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Poverty, choice and dying in the UK: a call to examine whether public health approaches to palliative care address the needs of low-income communities

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ABSTRACT

People living on a low income are less likely to access palliative care in the UK; however, beyond the statistics, little is known about the impact of poverty on attitudes towards death and experiences of dying and bereavement. Covid-19 has disproportionally affected poorer communities and foregrounded issues of social and health inequalities including experiences of loss and grief. Whilst this might suggest an opportune moment for embracing inclusive health-promoting approaches to palliative care, this paper argues that the centrality of concepts such as choice within such approaches, and assumptions about what constitutes a 'good death', disregard the ways in which structural, social and economic aspects of poverty interface with attitudes towards and experiences of dying, and may exacerbate inequalities in death and dying.

Introduction

The UK is considered as a worldwide leader in palliative care (The Economist Intelligence Unit, 2015). However, the UK Government's End-of-Life Care Strategy acknowledged that although some people receive excellent care at the end of life, many do not (Department of Health, 2008). Over a decade later, inequalities in access to end-of-life care services are still evident (Care Quality Commission, 2016; Dixon et al., 2015). The Care Quality Commission (CQC) report 'A Different Ending' (2016) states that whilst quality of end-of-life care is generally good it also varies, both in terms of the experience of different population groups and across healthcare settings. Although over 90% of hospices inspected by CQC were rated as good or outstanding, 42% of end-of-life care services in acute hospitals were inadequate or required improvement. Significantly, people with a lower socio-economic status are less likely to ask for a hospice bed and to die in a hospice (Kessler et al., 2005), more likely to die in hospital (Davies et al., 2019) and less likely to feel they had sufficient support to care for someone dying at home (Dixon et al., 2015) than those with a higher socio-economic status.

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The CQC report examines barriers to accessing quality care for 10 specific groups and cites examples of good practice addressing needs within these groups, for example, people with dementia, homeless people (Care Quality Comission, 2016). This population-specific approach is common in the research examining inequalities in access to palliative care. Although these studies provide important insight into issues for particular groups, examples of practice addressing these needs are the exception rather than the norm (Stajduhar, 2020). Perhaps because of the charitable status and undoubtedly valued care provided by the hospice movement, there may be an understandable reluctance to critique such services, however Stajduhar (2020, p. 89) asserts that palliative care remains 'an idea that only becomes reality for those privileged enough to access it', i.e. those who benefit from high socio-economic status and family support. Stajduhar questions whether palliative care is meeting its core mandate given that the original purpose of hospice care was to care for the 'poor, the abandoned, the isolated, people with no home, family or options for care' (Stajduhar, 2020, p. 91).

This paper argues that to better understand the underlying causes of socio-economic differences in access to palliative care, and the findings from health service focussed research in this area, we need to explore these questions about privilege and dying more broadly. It purposefully draws from a wide range of literatures and whilst recognising differences in definitions between palliative care, end-of-life care, public health approaches to palliative care and health-promoting palliative care (and indeed debates about those definitions), this paper will make deliberate reference to thinking and practice within all of these fields, as well as exploring perspectives on death and poverty from the social sciences and cultural phenomena such as the death awareness movement and changes in funeral practice. It examines the narratives and assumptions surrounding death (such as choice, demystification and responsibility) often present across these different fields, and why they might be problematic in the context of poverty. By casting a broad sweep across these different spheres, it aims to show the inter-relatedness of socio-economic factors (e.g. funeral poverty), cultural or public health approaches (e.g. death awareness events) and the accumulated effects of structural poverty across the life course in influencing experiences of dying. It will examine whether a public health approach to palliative care is capable of addressing these concerns and suggest that findings from the field of health inequalities can inform our understanding of the impact of poverty upon attitudes towards, and experiences of, death and dying and help identify gaps in knowledge.

There is no universally accepted measure of poverty; for example, the UK government defines relative poverty as households with income below 60% of the median in that year (Francis-Devine, 2021), whereas the Joseph Rowntree Foundation defines poverty as 'when a person's resources (mainly their material resources) are not sufficient to meet their minimum needs' (Joseph Rowntree Foundation, n.d.). Other terms used across disciplines include those utilising standardised measures such as 'socio-economic status', more relative terms such as 'low-income', and broader (and more contested) terms such as working-class which relate not only to income levels. As this paper argues for the benefit of drawing on a range of literatures, it mirrors the language used in research cited, and otherwise uses the terms poverty and low-income interchangeably to denote the situation described simply by the Joseph Rowntree Foundation as having insufficient resources to meet minimum needs.

