

Commentary

Bioethics and the Need for Activities Programs in Holistically Caring For the Enduring Spirit / Personhood in Dementia

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Abstract

Activities professionals are vital team members in nursing homes for providing holistic care for individuals with dementia. Their work is important for caring for the enduring spirit / personhood in dementia and providing quality of life.

Introduction

Secular western psychological theory has suffered from “hyper-cognitivism” tying personhood to cognitive ability in a utilitarian framework [1,2]. History has shown that this has the potential to lead to horrific outcomes [3]. A counterbalancing spiritual view holds that humans have innate worth, an enduring spirit / personhood, independent of cognitive ability, and that caring for the disabled elderly is of prime importance [4,5,6,7,8]. Graboys, a retired physician coping Parkinson’s disease and Lewy body dementia, describes how his soul has remained intact and his ability to find meaning in life is unbroken despite suffering other losses [4]. Downey, recounting her experiences running music activities, states that from what she has observed, Alzheimer disease can’t steal the spirit [9]. Thus holistic care involves the spiritual as well as physical needs.

Older adults often experience many losses [10]. Those with dementia face the loss of a former place in society, independence, health, and mobility [4]. In addition dementia can be confusing for the individual experiencing it, causing agitation [11,12]. It has been asserted that spiritual memory and emotion are well preserved in dementia and that individuals with dementia respond best to holistic care that considers their spiritual and emotional needs as well as providing for their physical care [9,13]. Thus a goal for holistic care is to facilitate the older adult feelings of connection, self-worth, acceptance, and serenity [10,9]. Activities staff and other healthcare professionals can assist in creating a calmer, more peaceful, more comfortable, and person-centered environment for individuals with dementia [9,11,14, 12]. This review of the literature will look at how palliative care professionals can provide holistic care that includes spiritual needs, with a special focus on care provided by Activities professionals.

Soothing Surroundings

Connecting with the marvels and beauty of creation can facilitate serenity. Enjoying the outdoors can be soothing for individuals with dementia [15]. Reflecting on life, while gazing at a garden scene, can bring back memories and can be filled with spiritual significance [16]. Gardens provide a harmonious multi-sensorial

experience delivering a feeling of peace and tranquility that can suggest something sacred. The “fresh air” of the outdoors and plant-derived “green odor” have been cited as stress-reducing aspects of spending time outdoors [17,18,16]. A visual tableau of water, flowers, trees, and sky can be invigorating [16]. Listening to the sounds of nature – the songs of the birds – can yield a sense of connection with the world. Activities professionals can provide outdoors Activities [19].

In climates not conducive to spending time outdoors, Activity professionals can bring aspects of the natural world indoors. Such is the case with “the Eden Alternative” model, which allows the elderly to be closer to the rhythms of the natural world [20,21]. The Eden Alternative features an environment with biological diversity by advising nursing homes to incorporate potted plants and companion animals. Individuals with dementia can find purpose in life by helping to care for the plants and animals. They can also gaze at the seasonal views from their windows [21]. Joyce Simard, founder of Namaste Care for individuals with end-stage dementia, recommends incorporating aroma therapy with lavender scent in creating a soothing environment [22].

Human Connection

Connection and relationships are an important need toward the end of life [10,23, 9,24]. Cognitive neuroscience tells us that the need for human connection is one of the most fundamental human drives throughout life [25]. Our brains are wired to be social [25]. This need for human connection and belonging persists in dementia [9,26, 12]. The literature recounts how Activities professionals and other healthcare workers, who interact extensively with individuals with dementia, find that even individuals with advanced dementia seek connection and a sense of belonging [9,12]. The interaction between healthcare workers and patients with dementia can retain

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its basic human essence and shared connection [27, 9] Downey shares how she uses eye contact, voice, facial expression, and touch to help individuals feel valued and connected [9]. She shares the importance of eye contact and how persons with Alzheimer Disease have a strong need to be seen and acknowledged.

Activity professionals are healthcare professionals who spend significant amounts of time with these individuals, thus can help fulfill this need to be seen and valued [19,14].

Music Activities

Music has long been connected with wellness programs for its refreshing and uplifting nature and its ability to enhance mood and promote serenity [9,28,29,12, 30]. This attribute of music may be due in part to involvement of the dopaminergic system [31]. Early in human history, in ancient Egypt, Greece and Rome, music was recognized as a part of the healing arts[14]. Today Activities professionals incorporate music into their dementia care programs [9]. Activities professionals may play music instruments, sing, play recordings of favorite music, or lead chair dance Activities to music [9,19]. Chair dance / exercise and music are a natural combination [32, 33]. Exercise can enhance the quality of life, including physical function, in individuals with various neurologic conditions [34,35]. Exercising to music has also been found to enhance levels of brain-derived neurotrophic factor (BDNF), a factor critical for synapse development and brain plasticity[36].

Music can enhance connection. This should not be surprising considering that singing or listening to relaxing music increases the level of oxytocin, the “love hormone” [37,38, 39]. Caregiver singing can cultivate more positive interactions with individuals with dementia [9,28,40, 41]. This can promote rapport between the individual and the Activities professional[9]. Downey describes how playing or singing the person’s favorite songs facilitates connection[9]. Downey described holding the hand of and humming to a woman, Iva, with end-stage dementia and her response – Iva turned her head and looked up at Downey. Downey sensed the connection and sacredness of the moment.

Uplifting memories enhance spiritual wellness at the end of life [23]. Music can bring out memories and positive emotions in individuals with dementia [28,12,42]. Research indicates that musical memory regions of the brain tend to be relatively spared in Alzheimer’s disease [43]. Thus music is often used in reminiscence Activities to help the individual with dementia connect with their inner self, their history, their relationships, their faith, and their personhood [9]. Downey describes how her use of music and approach to working with individuals with dementia helps them to reconnect with themselves and with their passions. She shares how when she played the ukulele in a nursing home where she was performing, a man stood up and started dancing expressively to the rhythm, a look of joy on this face as he remembered an activity that he had been passionate about earlier in his life. Another woman shared her past experience riding a bicycle-built-for-two after a sing-along that included the song “A bicycle built for two” [9].

Hymns and spiritual songs, consistent with the patient’s background, are a form of worship that has often been found effective in

spiritual care for those with dementia [12,44]. Londoño described using spiritual singing to bring a sense of peace and joy to a patient with dementia [44]. The spiritual aspects of wellness are important for the nursing home population and are included in Activities programming [23,24,14,45]. Music is a suitable part of this programming.

Summary

The secular western tendency toward “hypercognitivism” and a utilitarian framework needs to be countered with a more spiritual perspective that affirms the enduring spirit / personhood in dementia and the importance of person-centered care [1,2]. Faith traditions have long held the healthcare professions in high esteem – for example, the nursing profession has been considered a vocare (being called for a special purpose) – and faith teachings have advocated a special sympathy for the disabled elderly [46,47,5]. In that Activities professionals are called to affirm the spirit / personhood of individuals with dementia, it could be argued that Activities might be considered a vocare for holistic care.

References

1. Harris JG (2008) Biblical perspectives on aging: God and the elderly (2nd Ed) New York NY: Routledge Taylor, & Francis Group.
2. Kitwood T, Bredin K (1992) Towards a theory of dementia care: Personhood and well-being. *Aging and society* 12: 269-287.
3. Hohendorf G, Rotzoll M, Richter P, Eckart W, Mundt C, et al. (2002) [Victims of Nazi euthanasia, the so-called T4 action. First results of a project at the German Federal Archives to disclose records of killed patients]. *Nervenarzt* 73(11): 1065-1074.
4. Graboys TB (2012) Finding hope in the midst of despair: my decade with Parkinson’s disease and Lewy body dementia. *Movement disorders* 27(11): 1358-1359.
5. Jotkowitz AB, Clarfield AM, Glick S (2005) The care of patients with dementia: a modern Jewish ethical perspective. *Journal of the American Geriatrics Society* 53(5): 881-884.
6. O’Brien, M.E. (2001). *The nurse’s calling: A Christian spirituality of caring for the sick*. New York, New York: Paulist Press.
7. Post SG (2000) *The moral challenge of Alzheimer Disease: Ethical issues from diagnosis to dying*. (2nded). Baltimore, Maryland: The Johns Hopkins University Press.
8. Post SG (2013) Hope in caring for the deeply forgetful: enduring selfhood and being open to surprises. *Bulletin of the Menninger Clinic* 77(4): 349-368.
9. Downey K (2013) *Alzheimer’s disease - music activities for caregivers - how to integrate movement therapy and touch therapy to ease the disease - an elderly care professional’s guide* Kindle Edition, Sacred Ground Press.
10. Bickerstaff KA, Grasser CM, McCabe B, (2003) How elderly nursing home residents transcend losses of later life. *Holistic nursing practice* 17(3): 159-165.
11. Duffin C (2012) How Namaste principles improve residents’ lives. *Nursing older people* 24(6): 14-17.
12. Odbehr L, Kvigne K, Hauge S, Danbolt LJ (2014) Nurses’ and care workers’ experiences of spiritual needs in residents with dementia in nursing homes: a qualitative study. *BMC nursing* 13: 12.

13. Ennis EM Jr, Kazer MW (2013) The role of spiritual nursing interventions on improved outcomes in older adults with dementia. *Holistic nursing practice* 27(2): 106-113.
14. NAAP (2016) Activity professionals in action: Research, training, experiences, personal growth. St. Eau Claire WI: NAAP.
15. Whear R, Coon JT, Bethel A, Abbott R, Stein K, et al. (2014) What is the impact of using outdoor spaces such as gardens on the physical and mental well-being of those with dementia? A systematic review of quantitative and qualitative evidence. *Journal of the American Medical Directors Association* 15(10): 697-705.
16. Orr N, Wagstaffe A, Briscoe S, Garside R (2016) How do older people describe their sensory experiences of the natural world? A systematic review of the qualitative evidence. *BMC geriatrics* 16: 116.
17. Nakatomi Y, Yokoyama C, Kinoshita S, Masaki D, Tsuchida H, et al. (2008) Serotonergic mediation of the antidepressant-like effect of the green leaves odor in mice. *Neuroscience letters* 436(2): 167-170.
18. Oka T, Hayashida S, Kaneda Y, Takenaga M, Tamagawa Y, et al. (2008) Green odor attenuates a cold pressor test-induced cardiovascular response in healthy adults. *Biopsychosocial medicine* 2:2.
19. Hickman E, Frake T, Asante D (2014) Activity guide book for senior living: Activity program guide for assisted living, memory care homes & adult day programs Kindle Edition. Precision Books.
20. Koren MJ (2010) Person-centered care for nursing home residents: the culture-change movement. *Health affairs (Millwood)* 29(2): 312-317.
21. Thomas WH (1996) Life worth living: How someone you love can still enjoy life in a nursing home: The Eden Alternative in action. Acton MAVanderWyk& Burnham, Publicom, Inc.
22. Simard J (2013) The end-of-life Namaste Care Program for people with dementia. Baltimore, MD, Health Professions Press Inc.
23. Coulehan J (2011) Deep hope: a song without words. *Theoretical medicine and bioethics* 32(3): 143-160.
24. Mok E, Wong F, Wong D (2010) The meaning of spirituality and spiritual care among the Hong Kong Chinese terminally ill. *Journal of advanced nursing* 66(2): 360-370.
25. Lieberman MD (2013) Social: Why are brains are wired to connect. New York NY: Broadway Books.
26. Han A, Radel J, McDowd JM, Sabata D (2015) Perspectives of people with dementia about meaningful activities: A synthesis. *American journal of Alzheimer's disease and other dementias pii: 1533317515598857*.
27. DeHaan J (2013) Be joyful always. *Journal of Christian nursing* 30(1): 14.
28. Götell E, Brown S, Ekman SL (2009) The influence of caregiver singing and background music on vocally expressed emotions and moods in dementia care: a qualitative analysis. *International journal of nursing studies* 46(4): 422-430.
29. Hamilton JB, Stewart JM, Thompson K, Alvarez C, Best NC, et al. (2016). Younger African American adults' use of religious songs to manage stressful life events. *J relig health*.
30. Solanki MS, Zafar M, Rastogi R (2013) Music as a therapy: role in psychiatry. *Asian journal of psychiatry* 6(3): 193-199.
31. Zatorre RJ, Salimpoor VN (2013) From perception to pleasure: music and its neural substrates. *Proceeding of the National Academy of Science of the United States of America* 110 Suppl 2: 10430-10437.
32. Mathews RM, Clair AA, Kosloski K (2001) Keeping the beat: use of rhythmic music during exercise activities for the elderly with dementia. *American journal of Alzheimer's disease and other dementias* 16(6): 377-380.
33. Wade FL (1987) Music and movement for the geriatric resident. In "You bring out the music in me": Music in nursing homes. Karras, B. [Editor]. New York, NY; Routledge, Taylor, Francis Group.
34. Brett L, Traynor V, Stapley P (2016) Effects of physical exercise on health and well-being of individuals living with a dementia in nursing homes: A systematic review. *Journal of the American Medical Directors Association* 17(2): 104-116.
35. Tabak R, Aquije G, Fisher BE (2013) Aerobic exercise to improve executive function in Parkinson disease: a case series. *Journal of neurologic physical therapy* 37(2): 58-64.
36. Yeh SH, Lin LW, Chuang YK, Liu CL, Tsai LJ, et al. (2015). Effects of music aerobic exercise on depression and brain-derived neurotrophic factor levels in community dwelling women. *BioMed research international* 2015: 135893.
37. Eckstein M, Hurlmann R (2013) [Oxytocin: evidence for a therapeutic potential of the social neuromodulator]. *Der Nervenarzt* 84(11): 1321-1328.
38. Grape C, Sandgren M, Hansson LO, Ericson M, Theorell T, et al. (2003) Does singing promote well-being?: An empirical study of professional and amateur singers during a singing lesson. *Integrative physiological and behavioral science* 38(1): 65-74.
39. Nilsson U (2009) Soothing music can increase oxytocin levels during bed rest after open-heart surgery: a randomised control trial. *Journal of clinical nursing*, 18(15): 2153-2161.
40. Hammer LM, Emami A, Götell E, Engström G (2011) The impact of caregivers' singing on expressions of emotion and resistance during morning care situations in persons with dementia: an intervention in dementia care. *Journal of clinical nursing* 20(7-8): 969-78.
41. Raglio A, Filippi S, Bellandi D, Stramba-Badiale M (2014) Global music approach to persons with dementia: evidence and practice. *Clinical interventions in aging* 9: 1669-1676.
42. El Haj M, Fasotti L, Allain P (2012) The involuntary nature of music-evoked autobiographical memories in Alzheimer's disease. *Consciousness and Cognition* 21(1): 238-246.
43. Jacobsen JH, Stelzer J, Fritz TH, Chételat G, La Joie R, et al. (2015) Why musical memory can be preserved in advanced Alzheimer's disease. *Brain* 138(8): 2438-2450.
44. Londoño JM (2014) God can use us! *Journal of Christian nursing* 31(4): 2018.
45. Scott H (2016) The importance of spirituality for people living with dementia. *Nursing standard* 30(25): 41-50.
46. Grypma S, Jamison SL (2003) Caring for strangers. *Journal of Christian nursing* 20(3): 9-13.
47. Jun EM, Roh YH, Kim MJ (2013) The effect of music-movement therapy on physical and psychological states of stroke patients. *Journal of clinical nursing* 22(1-2): 22-31.