



White paper

The role of spirituality in human services

By Matt Estrade, MA, MBA



About the author

Matt Estrade, MA, MBA is a gerontologist in the Greater New Orleans area, where he helps families who are experiencing dementia through education, consulting, and conducting research. Matt is the author of the 2019 book, *The Peace with Dementia Rosary: Education, Intentions, Community*, and also hosts the Whole Care Network's "Peace with Dementia" podcast. He recently completed a Masters in Gerontology from the University of Louisiana at Monroe (2017) and holds a graduate degree from the University of New Orleans (2005) and a bachelor's degree from Auburn University (2000).

[A study by the National Alliance for Caregiving and AARP](#) (p. 68) asked how caregivers cope with the demands of caregiving. The most common response, identified by 73% of respondents, was praying.

This is just one example of the widespread reliance on spirituality and religion in our culture. However, these can be difficult domains for human service providers to address for many reasons:

- Discomfort with the topic
- Uncertainty about where to draw ethical boundaries
- Lack of understanding of the potential positive impact

This white paper will explore how to consider the religious and spiritual domains of persons experiencing conditions such as homelessness, addiction, dementia, disability, or chronic illnesses, and how religion and spirituality may impact clients and caregivers. This paper is not about any particular religion or spiritual persuasion, and acknowledges that not everyone has a religious or spiritual domain.

Ethical implications

It is critical to respect the right to self-determination, both of clients and their families. To direct a client toward a religious or spiritual system when they have not expressed interest represents a violation of that client's right to self-determination.

Conversely, it's important to meet the client where they are at in the recovery/coping process. So to not consider religion or spirituality as a possible intervention when a client has expressed such an interest would be similar to a physician holding back helpful medication or a remedy. In the same way, support for religion or spirituality should not be withheld when clients express that it is important to them.

Expressing interest

A client or family can express interest in several ways. It can be offered in a conversation with the provider, or it can be part of a provider's intake form. Such a form typically asks if there is a basic religious preference, and if so, what. Organizations can also make this determination easier for staff by specifically defining what "expressing interest" means, as part of a broader policy on spirituality and religion.



The role of the worker in this setting is not so much to explain the therapeutic benefit of prayer, but rather to support the client's process, regardless of any personal spiritual bias.

Scott E. Wilks, PhD
Louisiana State University

It is not the role of the social worker to bring spirituality to the client, but to understand there is considerable evidence behind the benefits of spirituality and religion, and to foster this domain on the client's terms.

Definitions

Religion and spirituality are similar ideas, but there are some differences.

Understanding the difference

Religion

the beliefs, practices and rituals related to the sacred, originating in an established tradition that arises out of a community with common beliefs and practices.ⁱ

Spirituality

an individual's quest for understanding the true meaning of life and the desire to integrate with the transcendent or the sacred. It is at the core and essence of who we are, that spark which permeates the entire fabric of the person and demands that ***we are all worthy of dignity and respect. It transcends intellectual capability, elevating the status of all humanity to that of the sacred.***ⁱⁱ (Emphasis added.)

This definition of spirituality speaks to the fact that a client may not have the intellectual or physical capability they had before, or may never have possessed the capabilities of a healthy person, but they are still owed their humanity, their dignity, and can experience spirituality.

Benefits to the client

There is considerable research on the benefits of religion and spirituality for those receiving care. This meta-synthesis of studies on ["The Experience of Spirituality from the Perspective of People Living with Dementia"](#) found several common themes.

Hope

Spirituality was a coping mechanism for persons living with dementia, especially for those who knew spirituality was a part of their life course. It offered hope, as well as comfort and familiarity.

Connection

Those with dementia tended to withdraw from society, pulling back from social events or even family, in part because they didn't want to expose themselves to comments or judgments. Volunteer opportunities in different organizations, including faith-based organizations, helped restore that connection.

Fulfillment

Reading, praying, or meditating were found to be aspects of human life that connect to an intangible or emotional level that's both satisfying and meaningful. The worlds of art and music, the wonders of nature, and the bonds of social relationships are all examples of spirituality that lead to meaning such as peace, wonder, joy, and love.





Benefits to the caregiver

Anyone in the inner circle of care for someone working through a chronic condition is a caregiver. It can be family. Friends. Professionals. They are all care partners. The term partner connotes collaboration, paying attention to cues, focusing on communication and on the client's preferences, as best as that client can communicate, and as best as the partner can decipher.

A study on ["Religiosity and Quality of Life: A Dyadic Perspective of Individuals with Dementia and Their Caregivers"](#) found that high religiosity of the care partner was associated with higher reported quality of life for the person living with dementia. This study surveyed both the care partner and the person living with dementia, if they were able to self-report their quality of life.

The researchers hypothesized that care partners with higher religiosity may feel a strong meaning in their role. They may look to examples of religious figures to help guide the work they do, to be optimistic, and to stay positive in this role.

Interestingly, when there was high religiosity with the person living with dementia, the care partner reported a lower quality of life. The researchers couldn't explain

this result, but one theory was that the person living with dementia may not have been able to practice in the way, or with the frequency, that they were accustomed to in the past.

Another study, ["Private Prayer Among Alzheimer's Caregivers: Mediating Burden and Resiliency"](#), found that caregivers experienced decreased burden and increased feelings of perceived resiliency. The study also found that prayer was a successful coping mechanism and a protective factor for resiliency.

A separate study, ["Spiritual Well-Being and Caregiver Burden in Alzheimer's Caregivers"](#), determined that care partners who had higher mean scores of spiritual wellbeing demonstrated lower perceived burden. The report went so far as to urge nurses to assess the spirituality of care partners and for health care providers to take a team approach that includes clergy, nurses, social services, and aging services.