Why look specifically at poverty?

Covid-19 has brought issues of mortality and inequality into sharp relief, underlining an urgent need to understand their interconnectedness (Pentaris & Woodthorpe, 2021) and the wider impact on families and communities. On the face of it, a good death should not depend on income in the UK, given that healthcare is free at the point of delivery. However, scratching beneath the surface a myriad of factors influence the experiences of people on a low-income at end of life.

Whilst some socio-economic barriers to practices thought to indicate a 'good death' have been identified, e.g. insufficient space for specialist equipment to die at home (Wahid et al., 2018), there is little research investigating the more nuanced ways in which poverty impacts end-of-life experiences (Lewis et al., 2014; Song et al., 2007). Whilst acknowledging ongoing debates about the definition of terms such as class (Bartley, 2016), this paper argues that there is an urgent need to understand how the structural, social and economic aspects of poverty, as well as cultural values of class and community, may interact with and impact upon attitudes towards preparing for end of life, as well as experiences of dying and bereavement. Most importantly, it argues for the need for research to listen to the lived experience of those living, and dying, on a low-income.

Much of the multidisciplinary and professional literature about dying is of a psychological nature, focussing on the experience of the individual or family (Thompson et al., 2016). Even within the field of sociology, Howarth (2007b) points out that death studies have largely focussed on issues such as identity, emotion and the body. Whilst there is much discussion about individual psychological and emotional responses to terminal illness and grief (Howarth, 2007b), little attention has been paid to either the wider social context that frames each individual's experience, or key sociological concepts such as power and alienation (Thompson et al., 2016) that impact upon both the individual's experience of dying and the practice of health and other professionals involved in their care.

Concerns about the medicalisation of dying, which originally sparked the birth of the hospice movement in the UK in the 1960's, have resurfaced more recently as part of a broader unease about the ways in which we, as a society, deal with dying. Debate has spilt out from the palliative-care field into more mainstream discourse and a swathe of books in the last decade by medics such as Atul Gawande (2014) and Kathryn Mannix (2017) have drawn attention to the dissonance between the highly medicalised and largely hidden approach to death that has become the norm, and what might, arguably, be called a 'good death'. Prominent displays of such texts in high street bookshops and plentiful coverage in broadsheets suggests that they have brought the topic to a ready and receptive public, however what we already know about health inequalities suggests that these debates are unlikely to be the immediate concern of those struggling to survive in the here and now. Whilst in the UK and other parts of the world, there has been a growing call to open up conversations about death and dying, there is a danger that for those living in poverty the concept of planning ahead for a 'good death' may be perceived as an unobtainable luxury. Without doubting the genuine, and experience-driven motivation of what can loosely be termed the 'death awareness' movement to improve end-of-life experiences, the tendency to focus on individual action and preparedness fails to address the wider social context, which undeniably affects the individual's ability to engage with the constructs, such as 'choice, implicit within it.

Why choice is problematic

In his critical exploration of 'What Death Means Now', Walter (2017) describes a 'new craft of dying' that is characterised by open communication, choice, control and a natural accompanied death. This, he argues, is rooted in three things: the hospice and palliative care movement's experience of caring for cancer patients, baby boomer values of choice, and a neoliberal ideology. Borgstrom and Walter (2015) point out that the word 'choice' appears 44 times in the UK End-of-Life Strategy and suggest that whilst this approach resonates with the neoliberal agendas that have more recently shaped the National Health Service (NHS), it may not resonate with the lived experience of frail and possibly confused elderly people at end of life. Central to this discourse is the assumption that the individual wants, feels able, and *is* able, to make choices about his or her life, death and affairs after life, which is also problematic when set alongside the experience of those affected by poverty because it a) ignores the fact that personal, social and economic context can limit choice and shapes experiences at end of life, and b) assumes that the middle-class model of a 'good death' fits all and therefore that a lack of awareness is the only barrier.

