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Dying 2 Talk: Generating a More Compassion Community for Young People

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Abstract

People in the Global North often have a problem talking about — and processing — the inevitability of death. This can be because death and care of the dying has been professionalised, with encounters of death within our families and communities no longer being ‘normal and routine’ (Kellehear 2005). Young people are particularly excluded from these conversations, with implications for future mental health and wellbeing (Ainsley-Green 2017). Working in Wolverhampton and Bradford, the Dying 2 Talk (D2T) project aimed to build young people’s future resilience around this challenging topic. We recruited over 20 young people as project ambassadors to co-produce resources that would encourage talk about death, dying and bereavement. The resources were used as the basis of ‘Festivals of the Dead’ which were taken to schools to engage wider audiences of young people (aged 11+). The project aimed to use alternative ‘ways in’ to open discussion, beginning with archaeology, and ultimately using gaming, dance, creative writing and other creative outputs to facilitate discussion, encourage compassionate relationships and build resilience. The resources succeeded in engaging young people from ages 11–19 years, facilitating a comfortable and supportive environment for these vital conversations. Project evaluations and observations revealed that the Festivals, and the activities co-created by the young ambassadors helped to facilitate spontaneous conversations about death, dying and bereavement amongst young people by providing a comfortable and supportive environment. The project was funded by the Arts and Humanities Research Council (AH/V008609/1), building on a pilot project funded by the Higher Education Innovation Fund at the University of Bradford.

Keywords Death, Dying and bereavement · Young people · Compassionate community · Resilience · Co-production · Archaeology

‘Death is a problem of the living. Dead people have no problems’ (Elias 1985: 3).

Extended author information available on the last page of the article

Introduction

Modern medicine has increased longevity, and as, ‘life grows longer, death is further postponed. The sight of dying and dead people is no longer commonplace. It is easier in the normal course of life to forget death’ (Elias 1985: 8). Thus, in the Global North ‘societies that stress rational choice, self-control, and privatised meanings’ (Ribbens McCarthy 2007: 286) — the normality of death has been displaced by a cultural reluctance to discuss death, leaving *talk* about dying, bereavement and grief as a specialist activity rather than an everyday occurrence. Therefore, talking about death can be problematic, with many people finding ‘discussion of these matters awkward, upsetting or morbid’ (Kellehear 2005:107). For many, the topic is difficult and ‘troublesome’, and as Walters describes, rather than an absolute ‘taboo’, conversations can be ‘shut down’ (1991, 2017). Semino et al. (2018) write about how this reluctance is reflected in the use of metaphor. Metaphor is a feature, not just of literary language, but of everyday discourse that can be used to obscure reality (Laskoff and Johnson 1980). For example, dying of cancer is often framed in terms of ‘losing a battle’. This is because in order to grapple with difficult concepts which are ‘abstract and not clearly delineated’ — like the concept of death — there is a tendency to relate them to more concrete constructs that ‘we understand in clearer terms’ (Laskoff and Johnson 1980: 115). That is not to say that metaphor is always unhelpful in the process of dealing with and talking about death (Semino et al. 2018; Hommerberg et al. 2020) but it can be disempowering if such metaphors suggest that death is an individual — or a medical — failure rather than being a natural part of the life course. This is particularly poignant in Global North societies where the professionalisation of death, resulting in the distancing of human beings from ‘the blind destructive powers of nature’ (Elias 1985), is narrated as an individual event rather than a universal experience. As Elias writes, ‘never before in the history of humanity have the dying been removed so hygienically behind the scenes of social life.... the screening-off of dying people from others, from children in particular’ (1986: 23).

Continuing Bonds: Challenging the Binary Relationship Between the Dead and the Living

In Global North societies, the death of the physical body has come to be ‘culturally shaped as the end of personhood’ (Ribbens McCarthy and Prokhovnik 2014: 25), linked to the medicalisation of death and the conflation of the physical body with ‘the modern way of being human’ (Cohen 2008). Other cultures across time and space have not created such a distinction between the body and the wider, physical environment. In contrast, the Global North conceives the ‘body-as-property’, separated out from nature (Cohen 2008). For Cohen, it is this neo-liberal conception of self — as a sovereign subject able to act freely — that results in a

binary between life and death, such that, ‘the absence of the body’s well-defined boundary results either in death or servitude’ (2008: 107). This conflation of the ‘person’ with the ‘body’ — and the denial of our shared being — limits our ability to see ‘our being as living beings together’ (Cohen 2008: 122). For the end of the ‘physical’ person does not result in the discontinuation of the ‘life’ of that individual amongst the living.

However, whilst physical death is a biological reality, responses to death and experiences of bereavement are not. Grief is a personal — and collective — experience (<https://www.mind.org.uk/information-support/guides-to-support-and-services/bereavement/experiences-of-grief/>) that continues to connect the dead to the living. However, the idea that there are linear stages¹ that must be experienced to complete a ‘healthy’ grieving process and leave the dead behind has been widely challenged by practitioners and academics (e.g. Stroebe et al. 2017). As highlighted by Klass and colleagues (1996), the living often maintain ‘continuing bonds’ with the dead through ‘activities, thoughts and conversations’ (Ribbens McCarthy and Prokhovnik 2014). For many, death itself is not the end of the relationship between the living and the dead (Walter 1996; Neimeyer et al. 2006). These ‘continuing bonds’ between the living and the dead often help people process death and bereavement, by encouraging the bereaved to talk about their loved ones and maintain their personhood as an influence on their own life.

Why We Need to Talk About Death, Dying and Bereavement with Young People

We cannot shield young people from death — and yet adults try. Indeed ‘silence is itself a language, a discourse, that speaks its own message’ (Kellehear 2005: 109). Experiencing the loss of a loved one, pondering their own mortality, and encountering death through films, the news and other media is not only likely for many young people, but will become a reality for all of us through the course of our lives. Nonetheless, social and cultural processes discourage ‘everyday’ conversations about death (Kellehear 2005), particularly with children and young people (Holland et al. 2010). As Ribbens McCarthy writes, ‘the conjoining of bereavement and young people’ suggests ‘a double jeopardy, invoking deep anxiety, whether among professionals, academics and researchers, or among people in their everyday lives’ (2007: 286). Bereavement is frequently treated as an occurrence marginal to young people rather than ‘a statistically “normal” part of growing up’ (Ribbens McCarthy 2007). Thus, a bereavement within a family setting can lead to young people feeling powerless and excluded. For, as adults grieve, young people are often not enabled to ‘deal with their bereavement experiences at the time ... to have their feelings socially acknowledged’, often not included in ‘key family decisions’ around the death (Ribbens McCarthy 2007).