Finally, ["The Moderating Effect of Religiosity on Caregiving Burden and Depressive Symptoms in Caregivers of Patients with Dementia"](#) found that care partners or caregivers with high-end scores for Organized Religious Activity (ORA), Non-Organized Religious Activity (NORA), or Intrinsic Religiosity (IR) had less perceived caregiver burden than those with lower ORA/NORA/IR scores.

Meaning on the Journey

A study of [“Existential Concerns of Families of Late-Stage Dementia Patients: Questions of Freedom, Choices, Isolation, Death, and Meaning”](#) found that finding meaning can assist with coping even after the care partner journey has concluded with the death of a loved one. Care partners were able to look back and find meaning in the care experience and the opportunity to serve their loved one in a difficult time.

Finding meaning during suffering is crucial to survival. The famous psychotherapist, Dr. Viktor Frankl, who wrote *Man's Search for Meaning*, was a prisoner in Auschwitz. His memoir captures his observations of himself and of his fellow prisoners, and the idea that meaning can get people through difficult times. When he was in the concentration camp, he would picture himself in an auditorium in Vienna after the war, addressing a huge class of students about logotherapy, his belief that human nature is motivated by the search for a life purpose.

Frankl noted that when everything has been taken away from us, the last freedom we have is to choose our response to hardship. He defines two types of meaning:

Provisional meaning. This is useful when thinking of the day-to-day tasks of a caregiver —helping someone to toilet or get into a vehicle. By finding meaning in those individual tasks, a caregiver finds the strength to get through.

Ultimate meaning. Caregivers also need to see the bigger picture of what they are doing, to see the enhanced quality of life they provide to their loved one. By seeing life through this lens, a caregiver is able to be more resilient, as the research noted earlier describes.

Putting the role of Spirituality into practice

The following are some practical ways that human services professionals can apply the principles discussed in this paper to each of the various players in the care continuum.

The client

Clients faced with a chronic condition — such as addiction, dementia, or disability — should make their wishes known to their loved ones, their health care providers, and their clergy if applicable. If the client is facing an end-of-life or permanently debilitating condition, this should include a power of attorney or other designee. The client should write down priorities and future plans for any religious and spiritual practice. Some questions to ask the client:

- Are there things that you want to do? Don't want to do?
- What do you think will be most important to you as you progress through your condition?

When possible, the client should also consider not only how they can be served, but how can they serve. For example, a person in the early stages of dementia can think about others in their situation and find ways to advocate for those peers. Or they may want to volunteer in some way.



The social component is often a key consideration. Who does the client want to share their time with? A church community? Close friends? Peers?

Finally, the client and his/her care circle should include logistical considerations like transportation. Are there loved ones to provide a ride? Is free transportation available in the community? Is visitation by clergy an option?

Care partners

If a loved one is not expressing what's important, and the care partner knows they have a history or preference of spiritual practice, the care partner should proactively start a conversation. Clients often have not thought about how their condition may affect the practice of their beliefs, or they may have diminished ability to express their wishes. It may be appropriate to invite clergy to speak with the client to answer questions, address issues, or share their experience.

Health care and human services providers

Medical and nonmedical professionals should consider the research presented in this paper on the benefits of spirituality, and then listen for clues of religious and spiritual preference. When those clues are identified, the provider should look for ways to support those preferences, fully respecting self-determination.

Providers should also develop a network of faith-based communities, clergy, or other resources that they can draw on, who can provide the appropriate support or counsel a client may need.

Clergy & faith-based communities

Faith-based communities should make sure that their events and worship opportunities are inclusive of persons in need. This may involve physical issues like handicapped access and transportation. Or it may require working with your community to create a welcoming environment for those who don't naturally "fit in." Seeking feedback from care partners and the people they serve can point you to possibilities.



There are also many ministry opportunities to help those with a condition that makes it difficult to assimilate into a faith-based community. Some of those opportunities include:

- Support groups for those facing challenges like dementia or addiction
- A health care ministry that connects those in need with local professionals
- Respite volunteers that can provide time off for overwhelmed caregivers
- A home modification team that can help with grab bars, ramps, etc.

If a faith-based community has a website or newsletter, articles about coping with specific disabilities and chronic conditions can be invaluable. Sites like [Dementia Friendly America](#) provide both a starting point and ideas for how to create a valuable resource to the community.

Conclusion

The research is conclusive that religiosity and spirituality can play an important role in the outcomes of care and the overall health of an individual. Care partners can also gain comfort, as they carry out what are often daunting and exhausting responsibilities.

Hope, resilience, and overall quality of life are just some of the benefits of supporting a faith journey for someone dealing with chronic challenges like dementia, addiction, or disability. Care providers and partners can confer these benefits to clients when they respect self-determination and see their role as supporting a process, rather than directing a belief system.

Finally, the role of religion and spirituality is part of a conscious decision-making process. Those receiving care must think through their beliefs and preferences, and communicate those desires to their loved ones or designees. Care providers and partners must look for clues and, in many cases initiate conversations so that



the wishes of their client can be fulfilled. And providers such as health care organizations and faith-based communities should assess their ability to support the spiritual needs of those facing chronic conditions.

Resources

- i. Koenig, H. G., King, D. E., & Carson, V. B. (2012). Handbook of Religion and Health. Oxford: Oxford University Press.
- ii. Jonas, W. B. [ed]. (2005). Mosby's Dictionary of Complementary and Alternative Medicine. St. Louis: Elsevier Mosby
- iii. McSherry, 2009, cited in Daly et. al, 2016



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