

# Gazing at Medusa: Alzheimer's dementia through the lenses of spirituality and religion

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## Abstract

Although religious and spiritual issues regarding Alzheimer's Dementia (AD) were not thoroughly investigated in the past, this review presents the most recent findings that can provide some scientific evidence about the experience and clinical usage of religious and spiritual beliefs from the perspective of the diagnosed patient, the caregiver-family members, and the health professional. Majority of the papers reviewed (50 out of 51) identified a positive influence of religiousness and spirituality. Thus, this review examines through a detailed analysis the possible pathways of the influence of these perceptions in cognitive, emotional, and behavioral aspects of AD. Findings support the paramount importance of religion and spirituality in coping with the diagnosis of this specific type of dementia. Future experimental research should consider these observed benefits with caution and include them in everyday life.

## Introduction

Although the quality of life movement had ignored the religious dimension of life and the part that these beliefs and practices may play in well-being (Ellison, 1983), religion/religiousness and spirituality are two terms that are not synonymous (Dyson, Cobb, & Forman, 1997), and are now widely used in healthcare research with researchers often giving vague definitions to these two constructs (George, Larson, Koenig, & McCullough, 2000; Giannoulis & Giannouli, 2020; Ellor & Bracki, 1995). Although there is a debate regarding these two terms, there is a basic distinction between them (Giannoulis & Giannouli, in press). Religion refers to a particular framework or doctrine that guides a system of beliefs that are followed by a broader faith community, by structuring not only how individuals' worship, but also by providing the tools for worship (e.g. prayer, sacred texts, and songs) (Shamy, 2003). In this line, there are two proposed types of religiousness, restful religiousness (praying, taking part in a religious organization and being religiously educated), which is associated with good levels of health, and crisis religiousness (praying without other religious activities), which is associated with objective measures of poor health (Ahrenfeldt *et al.*, 2017), while positive relations between religiousness and health have been explained by lifestyle habits (Ahrenfeldt *et al.*, 2018). On the other hand, spirituality is not necessary to be linked with a particular religion, as it seems to be a psychological construct more focused on the search for meaning in life, to a divine or transcendent sense of purpose (Stuckey & Gwyther, 2003; Worthington & Sandage, 2001). The latter (regardless of culture, time, and age) is linked to individual needs, taking three forms: 1) a need for biophysical exchanges, 2) a need for psychosocial exchanges, and 3) a need for spiritual-integrated exchanges, thus making it clear that spiritual needs cannot be separated from fundamental aspects of life, such as biological, psychological, social, and material (Missinne, 1991). Nurturing spiritual wellness (taking different meanings for each person and socio-religio-cultural context) is a prominent goal of most examined so far religious groups (e.g. Christians of different doctrines, Buddhists, etc.) and is a central notion to holistic health. Holistic healthcare is based on the premises that for well-being there is a balance between body, mind and spirit, and that each of the parts of this triad is interconnected, and affecting the others (Narayanasamy *et al.*, 2004). More specifically, higher levels of spirituality are found to relate to better mental and physical health and lower anxiety in older adults (McKinlay & Burns, 2017). Although spirituality, spiritual well-being, and maturity are relevant to gerontological theories, consensus on criteria for evaluating it in gerontology is not yet complete (Moberg, 1991).

Although religion in the modern era has been coloured in a rather negative way, with people worldwide dropping out of religion (Diener, Tay, & Myers, 2011), based on the philosophical movement of atheism, best described in the single phrase 'God is

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Dead' that Nietzsche supported (Williams, 2012), and given that for many decades, there was a fear of involving religious and spiritual beliefs in the treatment of patients, in our days it is a rather common practice to take into account these variables, as they may indicate not only a source of useful and important information about the patient(s), but also a new field of scientific study by itself (Huguelet & Koenig, 2009; Kimble & McFadden, 2002).