¹ This was the model developed by Kubler Ross in 1969 in relation to her work with cancer patients.

However, the impacts of unresolved bereavement are far-reaching. Indeed, for young people, this may persist into adulthood. Aynsley-Green's study (2017) indicates that child bereavement can result in depression, smoking, risk-taking behaviour, unemployment, poor educational attainment and criminal activity in adult life, and a study by the British Medical Association (2014) found a significant percentage of young people involved in the youth justice system had experienced a significant bereavement in their childhood, such as a parent or a friend. Bereavement is particularly 'harmful' for young people who already live with multiple disadvantage (Akerman and Statham 2014). However, positive, supportive relationships are important in enhancing the resilience of young people in the face of bereavement (Ribbens McCarthy and Jessop 2005). Therefore when family members or peers are overwhelmed themselves by a bereavement — or are unable to talk openly about death — external support can be critical in mitigating against further harm. As young people spend a significant portion of their lives at school, schools could be pivotal to that support. Based on the initial findings of the Atlas project aimed at developing support for bereaved young people in schools, Birch and Bridge state that schools have the potential to be 'a key source of support, constancy and consistency when families experience the turbulence of bereavement' (2018). Kellehear, too, argues, 'where experience cannot guide or give confidence to communities, education potentially can' (2005: 14).

Allan Kellehear's concept of a compassionate city is based on the premise that 'death and loss are predictable and permanent experiences, and that we can and should strive for quality of life rather than denial in their shadow' (2005: 44). Compassionate cities frame death, dying and bereavement as having a 'wider meaning than disease' and instead recognise the importance of supporting people through death, dying and loss in ways that recognise and accommodate social and economic inequalities, as well as 'the spiritual traditions of a community' (religious and cosmic beliefs) that provide a wealth of 'ideas about death, suffering and loss.....instrumental in the provision of support and comfort' (Kellehear 2005: 45). In this way, the compassionate cities concept reflects a desire to imagine 'better, more humane and rational communities to live in' (2005: 55), which encourages 'local neighbourhood people, actions, and resources to support people with serious illness, caregiving, or loss in a local area' (Kellehear 2020: 116).

Co-production as a Key Principle

The Dying to Talk project, funded by AHRC (2021–2022) and the previous pilot funded by University of Bradford (2017–2018) (Booth et al. 2020), drew on the principles of co-production. As professionals and adults, our world views do not necessarily reflect the world views of young people. Therefore, drawing on the expertise of young people was crucial. The concept of co-production was first coined by Elinor Ostrom in the 1970s to recognise that service user communities and local citizens have expertise that can enhance the delivery of welfare services. Co-production denotes the 'space and opportunity for individuals to contribute' to developing policy solutions to social problems where professionals and practitioners 'had

previously exercised full control’ (Strokosch 2013: 376). Advocates of co-production believe in its potential ‘to provide significant economic, political and social benefits’ (Pestoff 2018). Thus rather than policy solutions and services being imposed on citizens, the lived experience of citizens (that might be local residents, service users or, in this case, young people) is seen as enhancing the decision-making process and ‘the system’s productive resources’ (Durose & Richardson, 2016, p. 40). This repositioning is transformational and empowering (Strokosch 2013), redressing the imbalance of power between those designing, commissioning and providing services and those using the services (Pestoff 2018). Mayer and McKenzie distinguish this as ‘experts by experience’ versus ‘experts by qualifications’ (2017).

In the academic world, particularly in the social sciences, community-based research practices have also become increasingly visible. There are several approaches to community-based research, which differ in relation to the relative role of communities within the research process. Nonetheless, all converge around the principle that research should be carried out *with* communities² rather than *on* them. There are important reasons why academics should involve communities with lived experience in social research. Firstly, it recognises that lived experience is a valuable source of expertise that should sit alongside that of professional expertise. Kotzee (2012) talks about the ‘differentiatedness of expertise’, acknowledging that professional expertise is only one source of knowledge and that the knowledge embedded within communities — what Sandemann and Kliever call ‘knowledge from the community perspective’ — is essential in social research (2012: 23). For, engaging communities in defining ‘the problem’ is likely to generate a more realistic understanding of the dynamics at play (Beebeejaun et al. 2015). Rather than carrying out research *on* communities, social researchers need to carry out research *with* communities (Campbell and Vanderhoven 2016), disrupting the ‘knowledge hierarchy of the expert versus the layperson’ (Porter 2010, in Beebeejaun et al. 2013: 3).

Secondly, it is about transformation: empowerment of the communities themselves and transformation in terms of the lasting impact of the research. Valuing the voices of lived experience through engaging communities as equal partners in the research process can support communities, ‘to actively alter the social conditions in which they find themselves’, facilitating ‘greater community control’ over what is deemed ‘publicly valuable research’ (Beebeejaun et al. 2015). This transformation is argued to be crucial when looking at complex, multidimensional issues, such as the social, emotional and cultural barriers that inhibit talk around death. Brown et al. argue that we need ‘the personal, the local and the strategic, as well as specialised contributions to knowledge’ to develop solutions to complex problems (2010: 4). Thus, co-production repositions the boundary between the researchers and the researched, focusing on the ‘social worth’ of research rather than academic merit alone (Campbell and Vanderhoven 2016). Co-production aims to start

² This paper recognises that the term ‘community’ is a contested one in social science. However, for the purposes of this paper, and because of the limited work count, the term ‘community’ in this paper refers to the individuals and groups who may be affected by the research outcomes and who have relevant lived experience. This is particularly important for those from disadvantaged backgrounds.

