# **Research Article**

# Death without God: Nonreligious Perspectives on End-of-Life Care

# Helen Dempsey-Henofer\*

Licensed Clinical Social Worker, Practicing in Hospice Care in Charlottesville, 1051 Hopkins Court, Charlottesville, Virginia-22901, USA

# ABSTRACT

Nonreligious people are underrepresented in the literature guiding end-of-life care. Moreover, much of what is written about nonreligious patients is written from a religious perspective. To address this deficit, the author conducted descriptive research by surveying online social media group participants using a quantitative questionnaire and qualitative feedback (N=263). Participants responded from closed social media groups for nonreligious people. Survey questions and responses offer insight into a nonreligious end-of-life dyad on the interrelated perceptions and experiences of nonreligious people regarding end-of-life healthcare. Participants responded to questions that assessed individual worldview description, openness to hospice services, feelings regarding chaplain services, expectations regarding fear of death, feelings on religious phrases, experiences of marginalization

### Introduction

Death may be the one certainty of life. It is the end point of the measurable physical human lifespan for people holding every imaginable perspective. Among groups of people holding every imaginable perspective, nonreligious people are rapidly growing in numbers. In the United States in 2019, Pew Research Group identified that the number of religious unaffiliated increased from 19% to 26% from 2009 to 2019 (Pew Forum, 2019). Despite this truth, the needs of nonreligious people at end-of-life are generally overlooked in the literature. To gain insight pertaining to a nonreligious end-of-life dyad on the interrelated perceptions and experiences of nonreligious people; the author surveyed participants in closed online social media groups designated as being for "atheist," "agnostic," and "secular" social media users, categories encompassed by or used interchangeably with the category of nonreligious [1]. This article seeks to contribute to the field of end-of-life healthcare by enhancing practitioners' culturally sensitive practice informed by the nonreligious end-of-life dyad.

Many articles for healthcare providers working in palliative and hospice care speak to importance of spirituality and faith in providing care for the whole person to include a person's physical, emotional, social and spiritual wellbeing. There are many hospice agencies that provide end-of-life care from a religious perspective. This is somewhat unsurprising considering the history of hospice care, further discussed in the literature review. This is evident in Social Work Today's article "Spiritually Sensitive Hospice Care" [2] and in Plain Views' "Spiritual Care for the Nonreligious" [3]. The title of Thiel and associated with their nonreligious affiliation, and perspectives regarding healthcare providers' competency providing care for nonreligious people. Though not comprehensive, the survey results indicate common experiences and perspectives, which can in- form end-of-life practitioners providing care to this population. Through qualitative feedback, survey participants shared their experiences in healthcare settings and expressed a desire for healthcare professionals to be more aware of the needs of nonreligious people. Both the quantitative responses and qualitative feedback of participants is used to inform practice implications and recommendations made for caring for the whole nonreligious person.

**Keywords:** Hospice; Invisible minorities; Atheist; Agnostic; Humanist; Cultural humility; Professional boundaries; Patient-informed care

Robinson's article is also the title of the webinar training offered by the United States' organization for hospice care, the National Hospice and Palliative Care Organization [4]. While there is considerable diversity in the how survey participants specifically described their worldview under the umbrella of nonreligious, it is notable that 95% of respondents did not include belief in a higher power or deity or use the word "spiritual" to describe their experience. To this 95% of survey participants who do not include spirituality in their self-construct, an article title such as "Spiritual Care for the Nonreligious," may be interpreted to be equally as culturally sensitive as "Male Care for those without Y chromosomes." The author of this article contends that it is important for literature and trainings pertaining to a specific population to be informed by those populations' perceptions, which includes the language people use to describe themselves.

Though imperfect due to the limitations of the data collected, the premise of this article is guided by the value of representation of a minority populations' experience within the context of differences from the mainstream society. Following review of the survey results, discussion of implications for healthcare providers is provided. It is the hope of this author that end-oflife practitioners may be better informed by this article and that the experiences of nonreligious people in end-of-life care may be positively influenced.

# **Literature Review and Theoretical Framework**

In 2012 Free thought today, a publication of the Freedom from Religion organization published a personal narrative by Susan Fallon McCann regarding her family's hospice experience as her nonreligious father approached death [5]. While Susan describes hospice as "a caring and compassionate approach to death," her experience navigating her nonreligious father's death while participating in hospice services was an overwhelmingly negative one.

