

# SPIRITUAL CONCERNS OF PEOPLE EXPERIENCING HOMELESSNESS AT THE END OF LIFE: LITERATURE REVIEW

## **ABSTRACT**

### **Background:**

Spiritual care is a fundamental component of holistic end of life (EoL) care.

### **Aim:**

To explore what is known about the spiritual concerns of people experiencing homelessness (PEH) towards the EoL.

### **Method:**

A narrative literature review was conducted from 1997 to June 2018 using CINAHL Complete, MEDLINE and PubMed. This identified just 11 relevant papers; 8 report studies from the United States (US); 1 study is from the Republic of Ireland (ROI); 2 of the papers are literature reviews.

### **Findings:**

Both the ROI and US studies report the primacy of religious beliefs and spiritual experience for PEH considering EoL issues.

### **Discussion:**

It cannot be assumed that the spiritual needs of PEH mirror those of the housed population. The findings of studies from the US and the ROI are not necessarily transferable to the other populations of PEH

### **Conclusion:**

There is a call for further research into the international perspective, especially in secular countries.

**Keywords:** spirituality, homelessness, end of life, priorities, concerns

# INTRODUCTION

In this paper we offer a narrative discussion of the international literature surrounding the spiritual concerns of people experiencing homelessness towards the end of life (EoL).

Palliative care offers a holistic, multi-disciplinary team approach to the care of people with life-limiting conditions and aims to improve quality of life and prevent and relieve pain and suffering; physical, psycho-social and spiritual (World Health Organisation 2017). Within palliative care, the term 'end of life' (EoL) is generally understood to be the final months of life (The National Council for Palliative Care 2011); a time when people often review life's purpose and achievements and sometimes search for meaning in life, suffering and death.

## *SPIRITUALITY AND END OF LIFE CARE*

Spirituality is a more difficult term to define (Department of Health 2011a; Arli et al. 2017). No longer equated with religion, it emphasises much broader human principles (Tabei et al. 2016) and typically relates to the way in which people understand and live their lives in view of their core beliefs and values (Department of Health 2011a). Spirituality is concerned with highly subjective, existential issues such as purpose, relationships, vision, belief, hopes and fears, coping and making sense of suffering (Department of Health 2011a). As such, some assert that spirituality is a dimension of human experience affecting every human being, regardless of cultural heritage or religious affiliation (Department of Health 2011a; Yang et al. 2012; Arli et al. 2017). However, it is a broad and highly subjective concept (Caldeira et al. 2017); one that is subject to debate and is undoubtedly shaped by culture and personal world views (Yang et al. 2012; Emanuel et al. 2015; Arli et al. 2017).

Spirituality is of particular relevance when an individual is approaching end of life (Caldeira et al. 2017; Holyoke and Stephenson 2017) and a holistic approach to care is emphasised (Department of Health 2011b; Puchalski et al. 2014). Spiritual care has been a fundamental

component of palliative and end of life EoL care since the movement began (Holyoke and Stephenson 2017; World Health Organisation 2017).

### *ASSESSMENT OF SPIRITUAL NEED AND DISTRESS AT END OF LIFE*

Assessment of spiritual distress has received much attention in the international literature in recent years. One study identified 16 defining characteristics of spiritual distress; the 2 most important defining characteristics being the expression of suffering and lack of meaning in life (Caldeira et al. 2017). Holistic assessment and identification of spiritual need, which necessarily involves 'being alongside' and attentive listening, is sometimes treated as a specific spiritual care intervention (Department of Health 2011a; Caldeira et al. 2017; Holyoke and Stephenson 2017). However, active, attentive listening is arguably a skilled activity requiring an advanced level of communication skills and adequate time. Assessment of spiritual need can take many forms and some controversy remains around the fundamental characteristics of spiritual distress and how it should be assessed and diagnosed (Paley 2008; Emanuel et al. 2015; Caldeira et al. 2017). Some advocate the use of formal assessment tools (Puchalski 2014; Caldeira et al. 2017) while others suggest spiritual assessment through a process known as life review (Jenko et al. 2007; Chen et al. 2016). Life review can be an informal 'conversational' activity that occurs organically in individuals facing the end of life. However, it can also be a structured, formal activity that is increasingly being offered within hospices in the UK (Jenko et al. 2007); one which, like counselling (Werth 2013), has been shown to decrease depressive symptoms, improve quality of life and enhance self-esteem among individuals with life-limiting illnesses (Chen et al. 2016).