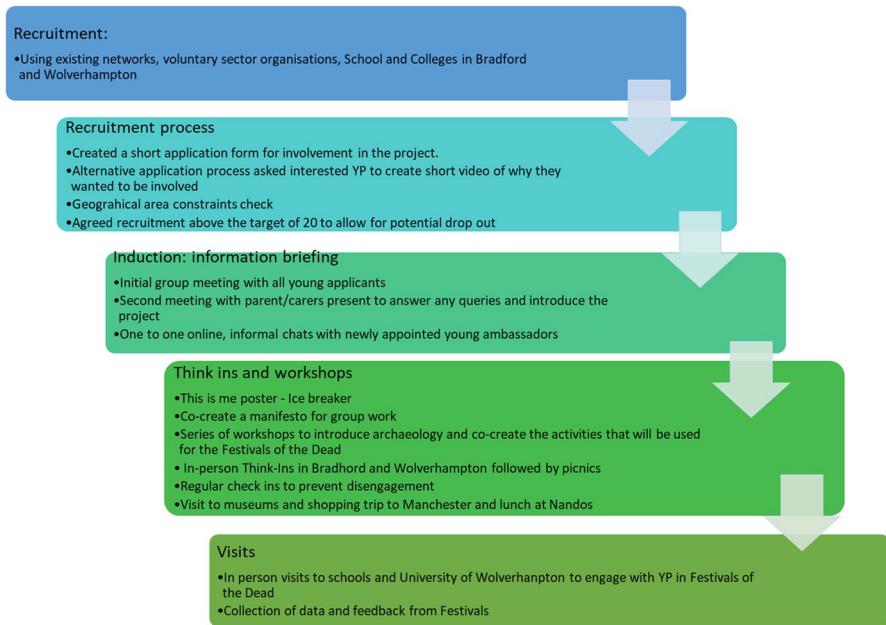


Fig. 1 The project timeline

with the concerns of the community itself and ensures that the *process* of research is an empowering and equitable one for all. In this way, the findings of the research are likely to be more impactful, as knowledge is shared and jointly ‘owned’ by university and community. Thus, in Dying 2 Talk (D2T), working with young people as partners was important to the success of the project. The project aimed to work co-productively with young people to create resources for young people to prompt discussions about death, to be trialled in Festivals of the Dead at schools. The project also benefited from a range of different academic and professional expertise, including those working in heritage, archaeology, the funeral industry, education and bereavement support (Fig. 1).

Working Co-productively with Young People

Involving young people in research reflects the emphasis on including the ‘Child’s Voice’ in policy decisions (Munford and Sanders 2004). Article 12 of the United Nations Convention on the Rights of the Child states: ‘States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child’. (https://downloads.unicef.org.uk/wp-content/uploads/2010/05/UNCRC_united_nations_convention_on_the_rights_of_the_child.pdf?_ga=2.14895030.1845113503.1583247457-1799231783.1583247457 p. 5.) In social research, the culture is shifting from a position of protectionism and exclusion on the grounds of a lack of competency, to one that recognises the agency

of young people and their right to participate in research and policy decisions that impact on their lives (Graham et al. 2015). The inclusion of young people as co-producers in this project aimed to enhance the interpretation of meaning for, ‘as more children become the primary source of information, the less adults will need to interpret their worlds for them’ (Camara et al. 2020: 674).

The term ‘co-production’ has become common parlance in policy and research circles. However, it is frequently attached to practices that fall short of the shift in power (Brandsen et al. 2018). Young people may be ‘in the room’ but the process of doing the research could simply reproduce paternalistic cultures of working. For if young people are perceived as ‘unfinished adults’ then academics may fail to reconcile ‘the politics of disagreement when young people’s preferences clash with those of the researchers’ (Pavarini et al. 2019: 744) and, consciously — or unconsciously — reassert their cultural power. It is vital, then, to focus on the quality of engagement, such that young people have ‘reason to believe that their involvement will make a difference’ (Sinclair 2004, in Thomas 2007: 199). As the power dynamic between young people and adults is societally uneven, our project necessitated a conscious and vigilant process of inclusion and mutual recognition, reflecting NIHR’s belief in the ‘sharing of power’, where ‘everyone is of equal importance’ and all benefit ‘from working together’, as a key principle of co-producing (<https://www.learningforinvolvement.org.uk/wp-content/uploads/2021/04/Guidance-on-co-producing-a-research-project-2022.pdf>). This is particularly important, as even the language and conventions of the research process can mean that ‘local knowledge’ — in our case, the knowledge of young people — can be marginalised (Thomas 2007). For, specialist terms and academic language can be a barrier to wider participation, ‘a matter of power and control, or colonisation and submission’ (Williamson and de Souza 2010). Therefore, the inclusion of young people in research should not simply be viewed as a research tool.

However, a note of caution: young people who do get involved in research projects may already have a sense of efficacy, with more marginalised young people being less likely to access opportunities to have their voices heard (Kellet 2009). Therefore, practitioners need to be reflexive, recognising and challenging power imbalances that persist in society between adults and young people, and between groups of young people. Graham et al. (2015) identify the 3 ‘R’s’ of engagement: reflexivity, rights and relationships. Thus, for young people to experience their ‘rights’ and feel powerful within the process, relationships need to be based on mutual respect and benefit, with decision-making processes being transparent and collectively owned. Coproducing research ‘requires that relationships are valued and nurtured and that efforts are made to redress power differentials’ (<https://www.learningforinvolvement.org.uk/wp-content/uploads/2021/04/Guidance-on-co-producing-a-research-project-2022.pdf>).

Therefore, this project set out to investigate the following.

Could archaeology be used to prompt initial conversations with the young ambassadors about death, dying and bereavement, supporting their confidence to engage in a project centred on this sensitive subject matter?

Would strategies and practices based on the principles of co-production break down (cultural) power differentials between adults and young people, and young

people from different backgrounds, so that we could work democratically and collaboratively?

Would the co-design of activities and resources, driven by the young ambassadors, successfully engage wider audiences of young people in the topic of death, dying and bereavement, without being a traumatic experience?

Method: How We Engaged Young People's Voices

Drawing on our established networks with local schools and voluntary sector organisations,³ and the networks of our university colleagues, we distributed an advertisement for young people aged 14–19 years to apply to become ambassadors. The application process encouraged young people from a range of backgrounds to apply. It asked a few simple questions which could be answered in written or video format (Appendix 1). The project set out to recruit 20 young people, 10 from Wolverhampton and 10 from Bradford. Whilst there is some debate over the issue of paying young people as co-producers (see Graham et al. 2015), the decision was taken to pay (using vouchers) the young people at the minimum wage for a 19-year-old.⁴ It was felt this would create a more equal footing — so that all co-producers in the project were compensated for their time — and that young people from more deprived backgrounds would not be deterred from participating. We had 27 applications; 2 were discounted because they were outside of the designated geographic areas. The decision was taken to accept the remaining 25 young people as this would maintain a sizable group whilst allowing for dropouts due to illness, other commitments or failure to engage. For those aged under 18, parental/guardian consent was gained; an online, interactive, information session was delivered, enabling parents and carers to find out more about the project before consenting.