This history of hospice care is intertwined with aspects of religion and spirituality. In 1983 the founder of modern hospice care, Cicely Saunders, was interviewed by Thames TV and discussed how hospice care developed out of her identity as a Christian seeking ways of service. However she expressed her intention in this interview for hospice care to be an inclusive experience, "You can certainly be an Atheist or an Agnostic in the middle of a Christian hospice and know you're not a second-class citizen in any way and not feel pressured either" [6]. Despite this intention of hospice's founder to provide care for all people at her hospice, there was also an expectation that providers "regard their work as religious vocation" [7]. Pentaris and Thomsen [8] observe that healthcare providers providing end-of-life care are likely to view their services as an extension of their religious beliefs. Kathy Ponce [9] acknowledges in her writing for the National Association of Catholic Chaplains that cultural humility is far from automatic with regard to chaplains working with nonreligious people.

She encourages practitioners to examine the frequency with which they automatically express religious sentiments such as "I'll keep you in my prayers," which may have the unintended con-sequence of contributing to the felt isolation of nonreligious people.

Experiences like Fallon Mccann's are unsurprising as nonreligious people are an invisible minority. Minorities are defined as individuals who are affiliated with low-status and low-power regardless of actual number of participants [10]. Both minority religious and nonreligious group affiliation are examples of an individual's status as an invisible minority. As nonreligious people are visually indistinguishable from many members of the religious majority, this status as an "invisible minority" requires providers to be self-aware and intentional not to marginalize invisible minority patients and families by assuming patients identify as part of the majority group. While visible minorities may be distinguished by visible traits to include skin color, apparent physical disability or group affiliated jewelry or garments, invisible minorities are "people who are not obviously part of a minority" (Immigrant Welcome Centre). Invisible minority group affiliation may include sexual orientation, health differences without observable physical presentations, nationality, and differences of religion from the majority. Whereas visible minorities, people for who minority status is indicated by an apparent physical difference, experience discrimination due to other's knowledge of their physical difference from the majority group; invisible minorities experience isolation and marginalization due to being treated without consideration for their own unseen group affiliation [11].

Prejudice and discrimination are common experiences for minority groups. A study by Gervais et al. [12] indicates that globally there is distrust of atheist people and that in large part this is related to the role of religion in moral teaching. Thiel & Robinson [3] assert in their article "Spiritual Care for the Nonreligious" that atheists face considerable prejudice and dis- crimination in the United States. This is confirmed in Gervais et al. [12] article which finds nonreligious people face discrimination that impacts employment, elections, family life and broader social inclusion. One such example of prejudice against nonreligious people can be found in the colloquialism, "There are no atheists in fox holes." This expression asserts that people for whom death is a very real possibility, everyone turns to belief in a higher power, discounting the experiences and identities of nonreligious people.

Trainings and articles that address the emotional needs of nonreligious patients at end-of- life are overwhelmingly written from a spiritual perspective. This framing of the experiences of all patients as a spiritual one appears to be a theme throughout the literature and demonstrates a lack of understanding of nonreligious people. While Kathy Ponce's article "Respect the unique spirituality of the nonreligious" calls for chaplaincy professionals to provide services from a position of cultural humility, the very title of the article defines the experiences of nonreligious people from the language of the religious majority. This article, that of Thiel and Robin- son, "Spiritual Care for the Nonreligious" and the NHPCO training by the same name are part of a pattern of defining the experiences of nonreligious people through a lens of spirituality. Nanete Page & herly Czuba [13] identify in their article for the Journal of Extension that empowerment is a transactional process that supports individual control of one's own life. Furthermore, Sanchez-Mazas [14] emphasizes the importance of the minority's "voice" in carving out space for itself within the majority-dominated social landscape. With the work of Sanchez-Mazas and Page & Czuba in mind, it is problematic to use the language of the religious majority to frame the experiences of nonreligious people in that it takes from nonreligious people the participatory power of defining their own experiences.

