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Introduction: Researching Death, Dying, and Bereavement

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Introduction

As early-career researchers studying the end of life, we recognise that scholarly activity in the field of death studies - an umbrella term for research spanning all aspects of death, dying and bereavement, including end of life care - is growing in popularity. Since we completed our PhDs (less than 7 years ago), the number of U.K. universities offering courses on death-related topics has increased, mailing lists and online chat groups have multiplied, and the range of international seminars and conferences addressing topics in the field is expanding. This mounting interest in death studies makes this an opportune time to consider the methodological issues that doing research on death, dying, and bereavement present.

Mortality is a flagship journal in this interdisciplinary field. Read by both academics and practitioners, and with an increasingly international authorship and audience, it is an ideal space to consider contemporary methodological issues and challenges. As editors of this special issue we have brought together a range of articles written by researchers which foreground and explore in detail matters pertaining to the study of death. As a collection, the articles seek to generate discussion about techniques, practices and socio-cultural contexts of death research, and the implications that these have for knowledge production. Moreover,

they intend to stimulate reflection on what is particular about engaging in death-related research specifically – teasing out key issues from more generic ongoing discussions about doing ‘sensitive’ (usually qualitative) research. In doing so, they offer practical tips and guidance – with the authors including key points and summary boxes at the end of each article. By placing these articles together and in dialogue with one another, we hope to encourage further substantive publications that deal with methodological aspects of death research, and that can continue these conversations.

If we look at the genealogy of death studies (in English-speaking nations at least), there is a history of key periods of academic reflection and activity. For example, in the late 1960s and early 1970s (in the United States in particular), we saw a plethora of research in the field which produced seminal works that are still regularly cited in research, teaching and professional education today (e.g. Kubler-Ross, 1969; Glaser and Strauss, 1965). In the 1990s, many important theoretical (e.g. Walter, 1994; Mellor and Shilling, 1993) and empirical (e.g. Young and Cullen, 1996; Howarth, 1996; Hockey, 1990) texts were published along with a number of edited collections (e.g. Klass, Silverman and Nickman, 1996; Clark, 1993). Now, in the 2010s, we have several further diverse and novel contributions to the field e.g. (Foster and Woodthorpe, 2016; Kellehear, 2014; Cann, 2014; Christensen and Willerslev, 2013). And yet, despite this established and continually expanding body of work, there are very few substantive publications devoted solely to methodological issues in death studies research (Woodthorpe, 2009). Likewise, although researchers are often required to justify why one would ‘choose’ to work in the (‘morbid’) field of death and dying (Hockey, 2007), there is little in the literature which reflects on matters of identity vis a vis doing death research. This special issue, therefore represents, a rare opportunity to pay extended and explicit attention to what is particular about doing research on the end of life and being a contemporary ‘death researcher’.

Methodology, reflexivity and death studies: a brief outline

Whilst death studies is a multi-disciplinary field, it is often the case that those undertaking research in the area look to published work within their own disciplines for methodological guidance. Informal conversations with current doctoral students confirmed our suspicions that less generic methodological texts devoted to issues particular to death research would be a welcome addition to the field. Nonetheless, we do not suggest that any such publications would be starting from a blank canvas, or that the existing more general literatures – particularly about doing sensitive research – are not relevant and helpful. They definitely are, and therefore it is important to acknowledge what has been published and to note (however briefly) certain key issues that have been considered as a way to provide some context for the special issue.

For, despite a lack of ‘go to’ textbooks or volumes that deal explicitly with the methodological and practical aspects of researching death, dying, and bereavement, there have been a few important accounts published (more so in recent years) that reflect on issues specific to doing death research. These usually appear as stand-alone chapters or articles drawing on experiences from a particular research project (e.g. Woodthorpe, 2011; Valentine, 2007; Rolls and Relf, 2006; Howarth, 1993) or consider concerns pertinent to a specific sub-field such as suicide research (e.g. Boden, Gibson, Owen and Benson, 2016; McKenzie, Li, Jenkin and Collings, 2016). It is more unusual for authors to attempt broader reflexive exploration of methodological matters, which muse on possible motivations for studying death-related topics and the wider cultural and social contexts or research environments within which one’s identity and experiences as a ‘death researcher’ are located (see Hockey, 2014 and 2007 for interesting exceptions and Cann and Troyer as well as Evans, Ribbens McCarthy, Kébé, Bowlby and Wouango in this special issue).

