Chen, 2016).

Obstacles to Becoming a Dementia-Friendly Faith Community

Because the greatest risk factor for dementia is age, the stigma associated with dementia—called "dementism" by ethicist Stephen Post (2022)—is potentiated by ageism. Stigma, whether associated with dementia or age or other human conditions like mental illness and poverty, has many components: "labeling, stereotyping, separation, status loss, and discrimination" (Link & Phelan, 2001, p. 363). Many studies in recent years have noted expressions and consequences of ageism, first named by Robert Butler (1969) when he observed middle class, middle-aged persons resisting the development of senior housing in their

neighborhood. Ageism has now been the subject of considerable research since the beginning of the 21st century (e.g., Nelson, 2002) and has been shown to have costs in terms of individuals' health and nations' economies (Levy et al., 2020). Research on stigma associated with dementia has revealed that it adds to caregiver burden (Werner et al., 2011) and prevents people from seeking help and treatment for their symptoms (Herrmann et al., 2017).

Are such stigmatizing attitudes found in faith communities? The answer is "yes" according to a publication by the United Church of Christ that offers support and suggestions for congregations wishing to be "age-friendly." In one chapter, Long-Higgins (2017) urges congregations to consider the language they use to talk about older adults. She also states the importance of recognizing diversity among older people, not only in terms of the way generations are defined and described (e.g., Boomers, Silent Generation) but also in terms of the varied interests and capabilities of people after retirement.

In addition to being self-critical about ageist attitudes, faith communities seeking to be meaningfully inclusive of persons with dementia need to be aware that people do not want to be defined by their disease (Harper, 2020). This means that congregations should not only resist and critique ageist language, but they also need to be aware of how "dementist" language creeps into conversation. This often happens when people refer to "dementia patients," a label that restricts individuals to a medical category. Also, while some congregations have developed special worship services for people with dementia, they may risk labeling and separating individuals from the wider congregational community.

Finally, all the obstacles that prevent older adults in general from fully participating in the life of the faith community also apply to persons having a type of dementia and their care partners. These include buildings that are inaccessible for persons using walkers and wheelchairs, lack of support for people with visual and hearing impairments, unavailable transportation for persons who no longer drive, and communication via technologies older persons may not use. All these conditions can contribute to older people's feelings of being cut off from the valuable social support of congregations as well as the meaning they once derived from participation in their faith communities. In addition, when persons become homebound or relocate to various types of care communities, contact with their congregation may be lost, thus intensifying feelings of loneliness. "The elder who feels she has retained the contact in her heart while the church has broken its contact with her may experience loneliness amplified by the negative emotions of rejection" (Payne & McFadden, 1994, p. 23).

Programs that Spread the New Culture of Congregational Care

Most faith communities reach outside the walls of their buildings to serve others in a variety of ways, whether by bringing the "good news" of their faith to people aching for a deeper and more meaningful spiritual life, stocking food pantries, advocating for people oppressed by poverty and injustice, or engaging in a host of other types of missions and ministries. One example of a program that is growing nationally is Respite for All which offers volunteer led, four-hour respite activities one or more times a week in faith community buildings. As described by its executive director, Daphne Johnston, Respite for All enables congregations to "show those with dementia and their loved ones the way to arrive at healing, hope, and inspiration" and offers opportunities to "reclaim joy, together" (Johnston, 2020, p. 179).

Alter™ is another congregation-based dementia-friendly program spreading throughout the US in Black churches. It promotes health and wellness among African Americans living with

dementia and loving persons having dementia through community education, modification of worship activities, and ongoing support for dementia-friendly activities (Gore et al., 2022). Interviews with African Americans about what they viewed as characteristics of dementia-friendly churches revealed that they see them as "(a) resourceful; (b) welcoming and friendly; (c) inclusive and comfortable; (d) understanding and accepting; and (e) concerned about personal well-being" (Epps et al., 2021, p. 556).

Faith communities can also demonstrate their embrace of a new culture of congregational care by advocating with local, state, and national governments for improved support for people with dementia and their care partners and by lifting up unmet needs in people with dementia who identify with culturally and linguistically diverse communities. They can find creative ways to use their physical spaces for community programs like memory cafés and support groups. They can also demonstrate to the wider community the joy and meaning that comes from recognizing the gifts of people living with dementia. Their gifts come in the form of challenging "the idols of rationalism and doctrinal abstractions," stripping us "of the illusion of individual autonomy," and reminding us "that human worth lies in bearing the image of God, not in physical and intellectual capacities" (Carder, 2019, p. 105). Appreciating these gifts is a way of resisting the common doom and gloom image of dementia that reinforces the stigma and leads to social isolation and loneliness. By offering a very different story about dementia, faith communities offer a new kind of hope, not based in pharmaceuticals but grounded in meaningful relationships.