The intent of this paper is to inform end-of-life care for nonreligious people from a non-religious perspective. It is important that care regarding any population is guided by that population's perspective. This article seeks to present the nonreligious perspective in order to inform end-of-life care.

### Data and Methods

#### Participants

Data was collected through use of an online survey including a quantitative questionnaire and qualitative feedback. This survey was circulated using Facebook's social media platform.

Survey responses were solicited from participants in social media groups for "atheist", "agnostic", and "secular" social media users. The vast majority of respondents came from the United States. Of 263 participants, 235 provided their age. Ages of participants ranged from twenty- three to seventy-four years of age (M=43.33). One participant who responded to demographic questions shared that they preferred not to do so because of research bias associated with age and gender. However, of participants who responded there was significantly more participation from individuals in their thirties (N=83) and forties (N=74) than any other age group. Additionally, females were much more strongly represented (N=189) as compared to

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males (N=45) and non- binary individuals (N=1). Participants were informed that data collected would be used for publication purposes to increase awareness of the experiences and perspectives of nonreligious people on end-of-life care. Data was not specifically collected related to occupation or education, though was sometimes offered by participants who identified themselves as members of the medical and end-of-life relate professions (N=5).

# **Data collection**

Survey participants were given multiple-choice questions to respond to which included: how they described their belief system, whether they would want hospice care in the event of a terminal diagnosis, whether they were receptive to chaplain services, about whether they were fearful of dying at the end of their expected lifespan, feelings on religious phrases, whether they had previously felt marginalized in healthcare settings due to their beliefs, and if they felt under- stood and empathized with by religious people.

Survey participants had the option of contributing to the survey by writing about their personal perspectives and experiences at the end of the survey. These experiences and perspectives offer insight to inform further discussion.

The resulting data is presented grouped by theme. The themes present in this research are

(1). group affiliation and perception of self,

(2). Attitudes toward end-of-life care,

(3). Experiences and perceptions of relationship to healthcare, and

(4). Preparation for end-of-life.

### Research Results Group Affiliation and Perception of Self

The survey begins by asking participants to describe their belief system as either at =heist, agnostic, or other. Those that selected other were asked to specify. Of the total number of survey participants, 90% chose atheist or agnostic, with sixtyseven percent describing their belief sys- tem as atheist and twenty-three percent as agnostic. Of the 10% who selected other, 8 identified as humanist, 6 as spiritual, 2 as Pagan, and 1 each of "Agnostic Atheist, Buddhist in Nature", Confused, Freeform, Nontheistic, Apatheist, Universal Unitarian, Gnostic and New Age.

What do these categories mean? The largest subgroup of nonreligious participants, Atheist, literally translates to without God. The New Oxford American Dictionary defines Atheist as "a person who disbelieves or lacks belief in the existence of God or gods." Agnostics, on the other hand, are defined as "a person who believes that nothing is known or can be known of the existence or nature of God or of anything beyond material phenomena; a person who claims neither faith nor disbelief in God." From these two definitions one could draw the comparison that while neither Atheists nor Agnostics believe in God, Atheists are certain in disbelief while Agnostics do not share that same certainty. Humanism, the largest of the outliers, is described as "a progressive philosophy of life that, without theism or other supernatural beliefs, affirms our ability and responsibility to lead ethical lives of personal fulfillment that aspire to the greater good (American Humanist Association)." If responses that may indicate belief in a super-natural being or higher power were separated from the rest of the data, that group might include the 6 spiritual, 2 Pagan, 1 New Age, 1 Buddhist, 1 Unitarian Universalist, 1 Freeform, 1 Confused and 1 Gnostic, for a total of 5% of the total respondents. This indicates that with 95% accuracy the survey responses on the remaining questions represent the views of nonreligious people.

Nonreligious people are very aware of the prejudice towards them [3]. A woman from Arkansas offered insight that nonreligious people may not self-identify due to fear of discrimination. A man living in Virginia reflected on the minority status of nonreligious people.

"There is a privilege that religion has in this society. This means that any religious interaction is deemed as charitable or beneficial. The corollary is that any rejection of religion is deemed as rude or crass. This puts atheists in a sensitive spot when it comes to dealing with these topics.

There is no easy answer, but (regarding the survey) it is good that you are at trying to at least understand the discomfort we go through when dealing with this."