The importance of context

Access to provision

Within the UK, there is a tension between the ideals expressed in the End-of-Life Care Strategy (Department of Health, 2008), which include identifying and agreeing a care plan for people approaching end-of-life and high-quality co-ordinated care and support for carers, and the realities of provision available. The combined pressures of an ageing UK population (Office for National Statistics, 2019b), increasing demand on the NHS and cuts to local authorities have culminated in a crisis in health and social care (Oliver, 2015), which has left many older people struggling to access the care that they need even before end-of-life. The need for palliative care is predicted to rise by 42% by 2040 in England and Wales (Etkind et al., 2017), yet even at the current level of need reports show the quality and availability of palliative care to be inconsistent, with significant levels of unmet need (The Choice in End of Life Care Programme Board, 2015). With socio-economic inequalities in access possibly increasing (Sleeman et al., 2016) the population most likely to experience multi-morbidity, to have complex needs and to require management of advanced disease are also those least likely to have the social and material resources to 'augment the gaps between formal and informal care contexts' (Lewis et al., 2014).

Impact of austerity on experiences of death and dying

As well as the crisis in health and socialcare provision, the UK has also been subject to a period of austerity over the last decade, which has widened inequalities in income and pushed a greater proportion of families into poverty (Marmot et al., 2020). Whilst the direct impact on end-of-life is in itself shocking – a widening of the gap in life expectancy years between those in the highest and lowest income brackets (Office for National Statistics, 2019a), a lowering of life expectancy for poorer women (Marmot et al., 2020),

cuts to end-of-life care services (Foster et al., 2019) – the more indirect ways in which austerity impacts on experiences of death and dying are less obvious. Although little evidence is as yet available, those working within low-income communities cite, for example, the difficulties faced by those employed in the gig economy needing to care for family members at end of life, to request bereavement leave or even to attend a funeral; or the stalling of attempts to develop end-of-life care in hostels for homeless people following cuts to services.

Welfare reforms have also impacted experiences of death in low-income communities; for example, charities in the UK recently reported that over a 6-month period 2,000 terminally ill people died while waiting for benefit payments that were issued too late (Butler, 2020) and changes to welfare conditionality have been linked to an increase in suicides (Barr et al., 2016). The construct of 'funeral poverty' has emerged relatively recently (Corden & Hirst, 2016) to describe the situation faced by bereaved families unable to meet rising funeral costs; a situation expected to become more common (Woodthorpe, 2014). Charities and media reportage have drawn attention to the acute financial crisis that can be associated with bereavement and the inadequacy of the current level of welfare support (Sprenger et al., 2019), however despite a Work and Pensions Committee inquiry and report (Work and Pensions Committee, 2016) which called for radical reform of the benefits system for bereaved people, government action to implement the recommendations has been minimal (Foster et al., 2019). Little is known about the impact of funeral poverty on those who do not qualify for state support, and more generally there has been little research into the ways in which the stress and trauma of the above impact upon attitudes towards death and dying, or experiences of grief, for those affected.

Covid-19

The longer term impact of Covid-19 on public discourse around death and dying cannot yet be known, and will of course differ between individuals and across circumstances, cultures and communities. What we do, however, know is that the virus has disproportionately affected Black and Minority Ethnic (BAME) individuals, has hit the poorest areas in the UK (and globally) hardest (Bhatia, 2020), both in terms of number of deaths and economic hardship (Patel et al., 2020), and that there are now 690,000 more people living in poverty in the UK (Legatum Institute, 2020). Whilst there are those in the field of palliative care hoping that the experience of living through a pandemic may encourage people to engage in conversations about dying (Selman et al., 2020), there is a danger, particularly for vulnerable or disenfranchised members of the population who may feel alienated from concepts such as rights or choice, that some of the implicit and explicit narratives about who 'deserves' emergency healthcare may have only served to increase fear and distrust. Indeed early indicators show vaccine hesitancy to be higher in the UK in people with no qualifications compared to those who are degree educated (Robertson et al., 2021), suggesting that mistrust of public health systems remains a significant factor.

Emerging evidence also suggests that a number of hospices and other charitable organisations offering support to people with terminal illnesses have been forced to cut services due to a reduction in fundraised income during the pandemic; a situation likely to have affected hospices in low-income areas most severely and one which increases the pressure on NHS services (Mahase, 2020).