References

Burholt, V., Windle, G., & Morgan, D. (2017). A social model of loneliness: The roles of disability, social resources, and cognitive impairment. *The Gerontologist*, *57*(6), 1020-1030. https://doi.org:10.1093;geront/gnw125

Butler, R. N. (1969). Age-ism: Another form of bigotry. *The Gerontologist*, 4(4, Part 1), 243-246.

Buckner, S., Darlington, N., Woodward, M., Buswell, M., Mathie, E., Arthur, A., Lafortune, L., Killett, A., Mayrhofer, A., Thurman, J., & Goodman, C. (2019). Dementia friendly communities in England: A scoping study. *International Journal of Geriatric Psychiatry*, *34*, 1235-1243. https://doi.org:10.1002/gps5123

Cacioppo, J. T., Amaral, D. G., Blanchard, J. J., Cameron, J. L., Carter, C. W., Crews, D., Fiske, S., Heatherton, T., Johnson, M. K., Kozak, M. J., Levenson, R. W., Lord, C., Miller, E. K., Ochsner, K., Raichle, M. E., Shea, M. T., Taylor, S. E., Young, L. J., & Quinn, K. J. (2007). Social neuroscience: Progress and implications for mental health. *Perspectives on Psychological Science*, *2*(2), 99-123.

Cacioppo, J. T., Hawkley, L. C., & Berntson (2003). The anatomy of loneliness. *Current Directions in Psychological Science*, *12*(3), 71-74.

Carder, K. L. (2019). *Ministry with the forgotten: Dementia through a spiritual lens*. Nashville, TN: Abingdon Press.

Charles, S. T., Röcke, C., Zadeh, R. S., Martin, M., Boker, S., & Scholz, U. (2021). Leveraging daily social experiences to motivate health aging. *Journals of Gerontology: Psychological Sciences, 76*(S2), S157-S166. https://doi.org:10.1093/gerong/gbab028

Epps, F., Heidbreder, V., Alexander, K., Tomlinson, A., Freeman, V., & Williams, N. (2021). A dementia-friendly church: How can the African American church support families

affected by dementia? *Dementia, 20*(2), 556-565. https://doi.org:10.1177/147130129900416

Gore, J., Toliver, J., Moore, M. A., Aycock, D., & Epps, F. (2022). A mixed-methods formative evaluation of a dementia-friendly congregation program for Black churches. International *Journal of Environmental Research and Public Health, 19*(8), 4498-4516. https://doi.org/10.3390/ijerph19084498

Harper, L. C. (2020). *On vanishing: Mortality, dementia, and what it means to disappear*. New York, NY: Catapult.

Hawkley, L. C., & Cacioppo, J. T. (2007). Aging and loneliness: Downhill quickly? *Current Directions in Psychological Science, 16*(4), 187-191.

Herrmann, L. K., Welter, E., Leverenz, J., Lerner, A. J., Udelson, N., Kanetsky, C., & Sajatovic, M. (2017). A systematic review of dementia-related stigma research: Can we move the stigma dial? *American Journal of Geriatric Psychiatry, 26*(3), 316-331. https://doi.org/10.1016/j.jagp2017.09.006

Holt-Lunstad, J., Smith, T. B., Baker, M., Harris, T., & Stephenson, D. (2015). Loneliness and social isolation as risk factors for mortality: A meta-analytic review. *Perspectives on Psychological Science, 10*(2), 227-237. https://doi.org:10.1177/1745691614568352

Idler, E. L. (1987). Religious involvement and the health of the elderly: Some hypotheses and an initial test. *Social Forces, 66*(1), 226-238.

Johnston, D (2020). *Reclaiming joy together.* Montgomery, AL: Respite for All Foundation.

Kevern, P., & Primrose, D. (2020). Changes in measures of dementia awareness in UK church congregations following a 'dementia-friendly' intervention: A pre-post cohort study. *Religions, 11*(7), 337-349. https://doi.org:10.3390/rel11070337

Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Philadelphia, PA: Open University Press.

Koenig, H. G., VanderWeele, T. J., & Peteet, J. R. (2023). *Handbook of religion and health* (3rd ed.). New York, NY: Oxford University Press.

Krause, N. M (2008). *Aging in the church: How social relationships affect health*. West Conshohocken, PA: Templeton Foundation Press.

Levin, J. (2017). "For they knew not what it was": Rethinking the tacit narrative history of religion and health research. *Journal of Religion and Health, 56*(1), 28-46. https://doi.org:10.1007/s10943-016-035-5

Levy, B. R., Slade, M. D., Change, E-S., Kannoth, S., & Wang, S-Y. (2020). Ageism amplifies cost and prevalence of health conditions. *The Gerontologist, 60*(1), 174-181. https://doi.org.1-.1093/geront/gny131

Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology, 26,* 363-385.

Local Government Association (2012). *Developing dementia friendly communities: Learning and guidance for local authorities*. London: Local Government Association.