The theme of religious privilege was also commented on by a thirty-three year old woman from Arkansas, "I would simply say that the most annoying thing is religious people feeling entitled to share their beliefs with others at the end of their lives, regardless of that individual's beliefs, because of threat of hell."

# Attitudes toward End-of-life Care

In assessing attitudes towards hospice care, survey participants were asked to imagine a scenario and predict their response. Participants were asked: *Imagine you are diagnosed* with a terminal illness and the doctor recommends hospice, noting that further medical interventions are likely to diminish your overall quality of life. The goal of hospice is to support you in dying at home, with a focus on comfort and quality of life, neither speeding nor slowing the disease process. Would you want hospice? Overwhelmingly, 96% of the total survey respondents indicated that if presented with a situation in which medical interventions were unlikely to improve their quality of life in the wake of a terminal illness, they would choose hospice care.

Another question assessed attitudes toward chaplain services. During admission, the ad-missions nurse explains that the core healthcare team includes your nurse, a social worker, and a chaplain with supervision from your physician to authorize medical changes in care. Other services such as home health aides and volunteers may be added. Chaplain services are optional.

The chaplain is interfaith and not specific to a particular religion. Would you want the chaplain?

Of the survey participants, 63% reported that they would decline chaplain services. The second largest group, 13% stated that they would agree to the chaplain for additional companionship and support. The third largest group however, representing 9.5% of the total group selected "other" in lieu of the provided responses and wrote their own responses either expressing uncertainty or defining the conditions under which they would be comfortable with chaplain services. Inability to assert one's needs due to marginalization in the context of minority status was represented by 8% of the surveyed participants who stated that they would not want the chaplain but would not feel comfortable declining the service. The smallest portion of the participants, representing 6% would welcome the chaplain to discuss end-of-life perspective and existential issues.

Of survey participants that were open to chaplain services, many expressed the importance of not being proselytized to. A 48 year old woman from South Carolina offered, "I may want someone to talk about dying and the meaning of life, but only if they can keep religion completely out of it." A 39 year old woman in Nebraska offered the following advice for healthcare professionals: "Be respectful of personal beliefs. If a patient doesn't share your beliefs don't force them on them. If you know they are nonbelievers don't ask them to pray with you, you're making it about your own beliefs. Feel free to ask if there is any spiritual practice they would like to participate in, some may want meditation time, but accept their answer. You can respect other people's beliefs without compromising your own faith, and it's not a slight against you."

This respondent brings up an interesting point, which is when the communication offered takes care of the needs of the person offering rather than those of the patient. She goes on to suggest that when religious perspectives, including platitudes are imposed into the healthcare setting, "I would consider this an attempt to make the situation inappropriately about them rather than about me."

A repeated theme in the feedback that survey participants provided was empathy for the needs of others and acknowledgement of varying world views. A 39 year old atheist man from South Carolina shared, "I respect my friends' and family members beliefs and would want them to receive whatever care they need when I die." A 65 year old atheist from California shared that she would want religious healthcare workers "to know I don't hate their god."

#### Experiences and Perceptions of Relationship to Healthcare

As nonreligious people are an invisible minority, an individual's status as a nonreligious person is not known by those around them, including healthcare teams, unless they provide dis- closure. Two survey questions addressed the unique experiences of non-religions people as patients and families in the health care setting. Participants were asked: Have you ever felt marginalized in a healthcare setting due to your belief system? In response to this a whopping 38%, indicated that they had felt marginalized in health-care settings due to their nonreligious affiliation. Over 90% agreed that religious people do not understand or empathize with the perceptions, feelings, and needs of nonreligious people at end-of-life. A Nebraska woman shared her concerns: "It has been my experience that during significant life events, religious people often put more pressure on the nonreligious to embrace religion. It can feel predatory. I feel most religious people feel the nonreligious will come around if only approached in the right manner, and there are several common sayings that support this, 'There are no atheists in foxholes', etc. and as this is the last chance 'to save their soul', I would be very wary of any chaplain."

It is reasonable to question whether having had the experience of feeling marginalized in a healthcare setting would change one's willingness to participate in hospice services at end-of- life. Despite this experience, the response of those who experienced marginalization in health- care settings remains consistent with the larger group with receptiveness to hospice care. Ninety seven percent (97%) of those participants who experienced marginalization expressed that they would want hospice care when appropriate.