### *HOMELESSNESS*

Homelessness has also received much attention in recent years from policy-makers, service-providers and the media, yet it continues to be a growing problem in the UK and internationally (MacWilliams et al. 2014; Fitzpatrick et al. 2017; Foundation Abbé Pierre 2017). The sixth

annual report of the Homeless Monitor in England (Fitzpatrick et al. 2017) reports a 134% rise in homelessness since 2010. This figure relates specifically to those who are sleeping rough on the streets but such statistics do not reflect the true scope of the problem (Fitzpatrick et al. 2017; Foundation Abbé Pierre 2017) and there remains much controversy concerning definitions of homelessness and the nature and extent of the problem. For example, in its broadest sense, a definition of homelessness can include those who are sleeping rough, squatting illegally, sofa surfing, living in bed and breakfast accommodation, hostels, women's refuges or other temporary accommodation, or those who are simply deemed to be unsuitably housed (Fitzpatrick et al. 2017; Foundation Abbé Pierre 2017). It is difficult to estimate global statistics of the number of people experiencing homelessness because of the hidden nature of the problem and because of differences between countries in the way that statistics are recorded.

People experiencing homelessness are a vulnerable population with complex needs (Fitzpatrick et al. 2017). Mortality rates are considerably higher among the homeless population; they die on average 30 years younger than the housed population (Thomas 2012; Fitzpatrick et al. 2016) and live in environments which are not generally considered to be compatible with palliative care provision. Lack of basic resources and complexity of need suggest that they may be in greater need of palliative care support and facilities than the housed population (Webb et al. 2018). However, people experiencing homelessness are considerably under-represented in UK hospices (Care Quality Commission 2016; Care Quality Commission 2017). In fact, they often die in difficult or degrading conditions, devoid of dignity, for example under bridges and in shop doorways, without access to specialist palliative care services (Care Quality Commission 2017). Some reasons for this have been documented and many barriers to access have been identified in the literature (Hudson et al. 2016; Care Quality Commission 2017). However, exploration of these barriers is beyond the scope of this paper.

## *AIM*

Narrative literature reviews are used to provide an overview of a topic. The aim of this narrative literature review is to explore what is known about the spiritual concerns of people experiencing homelessness towards the EoL.

## **METHODS**

### *LITERATURE SEARCH METHODS*

A CINAHL Complete and MEDLINE database search from 1st January 1997 to 1st June 2018 using the terms 'homeless\*' AND 'end of life care or palliative care or death or dying or terminally ill' AND 'spiritual\*' resulted in 12 hits of which 3 were relevant to the search. Omitting the word 'spiritual\*' resulted in 794 hits which were screened by title and abstract and where necessary a full text read to identify studies which specifically explored the spiritual concerns of homeless participants. This identified a further 3 papers. The same search using PubMed resulted in 464 hits, uncovering 1 further, relevant paper (Tobey et al. 2017). Reference lists and citation tracking identified 4 further papers bringing the total to 11. A grey literature search included the websites and electronic databases of 3 of the largest charitable organisations within the UK offering support relating to homelessness (Crisis, Homeless Link and Pathway). Of the 11 identified papers, 8 report studies from the United States (US), specifically discussing the spiritual concerns or spirituality of people experiencing homelessness towards EoL (Ratner et al. 2004; Song et al. 2005; Tarzian et al. 2005; Song, Bartels, et al. 2007; Song, Ratner, et al. 2007; Ko and Nelson-Becker 2014; Ko et al. 2015; Tobey et al. 2017). 1 paper outlines a significant qualitative study in the Republic of Ireland (Walsh, 2013). The other 2 more recent papers include a narrative literature review (Hubbell, 2017) and a thorough systematic review (Klop et al., 2018). To critically appraise the research papers that were found, modified versions of the Critical Appraisal Skills Programme (CASP) tools were utilised (Drummond et al., 2013).