Assumptions underlying the death awareness movement

The 'death awareness movement' has gained momentum in the UK and globally in recent decades, with voices from a variety of sources calling for more open discussion about the arguably taboo subject of death and offering a plethora of alternative approaches to preparing for death, care at end-of-life, and the rituals of death and grief (Doka, 2003). Examples include the death café model in which people come together to 'drink tea and discuss death' (Death Cafe, n.d.) and 'Coffin Clubs', an international initiative (with eight groups in the UK) where individuals meet regularly to make their own coffins and talk about death (Somvihian-Clausen, 2017). Perhaps indicating the lack of available and suitable care or knowledge at end-of-life within communities, the newly emerging role of 'death doula' or 'soul midwife' appears to be gaining traction, although little has as yet been documented about the scope or take-up of this service, which is self-regulating and can be paid or voluntary (Rawlings et al., 2019). The UK has seen a growth in more flexible, person-centred 'progressive funeral providers' advocating for greater choice in funeral arrangements (The Natural Death Centre, n.d.). There have also been a flurry of TV and radio series fronted by popular media figures such as Miriam Margolyes and Joan Bakewell encouraging us to deal more openly with death.

These are just a few examples of initiatives that form part of an amorphous 'death awareness' movement, and whilst each may have a subtly different focus or driver, they share a belief that the processes of death and dying should be demystified, as exemplarised in the strapline of the UK Dying Matters Coalition, 'let's talk about it'. As Walter (2017) points out, these messages urging us to discuss our feelings, to take control and make choices in order to have a 'good death' are largely driven by experience and passion rather an evaluation of evidence which is, as yet, largely absent or unclear.

There have been critiques (though limited) of the central tenets of death awareness or education, not only the lack of evidence for the notion that talking about death is good but the assumptions about what a 'good death' looks like. Howarth (2007b) and Conway (2012) both argue that sociology has neglected the death-related experiences of working-class people, and has privileged middle-class norms, such as the importance of verbal communication (e.g. open awareness of dying, counselling), control and individualisation (e.g. alternative and natural funerals).

Meier et al.'s (2016) literature review of studies seeking to define a 'good death' points out that whilst there is considerable lay literature describing positive approaches to dying, there is little agreement within the healthcare community about what specifically constitutes a good death. Most of the studies reviewed did not report the demographics of participants and the authors identify a need for more divergent perspectives. As people in lower socio-economic groups are under-represented in health research (National Institute for Health Research, 2020), it is unsurprising that poverty-related concerns have received little attention in debates about what constitutes a good death. Although there is literature exploring the financial impact of illness and bereavement, particularly on caregivers (Corden & Hirst, 2013), it often focuses on changes in economic status when someone becomes ill or dies, rather than examining how income and class may affect attitudes towards, and experiences of, death, dying and bereavement across the life course. In their review of evidence on the financial costs of informal care giving Gardiner et al. (2020) identify socio-economic status as one source of inequity alongside

diagnosis, gender, cultural and ethnic identity and employment status, and call for further research to inform a more detailed understanding of the systematic disadvantage faced by some carers.

Thinking about formal providers of care, Howarth cites Clark's assertion that 'too often hospices appear as white, middle-class, Christian institutions serving a carefully selected group of patients' and argues that as well as understanding a range of cultural belief systems there is also a need to acknowledge different social circumstances and power relations (Howarth, 2007a, p. 145). In terms of class, there has been little exploration of either cultural or social context in relation to death. 'Middle class reformers', Howarth argues, inaccurately perceive working-class people 'as lacking a sophisticated understanding of death, as needing to be "empowered" in order to more meaningfully engage with death' (Howarth, 2007b, p. 430). In reality, there is absence of in-depth knowledge within the palliative care and bereavement literature about the attitudes and needs of people on a low income.

Do community and public health approaches provide the answer to the equality gap?

The World Health Organisation has been advocating a public health approach to palliative care since the 1990s and Sallnow et al. (2016) argue that contemporary challenges (i.e. an ageing population, pressure on services, inequalities in access) have reignited an interest internationally in applying health-promoting principles to end-of-life care, as a sustainable response with the potential to counter the medicalisation of dying. Whilst there is no single definition of a public health approach to palliative care, they describe a range of practices that have been adopted across different countries including mobilising community resources to support those at end-of-life and/or the bereaved (either through naturally occurring social networks or by training volunteers), attempting to change public attitudes towards death and dying through education, and promoting awareness of and receptivity to ways of preparing for end of life, e.g. writing wills or advance care plans.

