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Ethical challenges in researching and telling the stories of recently deceased people

Research Ethics

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Abstract

This paper explores ethical challenges encountered when conducting research about, and telling, the stories of individuals who had died before the research began. Cases were explored where individuals who lived alone had died alone at home and where their bodies had been undiscovered for an extended period. The ethical review process had not had anything significant to say about the deceased ‘participants’. As social researchers we considered whether it was ethical to involve deceased people in research when they had no opportunity to decline, and we were concerned about how to report such research. The idea that the dead can be harmed did not help our decision-making processes, but the notion of the dead having limited human rights conferred upon them was useful and aided us in clarifying how to conduct our research and disseminate our findings.

Keywords

Dying alone, ethical challenges, ethically important moments, research ethics, rights of the dead

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Introduction

This paper explores the ethical challenges that we faced as social researchers engaged in a project involving recently deceased people as research ‘participants’, and it also traces the steps by which we came to a decision about how to manage those challenges. Recounting the story may make it appear to have been a smooth and well managed process; it was not, but we have endeavoured to provide clarity here, so that readers can make sense of both the challenges and our solutions.

Research into topics related to dying and death, and which involves people as participants, is generally considered to be sensitive and emotionally evocative for participants and potentially also for researchers (Borgstrom and Ellis, 2017; Evans et al., 2017). The need for ethical regulation is accepted amongst the research community, although the processes used are not always considered to be the most appropriate. This is particularly the case for qualitative research which is unlikely to involve the delivery of interventions but is more inclined to focus upon talking and spending time with participants (Guillemin and Gillam, 2004; Pollock, 2012).

We are both researchers with an interest in and enthusiasm for the field of death and dying research; we accept that ethical oversight is necessary and that the well-being of participants and potential participants requires protection. We are alive to the need to be open with potential participants about what would be involved for them if they should decide to take part in our research. We are also aware that talking about difficult experiences can feel beneficial to participants, even outside the field of counselling or therapy (Presson et al., 2008).

This paper is not about procedural ethics and the practices of research ethics committees (Van den Hoonaard and Hamilton, 2016). Our intention here is to focus on the ethical challenges we faced and the ways in which we sought a solution to them; that is, we are focusing on ethics in practice and the need for researchers to make decisions in the field (Guillemin and Gillam, 2004).

Between us we have much experience of conducting research about death and various aspects of it, and which involves people as participants. In the course of various projects we have interviewed terminally ill people, people who have been bereaved, young people with a terminally ill parent or guardian, family members and friends who are caring for a dying person, professionals whose work brings them into sometimes prolonged contact with people who are dying, bereaved or deceased. We have carried out observations in locations where people are very ill and dying, both in institutional and domestic settings; we have also conducted observations at funerals. We are used, that is, to engaging with living people about different aspects of death and dying, and in a variety of settings and using different qualitative methods.

The project we are describing here, however, was different. The key ‘participants’ in the project died before it began, and we found that our usual way of

addressing the ethical questions involved in researching dying and death were not fit for the purpose. We obtained ethical approval for the project from the Faculty of Medicine and Health Sciences ethics committee at our home institution in the UK.

As a serving member of the committee, although not present at the meeting when our application was considered, I (GC) am aware that I have never been required to review an application involving people who have already died. Protecting the rights of living human beings is the primary concern and expertise of the Faculty ethics committee. It should perhaps be incumbent upon those of us who research with the recently deceased to open up conversations with ethics committees about this work and explore the ethical issues and implications of such work.

The ethics committee was not in a position to make judgements about whether the dead themselves could be harmed by the research. From our perspective this highlighted the reality that ‘. . .it is at the level of “ethics in practice” that researchers must do the real ethical work in this regard’ (Guillemin and Gillam, 2004: 273).

Literature examining practices and procedures of researching the dead is mainly concerned with the bodies of the dead, their use in research, and the retention of bodies and body parts. Much has changed since the anatomy trade in England was at its height, with the poor and powerless most at risk from it (Hurren, 2012). Body donations for research and training now are reliant upon the consent of the person before death, and close family after death (Human Tissue Authority, 2015). Today we still see mummified bodies displayed in museums, but perhaps future generations will not see them, except with a certificate beside them showing consent on the part of the person before death.

Changing attitudes towards the dead human body were not very helpful for us, however, as our research was not concerned with people’s bodies; we were focusing on the stories of their lives and deaths. Our main ethical issue was, could we, through telling the stories of individual people’s lives and deaths, harm them? Philosophers hold different views on whether or not the dead can be harmed, and, if they can, what it is that can be harmed. There is a broad consensus that it is possible to harm the living through what one writes or says about a dead person, but that is not the same as harming the person who has already died.

After a brief exploration of the philosophical literature on the issue of harming the dead (Papineau, 2012) we turned to history and the work of historians who regularly work with the stories of people who have died, and the writings of a social scientist exploring the work of forensic anthropologists. We did this in order to map ourselves a path through our ethical challenge which would allow us to carry out the research and report it, whilst simultaneously acting in a way that we

felt was ethical and fair to our ‘participants’ who had died before the work began and who had no say in whether or not they should participate.