What has been published tends to be highly personal and reflexive, pointing to the emotional labour involved in undertaking a project dealing with mortality and with many offering ‘confessional’ style narratives about what was experienced in the field. Several authors also point to the fallibility of their pre-fieldwork ‘preparations’ (Visser, 2016; Woodthorpe, 2009; 2007; Rowling, 1999) and make recommendations regarding how to better support researchers undertaking future death-related research. They consider various reflexive practices, ‘emotional safety protocols’ (Bowtell, Sawyer, Aroni, Green and Duncan, 2013) and aspects of self-care management (Rager, 2005), such as keeping a diary (Valentine, 2007; Howarth, 1993), scheduling plenty of time between interviews (Rowling, 1999), and taking part in regular debriefing opportunities (Rolls and Relf, 2006). However, as Visser (2016) notes, there is probably a limit to which one can ever be prepared for such work. She also adds that debriefing in particular can have implications for participants’ anonymity and confidentiality, and that such ‘off-loading’ opportunities are often managed in an ad hoc manner (whilst many authors attest to the need for more formalised arrangements). Therefore, in the spirit of cultivating a community of support, some scholars have called for greater transparency in research accounts and a more nuanced understanding of how the researcher’s own emotions become an integral part of analytical processes and knowledge production (Valentine, 2007; Woodthorpe, 2007; Rolls and Relf, 2006, see also Brennan and Letherby in this special issue), as well as inform their ethical sensibilities (Boden et al., 2016). They argue for less filtering out of the researcher self (Valentine, 2007) and to make personal experience a central tenet in reporting research; or as Visser (2016) has put it, ‘to take “the emotional” out of the margins’ of our project outputs (p.6).

Some of the issues these writers discuss have clear resonance with more generic publications about the emotional nature of conducting sensitive (qualitative) research on a range of topics, where effects on the researcher and the importance of reflexivity are now

more readily acknowledged (Dickson-Swift, James, Kippen and Liamputtong, 2009; Rager, 2005; Johnson and Clarke, 2003). However, in the aforementioned accounts a number of issues that relate particularly to death studies have been identified. As Woodthorpe (2011) has argued, ‘death is more than’ a sensitive subject – ‘[e]veryone is an ‘insider’ when it comes to death’ due to its ‘universal reach’ (p.100). Thus unlike when researching many other ‘sensitive issues’ such as domestic abuse or criminality, death researchers will be attending to matters they too shall experience personally at some point in their lives (Rowling, 1999) and so encounter an inevitable blurring of the perceived or intended boundaries between researcher and self (Woodthorpe, 2011). Their work can resonate with personal losses and exacerbate feelings of grief, and also prompt pertinent questions about professional roles and how researchers ‘should’ feel when their participants die (Visser, 2016) – including deliberations about ‘appropriate’ courses of action to take with implications for researchers and ethics committees (e.g. sending condolence cards, see Bowtell et al., 2013).

Researching end of life issues can also provoke more general anxieties about mortality and the ‘fragility of life’ (McKenzie et al., 2016), such as anticipating the death of loved ones (Woodthorpe, 2007) as well as feelings of despondency (Lawton, 2000) and helplessness (see Burles in this special issue). Some suggest that less experienced (Woodthorpe, 2009) and non-clinically trained researchers (McKenzie et al., 2016) in particular, may experience negative and challenging feelings. Moreover, McKenzie et al., (2016) warn not to focus exclusively on support for researchers involved in interview-type encounters, for indirect engagement with ‘participants’ – such as when examining documents, case files and clinical notes – can also expose researchers to difficult, stressful and emotional content (see also Fincham, Scourfield and Langer, 2008 and Scott Bray in this special issue).