Developing public health approaches to palliative care is a growing practice and field of study in many countries (Zaman et al., 2018). The Compassionate Communities model founded by Allan Kellehear (2005) is a well-developed framework that has been widely adopted in different international contexts including the UK (Paul & Sallnow, 2013). A specific and widely cited example of a successful community approach is the regional model that has been developed in Kerala, India, where local networks of volunteers identify chronically ill people in their neighbourhood, organise support and care, and liaise with medical services (Kumar, 2007). Kumar describes as important to its success an early recognition that a hierarchical doctor-led initiatives were inadequate, both in terms of reach and other aspects of 'total care'. The model therefore evolved to become 'community-owned' – led by volunteers who mobilise local resources and respond holistically to needs, with active support from professionals. It also addresses the wider determinants of health, supporting communities to live well, for example, by promoting access to education.

Different terms such as community development, community engagement and death literacy can be found within the literature; as well as describing a range of activities, they also represent varying levels of community involvement, from more traditional

consultation or volunteering services to more collaborative and community-led initiatives (Abel et al., 2013; Sallnow & Paul, 2015), as is perhaps reflected in the diversity of terms. What they have in common, however, is an ethos that end-of-life and bereavement care is 'everyone's responsibility', and should not be the sole preserve of professional health or social services (Kellehear, 2013). On the face of it, an approach which is based within a local community, and looks to the needs of the individual, would indeed appear to be a major step forward in terms of addressing the needs of people who may find it difficult to access help from professional services, or for whom the help on offer might not feel appropriate. However as described, the ways in which a public health approach are being implemented are diverse, and whilst some are clearly deeply rooted within the communities in which they operate, others are instigated by institutions such as hospices or statutory services. Whilst not necessarily problematic in itself, it is important to pause to consider some of the assumptions that may be inherent within them, and whether in fact there is a danger that these approaches could inadvertently perpetuate the inequalities that they seek to address.

What don't we know?

Despite the fact that a majority of people in the UK say that they are comfortable talking about death, a survey in 2016 found that only 25% of people had talked to someone about their own end-of-life wishes, and 7% had written down any wishes or preferences about their future care (The National Council for Palliative Care, 2016). Unsurprisingly, it also showed differences in age, with older people more likely to be willing to engage in end-of-life conversations. There is some research looking at the communication needs and priorities of particular groups, e.g. people with a cancer diagnosis (Lamont & Siegler, 2000; Leydon et al., 2000), or the homeless (Song et al., 2008), however the lack of literature about the needs of those living in poverty in the palliative care field is acknowledged by those researching disenfranchised populations (Song et al., 2007). As barriers to preparing for end of life in the general population have been found to include a lack of knowledge and accessible resources, the need to be computer literate and the cost in time and finances (Webb et al., 2020), the absence of knowledge in relation to potential links between socio-economic status and engagement in end-of-life preparation is of concern.

Given that little is known about what is important to people living on a low-income, and those caring for them, at end of life, it is hardly surprising that there is also an absence of discussion, within practice and policy, about how low-income communities can best be supported to engage in end-of-life planning. The evidence base around who benefits, how, and who is excluded is, as yet, missing from the field of health-promoting palliative care (Sallnow et al., 2016) and death awareness initiatives more generally.

Choice and responsibility

Research into the health needs of low-income communities has largely neglected the end-of-life stage (Lewis et al., 2014) thereby paralleling the knowledge gap in death studies; however, literature examining the complex relationship between poverty, health and concepts such as choice, responsibility and shame can provide important insight (Thomas et al., 2018; Walker, 2014).

The language of 'fighting', a 'struggle' or 'succumbing' within narratives surrounding life-threatening illness remains pervasive, as evidenced recently in the UK when the British Foreign Secretary announced to the press that he was 'confident' of the Prime Minister's ability to recover from Covid-19 because 'he's a fighter' (BBC News, 2020). Such narratives have been challenged, both by activists and academics, particularly in the field of cancer, for placing responsibility upon the individual to combat a disease over which they have no control, and implying that those who lose their 'battle' do so because of a lack of commitment or strength (Harrington, 2012).

Similarly, whilst the 'new craft of dying' may include acceptance, it also, as previously described, centres firmly on choice and control as key components of a 'good death'. Conway's exploration of the limited research on death and class cites Young and Cullen's 1996 study of cultural practices in relation to dying which found that one working class way to face death was to accept the relinquishing of control (Conway, 2013). There has, however, been little recent research regarding perceptions of choice, and what might be important in terms of a good death, from the perspective of people living on a low income. In the search for more recent literature examining death and class, it is perhaps research related to cultural competence in health care that comes closest. However in their review of the British literature on palliative care and cultural competence, Evans et al. (2012) state that whilst there is a common thread urging practitioners to recognise that everyone is influenced by their cultural background, recommendations for the use of cultural competency approaches in UK end-of-life care policy refer solely to race, and not class or other cultural factors.