According to the recruited ambassadors, motivations for applying for the project ranged from wanting to help others, to gain experience of project work, and to share their own experiences of death and bereavement with others. By far, the most mentioned reason for starting the project was to help others become more comfortable in talking about death, dying and bereavement. This is highlighted in some of the following quotes in response to the sentence, 'tell us why you want to be a part of the project':

- I want to help others gain confidence about speaking aloud about death and bereavement as this is an unavoidable part of our life.
- I think it's important to become comfortable talking about difficult topics like death and want to help with this.

³ These included Child Bereavement UK, Making Your Mind Up (MYMUP — a Bradford organisation offering web-based digital resources promoting wellbeing and self-care for young people); Speakers' Corner (a voluntary group that works to empower young people in Bradford), Wolverhampton Council's Education and Schools Department and Bradford Council's Education and Skills Department.

⁴ However, due to legal and university requirements around payment of young people, payment was made via shopping vouchers.

Table 1 Demographic data of ambassadors

Category	Subcategory	Frequency (<i>n</i> = 25)	Percentage
Age	14	3	12%
	15	8	32%
	16	6	24%
	17	6	24%
	18	2	8%
Gender	Female	18	72%
	Gender fluid	1	4%
	Male	5	20%
	Non-binary	1	4%
Sexuality	Heterosexual	15	60%
	LGBTQ+	4	16%
	I prefer not to say	6	24%
Ethnic origins	Asian (Indian)	3	12%
	Asian (Pakistani)	4	16%
	British (White)	9	36%
	White (other)	2	8%
	Black (African)	2	8%
	Mixed parentage	1	4%
	Prefer not to say	4	16%
Religion	Islam	7	28%
	Christian	7	28%
	Atheism	6	24%
	Sikhism	1	4%
	Hinduism	1	4%
Address	I prefer not to say	3	12%
	Bradford	13	52%
	Wolverhampton	12	48%

- I want to help others understand and become more comfortable with loss.
- Because it's interesting, it's a really important topic, and it's improving services for the future, and I am pleased to be a part of it.
- I want to be part of this project to work with young people to try to make a difference to the way people think towards death.

Of this group of 5 identified as male, 1 young person identified as non-binary and 1 as gender fluid, and the other 18 identified as female. In relation to sexuality (an optional question due to the age of the participants), 15 described themselves as heterosexual and 4 identified as LGBTQ+, whilst 6 preferred not to say. The religious question revealed that 7 identified as Christian, 6 as Muslim, 3 as atheist and 1 as Sikh, whilst 8 preferred not to say. Nine ambassadors described themselves as White British, 2 as White/other, 3 as Indian, 3 as Pakistani and 2 as Black/African whilst 4

preferred not to say. The majority (68%) of young ambassadors were 16 years old or under (see Table 1). Of this group, 13 were active and attended most if not all of the Think Ins and the social events, as well as being active co-producers in the activity groups and the Festivals of the Dead. However, some did drop out from the project. This was due to a variety of reasons, ranging from family issues to school commitments. Additionally, COVID limited face-to-face interactions at the time which may have been discouraging to some. By the end of the project, 12 had gradually disengaged from the project, 9 citing competing pressures, 1 young person dropped out because of pregnancy and another had moved away from the Bradford area.

Whilst writing the bid, the academic team worked collaboratively with volunteers from the young people who had been involved in the first iteration of the project to identify proposed project outcomes and outputs for the funding bid. We drew on their written and oral evaluations to reflect critically on the project and our co-productive practices — such as the link-ins and small group work. We were mindful of the issue of group dynamics that some of the former ambassadors raised in their evaluations — that sometimes group work was dominated by louder members of the groups. As Beebeejaun et al. (2013) state, some individuals may be more skillful at negotiating ‘networks of power to gain an effective voice in decision-making’, whilst others may find it more difficult ‘to secure influence and voice’. Therefore, in this iteration of the project, a ‘manifesto’ of engagement was drawn up by the ambassadors, to nurture an inclusive working environment for all. However, the (adult) academic team remained vigilant and self-reflective, to ensure the power differential between adults and young people did not unintentionally manifest itself. However, sometimes the young people were reluctant to take charge of some aspects of the project, such as negotiating the Festivals with the schools. As adult researchers, we recognised ‘the competence and credibility of young researchers’ giving them the power to decide what they were willing and able to contribute to (Clark & Laing 2018, in Camara et al. 2020: 675).

The D2T team came together in non-hierarchical workshops called ‘Think Ins’,⁵ inclusive and positive spaces where all voices, opinions and ideas had equal value, ‘irrespective of age or status’, facilitating a ‘collaborative and democratic’ way of working (Dunn et al. 2018). To start this process, one of our volunteers suggested a ‘This is me’ poster (see Fig. 2) — to share personal stories about favourite celebrations, people or pets important to our lives, and thoughts about archaeological death practices.

At the ambassadors’ request, we held a death café — sharing personal stories about death, dying and bereavement. By adults and young people sharing personal stories, and nurturing relationships through social events,⁶ we aimed to enhance the confidence of the young people to contribute to the project by minimising power differentials. For, as young people are positioned in society as having — and needing — less efficacy in public life, accessing the young person’s voice requires that

⁵ These were initially held online due to COVID and continuing social distancing measures.

⁶ Once COVID restrictions were lifted, this included going to restaurants, visits to local museums and exhibitions.