## Materials and Methods

The purpose of this review was to examine the role of religiousness and spirituality in dementia. The search period was from 1990-2019. As in other reviews, the search was not restricted by language or geographical region (Caponnetto, 2019). The keywords that were used were: Alzheimer's Dementia, Spirituality, Religion, Quality of Life, Caregivers, Patients, Health Professionals. Databases searched included MEDLINE, PsycINFO, Web of Science, Scopus, and Cochrane Library. Original articles presenting raw data as well as review articles (that did not include as references the presented here original research articles) were included.

### Alzheimer's dementia, religion and spirituality

Alzheimer's Dementia (AD) is a complex chronic illness that causes significant stress to the patients themselves as to their caregivers. Throughout its course, this disease creates dramatic role alterations in families, imposes increasing biopsychosocial demands, and may compromise the health and well-being not only of the patients, but also of family members/caregivers (Smith & Harkness, 2002). In the next sections, a detailed examination of findings regarding the influence of spirituality and religion on family members/caregivers, patients, and clinicians related to AD will be presented.

## Results

Forty-nine articles (reviews and articles presenting only quantitative raw data) were selected for inclusion in the current review (see the following three sections - A, B, and C). Research into the associations between spirituality/religiousness and quality of life and/or cognition in patients suffering from AD, and spirituality/religiousness and the quality of life (anxiety, depression) in caregivers and healthcare professionals of AD patients, is a relatively large and new field that is gaining increasingly more interest. The majority of quantitative studies were primarily conducted in the USA (44), with single representations from Japan (1), Iran (1), England (3), and in the case of reviews: France (1) and Malaysia (1).

### Family members and caregivers of patients with Alzheimer's Dementia

Family members and/or caregivers have to manage a chronic condition, which in the case of AD is 'a day-to-day responsibility of caring for a person which often exacts a toll upon the caregiver, which may be manifested psychologically, physically, socially and financially' (Brodsky & Green, 2002). From a spiritual perspective, family members/caregivers may find themselves in a state of spiritual exhaustion (Ewing, 2005). Several studies have mentioned that religion and spirituality, in conjunction or alone, can indeed play a crucial role in the experiences of caregivers, as well as in assisting their caregiving efforts, the effectiveness of their actions

(Kaye & Robinson, 1994; Picot, Debanne, Namazi, & Wykle, 1997; Stolley, Buckwalter, & Koenig, 1999; Stuckey, 2001) and their perception of self-efficacy (Salamizadeh *et al.*, 2017). Significant relationships were found among several religiosity variables, stress, and well-being in caregivers of Alzheimer's patients (Burgener, 1994). This finding is also supported by a survey with the majority of caregivers expressing their belief that 'spirituality and/or religious practices shaped how they approached providing care. Most stated that religious practices and spirituality affected how they felt about providing care and that religion and spirituality helped them deal with difficult challenges' (Nightingale, 2003). Additionally, spiritual coping and stigma-related stress mediate the relationship between the patients' instrumental activities of daily living impairment and caregiver psychological health (Saffari *et al.*, 2018), while spiritual care reduces caregivers' strain when taking care of AD patients at home (Mahdavi *et al.*, 2017). Even the use of formal services and informal support in male and female family caregivers of AD patients show differences based on religiousness beliefs (Sun *et al.*, 2008). Of course, it is necessary to mention here that not all caregivers have positive feelings about these dimensions (depending on their personality characteristics, previous life events, etc.), and that individuals who feel anger or distance from God and who question the faith in general or their own faith and/or religious beliefs have also increased levels of self-reported depression and perceived burden (Shah, Snow, & Kunik, 2001), thus posing problems regarding the use of religion/spirituality in support groups and/or individual counseling approaches. Nevertheless, the frequent feeling that the person(s) are no longer in control of their future, drives families often to look toward whatever in the universe that they believe is in control, and many diagnosed individuals and their families cope by drawing on spiritual and religious beliefs and practices (Stuckey *et al.*, 2002). Although the recent advances in technological progress and the availability of medication approaches could alleviate this burden, the emotional aspects of spirituality could be of increased significance for the family members of all ages in order to maintain connections with family members diagnosed with any form of cognitive deficits, and more specifically with neurodegenerative dementias (Gwyther, 1995). In this regard, places of worship (such as churches, synagogues, mosques, and other) have a unique role to play in maintaining and supporting those family connections (Stuckey & Gwyther, 2003). In addition to that, the practice of prayer is reported as a coping strategy for the everyday difficulties of living with a patient with AD, as well as a way of making sense out of stressful situations, and in coping with unrelated to the disease adverse life events (Stuckey, 2001). Of course, the use of computers and internet has already provided a way of establishing a network that confront the emotional, spiritual and informational needs of caregivers of people with AD (Gallienne, Moore, & Brennan, 1993). When demographic data are taken into account in the analyses, there are numerous reported differences regarding the age, the gender, the race, and the religion of the caregivers, even in the beliefs that the caregivers hold about the influence of these variables, as reported by Nightingale (2003) who supports that caregivers acknowledge that they are influenced by their ethnic background. Therefore, religious/ethnic factors may both aid and impede the help seeking thoughts and behavior of caregivers (Levkoff, Levy, & Weitzman, 1999). This is particularly true for Afro-American caregivers in the U.S.A., who perceive God as an integral part of their social support system (Dungee-Anderson & Beckett, 1992; Stuckey, 2001). Spiritual support, in particular, impacts in a positively significant way the resilience among African Americans caregivers of Alzheimer's patients (Wilks *et al.*, 2018). In Latino culture, church attendance plays a prominent moderating