End-of-life preparation, as advocated by organisations like Dying Matters, typically focuses on making choices regarding medical care (e.g. advance care planning), finances, funeral arrangements and legal issues such as wills. More recognition is needed not only that making such arrangements may be inaccessible to many but that they may also seem of little relevance to people who are aware that their choices are limited and do not have the resources to pay for care or a funeral.

Interestingly, although the field of health literacy has conventionally focussed on the need for patient education, there has been an increasing recognition within the literature of the importance of considering contextual issues, including socio-political environments and the communication skills of health professionals (Rudd, 2015). Reviewing the literature on palliative care and socioeconomic deprivation, Lewis et al. (2011) note a lack of discussion of health literacy, and little discourse seeking to address the communication needs of this group. Whilst a re-examination of communication methods might be timely, there is a danger that a conventional focus on 'health literacy' will be perceived as a need for education – and will return full circle to a well-meaning 'awareness-raising' approach. It may equally be about recognising the cumulative effects of inequality across a lifetime, i.e. the reality that people may be living with structural barriers that deny choice. It may also be about educating professionals to understand that worries and concerns about facing death may go beyond the issues addressed by, for example, an Advance Care Plan or funeral plan.

The impact of shame

The negative impact of shame as an effect was alluded to above in the discussion of the 'fighting' narrative and its implications of failure for the terminally ill. The role played by feelings of shame in determining help-seeking behaviour cannot be underestimated,

whether in relation to health care or other support such as welfare (Thomas et al., 2018). Research shows that people with life-limiting health conditions perceived to be caused by 'irresponsible' behaviours (e.g. liver disease, lung cancer) particularly experience feelings of shame, which can lead to a fear of being judged by healthcare professionals as less entitled to care, or to internal feelings of being undeserving (McNeil & Guirguis-Younger, 2012).

Walker's (2014) research exploring the global experience of poverty found that people in low-income communities almost invariably feel ashamed at being unable to fulfil personal aspirations or live up to societal expectations, and that this shame undermines confidence and individual agency. This suggests that there may be a 'double whammy' for people dealing with both poverty and life-limiting illness. With the exception of some studies exploring attitudes to end-of-life care amongst homeless people (McNeil & Guirguis-Younger, 2012; Song et al., 2007), there has been little exploration of the impact of shame within palliative care literature. However, findings from more general research on health inequalities suggest a complex relationship between shame and health (Smith & Anderson, 2018). Given some of the characteristics of palliative care (for example, that hospice provision is provided by charities, that health professionals often need to visit patients in their home) further exploration of the impact of shame may help improve understanding of inequalities in access to end-of-life care.

Understanding need

These considerations suggest that there may be need to step back from examining inequalities in access to services, to firstly try to understand what *kinds* of care, support, information or structures would better support people in thinking about end of life. In her discussion of poverty in relation to death, Bevan (2002) highlights the danger of a functionalist concept of need, i.e. one in which needs only exist where there is a service available to meet them, and so needs that are difficult to define or respond to may not be identified. The underlying ethos of palliative care and indeed 'death aware-ness', whilst looking beyond the biomedical to the social, emotional and spiritual needs of the individual, may inadvertently maintain the status quo (in terms of reach) by not attending to the social and political structures denying access to its world. A world which Bevan (2002, p. 106) claims will not alter until 'inclusive participation in policy development is developed'.

Conclusions – key questions for future research

How might a focus on choice and responsibility alienate certain populations?

The current Dying Matters campaign in the UK centres on '5 things you can do to die well'- the first three of which are to make a will, record your funeral wishes and plan your future care (Dying Matters, n.d.); we need to understand better whether the framing of initiatives such as this resonates with people necessarily focussed, for example, on more immediate concerns such as food or heating bills, or insecure housing.