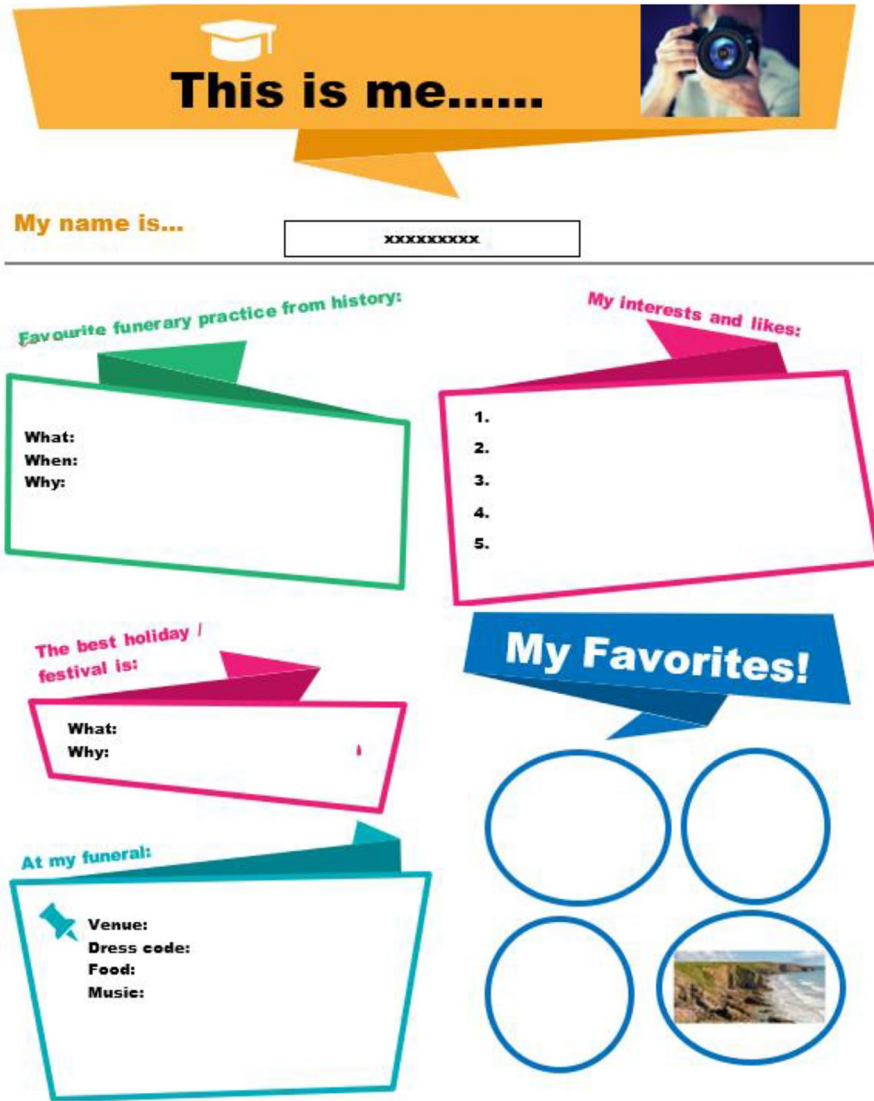


Fig. 2 'This is me' activity

researchers 'transcend the cultural boundaries' (Kellet 2009). The Think Ins enabled the young ambassadors to have the confidence, language and opportunity to contribute to conversations and activities as equal citizens.

Archaeology was used to prompt initial conversations with the young ambassadors, as it has shown to be an effective tool for prompting conversations about death (Büster et al. 2018; Croucher et al. 2020). However, ambassadors were encouraged to draw on their knowledge to codesign activities to help other young people explore

the theme of death. The ambassadors organised themselves into activity groups, based on individual interests and skills, with some joining more than one group. The activities they codesigned encapsulated Beebejaun et al.'s 'beyond-text tools' in which 'story-telling, performance, art and photography' are used to enhance engagement of young people (2013). Moving beyond the written word allowed the young people to explore this sensitive topic through creative means — art, music, dance, food, writing, photography, gaming and video. These tools formed the basis of the resources for the Festivals of the Dead.

The bank of resources codesigned by the young ambassadors included a colouring book, story book, Minecraft activity, recipe cards, zine-making, cake-decorating, songwriting and choreography. The music and dance groups made videos of themselves singing and dancing. This video was used as an introduction to the Festivals, alongside a 5-min talk from the academic members of the team looking at different death practices across time and culture. The introductory talk served to start conversations about death — and to introduce the participants to the activities.

The team employed several methods to evaluate the Festivals of the Dead. One of the academic teams observed the sessions and made notes on how the pupils engaged with the activities. At the end of each Festival, pupils were asked to write comments on Post-it Notes. They would also complete an emoji chart which asked them 'How do the activities from today make you feel?' This feedback method was co-designed with our ambassadors, who felt emotional responses rather than a lengthy questionnaire would be less 'off-putting' for young people. This was particularly important for the SEMH school where we were made aware by school staff that their pupils would respond better to 'beyond text' methods. Pupils were permitted to select as many emojis as they wished.

A thematic analysis was carried out on the Post-it Notes. Thematic analysis is a technique for identifying, analysing, organising, describing and reporting themes (Braun and Clarke 2006) embedded in qualitative data. It is an important method of 'examining the perspectives of different research participants, highlighting similarities and differences, and generating unanticipated insights' (Nowell et al. 2017: 3). Our approach to thematic analysis was guided by the model proposed by Nowell et al. (2017) which proposes 6 stages:

- Phase 1: Familiarising yourself with your data
- Phase 2: Generating initial codes
- Phase 3: Generating themes
- Phase 4: Reviewing themes
- Phase 5: Defining and naming themes
- Phase 6: Producing the report

The academic team familiarised themselves with the Post-it Note data from the Festivals and carried out an initial search for codes on 'aspects of the data we were most interested in exploring' (Nowell et al. 2017) such as emotional response and learning about different death practices. The codes were then collated into a table with the corresponding Post-it Notes quotes. In a subsequent meeting, themes were generated from the codes that would bring 'meaning and identity to a recurrent

experience’, capturing and unifying ‘the nature or basis of the experience into a meaningful whole’ (DeSantis and Ugarriza 2000). In the process of refinement, we found that some themes could be amalgamated whilst other themes were too broad and needed to be broken into separate themes. The thematic analysis was shared with the ambassadors, via email, asking whether they felt the themes reflected their experiences of the Festivals. As the ambassadors were no longer formally part of the project and were no longer being paid, only 2 ambassadors contributed to this discussion.

Results

In total, 6 Festivals of the Dead took place in schools across the Bradford and Wolverhampton areas. School 1 was an SEMH school (social, emotional and mental health needs). A total of 237 pupils attended the Festivals. This included 49 pupils from year 7 (11–12 years), 13 pupils from year 8 (12–13 years), 38 pupils from year 9 (13–14 years), 58 pupils from year 10 (14–15 years), 15 pupils from year 11 (15–16 years), and 16 pupils in 6th form college (18–19 years). Some schools brought groups of pupils from mixed years to the Festivals and so 48 pupils aged 11–19 years attended but we could not identify their year group. Ambassadors attended each Festival and were given the choice about which activity they wanted to showcase to the pupils.⁷

Results: Festivals of the Dead

As the evaluation showed (Fig. 3), the responses to the activities in the Death Festivals were overwhelmingly positive. Only 16% of emoji sheets indicated that the Festival activities made them feel bored, strange, sad, confused, sad or were pointless. Contrastingly, 70% of emoji sheets indicated positive responses to the Festivals, notably interesting, happy, enjoyable and important. However, feeling ‘emotional’ (8%) and ‘sad’ (3%) is not in itself a negative result, as sadness is a common reaction to losing someone through death (see for instance, <https://www.mind.org.uk/information-support/guides-to-support-and-services/bereavement/experiences-of-grief/>).

