BSG Annual Conference 2023
Hosted by University of East Anglia (UEA): Norwich

Symposium: The role of volunteering in end-of-life care

09:00-10:30 Friday, 7 July, 2023, New Science Building 0.04

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Abstract

This symposium will assess and discuss the role of volunteering in end-of-life care. The format of this symposium is deliberatively co-productive, involving academics, practitioners and people with lived experience.

Volunteers are becoming a fundamental part of the end-of-life care system. In this context good end-of-life care requires networks of support across settings. At home, and in other community settings, approaches to care work best when the people involved know and are familiar with the context of an individual case. Most often these are close associates of the family, such as neighbours or friends. In institutional settings, more structured approaches exist, with more defined boundaries of roles and responsibilities, however, these appear to be rapidly changing due the new developments within Integrated Care Boards.

As Daniel Kahneman, the Nobel prize-winning economist wrote, 'endings matter'. How a person completes their life resounds in the memory of the people that live on. At the end of life, medical care is far from the sole consideration. Civic, social action before, during, and after a death can make the difference between an isolating and potentially traumatic experience and a supported and relational experience.

Looking ahead the symposium will discuss public policy with regards to volunteering and the attitudes of health care providers and volunteer involving organisations.

Provocation

Volunteers are a fundamental part of the end-of-life care system due to three main challenges of increased demand, depleted care workforce, and challenging workload conditions of care staff, which increasingly affect experiences of care in the period approaching the end-of-life. The number of people dying each year has been steadily increasing since 2008 and is set to continue to 2040.

In 2022 there were over 575,000 deaths in England and Wales. Over the course of the year this equates to approximately 1575 deaths every day, and 65 deaths each hour. The multiplicative bereavement impact of each death has been estimated to reach nine other people (Verdery et al, 2020). Using this estimate, the number of people who experienced a bereavement in England and Wales in 2022 was approximately 14,175 each day and 590 people each hour. The demand for end-of-life care and bereavement support cannot be met by health and care services alone. It requires collaboration across all sectors of society. Appropriate support and care in the final phase of life is a public health concern. In 2021, NHS England adopted a series of ambition statements to guide improvement work. Ambition Six is entitled, 'Each Community is Prepared to Help' which highlights the need to view end-of-life care experiences as everybody's responsibility (NHS England, 2021).

Within this symposium we want to provoke a discussion around how volunteering in an end-of-life care context can influence behaviour across three contexts: Individual, Social and Material using a tool commissioned by the Scottish government (Darnton & Horne, 2013).

The individual context includes factors such as a person's values, attitudes, skills, and emotional response, as well as the personal evaluation of costs and benefits of engaging in certain activities. In recent decades the advances in medical science have extended life expectancy, and yet the opportunities to talk about death have diminished. As a society we delay these conversations, or for some, avoid them altogether. It is a cause for concern because as individuals situated in a family or community dynamic need knowledge, skills, and confidence to support, manage and care for people with serious illness who are in the period approaching the end-of-life. This is a concept referred to as Death Literacy (Noonan et al, 2016). Death literacy can be viewed in the context of health promotion. Ivan Illich suggests that health, "*is the capacity to cope with the human reality of death, pain, and sickness,*" (Illich, 1974).

In the symposium we will discuss how end-of-life care volunteering can help develop personal death literacy, re-evaluate priorities in life in relation to mortality, and reduce symptoms of anxiety through exposure and personal contemplation. The reciprocal value of end-of-life care volunteering is not discussed overtly in policy documents such as the NHS England Long Term Plan (2019). Policy documents tend to view volunteering through a transactional lens – to allocate system resource – instead of exploring the opportunity for personal growth and learning derived from the relational and participatory nature of end-of-life care volunteering activities.

The social context includes networks and relationships, social norms and group behaviour. Illich wrote, "*In every society the image of death is the culturally conditioned anticipation of an uncertain date. This anticipation determines a series of behavioural norms during life and the structure of certain institutions.*" (Illich, 2003) Over time, the decreasing popularity and influence of the church and greater cultural diversity, may have reduced the instances of rituals known to play a supportive role in coping with death, bereavement and loss, or may have led to different norms and approaches (Curtice et al, 2019). The lack of death literacy at a societal level was made clear during the pandemic when many people felt ill-prepared to cope with loss.

