

Methodology: Researching Death, Dying and Bereavement

Friday 13th November 2015; 10.00am - 4.30pm

BSA Meeting Room, Imperial Wharf

Social Aspects of Death, Dying and Bereavement Study Group

List of Abstracts

Is the sociological autopsy an effective and ethical methodology for researching the deaths of people who lived and died alone?

Glenys Caswell

University of Nottingham

Some individuals who live alone stay at home alone when they are dying, and for those with fewest social contacts this can mean that their body lies undiscovered for an extended period of time. While media reports of such deaths suggest either an uncaring society or a flawed individual, there is also the possibility that some individuals choose to die alone and do not care about their body not being found. This paper draws on a pilot study which tested the sociological autopsy, a methodology involving the ethnographic study of documents produced by the coroner's office in England, as a way to investigate such deaths. The paper explores a number of issues. It discusses whether the findings from the pilot are sufficiently robust to justify the use of this methodology in future work, and whether the findings contribute to our understanding of the circumstances in which such lone deaths occur. It also debates the ethical issues involved in researching the deaths of people who cannot say no because they are dead and who, when alive, appear to have had limited contact with other people. A case study from the pilot project will be used as a basis for the discussion about the efficacy and ethical status of using the sociological autopsy to research the deaths of people who live and die alone.

Should researchers interview the dying? The ethical importance of telling your story at the end of life

John MacArtney, Alex Broom, Emma Kirby, Phillip Good & Julia Wootton

University of Oxford

Health professionals, while broadly supportive of a research agenda, are most likely to have concerns about involving patients at the end of life (EoL) in research. In particular, there is a concern about the ethics of conducting research with those at the EoL who have been (implicitly) identified as 'vulnerable' and it is therefore not morally justifiable to engage this group of patients in (qualitative) research, given the distress and potential for exploitation that it exposes them to. Yet while these mainly theoretical debates raise important questions, we prefer to consider the evidence from empirical

studies that have asked patients about their experiences after they have been interviewed.

This presentation will reflect on a period of research in the field of EoL and palliative care in which we interviewed patients and their carers about their experiences of palliative and end of life care. Drawing on our experiences during that study we considered to what extent we might be able to use our observations to inform the discussion around the ethics of conducting qualitative research with those that the EoL.

We will explore how it is important to recognize the socio-political context within which qualitative research takes place and how being provided with the opportunity to tell your story has positive benefits for many patients. We then reflect on how health professionals' decisions to not provide people with the opportunity to take part in qualitative interviews can represent a denial of voice and have (unintended) ethical and democratic consequences.

'I'm sorry I couldn't share all my stories with you': Reflections on researching older people

Renske Visser

University of Bath

The current End-Of-Life care strategy claims that the majority of people in the UK want to die at home. My research focuses on the meaning of 'home' in the lives of older people living alone in the Southwest of England. In my project I try to unpack the concept of home and aim to explore older people's expectations of ageing and dying 'at home'.

In this paper I will discuss my research journey with a participant who passed away during my research project. Specifically, I will illustrate the process of her being part of my research, including how we negotiated both the appropriate research methods and her continuation in the project. Additionally, I will address the emotional aspect of conducting research with older people given the greater likelihood of participants dying during, or shortly after the research concludes. Lastly, I will discuss the challenges of being a researcher studying death and dying and the boundaries between personal life and the life of a researcher. More specifically, I will describe my struggle with separating the emotions I felt for my ageing and dying relatives from those of my participants.

On call Ethnography, situational ethics and shared vulnerability – methodological reflections on studying death and dying in Danish organ donation cases

Anja Marie Bornøe Jensen

University of Copenhagen

Based on 20 months fieldwork in Danish Neuro-Intensive Care Units, this paper explores the interactions between health professionals, families and anthropologist. The paper will examine how to gain and remain access to these highly sensitive medical settings and discuss the emotional consequences of practicing anthropology in the presence of sudden tragic deaths.

Observing organ donation practices and family conversations on organ donation entails

being available 24/7 ready to travel to the hospital whenever such cases happen. The unpredictability of such research endeavors challenges the boundaries between work and private life for the anthropologist but simultaneously provides insight in the working conditions of donation professionals.