All pupils were encouraged to provide a comment about their experience of the activities, but this was not compulsory. The Post-it Notes were then collated and, as a team, we evaluated whether the comments were positive, negative neutral or factual (Table 2). This method aimed to explore whether engaging in activities — and the conversations these prompted — about death, dying and bereavement would be perceived as upsetting to young people. Or whether, as we predicted, it would have a positive impact on the efficacy of young people to talk about death and dying.

In addition, the thematic analysis of the Post-it Notes revealed the following themes:

⁷ At least 3 ambassadors attended each Festival; however, this was very much dictated by their availability and school commitments.

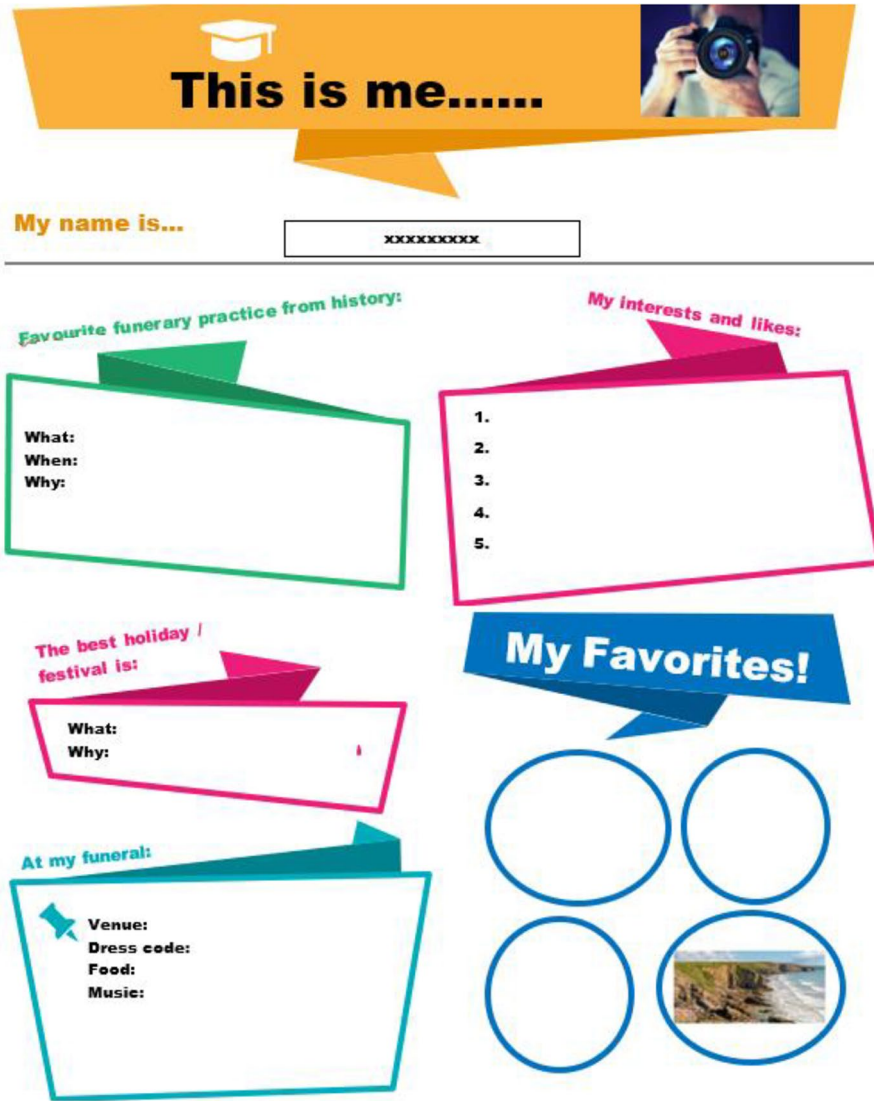


Fig. 3 Emoji responses per school year

- Efficacy/gaining confidence talking about death
- Different ways of remembering the dead that are not always sad
- Learning about death through different cultural practices
- Enjoying the Festivals
- The space to reflect on death and explore personal bereavements

The Post-it Notes revealed some deep reflections on death, such as:

Table 2 Post-It Note feedback rated by positivity, negativity, neutrality or factual

Age group	Positive	Negative	Neutral	Factual
11–12 years	13	1	1	18
12–13 years	1	0	0	3
13–14 years	4	1	0	5
Mixed years	20	3	0	21
14–15 years	14	1	1	5
15–16 years	0	0	0	6
18–19 years	8	0	1	6
Total overall	60	6	3	64

I think today was very helpful and therapeutic as you got to talk about your feelings and thoughts

It is important to normalise talking about death and being able to ask for help

For some, they were surprised by what they experienced during the Festivals:

It wasn't what I expected. I enjoyed the activities

Intrigued and wanting to know more

Talking about death or loss doesn't have to be dark and gloomy we can celebrate the person and the joy they brought while they were with us

Thank you. I feel more informed about death - it is such a taboo subject and everyone has such different perceptions of it

Overall the Post-it Notes, the observations and the emojis provided evidence that young people engage in the topic of death, dying and bereavement in a positive and progressive way, through creative activities. From our observations, several pupils engaged in conversations about their own private bereavements during the activities. One year 8 pupil made grave goods 'to put in my dog's coffin' whom recently died, a blanket and their teddy. They were unable to talk about how sad they were with family and friends because they felt 'silly'. Another pupil, whilst colouring in the colouring book, talked about the death of a grandparent and how they were cremated — and during that conversation indicated they would prefer to be buried and have a big party where people could be happy and celebrate their life. One of their peers disagreed, saying, 'I want people to be miserable at my funeral—I want them to miss me!' This response was met by laughter by both pupils who continued a supportive conversation about funerals. Indeed, the role of humour had been identified by ambassadors as an important communication strategy, when used sensitively.