role in the relationship between subjective forms of stress and depression, and at the same time church attendance exhibits direct effects on depression (Sun & Hedge, 2014). Therefore, spirituality in American Latinos is positively related to positive aspects of caregiving and may partially mediate the effect of subjective stress on positive aspects of caregiving (Hodge & Sun, 2012). In contrast to the above, in multicultural regions such as Vietnam, the caregivers often combine multiple strands of different religions and/or spiritualities (e.g. Animism, Buddhism, Taoism, Confucianism and Catholicism) (Hinton *et al.*, 2008). It is worth mentioning that in the U.S.A., religion can have both positive and negative impacts on caregiver burden and self-reported levels of depression, but these religious influences appear greater for Caucasians and African Americans, and less so for Latinos (Shin *et al.*, 2017). In UK, spirituality was found to be supportive in relation to life stresses both in female AD patients and their caregivers when examined simultaneously (Jolley *et al.*, 2010).

In addition to that, female caregivers (wives of diagnosed patients) use more frequently symbols (e.g. God), and spiritual behaviors (e.g. private prayer, reading of spiritual materials, seeking spiritual guidance in making decision in their everyday life, and forgiveness) as coping mechanisms, a finding suggests that interventions with churches as natural networks for female caregivers may be useful (Kaye & Robinson, 1994). As a conclusion, based mainly on findings conducted in the U.S.A., it is supported that religion influences care in AD patients in two ways: (1) religion hinders access to the traditional health care pathway, or (2) religion assists in positive coping, therefore rendering necessary the collaboration between religious institutions and health care providers in order to improve care referral, provide information dissemination and relieve care-giver burden (Regan *et al.*, 2013; Regan, 2014). Although further empirical research is needed in different cultural settings, 'promoting adaptive religious beliefs and fostering the notion of free will may serve as beneficial strategies for caregivers of individuals with dementia' (Weisman de Mamani, *et al.*, 2014).

Finally, there is only one review that supports ambiguous results from 83 studies (with 37% of the articles published between 2000-2005) regarding the effects of religion/spirituality. More specifically, the preponderance ( $n=71$ , 86%) of studies found no or a mixed association (a combination of positive, negative, or non-significant results) between religion/spirituality and well-being in caregivers of AD patients (Hebert *et al.*, 2006).