One way in which caring is communicated by healthcare professionals responding to a person who is dying or experiencing grief is to provide reassurance and comfort. One survey question asks about expressions commonly used in end-of-life settings. In response to the scenario question asked of the participants, *If anyone were to say to me a religious phrase such as "It's in God's hands," or "God is/isn't ready to call him/her home" regarding myself or my loved one dying I would feel, 77% indicated that they would either feel angry or annoyed. Of the respondents, 13% expressed being unaffected by such comments and 10% provided an answer of other and specified factors related to their response. Three survey participants skipped this and the following two questions, all of which appeared on the last page of the survey.* 

Several respondents that were among the majority that agreed that religious expressions offered for comfort and reassurance would cause them to feel angry elaborated on that. A 49 year old woman from Virginia reflected, "I think I would just want to try to be joyful about the time I have left and not hear platitudes." Another 55 year old Virginia woman elaborated: "Almost all death related platitudes involve god even if they don't mention him. 'Your mom and dad are waiting for you,' and 'she's in a better place now' are examples. Avoid all platitudes. Focus on the present needs and comfort of the patient. Ask if they have unfinished business or something they would like to accomplish in the time they have left. Do your best to encourage their loved ones to visit. Make them feel loved and not alone. Do what you can to ease worries they might have about their children and grandchildren."

#### Preparation for End-of-life

Survey participant's perspectives regarding their expected emotional preparation for end-of-life are assessed. The related survey question asks participants whether they *are Fearful or Comfortable/accepting regarding a natural death at the end of my (their) expected lifespan*. A significant majority, 82% stated that they feel comfortable or accepting regarding a natural death at the end of their expected lifespan while 18% stated that they felt fearful. One respondent indicated, in space provided for another question that their response to this question would have been "both" if that had been an option.

A repeated concern represented in the qualitative feedback of the survey participants was access to "aid in dying," and "death with dignity," options. A 44 year old Humanist woman from Maryland expressed her frustration, "I... feel the main objections come from religious folks. It frustrates me to be denied the option based on their 'soul' beliefs."

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### **Discussion and Implications for Care**

It is important health care professionals keep in mind that each person that they provide care to may identify with an invisible minority status. Status as an invisible minority is one factor impacting the experiences of nonreligious patients in end-of-life care. Survey results indicated that words that may provide comfort and reassurance to religious people, such as those reflected on in the literature review by Kathy Ponce (2016) of the National Association of Catholic Chaplains, are likely to cause nonreligious people to feel further isolated and marginalized. For this reason, assessment for the patient's identity should be part of the initial healthcare assessment.

Knowledge of the patient's potential status as an invisible minority (including their religious or nonreligious perspective, sexual orientation and gender identity, immigration status, and physical and mental health conditions) should be part of a thorough assessment. Bringing to light other- wise invisible aspects of the patient's identity can provide information that allows the medical team to provide individually tailored personcentered care.

Keeping in mind that many nonreligious people have felt marginalized in healthcare set- tings, developing a trusting relationship with healthcare teams may present its own challenge.

When a patient's religious or nonreligious affiliation is unknown inclusive language should be used. Inclusive language allows for differences and reduces the isolation experienced by minority patients [15]. Approaching care from a perspective of cultural humility and offering acceptance and genuine caring curiosity offers patients and families an opportunity to talk openly about their experiences when caring and acceptance is established by the healthcare team. While a voidance is a potential pitfall that healthcare workers may fall into out of fear for overstepping boundaries or being offensive; the nonreligious person, just like the religious person, has a need for nurturing of the whole person. Yeager and Bauer-Wu [16] suggest that when providers embrace a position of cultural humility, they offer patients the space and the connection to be able to openly express them. It is of utmost importance that the values of the end-of-life practitioner are not imposed on any patient, but this may be particularly true for those groups who have previously felt marginalized or misunderstood in healthcare related to their group affiliation.

