



Life's hard and then you die - with no choice and no voice: Exploring end of life priorities within the homeless population in the UK

By **Wendy Ann Webb**

Wendy Ann Webb is a Doctoral student at the University of Worcester in the UK. Her PhD is exploring end of life priorities within the homeless population. Here she discusses the background to this research and the philosophy underpinning it. Data are currently being analysed and will be reported separately in due course. Associate Professor Theresa Mitchell is the Director of Studies for this PhD. Dr Brian Nyatanga and Dr Paul Snelling are PhD supervisors.

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END OF LIFE PRIORITIES

End of life priorities could be defined as the issues and concerns deemed as most important to the person considering end of life. Over recent years, end of life priorities and preferences of the general population have been the focus of much attention in the United Kingdom (UK) as elsewhere in Europe and indeed throughout the developed world. The evidence suggests that most people would prefer to die at home, free from pain with family nearby (1–3). The evidence also points to the importance of peaceful acceptance of death; spiritual concerns being addressed; relieving stress on family members; avoiding a prolonged death; and achieving a sense of control (2,4,5). It has been demonstrated that there are many diverse factors affecting end of life priorities and decision making including; culture and ethnicity (6); spiritual beliefs (7); sexual orientation (8); and personality (9). Research into the preferences of people experiencing homelessness at end of life is sparse. What is known is largely based on research conducted in North America. The exception being a study conducted in the Republic of Ireland (ROI) (10). Some particular and unique concerns and fears were expressed by homeless people in these studies (10–18). People experiencing homelessness want to be accepted and cared for by non-judgmental professionals (15,16,19). They also want to die in the same way that they have lived (20). They are more likely to want to receive CPR (17,18,21) and are happy for medical staff to act as surrogate decision-makers (18,22). Some also voiced a desire to reconnect with estranged relatives (13,14). The assumption that the findings of these North American studies are transferable to the homeless population in the UK should be avoided. There is therefore a distinct call for further research ‘outside of North America that provides a platform for the voices of homeless people’ (22 p15).

NO CHOICE AND NO VOICE

Choice, dignity and respect have been widely promoted as the core principles underpinning high quality end of life care. As such, in the UK, national campaigns (24) promote discussions around end of life preferences. Individuals are encouraged to record their end of life care preferences: particularly their preferred place of care. And as a result, people have come to expect to have choices around the end of life care they may receive. However, people experiencing homelessness do not generally hold the same expectations. Even in the UK, where healthcare is still free at the point of need, they often have trouble accessing regular healthcare services. They have even greater difficulty accessing specialist palliative and end of life care services. The barriers they face regarding access to end of life care in the UK are well documented (23,25). Many homeless people die alone on the streets in undignified situations. Or else they die in hostels without adequate specialist support. They have been described as the ‘doubly disadvantaged’: a population having ‘no choice and no voice’ (26). Healthcare services in the UK are therefore now being encouraged to find creative solutions to address these stark inequalities (25) so that this vulnerable population may receive the same high quality care at end of life that the rest of the population have come to expect.

ENGAGEMENT AND COLLABORATION

As a result of the Care Quality Commission document highlighting gross inequalities in end of life care for marginalised groups (27), many hospices in the UK have now employed ‘engagement officers’ to address some of the barriers to accessing care. This is a positive step which has resulted in hospice staff and hostel staff meeting together to discuss how to collaborate



more effectively. However, there seems to be an underlying assumption, that in the absence of appropriate alternatives, hostels are probably the most appropriate places for people experiencing homelessness to be cared for as their health deteriorates and as they move towards end of life. The problem is, this is an assumption without an evidence base for we still do not know what matters most to individuals experiencing homelessness when they consider their own end of life. End of life preferences, concerns, needs and wishes within the homeless population in the UK have not yet been sufficiently explored and we cannot simply assume that they will automatically reflect those of homeless populations in North America or the ROI. Neither can we assume that they will mirror those of the general population: people who have a home, supportive networks and adequate resources.

RESEARCH UNDERWAY IN THE UK

In the UK, there have been no published research papers to date specifically exploring end of life preferences within this marginalised group. Therefore, this qualitative PhD research project (28) is underway. 21 older homeless participants have taken part. Each participant has been interviewed in depth by an experienced palliative care nurse about important matters of life and death. The questions have been carefully selected to help the participants to talk about their lives, including general priorities in life, and then their concerns, preferences and priorities around end of life. A broad range of open questions were used in the audio-recorded interviews so that participants could explore what is important to them. Data are currently being analysed and findings will be published in due course. It is hoped that the findings will help to bridge the current gap in knowledge and inform new service provision.

This UK research project is underpinned by the philosophy of Maurice Merleau-Ponty (29): the French C20th philosopher who introduced holistic concepts to the philosophical debate of the day. He understood the complexity of human life and experience. His holistic philosophy of 'embodiment' reveals how life experience is multi-sensory, has intertwined physical, psycho-social and spiritual components and always unfolds within a context of time and space. Life is always lived from a unique perspective. According to Merleau-Ponty, a view is always a view from somewhere specific. His philosophy is of immense significance and value in this project exploring end of life preferences within the homeless population. It provides an ideal lens through which to view, discuss and offer an interpretation of the perspectives of the homeless participants. Let us now explore the reasons for this.

THE IMPACT OF HOMELESSNESS ON END OF LIFE PRIORITIES

Merleau-Ponty was Professor of child psychology at The Sorbonne in the early 1950s. This may explain his early understanding of the way that adverse childhood experiences (ACEs) affect the way a person learns to see the world. Decades before it had entered mainstream thinking, Merleau-Ponty understood how past experiences impact upon physical, mental and spiritual health and upon the way we interpret reality and make decisions. He understood about ACEs which are now a familiar concept within social work, mental health, inclusion health and addiction services and are a known risk factor for homelessness. Many people experiencing homelessness have a history of ACEs including abuse, trauma and loss. Many homeless people also feel constrained by their circumstances. Mental illness and addiction issues are prevalent in this population and these illnesses can place further restrictions on the choices available to a person experiencing homelessness. Merleau-Ponty's philosophy helpfully outlines the concept of 'situated freedom'. For example, when people long for a different path in life but feel constrained by the circumstances in which they find themselves: circumstances beyond their control. According to Merleau-Ponty, this is situated freedom: something that most, if not all, homeless people will have experienced. His holistic philosophy helps us to appreciate how the experience of homelessness is likely to impact on the individual's outlook. It helps us to recognise how the embodied-psycho-social-spiritual experience of homelessness can affect the way the whole world is perceived. Additionally, it facilitates an understanding that homelessness is likely to impact upon the way that decisions are made, and future priorities are determined.

CONCLUSION

The lens of Merleau-Ponty's philosophy is a powerful tool to be used in research around homeless health, which is why it has informed and influenced every methodological decision that has been made and is also being used as a framework to organise the findings of the study. His philosophy is capable of sharpening vision relating to the impact of homelessness on decision-making and health behaviours. It clarifies the importance of exploring end of life priorities with this population of society before attempting to plan services to meet their needs. It also highlights the importance of seeking to understand the specific socio-cultural embodied perspective of people experiencing homelessness here in the UK.

All of life's experiences unfold within a specific context of time and space and there is a clear call to explore end of life priorities within the UK homeless population. This PhD responds directly to that call in the hope of influencing service provision for this doubly disadvantaged group of society.



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