## FINDINGS

The table below offers a summary of these 11 papers.

<u>Author and Title</u>	<u>Place</u>	<u>Participants</u>	<u>Study design / methods</u>	<u>Analysis</u>	<u>Key findings</u>
(Klop et al. 2018) <b>Palliative care for homeless people: A systematic review of the concerns, care needs and preferences, and the barriers and facilitators for providing palliative care</b>	N/A	Included 27 publications from 23 studies	Systematic literature review to May 2016	Systematic review based on the PRISMA statement	A patient-centred, flexible and low-threshold approach embodying awareness of the concerns of homeless people is needed so that appropriate palliative care can be provided timely. Training, education and experience of professionals can help to accomplish this.
(Tobey et al. 2017) <b>Homeless Individuals Approaching the End of Life: Symptoms and Attitudes</b>	USA	20 HPs approaching EoL from one medical respite home	Surveys completed during a 1:1 interview with each HP approaching EoL	Symptoms and attitudes of HP approaching EoL were explored using the Memorial Symptom Assessment Survey. Results were analysed statistically and then compared with other populations	HP may experience a higher frequency of pain and other symptoms at end of life and require a tailored approach to care. 65% of the HPs surveyed considered themselves religious or spiritually orientated 75% feared no one would know they had died 85% worried about EoLcare
(Hubbell 2017) <b>Advance care planning with individuals experiencing homelessness: Literature review and recommendations for public health practice</b>	USA	Included research papers from 9 studies	Narrative literature review	Papers reviewed using the Johns Hopkins Nursing Research Evidence Appraisal Tool	End-of-life concerns among homeless persons included fears of dying alone, dying unnoticed, or remaining unidentified after death. Research participants also reported concerns regarding burial and notification of family members. Public health practitioners should facilitate advance care planning for people who are homeless

					by providing opportunities for education and discussion on care options and advance directives.
(Ko et al. 2015) <b>What Constitutes a Good and Bad Death?: Perspectives of Homeless Older Adults</b>	USA	21 residents/ HPs at one single transitional housing facility	Face to face interviews using a semi-structured interview guide	Constant comparative method used in Grounded Theory (GT). Peer debriefing and member checking.	Themes associated with a good death: -Dying peacefully and not suffering -Spiritual connection and making amends Themes associated with a bad death: -Violent or accidental death -Prolonged life -Dependency -Dying alone
(Ko and Nelson-Becker 2014) <b>Does End-of-Life Decision Making Matter?: Perspectives of Older Homeless Adults</b>	USA	21 HPs in one housing facility	GT approach. Face to face interviews	GT approach to identifying emergent themes	-EoL is an uncomfortable topic and sensitivity is needed -God plans EoL care so it is not a priority -Doctors preferred as surrogate decision-makers
(Walsh 2013) <b>Homelessness, aging and dying</b>	Republic of Ireland	16 participants with experience of homelessness	Qualitative study using 1:1 interviews	Not documented	Key needs of older HPs include: -Access to appropriate health care -Services which contribute to good health and well-being -End of life care -Suitable and stable accommodation and accommodation support -Information and research 16 key recommendations follow: one of which is to raise the awareness of the spiritual needs of older people who are homeless among staff.
(Song, Bartels, et al. 2007) <b>Dying on the streets: Homeless persons' concerns and desires about end of life care</b>	USA	53 HPs recruited into 6 focus groups from various homeless support agencies	Qualitative study using audio-recorded focus groups	3 step Consensual Qualitative Research (CQR) approach to data analysis	-8 themes related to experience with death, fears, hopes, ACP documentation, spirituality, veteran status, relationships with family/friends, relationships with strangers e.g. HCPs
(Song, Ratner, et al. 2007)	USA	53 HPs from one city		3 step analytic process of	-7 revealing themes related to early loss, experience with