Participant observation during organ donation conversations also necessitates sincere ethical considerations since the true agenda of the observing anthropologist could not be revealed to families still hoping for the survival of their loved one. The paper will discuss how to navigate such difficult ethical terrains using your informants, in this case doctors, nurses and donor families as advisors. Inspired by these premises for researching death regarding organ donation, the paper will also discuss the analytical potential in the particular ethical circumstances of a field site and the careful timing and strategic delivery of information performed by health professionals in these particular medical settings.

Finally the paper also discusses how the outsider position of the anthropologist and the personal vulnerability of the researcher are one of the most powerful tools for investigating death issues when daring to share such emotions with your informants and your colleagues.

Embalming as method: Researching death in Chinese society

Ruth E Toulson

University of Wyoming

In many Chinese societies, death remains a taboo topic. To mention death is to tempt it, and therefore it would be unfilial for children to discuss end-of-life planning with elderly parents. Funerals are avoided at all costs, funeral parlors are hidden, and working with the dead is considered the worst of possible careers. Such attitudes make the study of death and dying challenging. However, since 2003, I have conducted ethnographic research in Chinese funeral parlors in Singapore, documenting a society that is in the midst of a slow transformation of rituals chosen to mark death and attitudes to grief. Such access to this otherwise hidden world is only possible as, in addition to being a social scientist, I am also a certified mortician.

In this paper, I examine what this research method—participant observation at its most hands-on—reveals and conceals. Studying death means, for example, that I could never attend a wedding or the celebration of a child's birth. My focus on the funeral parlor means that my contact with grieving families is frequently shallow and brief. However, my long-term relationships with death workers, particularly a new generation of funeral professionals at the vanguard of the industry, allow me to examine how mourning is being purposefully transfigured from within. I also probe the ambiguity of my status: I am viewed as both "respected professor" and "polluted corpse handler." I conclude with reflections on how else one might study death and dying in societies where its very mention is problematic.

Researcher identity and experience in participant observation:

Generating data through reflexivity and conscious subjectivity

Liz Rolls

University of Gloucestershire

This paper explores the identities that arose when participant observation was used as a method in researching childhood bereavement services. It argues that the place of the identity and emotional work of the researcher in participant observation is fundamental to the social construction of knowledge.

Participant observation was used in a three-year study of the work of UK childhood bereavement services. As part of this multi-method study, six participant observations of group interventions for bereaved children and their families were undertaken to generate data about the nature of this aspect of service provision. Participant observation was chosen as it gives access to 'a realm of data that cannot easily be approached by other paths, the realm of personal meanings within given social contexts' (Ashworth, 1995:367).

The paper will describe how participant observation was used in the study, before illustrating the range of researcher identities that emerged whilst 'participating' and 'observing' in group interventions. It will consider the ways in which, through 'conscious subjectivity' (Cotterill and Letherby, 1993) and the reflexive *use* of autobiography within a framework of 'bracketing interviews' (Rolls and Relf, 2006), participant observation illuminated crucial data. Most notably, the researchers experience paralleled the tensions that exist for childhood bereavement service providers in managing their own identity and emotions in the facilitation of group-based interventions and emotional support for bereaved children and their parents, and this 'parallel process' contributed to a theory of the emotional work of UK childhood bereavement services.

References

- Ashworth, P. (1995) The meaning of "participation" in participant observation. *Qualitative Health Research*, 5, 3, August, 366-387.
- Cotterill, P. and Letherby, G. (1993) Weaving stories: Personal auto/biographies in feminist research. *Sociology*, 27, 1, 67-79.
- Rolls, L. and Relf, M. (2006) Bracketing interviews: Addressing methodological challenges in qualitative interviewing in palliative care and bereavement. *Mortality*, 11, 3, 286-305.