Results: Co-production and Ambassador Experiences

Co-production was pivotal to the success of these Festivals. Giving young people a critical role in designing the project outputs not only resulted in resources that were engaging and accessible to other young people, but the experience also had a positive impact on the ambassadors themselves. The ambassadors were asked to

25 responses

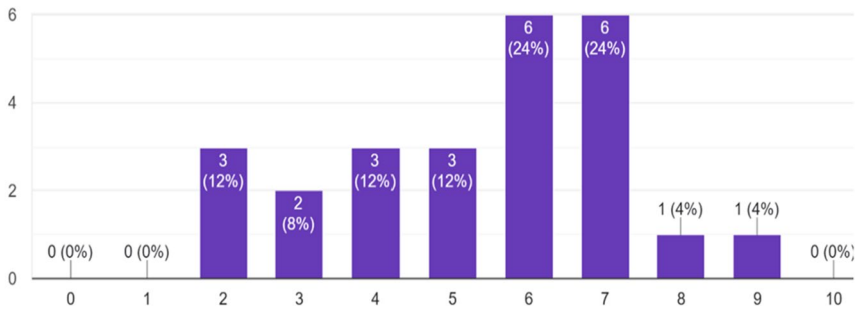


Fig. 4 Answers to question ‘On a scale of 0–10 how challenging does the topic of death, dying and bereavement feel?’ from Evaluation Questionnaire 1

10 responses

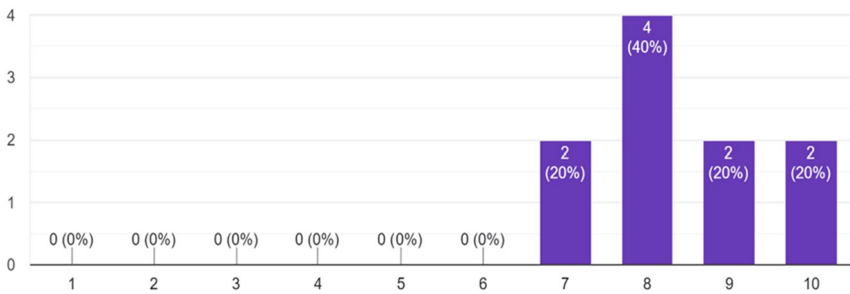


Fig. 5 Answers to question ‘On a scale of 0–10 how challenging does the topic of death, dying and bereavement feel?’ from the final evaluation questionnaire

complete 3 evaluations: the beginning of the project in February 2021, the midpoint in August 2021 and the end of the project in March 2022. Given the multiple strands of the project — the topic of death, the process of co-production and the use of archaeology — there were several areas we wanted to evaluate. There were 35 questions in questionnaires 1 and 2 and 19 questions in the final questionnaire. The first questionnaire was completed by all 25 of the ambassadors. However, questionnaires 2 and 3 were only completed by 9 and 13 respondents respectively.

In relation to the subject of death, and how challenging the ambassadors felt about the topic, evaluation 1 revealed that 3 individuals (12%) were neutral; 14 ambassadors (56%) felt it was challenging, to various degrees, whilst 8 ambassadors (32%) felt more comfortable with the topic (Fig. 4).

By the mid-project evaluation, there had already been a shift, with only 1 person (11%) reporting that the topic of death was challenging, 3 were neutral (33%) and 5 respondents (56%) felt the topic was not challenging. By the end of the project, 100% of the ambassadors reported feeling confident about the topic of death (Fig. 5).

13 responses

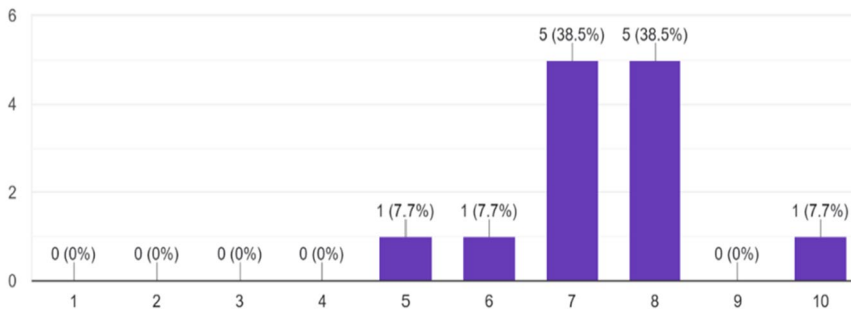


Fig. 6 Answers to question ‘Do you think archaeology is a useful way to encourage young people to talk about death and dying?’ in the Final Evaluation questionnaire

There was also a positive shift in attitudes towards archaeology having contemporary relevance to the topic of death and dying. Whilst only 9 ambassadors completed the mid project evaluation, all answers were scale 6 and above, indicating a positive attitude towards the use of archaeology, with 7 out of the 9 responses scoring 8 or above (77%) compared to 44% in the first evaluation.

The final question asked specifically about the use of archaeology in helping young people talk about death and dying, in light of their involvement in the Festivals. These responses were all positive (rank 6 and above) except for 1 neutral response (see Fig. 6).

Ambassadors who attended a Festival were asked to rate how successful they felt the D2T resources were at prompting young people to talk about death and dying, on a scale of 1 to 10. All ambassadors reported that they felt the resources were successful with 3 out of the 13 ambassadors giving a 7/10 rating; 8 gave an 8/10 rating and 1 ambassador each ranking 9/10 and 10/10. This question revealed positive interactions between ambassadors and pupils at the Festivals with the ambassadors observing the success of their resources in prompting conversations about death, dying and bereavement.

By the end of the project, 100% of the ambassadors who responded stated that they would recommend the D2T project to other young people. By recommending the project, the ambassadors revealed the value of their involvement, as peer researchers, on this project. They stated:

Being an ambassador not only gave me more confidence in sharing my views but it developed my communication skills and helped me speak about sensitive topics.

The staff are doing such a great job of changing lives. Thank you so much for helping get out of my shell. I’ll never forget this.

It is a rewarding way to contribute to society, as there aren’t many organisations that help young people overcome the stigma of death.

The ambassadors not only gained confidence because of their role in the project, but they felt their contribution had been valued and valuable to the project with 12 out of the 13 respondents saying ‘yes’ to the question, ‘Do you think you were able to have a voice throughout the project?’.