### Patients with Alzheimer's Dementia

Religion and spirituality are linked to a plethora of issues as reported by the patients themselves, such as: 'the role of religion or spirituality in finding meaning in dementia, the role of religion or spirituality in coping with the disease, the influence of dementia on religious or spiritual practices, and the influence of dementia on faith' (Snyder, 2003). Religion and spirituality may offer alternative pathways to continue to find meaning after the diagnosis in the chronically ill older patients through the long course of the disease (Bell & Troxel, 2001; McFadden *et al.* 2000; Young, 1993). Chronic illness, such as AD, can bring thoughts and feelings of disruption and disorganization in the sufferer, resulting in spiritual distress (Narayanasamy, 1996). More specifically, spirituality may represent a source of comfort and/or a form of emotional support for some patients with AD (Harris & Durkin, 2002). Teleological explanations as well as beliefs that God or some other form of an ultimate designer-supreme being provides a sense that all is not lost and that there is external control left in order to improve the current experienced situation, is frequently found in patients with AD

(Lombrozo, Telemen, & Zaitchik, 2007).

The experiences of the majority of diagnosed elders with AD reveal intensely spiritual aspects of the disease regarding the coping with the diagnosis and planning based on hope for the future) (Snyder, 1999). 'Spiritual needs' (e.g. including needs ranging from the need to be connected to others, or to still be 'in the flow of life', and to love or to be loved) are indeed present among patients suffering from dementias and these needs must be met by sensitive, well-trained family members/caregivers and professionals in order to promote well-being (Bell & Troxel, 2001; Kirkland & McIlveen, 1999). Therefore, these pervasive needs can be found not only in the mild, but also in the moderate and severe stages in the progression of the AD, and there are reported ways to nurture spiritual well-being (Everett, 1996; Richards, 1990). In this line, spiritual needs in patients with dementias may be met with faith rituals and symbols, thus using communication channels (e.g. music, poetry, and symbols) could bring forth long-term memories (Richards, 1990).

Especially in the early stages of AD, the opportunity of participating in religious events is found to be linked to self-reports of a better quality of life, while believing in God is claimed to play the role of a significant coping resource (Katsuno, 2003). Personal faith, prayer, connection to church, as well as family support are found to enhance the ability of people with early-stage AD to keep a positive attitude as they face everyday augmenting living problems (Beuscher & Grando, 2009). Of course, following the dyadic coping theory, that takes into consideration both the patient's as well as the caregiver's perspectives, the importance of both sides is reported about a clear influence of religiosity on quality of life (Nagpal *et al.*, 2015).

In the cognitive domain, religiosity can positively affect cognitive functions (Jung *et al.*, 2019), while higher levels of spirituality and private religious practices, are associated with slower progression of Alzheimer Dementia, but no relationship was found between the above variables and improved quality of life (Kaufman *et al.*, 2007), although in a recent systematic review, spirituality and religion seem to slow cognitive decline in AD, and help patients use coping strategies to deal with their disease and also have a better quality of life (Agli, Bailly, & Ferrand, 2015). In a relevant review, several articles presenting raw data are mentioned that show the positive role of religion in the health (physical and mental) of older patients with anxiety and depression as well as of older inpatients (AbdAleati, Zaharim, & Mydin, 2016), a finding that is also supported specifically for the group of AD patients who demonstrate higher levels of religiosity, something that correlates with a slower cognitive and behavioral decline in time, with a corresponding significant reduction of the caregiver's burden (Coin *et al.*, 2010). Given that many spiritual-religious activities rely on more resilient cognitive features (e.g. procedural memory and limbic system aspects of attachment and motivation), the therapists could use this approach (also known as Procedural and Emotional Religious Activity Therapy) to involve patients in rehabilitation attempts (Vance, 2005).