Ironically, whilst Thompson et al. (2016) makes a case for the potential for sociology, as a 'listening art', to provide insight into the social processes and structures contribut-ing to inequalities in death and dying, he cites the emergence of the death café

movement as a positive example of this. Although little has yet been documented in terms of attendance at death cafes, anecdotal evidence suggests that those who participate tend to be predominantly white, middle-class, middle-aged and older women. Whilst not suggesting that any of these initiatives are not of benefit to those that participate, we need to look more closely at whose needs are not being responded to and addressed.

How useful is 'funeral poverty' as a construct?

The concept of 'funeral poverty' has undoubtedly drawn much needed attention to the enormous financial pressure experienced by some families at a vulnerable time, and exposed exploitative elements within the funeral industry. However, the narrow focus of the term does present the issue of poverty at end of life as solely economic, and ignores other structural factors confronted by those dealing with terminal illness both before and after death, e.g. social isolation due to inaccessible housing, or a lack of entitlement to bereavement leave for workers dependent on the gig economy.

Foster et al. (2019) argue for a co-ordinated social policy approach to death, pointing out, for example, the disconnect between local authorities in the UK increasing cremation fees and the inadequacy of the government's Funeral Expenses Payment. Developing this idea further, it may be more effective to draw attention to the broader ways in which poverty impacts end-of-life experiences (as opposed to a focus on funeral poverty) and consider the ways in which social policy changes may complement a public health approach to death and dying. One example may be the commitment within initiatives such as the compassionate city charter for authorities to review the impact of housing policies on the dying and bereaved (Abel & Kellehear, 2020).

How can public health approaches be community-led?

In recognising that death is 'everyone's responsibility', the compassionate city charter (as one example of a public health approach to palliative care) challenges the narrative of death and dying as an individual responsibility and places it in the community rather than solely with professionals. But the danger is that such approaches rarely acknowledge or call to account the impact of social policy, as suggested above, and the power of the state to affect individual experience. Public health approaches are implemented differently in different places; it may be useful to examine whether some initiatives may rely on communities to be resource-rich (e.g. a retired population with capacity to volunteer; employers willing to voluntarily adopt compassionate policies rather than a workforce predominantly dependent on the gig economy), or whether, by being led by statutory or medical institutions, they are failing to understand the priorities of those living on a low income.

It would be useful, therefore, for research to consider whether public health approaches are addressing the issues that are important to low-income communities, and explore ways in which already existing peer networks might extend to end-of-life and bereavement support, to avoid imposing a 'top down' model which may not be appropriate. Crucially, engaged research exploring the views and lived experience of people

within low-income communities in relation to other health issues (e.g. mental health) has found that informal peer support is highly valued (Thomas et al., 2020), and this may be the case with support at end of life.

There is potentially an underdeveloped idea within the literature that caring at end of life can be reconceived as two-way; that we have something to learn from the dying. One example is Malcolm Johnson's experimental 'Old People's home for 4 year olds' exposing the untapped social capital of the elderly who are often isolated from other generations (University of Bath, n.d.). It would be useful to explore, therefore, how public health approaches might facilitate a mutual learning and caring process within communities rather than solely a support service for those approaching end of life.

What is a 'good death'?

Conway asserts that whilst dated, the limited literature that does explore death and class in the UK 'may challenge the idea that the "good" death derives from individual psychology, professional prescription or middle-class know-how' (Conway, 2012, p. 447). What constitutes a 'good death' for each person cannot be pre-supposed; research in this area perhaps then needs to go back to basics to listen to the lived experiences of people whose views are currently under-represented.

These four questions are not, of course, exhaustive. Whilst this paper purposefully focuses on income inequality, we of course know that other factors such as diagnosis, age, cultural, religious and ethnic identity impact on engagement with and access to palliative care (and health care more generally). The widening of inequalities during the Covid 19 pandemic has exposed the urgent need to better understand the ways in which these factors intersect and influence attitudes towards, and experiences of, end of life. If we are to affect the systems that impact most on the way that people experience end of life (i.e. health care, social care, housing, welfare) such that they are responsive to the needs of under-served populations, we need to conduct our research in different ways too. We need to co-create research with people within low-income communities, paying attention to their experiences, needs and priorities. We also need to consider the implications of our findings not only for palliative care practice but for social policy, and identify system changes that might better support 'compassionate communities' and address inequalities at end of life.

Data access statement

This study did not generate any new data.

Data availability statement

The data that support the findings of this study are openly available in the UK Data Service at https://beta.ukdataservice.ac.uk/datacatalogue/studies/study?id=853488 ReShare record 853488.

Disclosure statement

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