Humanist end-of-life practices have the potential to offer powerful end-of-life opportunities for reflection and closure and may enhance the resilience of both the patient's family and healthcare teams. Practices that are Humanist in nature seek to promote overall wellbeing and enrich our personal lives (American Humanist Association). "The Pause," credited to University of Virginia trauma nurse and palliative care team member Jonathan Bartels is an example of a Humanist practice. The pause is an end-of-life practice in which a healthcare provider asks those present to pause at the end of the patient's life to reflect on them as a person [17,18]. This humanizing of death in medical settings is evidenced to increase resilience in healthcare teams. In the experience of the author of this paper, when families have been present for a pause, they have shared that it was personally meaningful for them. Cultural competence and cultural humility have been buzzwords in creating competencies for healthcare providers. With regard to competence, healthcare professionals should know that nonreligious people are a growing invisible minority population [18] which they may regularly encounter even unknowingly as nonreligious people may not disclose due to fear of discrimination. Minority populations may express difficulty trusting, anger, and suspicion to- wards contrasting majority populations due to previous experiences of marginalization and dis- crimination. Cultural humility as a process of self-awareness and open curiosity about others will support healthcare providers in building rapport and strengthening their ability to provide high- quality healthcare experiences.

It is notable that although the author of this article identifies that the framing of nonreligious peoples' experiences as a "spiritual" in the literature is problematic in that it is not representative of the experiences of many, if not most, nonreligious people, those trainings and articles regarding "spiritual care for the nonreligious" come from a place of good intention.

Providers have an opportunity to become advocates for, and join with, nonreligious patients. When majority group members join forces with minority group members, they become allies. Each person's right to experience dignity through the lens of their own belief system is a social justice issue. By becoming allies for non-religious people, healthcare providers can practice compassion and advocate for systemic changes to improve every patients' healthcare experience.

#### **Limitations of Research**

The data collection has three main limitations, that the data is self-reported, participants are self-selected, and data is descriptive in nature. The self-reported nature of data may con- tribute to misclassifications on several questions. This may be especially true due to the varied interpretations of words associated with belief systems. Due to the use of an online survey distributed through closed groups on social media, the participants were self-selected and limited in that the demographic makeup of survey participants were closely aligned with the demographic makeup of social media users. This limitation makes the surveyed population much narrower in its attributes than that of the general population. Additionally, while this method was chosen due to the challenges associated with surveying hospice participants, it influences the accuracy of the self-reported data as the distance between what participants expect would happen in situations, and how they may actually behave, may not be aligned. Finally, the descriptive nature of the re- search illustrates the experiences of the participants. However, it does not identify root causes or associations between variables. With consideration of these limitations, the author of this article hopes that further research may overcome these limitations and provide further support for practitioners and nonreligious patients involved in end-of-life care.

#### Conclusion

This article offers insight into the perspectives of the nonreligious population's needs. Trends in this research suggest that this is a resilient population and despite over a third having

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had experiences in which they felt marginalized in healthcare settings due to their minority status as a non-religious person, 88% shared that while they felt that religious people, including health care providers, did not understand or empathize with them, that does not prevent them from seeking healthcare. This was reinforced by 96% of survey participants who shared that, if appropriate, they would want hospice services as they neared end-of-life. Due to their experience as an invisible minority, nonreligious people would benefit from healthcare services provided from a framework of cultural humility. Healthcare providers would reciprocally benefit from strengthening services to meet the needs of this growing population.

Making up twenty-three percent of the population in the United States, nonreligious people have the potential to significantly impact patient satisfaction outcomes and, ultimately, the bottom line. Self-awareness of healthcare providers is essential for providing care that is supportive of patients whose cultural differences, including their worldview, may be different than that of the provider. This may be especially true in end-of-life care settings in which providers may view their work as an extension of their religious beliefs [8].

Opportunities exist to improve the nonreligious patients' experience of healthcare. While this article begins to shed light on the unique position of this population, it is only a beginning. Further research and implementation of new practices specific to this population needs has the potential to positively transform future engagement between non-religious patients and families and end-of-life care.

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ADDRESS OF CORRESPONDENCE: Helen Dempsey-Henofer, Licensed clinical social worker, practicing in hospice care in Charlottesville, 1051 Hopkins Court, Charlottesville, Virginia-22901, USA, Tel: +18032064625; E-mail: helen. dempsey@gmail.com

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