Finally, internalizing one's religious beliefs within a religious community-social network may provide a psychological buffer against worry of dementia to the elders themselves, as well as to their family members who will later on face this fear of developing the disease (Roberts & Maxfield, 2018)

### Health professionals of patients with Alzheimer's Dementia

As in the case of family members and caregivers (relatives or





paid people), the health professionals (psychiatrists, neurologists, general practitioners, psychologists, nurses, etc.) who come in contact with patients having a diagnosis of AD, face (not necessarily similar) emotional changes, that most of the times go unnoticed (Ofri, 2013). Special attention must be given to spirituality and religion which are reported as not adequately respected in the clinical settings, partly because health care professionals may not be aware of their potential importance both for patients and families (Killick, 2004; Stuckey *et al.*, 2002).

Although cognitive deficits (Kitwood, 1997; McFadden, Ingram, & Baldauf, 2000), and more specifically memory impairments are the most prominent characteristics of AD (Sapp, 1997), the individual patients as persons are more than just a complex of symptoms (Giannouli, 2017a). Given that one of the major problems of AD is the disruption of the use (expression and understanding) of speech in normal communication, the clinician may confront this loss by focusing on a holistic view of the patient's spiritual background and by incorporating this comprehensive holistic view into the care plan (Lawrence, 2003). This improvement can also be achieved, even by pastoral visitors, when individualized, person-centered strategies are used to improve communication based on enduring abilities in these patients (Ryan, Martin, & Beaman, 2005). Of course, pastoral and spiritual care may be used effectively to help alleviate depression and support older patients suffering from dementias, only when spiritual needs are assessed beforehand (McKinlay, 2006). Additionally, the incorporation of a bio-psychosocial-spiritual model of healthcare may optimize not only the patients', but also the caregivers' well-being (Forbes, 1994), something that can be achieved by therapists when spiritual beliefs and faith communities are included in the design and delivery of services in individual as well as group therapy (Smith & Harkness, 2002).

### Methodological limitations

One major methodological difference across studies was the sample size, and therefore the statistical power, which varied. Differences in sample size and characteristics make it difficult to generalize interpretations across studies. It is therefore difficult to generalize across studies given the heterogeneous nature of AD and the AD stages of the patients as well as the frequent use of unrefined measures of religion/spirituality and of atheoretical approaches to studying this topic (Hebert *et al.*, 2006).

### Future research directions

Although there is a growing body of research literature regarding the quantitative data from different religions, cultural settings and healthcare systems (Giannoulis & Giannouli, 2020), still the effects of ethnicity and cultural background are not clear in mental illness (Giannouli, 2017b). In these studies, the dimension of intensity of religious and spiritual beliefs should be taken into account, as in different cultural traditions there are different connotations for the measured aspects of religion and spirituality, thus, rendering qualitative, or mixed quantitative-qualitative approaches more suitable (Higgins, 2005; Giannoulis & Giannouli, 2020).

### Conclusions

This review emphasizes the importance of recent findings regarding the role of religion and spirituality in different aspects of

AD. Thus, this review underlies the importance of incorporating these findings in interventions either aiming at the patients, or at the family members/caregivers, as well as in informing the clinical practice and practitioners about the need for considering a holistic approach of this disease. This review indicates the importance of developing more knowledge about how people with dementias express their spiritual and religion-related needs in different contexts, as well as how family members/caregivers and professionals should observe and interpret such needs, and therefore the importance of indentifying the possible barriers to spiritual care in dementia (Carr, Hcks-Moore, & Montgomery, 2011; Ødbehr *et al.*, 2014). Although religion and spirituality are not a panacea, creating more questions than answers regarding their utility and importance as mediator variables regarding quality of life and psychological/cognitive status (Giannouli, 2017c; Labun, 1988; Miller & Thoresen, 2003), and by highlighting their clinical importance could be a starting point for exploiting all resources that could be of assistance in the fight against the course of AD.

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