Given the aforementioned issues, it is significant that Kendall et al., (2007) report that research managers in end-of-life care are concerned about factors that shape research environments – specifically the lack of career structure for researchers – and make it difficult to retain skilled personnel that are most appropriately equipped to work in this complex field. Indeed, researchers working in palliative and end-of-life care have drawn attention to particular challenges that they face when undertaking research which involves dying people (Gysels et al., 2013; Seymour et al., 2005). Although more candid insight is still needed, it seems that relatively, this sub-field of death-related research has a more established dialogue regarding methodological issues (for instance, Addington-Hall, Bruera, Higginson and Payne's, 2007 volume devoted to methods)ⁱ. In particular end-of-life care researchers have deliberated whether it is 'fair' to ask dying people to take part in research (Barnett, 2001) - including children and young people (Downing, 2016) – considering the potential for this to be burdensome (Milne and Lloyd, 2007). In doing so they have also problematised how participants are defined by those outside of 'the field' – for example, ethics committees pre-asserting that end-of-life care or bereavement research is 'sensitive' and that participants are 'particularly vulnerable' (Witham, Beddow and Haigh, 2013; Addington-Hall, 2002).

Patently, research with people near the end of life (and not just those receiving palliative care) is characterised by complexity due to negotiating unpredictable illness trajectories, a challenge which we have both experienced first-hand in our own work with people who are considered to be dying. It requires an inherent need for methodological flexibility to deal with uncertainty – especially issues related to the limited time for recruitment, and issues with attrition due to (potential) participants dying, and alternative approaches to gaining informed consent necessitated by fluctuating states of mental capacity (Gysels et al., 2013). These are not always easy to negotiate in reality and within the constraints of a pre-approval ethics regulatory framework. Furthermore, lesser discussed

complexities can arise around issues to do with what are usually considered ‘best practice’; for example, asking participants to verify interview transcripts or sending details of study findings once the research has ended. These tasks might not be possible, or even deemed ‘appropriate’ to ask about in the context of interviewing a person who may die very soon (Kendall et al., 2007). Similarly lengthy ‘standard’ participant information sheets can be exhausting for someone with serious health complications (Gysels et al., 2013) and researchers cannot assume that participants understand or accept their prognosis or if words like ‘dying’ or ‘end of life’ are suitable and ethical to use (Kendall et al., 2007).

Referring to less apparent complexities in death-related research, Valentine (2007) identified ‘protectiveness towards the dead’ and ‘honouring the deceased’ as key mediating aspects in her relationship with the bereaved individuals she interviewed. She reminds us that small tasks involved in the process of doing research can be important for the integrity of a deceased person’s memory, such as participants correcting misspelt names in interview transcripts. Similarly, Hockey (2007) suggests that the use of real names rather than pseudonyms when reporting data can serve as a memorial for the deceased and can be something actively desired by participants involved in death-related research. Thus in this field, researchers are challenged to avoid making presumptions about the ‘ethics’ of standard research practices such as anonymisation (see also Grinyer, 2002).

Finally, often accounts about doing sensitive research focus on the potential for harm to participants and researchers whilst generating data in the field. However, as indicated by the previous example of assigning pseudonyms, the emotional repercussions of doing death-related research can linger into the post-fieldwork stages of our work (see Burles in the special issue for a more in-depth discussion of these issues). Thus Hockey (2014), as an experienced death researcher, writes evocatively about how she now considers the practices of her bereaved participants as not so different from those of a researcher interpreting

interview data. About working with data she writes: ‘Like the survivor of someone else’s death, I am left with traces of times, places and people no longer present’ (p.105). These ‘traces’ are the ‘material outcomes of interviews’ – digital recordings and transcriptions that on one hand ‘constitute a kind of commodity’ (p.95). Indeed, we use these to write publications which become aggregated as metrics and then contribute (or not) to promotions and the generation of personal and institutional income. Hockey suggests this can create a generalised sense of uneasiness about the status of data, and can be seen, for instance, in the difficulty researchers might have fragmenting narratives when coding and selecting data extracts for publications (e.g. Valentine 2007). Based on our own research experiences, we know that these issues can feel all the more unsettling when working with emotive death-related data. Thus feelings akin to guilt experienced by some death researchers when approaching participants in the field (as discussed by Woodthorpe, 2009) can also manifest in perhaps less apparent ways throughout the research process. Indeed, a sense of ambivalence about being awarded a PhD based on observations of many individuals who have now died, is a complicated feeling which we have both struggled to make sense of and articulate publicly. As we now turn our attention to describe how the current special issue came about, it should be noted that our own desire to exchange stories and explore complicated feelings around doing research about the end of life has been a key motivator in developing this reflexive space to discuss methodological issues.