<b>Experiences with and attitudes toward death and dying among homeless persons</b>			Qualitative study using focus groups	coding and identifying themes. Atlas software used.	death, fears, coping strategies, personal life-threatening experiences, approach to risk and relational issues
(Song et al. 2005) <b>Dying While Homeless: Is It a Concern When Life Itself Is Such a Struggle?</b>	USA	A pilot study using 3 focus groups.  1 group of 11 HPs 2 groups of service providers (9 social workers)	Semi-structured focus group interviews conducted by 3 investigators	Transcriptions coded by each investigator according to domains. They then convened to agree revised domains.	Homeless people have a desire to talk about EoL care and death and dying. They have some distinct EoL concerns not previously reported eg dying violently. Religion, God and the afterlife were commonly expressed concerns and themes.
(Tarzian et al. 2005) <b>Attitudes, Experiences, and Beliefs Affecting End-of-Life Decision-Making Among Homeless Individuals</b>	USA	5 Focus groups (4 HP in each group)	Moderators used semi-structured interview guide in focus group settings. Discussions were audio-recorded.	Thematic analysis and researcher-written interpretive summaries	5 themes emerged: -Valuing individual wishes -Emotions affecting decisions -Religious beliefs and spiritual experience -Relationship-based care -ACP as goal-setting
(Ratner et al. 2004) <b>A Perspective on Homelessness, Ethics and Medical Care</b>	USA	Focus groups 57 HPs	A preliminary report on a qualitative study using focus groups	Not described	The authors state they are 'in the process of identifying themes' (p.50) which reveal ethical concerns regarding autonomy and justice. Participants' expressed preferences often appear to be associated with significant religious faith and spiritual beliefs.

**TABLE 1**

List of abbreviations used in table 1:

- ACP Advance care planning
- EoL End of life
- GT Grounded Theory
- HCP Health care professional
- HP Homeless participants

**SPIRITUAL CONCERNS TOWARDS EoL WITHIN THE HOMELESS POPULATION:**

The search revealed only 9 studies exploring the spiritual needs of people experiencing homelessness towards the EoL and only 1 of these studies is from outside the US. 2 of the 11 papers are literature reviews. The US perspective is discussed first below.

### *THE US PERSPECTIVE*

In the US homeless population, spiritual belief has been documented as a barrier to Advance Care Planning (ACP), particularly where individuals believe that end-of-life is in the hands of a higher power (Ko and Nelson-Becker 2014; Ko et al. 2015) and research in the US reveals that homeless people consider a good death to include dying peacefully, not suffering, experiencing spiritual connection, and making amends with significant others, all of which represent spiritual needs (Ko et al. 2015). In contrast, themes for a bad death, for homeless people in the US, include experiencing death by accident or violence, prolonging life with life supports, becoming dependent at EoL and dying alone (Ko et al. 2015). One study revealed that 75% of the homeless participants feared that no one would know they had died and that 85% worried about the EoL care they might receive (Tobey et al. 2017). Other US studies confirm the primacy of religious beliefs and spiritual experience for homeless people considering EoL issues (Tarzian et al. 2005; Song, Bartels, et al. 2007; Tobey et al. 2017).

Data from one study is reported in 2 separate papers; one dealing with experiences of death and attitudes towards death and dying (Song, Ratner, et al. 2007) while the other specifically focusses on concerns and desires around EoL care (Song, Bartels, et al. 2007). They report that religious beliefs are important to the homeless participants in this study when they consider EoL. This detailed qualitative study was conducted over 10 years ago and yet remains hugely significant in this niche area, yet a critique of this study reveals limitations as well as strengths. The major strength of the study is the significant sample size; a sample of 53 participants being large for a qualitative study of this nature. The study was funded by the National Institute for Nursing Research (NINR) which, being an independent nursing