They reported:

The ambassadors and project managers were very welcome and everyone always made sure to listen to others whenever someone had something to say. Before I didn’t like talking much about how I feel. Joining this project let me talk to people... The staff worked hard to make sure we never felt embarrassed or scared and that makes me appreciate this project that much more

Discussion

Despite our project demonstrating that young people can engage with the subject of death in a supported and creative environment, adults tend to be reticent. Thus, we held introductory meetings with parents/carers, not only to fulfil safeguarding and consent requirements, but to reassure parents/carers that our prior project findings show that young people deal with the topic of death pragmatically and that participation was a positive experience (Booth et al. 2020). Adult perceptions of vulnerability are reproducing the reluctance to engage with the topic of death, rather than responding to the needs and abilities of young people. For, young people’s voices need to be heard outside of ‘adult conversations and actions’ (Kellet 2009). Therefore, we took steps, through Think Ins and shared activities, to avoid reproducing situations where adults are privileged (Kellet 2009). Therefore, it was important that, as adults, we positioned ourselves as ‘learning alongside’ the young ambassadors (Davis 2009), the voices of young people being critical to achieving the project objectives. As a result of working as equal partners, the project outputs were shown to be appealing to young audiences in the Festivals of the Dead, and thus more likely to leave a legacy of improved confidence and efficacy around the topic of death. This is a promising basis for similar school-based projects in the future.

The results show that the Festivals of the Dead were well received, with young people from a range of social and economic backgrounds aged 11–19 engaging enthusiastically with the activities and resources, including pupils from an SEMH school. Conversations about personal bereavements, reflections about the different ways of dealing with the dead over time and space, and thoughts about how the young people themselves would want to be commemorated flowed throughout the Festivals. Engaging in activities, such as colouring and making grave goods out of modelling clay, promoted those conversations by creating a positive and inclusive space for reflection, breaking down barriers to talking about death, dying and bereavement. As Dunn et al. confirm, ‘creative techniques offer opportunities to draw on emotion and imagination and do not rely solely on participants’ verbal or written capabilities’ (2018: 48). It also showed that employing young people as co-producers supported the development of resources that were accessible to other young people, and that young people were able to engage in conversations about

death without it being a traumatic or depressing experience. Participation also prompted some personal expressions of grief. By engaging in creative activities, these conversations were facilitated in a safe and supportive space. Through explorations of different ways of dealing with the dead, young people understood that there were many ways of grieving and that continuing bonds were not only important but also comforting.

The evaluations also revealed positive results in relation to the young ambassadors who reported feeling more confident and comfortable talking about death. They reported higher levels of confidence and efficacy, over 92% stating that they were able to influence the project outputs (designing the resources) and 100% claiming a positive influence on the project outcomes (helping other young people to talk about death, dying and bereavement): ‘It’s a natural part of life so there’s no point in avoiding it’.

Limitations

The project did have limitations. Firstly, not being able to recruit many male ambassadors was a disadvantage as the resources needed to be attractive to all genders. Anecdotally, the young men who were recruited as ambassadors reported that male peers were ‘put off’ as they thought it would involve ‘sitting around talking about emotions’. However, the resources were positively evaluated by the vast majority of pupils, so this did not appear to disadvantage the project outcomes, as observations showed that there was no obvious gender split in relation to participation in the activities in the Festivals of the Dead. Secondly, 12 young ambassadors did not fully engage in the project, gradually fading in responses to social media messages, texts or emails. Whilst it is harder to pinpoint reasons for this lack of engagement, our reflections focussed around issues with group dynamics and lack of efficacy of some of the young people, as well as outside circumstances. Working co-productively is not easy. It demands, ‘thorough planning, commitment, people, resources and time, which should not be underestimated’ (Dunn et al. 2018). We had a one-to-one introductory chat with each of the ambassadors, to build relationships (and break down power barriers between adults and young people) and to acknowledge and value their participation. The project fund paid for social events — trips to a popular restaurant chain (at the young people’s request) and local museums — so that we could build a sense of team belonging. However, COVID-19 restrictions were still in place, with Think Ins having to be online for the first 6 months. This may have been a barrier to generating a stronger sense of belonging and purpose. Additionally, questionnaires 2 and 3 were only completed by 9 and 13 respondents, respectively, despite being paid for their time to complete questionnaires. On reflection, it is likely that 35 questions was overwhelming for some ambassadors. This is something to be reflected on in future projects, potentially employing different ways of providing feedback, such as media diaries. A further limitation was accessing secondary schools for Festivals of the Dead. Despite being free of charge, the impact of

COVID lockdowns on delivering the curriculum resulted in several schools declining to take part, with extracurricular activities viewed as a low priority. Therefore, the sample size of the schools was limited.

Conclusion

Overall, the project was transformative for the whole project team and project participants, successfully working together to develop tools to encourage young people to talk about death. This was particularly poignant in a post-COVID environment. By giving young people a voice, the project had a ‘transformative capacity’, allowing young people ‘to influence the services, institutions and decisions which affect their lives’ (Dunn et al. 2018). Furthermore, by exploring the importance of continuing bonds, through activities that prompted spontaneous conversations about death, the project took a step forward in creating a compassionate community. The next step for D2T is developing a model for a compassionate community for schools. Moving beyond reactive support to young people faced with bereavement, a compassionate school community would focus on developing language — how to talk about death — and enhancing confidence around the topic of death as part of the everyday life of a school. It would take a proactive approach in which talk about death is embedded in school life, both within the curriculum and in additional activities and spaces for young people to explore this sensitive subject in a supportive environment. It aims to break down taboos around death for future generations, treating death as a normal occurrence. Mirroring the trauma-informed school model (<https://www.traumainformedschools.co.uk/>), it will aim to develop training and resources for schools to become designated ‘compassionate schools’. In doing so, it aims to enhance the wellbeing and resilience of future generations.

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Author Contribution Dr JB: main author, drafted the manuscript and contributed to the analysis.

Prof KC: contributed to the manuscript and the analysis.

Dr EW: conducted the quantitative analysis.

AS-B: collated the qualitative analysis.

EB-B: contributed to the research project.

MC: contributed to the research project.

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Data Availability The research data from the evaluations of the project are available for readers.

Declarations

On behalf of all authors, the corresponding author states that there is no conflict of interest. The authors also confirm that the project involved research involving human participants. However, we can confirm that the project gained both informed consent from the parent carers of all the participants who were under 18 years old, and informed consent from the participants themselves who were over 19 years old. The project also gained ethical approval through the University of Bradford Ethics committee.

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