Navigating the liminal space of grief and bereavement: A researcher perspective

Caroline Pearce

The Open University

In this paper I would like to suggest that researching into death, dying and bereavement can feel like navigating a liminal space. My PhD research has been exploring different understandings of grief and recovery asking what it might mean to 'fail' to recover from grief. In this paper I would like to discuss some of the dilemmas I encountered in the course of carrying out my PhD research into grief and bereavement. These dilemmas were at once ethical concerns, often emotional and exhausting to experience, and yet came to be central to the findings of the research. As I set out to explore what contemporary grief researchers define as 'complicated' and 'prolonged' forms of grief, my first dilemma arose as I found I was searching for a subject that did not exist in a clear and identifiable form. In my interviews with both bereavement counsellors and people who had been bereaved, conflicting definitions of 'complicated grief' emerged. What felt at first like a failure to obtain the data I needed, in turn allowed me to view the definition of 'complicated griever' as not so much a hard reality but as a liminal subject that became recovered or not depending on who was drawing the boundaries. This fed into how I perceived my own role as researcher in the field. Grief and its recovery were a liminal space through which both my participants and I as researcher were traversing

with varying degrees of success. In the liminal space of grief there were few helpful guides to be found to aid the research process and the boundary between emotions and identities – whether researcher, participant or griever – were in constant negotiation and flux.

(Auto/Biographical) Reflections on researching death and dying from a 'distance'

Michael Brennan

Liverpool Hope University

It might readily be assumed that researching the grief occasioned by the deaths of “distant” disasters or celebrities, or the public dying practices of individuals who choose to narrate their experiences through the genre of “pathography”, might mitigate the effects of researcher involvement, precisely because these are deaths “at a remove” (Walter, 1991: 295): mediated, abstracted, intellectualised. Yet, following various post-positivist “turns” (biographical, cultural, narrative) within the social sciences during the last thirty or so years, and as theory and research has indicated, the boundaries between self/other, public/private, researcher/researched are porous and cannot easily be bracketed off, regardless of whether these relationships are mediated or experienced “face-to-face”.

To this end, this paper will reflect methodologically upon my own experiences of researching public mourning and public dying, posing a series of questions and raising a number of issues of epistemological relevance. For example, to what extent has my own research into the public mourning for, and public dying of, “distant” others been guided by (and benefited from) auto/biographical reflection? How does the choice of research topic reflect (un)conscious identificatory dis/investments in the individuals or events that have been the focus of my inquiries? What does this tell us about the value of subjective knowledge – about its uses and risks, and the extent to which it provides a basis for reflexive self-monitoring? How, moreover, might our feelings toward the subject(s) of our inquiries shift during the process of research? And how might the use of auto/biography – as a form of auto-ethnography – help narrow the gap between researcher and researched by placing ourselves as researchers on the same critical plane as those whom we research?

Auto/Biographical reflections on auto/biographical method/ologies: researching, writing, learning about death and bereavement

Gayle Letherby

Plymouth University

My father died when I was 20, I miscarried my only (to my knowledge) biological child in my mid 20s and was divorced from my first husband in my early 30s. My second husband died five years ago, when I was in my very early 50s and three and a half years ago the person who was my main support and source of comfort throughout all of these experiences – my mum - died.

My academic work over the last 25 years has included (but not been limited to) work on the disruptive reproductive experiences of others (including pregnancy loss, ‘infertility’* and ‘involuntary childlessness’*) and **auto**/biographical writing on bereavement and grief. I suggest that an experience of loss (my miscarriage) led me to sociology and that sociology has impacted on the way that I do grief. In recent years I have begun to

experiment with different types of writing – including auto/biographical ‘fiction’* and blogging – and these pieces often relate to my own experiences and that of my respondents across various research projects.

In this paper I reflect on my auto/biographical approach to researching, learning and writing about death and bereavement highlighting some of the challenges I have faced and the benefits I feel this approach offers to the writer (and more generally) not least as Laurel Richardson (1994: 515) suggests because ‘[life]writing [i]s a *method of inquiry*, a way of finding out about yourself and your topic’.

Richardson, L. (2001) ‘Getting Personal: writing-stories’ *International Journal of Qualitative Studies in Education* 14(1): 33-38

*I write various words in single quotation marks to challenge simplistic definitions.

There will be a separate call for papers on this Symposium theme for a special issue in the journal *Mortality*. More details to follow in late 2015.

Registration:

<http://portal.britsoc.co.uk/public/event/eventBooking.aspx?id=EVT10418>

Venue:

http://www.britsoc.co.uk/media/25083/BSA_Imperial_Wharf_directions041209.pdf

DDB Study Group Page: <http://www.britsoc.co.uk/study-groups/social-aspects-of-death,-dying-and-bereavement.aspx>

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