organisation would be unlikely to influence the researchers conducting the study. A further strength lies in the comprehensive and appropriate methodological approach used by the researchers. However, the study also has limitations. Firstly, the interview guide for focus groups (Song, Bartels, *et al.*, 2007 p.436) contains a significant number of closed questions. Such questions, if used too often, could be leading the participants and indirectly influencing the data. However, it is most likely that the questions served as prompts and guides, rather than, for example, a prescriptive set of survey question. The authors also adopt a rather narrow understanding of spirituality and appear to use the term 'spirituality' synonymously with 'religious beliefs'. This will clearly affect reporting and interpretation of spiritual concerns. A further acknowledged limitation of the study is that participants, homeless individuals, were all recruited from one single urban locality. Given that all participants may have accessed the same specific service providers, there is potential for a degree of selection bias. The researchers admit that 'a significant representation' of participants came from the Native American community, but closer inspection of the demographic data collected reveals that 71% of participants belong to an ethnic minority. It should therefore be emphasised that while the results of this study into the attitudes and concerns of homeless people towards EoL care are both interesting and enlightening and provide a thought-provoking springboard for future international research, they are not necessarily transferable to the wider population of homeless people in America, and even less so to the homeless population in the UK or elsewhere because culture and ethnicity can be important factors affecting EoL decision making (Barnato *et al.* 2009). A recent and important systematic review supports this critique (Klop *et al.* 2018).

The same researchers published 2 earlier papers (Ratner *et al.* 2004; Song *et al.* 2005). The first paper outlines early findings of a focus group study and is written from an ethics perspective. The authors state that they are 'in the process of identifying themes' (Ratner, Bartels and Song, 2004 p.50) and report ethical concerns regarding autonomy and justice and participants' expressed preferences often appearing to be associated with significant religious

faith and spiritual beliefs. The second paper also describes a pilot study involving focus groups. These studies could possibly have been the pilots for the NINR funded studies, which were published a few years later and have been critiqued above. However, it is impossible to verify this as neither paper details the NINR grant application numbers.

### *THE GLOBAL PERSPECTIVE*

Spiritual concerns and needs of homeless people approaching EoL in other countries remain under-reported (Klop et al. 2018). Walsh (2013) conducted a significant piece of qualitative research in The Republic of Ireland (ROI). In this study, 16 participants with experience of homelessness were interviewed in depth about their preferences and concerns regarding end of life. The purpose of this research was to identify and examine the needs of older people who are homeless in the ROI or who have previously experienced homelessness as they age and are faced with the issues of serious ill health, dying and death, with a view to influencing policy and practice. The 64-page report is detailed and comprehensive with respect to participant demographics, quotations and case studies, but lacks methodological depth of reporting. There is no section on data analysis and this is a major weakness of an otherwise detailed report. As such, it has only been made available online and not published in an academic journal. The research clearly identifies the need for assessment of spiritual and religious needs with religious belief or belief in the existence of a higher power being identified as a source of comfort for many participants in this study. The report states that most participants believed in God or a higher power, outlining how 'some interviewees spoke about how they had lost their faith and that made the thought of dying 'difficult' although most still hoped that there might be an afterlife' (Walsh, 2013 p.45). Perhaps this result demonstrating the importance of spiritual concerns is unsurprising, given that the ROI is a predominantly Catholic country.

A recent UK research paper highlighted a lack of meaningful conversation around the specific wishes, concerns and EoL care preferences of people experiencing homelessness in the UK (Shulman et al. 2017). Reasons for the lack of such discussions within the UK homeless population (Hudson et al. 2017) include hostel staff anxiety around discussing death with homeless individuals who are struggling to survive from day to day and often use alcohol and drugs to obliterate the trauma of psycho-spiritual pain or distress. The team leading this particular UK project (Hudson et al. 2017) acknowledges that spirituality has been identified as an important factor in previous (US) studies, but conclude that this is not reflected in their findings. There is a call for further research into the international perspective, especially in secular countries (Klop et al. 2018).