Background to the special issue

For the last three years, we have worked together as co-convenors of the British Sociological Association’s (BSA) Social Aspects of Death, Dying and Bereavement Study Group (DDB)ⁱⁱ. Although sponsored by the BSA, the group is distinctly multi-disciplinary, and it is not uncommon for artists, healthcare practitioners, or representatives from charitable

organisations to attend and present at the annual symposium. Along with Kate Woodthorpe (University of Bath), a past co-convenor of the group, we have noticed that reflections about methods and methodology (as topics in their own right), reoccur every year in presentations at the symposium, regardless of the substantive theme stipulated as the focus for the day (e.g. death and family, death and social difference etc.). In particular, we have observed participants sharing their experiences of doing research and exploring the implications – both personal and professional – of being a ‘death researcher’. Attendees regularly share experiential and personal insights on a range of issues, including: the procedural and interpersonal nature of research ethics; attending to and coping with grief during their work; managing gatekeepers and recruitment; and negotiating particular challenges due to the (perceived and actual) ‘sensitive’ nature of their research and the ‘vulnerability’ of the populations being researched.

Recognising the apparent need and desire to have a space for these kinds of conversations, we dedicated an entire symposium in November 2015 to the topic of methodology and research reflections. Symposium abstracts were initially solicited, and later a wider call beyond the DDB group was made for extended paper outlines for the current special issue. We received over 40 submissions from around the world that spanned different disciplines. The selection of five articles was based on the ability of each proposed paper to make a specific methodological contribution. It was important that the authors had a clear view of how they would address the mandate of the special issue – to not only describe research practices, but also to think about the consequences of how doing research in particular ways reflects methodological, epistemological and personal positions; to think through the interrelationship between research, reflexivity and the kinds of knowledges produced. Moreover, we selected a range of articles that we felt could stimulate dialogue

about future empirical directions in the field and which promised to draw out specific issues of particular relevance for being a death researcher.

Having said all this, we do acknowledge that this issue alone cannot reflect the disciplinary and methodological diversity of death studies. The potential scope invited by a call related to method is obviously vast, and we acknowledge that in selecting a particular collection of papers we have addressed some methodological issues, and inevitably neglected others. Perhaps most notably, the special issue does not adequately consider the implications for death studies of three key contemporary methodological developments. Firstly, there is an absence of papers dealing with quantitative research and using ‘big data’ specifically (see Davies et al. 2016). This reflects a limited interest in quantitative methods amongst the abstracts received. Secondly, the papers do not address ethical and practical issues involved in using online methods when doing death research (see Giaxoglou, 2016; Carmack and Degroot, 2014). Whilst thirdly, the ‘sensory’ turn evident particularly in the social sciences (Mason and Davies, 2009) is only partly attended to in Scott Bray’s paper focusing on the visual. These are clearly areas where future death studies methods publications can make a contribution. Nonetheless, this special issue offers a place to instigate more sustained methodological dialogue in the field. It is a platform to encourage other accounts that focus explicitly on the doing of death research, and in particular, the relationship between how research is done and experienced, the kinds of knowledges it produces and the social impacts it can have.