Examples to counter this have been driven by instances of grassroots community activism – to help bridge relationships and navigate the interface between families, communities, and care services. Community roles, such as the role of an end-of-life doula, attempt to shift the increasing professionalisation of dying and grieving and resituate it back into the domain of family, and friends.

In the symposium we will discuss how enhanced death literacy of end-of-life volunteers can spread across family, extended family, and community networks to enhance social capital. The increase in knowledge and skills gained by end-of-life care volunteers enable them to engage in important conversations within and across their social networks. Most often these conversations are held informally, without the time pressure of a clinical consultation. As such, end-of-life care volunteers facilitate an important bridging function between professionals and communities and contribute to social cohesion.

The Material context includes details that can shape or constrain volunteering behaviours including governance policies, societal inequities, and opportunities to reach diverse sectors of society. The report from the Lancet Commission on the

Value of Death published in 2022 explored the challenges of contemporary dying from a global perspective (Sallnow et al, 2022). The way people die in the 21st century has changed compared to preceding decades. The Commission concluded that that dying today is paradox. For some, it is both over-medicalised, but others have no access to basic pain relief or symptom control at the end-of-life.
In the symposium we will introduce several notes of caution:

i) What is the potential for the health and care system to become increasingly dependent on unpaid citizen initiatives and benevolent volunteers?
ii) How can diversity among end-of-life care volunteers be expanded to extend our current reach into communities from whom we seldom hear?
iii) We will also discuss NHS England's Ambition statement: Each Community is Prepared to Help and reflect on whether the organisation is in a sufficiently flexible position to accept the help that may be on offer.

Collectively, our discussions will consider the future of end-of-life care volunteering. We will draw attention to the Institute of Healthcare Improvement's Quintuple Aim involving: better outcomes, better use of resources, better experiences in receiving care, better experiences in delivering care, and reducing health inequities (Nundy et al, 2022). Inequity is defined as, "*the state in which everyone has the opportunity to attain their full health potential and no one is disadvantaged from achieving this potential because of social position or other socially determined circumstances.*" (National Academies of Sciences, Engineering and Medicine, 2014). We will use a definition of health provided by Illich's in the preceding quote.

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Bios

Guy Peryer

Guy is a chartered psychologist and chartered scientist at the University of East Anglia. Guy has trained as an End-of-Life Doula and co-leads the community theme for the Norfolk and Waveney NHS Palliative and End-of-life Care Collaborative. His main research interests include death literacy and methodological approaches to

expand community involvement in palliative and end-of-life care.

Caroline Stevens

Caroline is the Butterfly Volunteer Co-ordinator at the Norfolk & Norwich hospital, responsible for recruiting, training, and supporting volunteers who sit with palliative and End-of-life patients and their families to offer companionship, support, signposting, and respite. Caroline has worked in a variety of roles at the NNUH for the last 25 years but feels she has finally found her vocation working in End-of-life care and is passionate about developing the service further.

Amy Bramble

Amy Bramble is the Community Fundraising and Marketing Manager at Priscilla Bacon Hospice Charity in Norwich. She is currently involved in developing volunteer requirements for the new hospice in Norwich which will be opening this summer. Amy has worked at three other hospices across East Anglia and was previously a yoga teacher and yoga therapist in Essex.

Jurgen Grotz

Jurgen Grotz PhD is the Director of the Institute for Volunteering Research (IVR) at the University of East Anglia. He is an author, academic and practitioner with 30 years' experience of applied research, working with a strong focus on participative and inclusive approaches. His mainly interdisciplinary research covers volunteer involvement in the public, private and voluntary sectors, focusing on the role of agency for everyone being involved as volunteer or involving volunteers and the difference this makes to individuals, organisations, communities and societies. His publications include:

Grotz, J., Ledgard, M., & Poland, F. (2020) *Patient and public involvement in health and social care: An introduction to theory and practice*. Imprint Springer Nature and Palgrave Macmillan.

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