Long-Higgins, B. (2017). Rules of engagement: Helpful guidelines for talking about aging and ageism in a congregational setting. In J. G. Guess & B. A. Powell (Eds.), *Age-friendly congregations: A new curriculum that explores how to minister with, to, and for older adults* (pp. 19-23). Cleveland, OH: United Church of Christ Council for Health and Human Service Ministries.

McFadden, S. H. (2021). *Dementia-friendly communities: Why we need them and how we can create them*. Philadelphia, PA: Jessica Kingsley Publishers.

McFadden, S. H., & McFadden, J. T. (2011). *Aging together: Dementia, friendship, and flourishing communities*. Baltimore, MD: The Johns Hopkins University Press.

Murthy, V. H. (2020). *Together: The healing power of human connection in a sometimes lonely world*. New York, NY: HarperCollins.

National Institutes of Health (2022). Notice of Special Interest (NOSI): Administrative Supplements to Support Research Infrastructure on Exposome Studies in Alzheimer's Disease (AD) and AD-Related Dementias (ADRD). https://grants.nih.gov/grants/guide/notice-files/NOT-AG-22-022.html.

Nelson, T. D. (Ed.) (2002). *Ageism: Stereotyping and prejudice against older persons*. Cambridge, MA: The MIT Press.

Payne, B. P., & McFadden, S. H. (1994). From loneliness to solitude: Religious and spiritual journeys in late life. In L. E. Thomas & S. A. Eisenhandler (Eds.), *Aging and the religious dimension* (pp. 13-27). Westport, CT: Auburn House.

Plunkett, R., & Chen, P. (2016). Supporting healthy dementia culture: an exploratory study of the church. *Journal of Religion and Health, 55*(6), 1917-1928. https://doi.org:10.1007/s10943-015-0165-8

Post, S. G. (2022). *Dignity for deeply forgetful people: How caregivers can meet the challenges of Alzheimer's disease*. Baltimore, MD: The Johns Hopkins University Press.

Riesman, D. (with N. Glazer & R. Denney). (1961). *The lonely crowd* (Abridged ed.). New Haven, CT: Yale University Press.

Slater, P. (1976). *The pursuit of loneliness: American culture at the breaking point* (Rev. ed.). Boston, MA: Beacon Press.

Stites, S. D., Midgett, S., Mechanic-Hamilton, D., Zuelsdorff, M., Glover, C. M., Marquez, D. X., Balls-Berry, J. E., Streitz, M., Babulal, G., Trani, J-F., Nenderson, J. N., Barnes, L. L., Karlawish, J., & Wolk, D. A. (2022). Establishing a framework for gathering structural and social determinants of health in Alzheimer's Disease Research Centers. *The Gerontologist, 62*(5), 694-703. https://doi.org:10.1093/geront/gnab182

Sundström, A., Adolfsson, A. N., Nordin, M., & Adolfsson, R. (2020). Loneliness increases the risk of all-cause dementia and Alzheimer's disease. *Journals of Gerontology: Psychological Sciences, 75*(5), 919-926. https://doi.org:10.1093/gerong/gvz139

Sutin, A. R., Stephan, Y., Luchetti, M., & Terracciano, A. (2020). Loneliness and risk of dementia. *Journals of Gerontology: Psychological Sciences, 75*(7), 1414-1422. https://doi.org:10.1093/gerong/gby112

Upenieks, L. (2023). With you until the end of age? A longitudinal study of changes in religiosity and loneliness in later life. *Research on Aging, 45*(3-4), 299-319. https://doi.org:10.1177/01640275221104720

Werner, P., Mittelman, M. S., Goldstein, D., & Heinik, J. (2011). Family stigma and caregiver burden in Alzheimer's disease. *The Gerontologist, 52*(1), 89-97. https://doi.org:10.1093/geront/gnr117

Yeginsu, C. (2018, January 17). U.K. appoints a Minister for Loneliness. *The New York Times*. https://www.nytimes.com/2018/01/17/world/europe/uk-britain-loneliness.html

Appendix

Dementia Friendly America: Faith Communities

https://www.dfamerica.org/sector-guides

The Dementia Friendly America organization publishes several "sector guides" including for faith communities. It lists concrete steps for faith communities to become more welcoming for people with dementia.

Developing a Dementia-Friendly Church (Livability; Faith in Older People)

https://faithinlaterlife.org/fill-resource/developing-dementia-friendly-churches-livability/

This British organization has been helping congregations become dementia friendly for many years. The website has a downloadable 16-page PDF with many helpful ideas.

Loving Through Dementia

https://lovingthroughdementia.org/

This program from Due West United Methodist Church in Marietta, GA, offers 14 topics for congregations to consider as they minister with people living with dementia.

USAgainstAlzheimer's (Faith United Against Alzheimer's)

https://www.usagainstalzheimers.org/networks/faith

The website offers a list of practical ways faith communities can become more dementia friendly.

Wisconsin Department of Health Services

https://www.dhs.wisconsin.gov/publications/p01269b.pdf

This PDF offers concrete suggestions for faith communities that want to be more dementia friendly and inclusive.