Researching death, dying, and bereavement

To begin the special issue, Candi Cann and John Troyer’s paper offers an especially novel contribution. Comparative, cross-cultural work is limited in death studies (Walter, 2005), whilst national, socio-cultural factors that have shaped the methodological genealogy of the

field, remain particularly under-scrutinised. The authors address both these issues in an ambitious paper that pushes at the perimeters of how ‘methodology’ is conventionally defined and understood. With a macro focus on how approaches to ‘managing’ death differ between the U.S. and the U.K., Cann and Troyer ‘position methodologies as a series of concepts, as well as practices, that articulate different conditions of possibility’ for death-related research in each national context (p.??). By examining key sites where divergent discursive approaches to death are (re)produced and enacted (e.g. pedagogically in death education and financially in research and healthcare funding), the paper aims to open up conversations about how to generate new and integrated approaches that can benefit both countries. Ultimately, Cann and Troyer argue that the U.K.’s more transdisciplinary, collaborative methodologies create better ‘conditions of possibility’ for research to impact death education, knowledge generation and policy-making. The challenge this paper poses for researchers across the two nations is to (re)find points of convergence vis a vis their shared history in death studies; to generate ‘a new kind of methodological approach’ (p.??) that facilitates greater trans-Atlantic dialogue on death-related issues such as policy, education and end-of-life care, which will benefit citizens in both countries and death studies internationally.

As is apparent in Cann and Troyer’s article, Anglophone perspectives dominate conceptual and empirical scholarship in death studies. The ethical and epistemological issues this engenders are critically examined in the next paper by Ruth Evans and colleagues as they problematise the lack of empirical work exploring Majority world perspectives. They argue that scholars must recognise the limitations and cultural specificity of conceptual frameworks about death developed mostly in (Minority) European contexts. In their reflexive contribution to the special issue, the need for more comparative and culturally diverse accounts of death-related experiences is identified, as are some of the methodological

challenges that addressing this gap would present. Describing experiences of participating in a multilingual project about grief and responses to death within families in urban Senegal, the focus of this paper is on translation and the pragmatic and epistemological complexities involved in working with research data in multiple languages. As the authors state, the cultural nuance of language can significantly affect the analysis process and ultimately the production of knowledge, and yet this is so often glossed over in research outputs. Therefore, Evans et al. offer an important addition to the methods literature on doing death research (and multilingual research in general) by stressing the significance of this epistemological issue. Providing insights that promise to enhance methodological capabilities within the field, the authors give practical advice on how to manage interpretation and translation issues, referring to illustrative examples about interviewing and transcription based on their own research experience. Whilst the pragmatics of how to do this kind of research remain a central part of the paper, the epistemological and ethical ramifications of the inherent interplay between language, meaning, and power in the context of doing research, are also judiciously impressed on the reader.

This is also the case in Rebecca Scott Bray's paper, which explores a myriad of ethical issues related to the scholarly (and artistic) use of criminal evidence for 'extra-legal' purposes such as research. In this paper she refers specifically to images of fatal violence (e.g. forensic crime scene pictures) and considers the complex tensions and challenges involved for researchers who encounter these images, use them as data, and further reproduce them in the dissemination of their academic work. A key question posed is how scholars engaged in visual work can/should bear witness to pain and trauma, and represent their findings about violent death to others. Thus at the heart of her paper, Scott Bray, like Evans et al., also deals with matters of 'translation' and their epistemological possibilities. To think through these issues she asks whether as researchers we can 'take clues from aesthetic

practices in how we might wrestle with the challenge of researching death's pictures' (p.??) and offers examples from the art world that may provide useful frameworks for researchers to 'move from exposed to exposure with careful concern' (p.??).

The critique has often been levelled within death studies that the diversity of dying experience is not adequately reflected in the work produced (Kellehear, 2009). Scott Bray makes an important contribution in her paper here with a deeply reflective and thorough examination of if/how knowledge created about a marginalised death experience (murder) can be communicated sensitively and responsibly to research audiences, both academic and public. The concern in this article, then, is with visual methods – again, something relatively underexplored in death studies. It describes the 'cultural turn' in legal and criminological scholarship that, Scott Bray argues, has developed without the necessary 'visual competence' to manage the material with which it engages. The methodological contribution of the work therefore extends beyond death studies and informs debates within cultural criminology (and the field of 'visual methods' more broadly). In particular it raises important questions about researcher well-being when working with disturbing material where, as the author points out, the focus to date has been limited mainly to methods of primary data collection (e.g. interviews and observation).