The paper begins with a description of the research project and methods of data collection, before moving on to explore the ethical challenge encountered in research involving those who have recently died, and the approach we took to address this challenge.

The research

The research project which has provoked this ethical challenge was concerned with the exploration of lone deaths. We define a lone death as one which occurs when someone who lives alone then dies alone at home, and their body is undiscovered for an extended period of time. It is not unusual for someone to die alone and it can happen in different settings, such as hospitals and care homes, as well as in people’s own homes (Caswell and O’Connor, 2019). When this happens, the likelihood is that they will be found soon after their death has occurred, and what makes a lone death different is that the individual’s body will not be found swiftly. The body of someone who has undergone a lone death may be found anything from a day or two to several months or even years later. The project, which was funded by the Leverhulme Trust, involved us establishing a small number of case studies, each focused around a specific lone death.¹

Lone deaths are often reported in the media, either at a local level or nationally when the body has lain undiscovered for a period of years, and such deaths are treated as intrinsically bad events. One purpose of news media is to report news that has been deemed of interest to the public (Tuchman, 1978), but media reporting of lone deaths tends to paint a negative picture. Reporting seeks to assign responsibility for the lone death, suggesting perhaps that the deceased person was overly independent, a loner or a drinker, or that they had been abandoned by society; there is rarely an acknowledgement that the person may have made a positive choice to be alone (Seale, 2004; Turner and Caswell, 2020).

The aim of our research was to take a measured approach to the issue of lone deaths, as is consonant with an academic research project. We were trying to understand more about how people come to die in this way, and to establish whether it is a matter of choice for some individuals, whether it represents the best of several bad options for them, or is an unconsidered consequence of choices they have made in other aspects of their lives.

When someone dies a lone death there is usually some form of investigation to establish the identity of the person who died, when the death occurred, how it happened and whether there was third party involvement or suspicious circumstances. In England and Wales such deaths are reported to the coroner. The coroner will

probably order a post-mortem and there may be an inquest, which is a public hearing, to examine the circumstances of a death (Dorries, 2014).

We began the process of establishing our research case studies with the coroner's file on the death, which included post-mortem reports, witness statements and the coroner's conclusion about the death. We took an ethnographic approach to the study of these documents. They were a source of data about the person who died and what happened to them, but they were also objects of analysis in their own right. Witness statements in a coroner enquiry do not simply state the facts, they are written for a purpose and from a particular viewpoint, and it was our analytic intention to explore this (Fincham et al., 2011; Prior, 2003).

We also reviewed any media coverage, and attempted to interview anyone who had known the deceased person. The initial approach was made through a gatekeeper and we waited for potential participants to get in touch with us. Recruitment rates were low and there were various reasons for this. There were, for example, few people identified who knew the deceased individual, gatekeepers were sometimes unwilling to pass on information about the project and people who were approached may have been unwilling to be involved. It appeared that research into lone deaths is hyper-sensitive; fear of being criticised for the nature of the death may have caused anxiety for some, although such was not our intention and we tried to make this clear in the participant documentation (Kirchhoff and Kehl, 2008).

In addition to interviewing people who knew the deceased individual on a personal level we also interviewed professionals whose role involved them in dealing with the aftermath of lone deaths. Recruiting for such interviews followed the same ethical processes as above, with the exception that it was possible for us to approach professionals directly and not rely on gatekeepers.

That, in brief, is what we were doing in this project. It was a difficult project to recruit to, but we expected that. Our most pressing difficulties came from the ethical challenge that we encountered in the process of establishing case studies focused on specific deceased people, and the consequent decisions related to reporting the findings.

Ethical issues involved in researching the newly dead

There were two main ethical issues for us in our work exploring the stories of people who had undergone lone deaths. The first was to ask whether it was ethical to carry out this exploration, given that the individual concerned was not in a position to express a view one way or the other. The second issue was, assuming that it can be ethical to explore the stories of deceased people, how could we report our research findings in an ethical fashion? We will consider each of these issues in turn.

The ethics of researching the recently dead

People who undergo lone deaths tend to have few social connections, and to have lived quiet, private lives gathering little attention to themselves. Was it right, therefore, to draw attention to them by bringing them into a research project?

We were not, in fact, the only ones bringing the subjects of our case studies back into the social community. The coroner has a legal responsibility to examine such deaths, which enables them to be categorised in terms of place and cause of death so that they can be included in the national statistical data sets (Dorries, 2014; Prior, 2003). As noted above, lone deaths are reported by the news media; such reporting pulls no punches, giving names and other details and often including the person's address. Sometimes there is a photograph of the house or street where they lived, and occasionally even a picture of the person.

The coroner's office and the news media therefore both contribute to giving the deceased individual a form of revitalised social life, and the research also played a part in this. