

## 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 with 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.

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