Whilst Scott Bray's principal focus is on how to establish - through dissemination practices - an 'appropriate' closeness between research material and those that encounter/consume it, in Michael Brennan and Gayle Letherby's contribution to the special issue it is the death researcher's own personal proximity to what is being researched that is reflected upon. As researchers who have both used autobiographical and biographical methods to study death, dying, and bereavement, the authors argue that these epistemological approaches exist on a continuum, where the relative focus on self or other(s) in a piece of work often entails 'slippage'. In other words, autobiographical or biographical writing can

interweave as these are rarely clear-cut and demarcated approaches. In the article they provide examples from their own death-related research to illustrate these connecting and contrasting permutations in methodological approach. Refuting the accusation that these methods are self-indulgent and merely subjective, Brennan and Letherby argue that auto/biography is rigorous precisely because it highlights explicitly the social location of the researcher and makes clear their 'role in the process of constructing rather than discovering the story/ the knowledge' (p.??). They identify a tradition of using these approaches in death studies, and underscore the affinities between a methodological approach that acknowledges personhood is inherent in the process of undertaking research, and the universal nature of death that positions researchers studying it as inevitable 'insiders'.

Extending Brennan and Letherby's focus on the boundaries between death researchers and what they study, the final paper in the special issue by Meridith Burles, offers a very personal account of a difficult experience particular to doing research with dying people. Writing candidly about the complex emotions she felt on learning about the death of her research participants after the study in which they were involved had ended, Burles discusses an experience that has not been sufficiently examined in the literature. Describing her decision to restart keeping a research journal as a means to manage her feelings about these deaths, Burles shares extracts from her diarised thoughts on a period about which she had not originally intended to be reflecting. She argues that research training and regulatory frameworks (e.g. ethics processes) fail to adequately prepare researchers for the emotional ramifications of possible ongoing engagement with participants once a project has ended. Her article argues that recognition of the need for ongoing support to be made available to researchers is therefore imperative, and especially pertinent for research involving dying people, whose fate researchers may continue to ruminate over long after study-based contact is complete.

While the identification of ethically ‘appropriate’ boundaries for researchers to establish when ‘leaving’ a field of study has received methodological attention (see chapters in Shaffir and Stebbins, 1991), Burles’ takes the reader into less explored territory by describing a myriad of ways in which unexpected ‘encounters’ with participants can be experienced after the research has officially ‘ended’ (for instance, via social media). This paper thus raises important questions about the artificialness of boundaries between different phases of the research process, and those concerning the researcher and researched. In so doing it echoes sentiments expressed by many contributors to the special issue that reflexive thinking (including about emotional responses) can serve as an additional source of data. What is novel about Burles’ paper is that it identifies how knowledge pertaining to death, dying, and bereavement can also be produced by reflecting upon post-research encounters.

As can be seen in this brief overview, the articles in this special issue speak to several important methodological themes, many of which are specific to engaging in research about the end of life. In particular they examine and problematise issues related to the researcher self and positionality, the structural and /or socio-cultural contexts informing death-related research, ethics and ethical practice, and boundaries of/ within this research (interpersonal, epistemological, methodological and processual). Ultimately, they call for a kind of reflexivity that includes and moves beyond emotive personal descriptions of research encounters, as a way of accounting for and discussing methodological implications of doing research in this field. As researchers we know there is a constitutive relationship between how research is done and the knowledge generated through this activity. The authors writing in this special issue have critically assessed the kinds of knowledges being generated within death studies at present by offering reflections on particular aspects of doing of death-related research. Appearing within a journal which acts as a foci for the dissemination of new death-related knowledge, we hope that this collection of papers provides a reflective ‘stop-gap’ for

readers; it can be somewhere to take stock regarding how knowledge is produced and its effects on the researchers involved. If this contributes to opening up novel empirical directions in the field and aids the development of new avenues of research that would be one aspiration met. However, as editors, we hope it primarily offers practical guidance to death researchers, and precipitates further publications that can provide similar support by exploring the doing of death-related research in equally reflexive and explicit ways.

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ⁱ Especially when compared to methodological literatures dealing with researching sudden, for instance, violent deaths.

ⁱⁱ For more information about the group see: <https://www.britsoc.co.uk/groups/study-groups/social-aspects-of-death-dying-and-bereavement-study-group/>