Of the 2 literature reviews, one narrative review explored advance care planning with people experiencing homelessness (Hubbell 2017). The other, a systematic review, explored the concerns, care needs and preferences, and the barriers and facilitators for providing palliative care (Klop et al. 2018). While Hubbell (2017) recommends that health care professionals recognise the importance of religion and spirituality in end of life discussions with people experiencing homelessness, Klop et al. (2018) call for further research outside the US to establish the global perspective on spiritual need in this population of society.

## DISCUSSION

### *UNEXPLORED AND UNMET SPIRITUAL NEED*

People experiencing homelessness often have lives characterised by complex trauma, adverse childhood experiences and tri-morbidity; the combination of physical ill health, addiction and mental health issues (Hudson et al. 2016; Hudson et al. 2017; Shulman et al. 2017). It could therefore be argued that those experiencing homelessness, like refugees, war veterans and indeed all other groups who have experienced substantial trauma and spiritual distress during their lifetime, may benefit from additional spiritual support as they seek to find

existential meaning towards the EoL. In reality, people experiencing homelessness often experience difficulties accessing even basic health care (Department of Health 2010) and are even less likely to access holistic palliative care services (Hudson et al. 2016; Care Quality Commission 2017). As such, their physical, psycho-social and spiritual needs at EoL often remain unexplored and, consequently, unmet.

Research into the EoL needs and priorities of the general, housed population is thoroughly documented and reveals several common priorities such as physical comfort and freedom from pain, the presence of family and strengthening of family relationships and a peaceful acceptance of death (Khan et al. 2013; Van Scoy et al. 2016). In contrast, research reporting the EoL priorities of the homeless population is sparse. Moreover, most of the published research in this area to date is from North America. The wider global perspective of this marginalised group as they approach EoL is simply under-researched (Klop et al. 2018).

### *FUTURE RESEARCH*

Despite homelessness being an increasing global problem (Fitzpatrick et al. 2016), research specifically into both the EoL care priorities and spiritual care needs of this population has not yet been prioritised outside of North America and The Republic of Ireland. There have been no academic studies to date in the UK, specifically exploring what matters most to homeless people as they consider their own EoL. Their priorities are not yet known, and it cannot be assumed that they will match the priorities of the general population who have a home and numerous support networks and resources. Neither can it be assumed that the priorities and spiritual concerns of European and British people experiencing homelessness will mirror those of people experiencing homelessness in the US or The Republic of Ireland. Further research is needed into the EoL priorities and spiritual concerns of homeless people approaching EoL so that culturally relevant, holistic, person-centred EoL care can be provided for this marginalised, vulnerable population. The first author of this paper is therefore currently

conducting a phenomenological PhD study (Webb et al. 2017) involving in depth interviews with homeless adults in the UK to explore individual concerns, worries or fears around EoL and to identify individual preferences for care and treatment. The findings will be the first attempt at providing evidence of the EoL priorities and concerns of the homeless population in the UK. Data collection is now complete and early analysis suggests, in contrast to Hudson *et al.* (Hudson et al. 2017), that spiritual issues may be important at EoL for people experiencing homelessness in the UK (Webb et al. 2017).

## CONCLUSION

Spirituality is of special relevance when an individual is approaching end of life for it concerns existential issues such as hope, vision, belief, purpose, relationships, coping and making sense of suffering. It is also a highly subjective phenomenon shaped by culture and personal world views. Research in the US indicates that both religion and spirituality are important for people experiencing homelessness when they consider EoL issues. Research also suggests that spiritual concerns are significant for this population in the US when they approach EoL. One study in the ROI corroborates with the findings of US research but the wider international perspective is not yet understood. Given that people experiencing homelessness have often experienced significant psychological trauma before they approach EoL, it is important to be able to understand and address their spiritual needs at EoL if culturally-relevant, holistic, person-centred end of life care is to be provided to this marginalised population. There is therefore a call for further research into the wider international perspective.

## REFLECTIVE QUESTIONS

- What is your own understanding of the term spirituality?
- How do you assess spiritual distress in your workplace? Is there a formal process or tool that is used?

- Can you think of an incident when a patient in your care was exhibiting signs of spiritual distress? Reflect on how this made you feel. How was the patient helped?

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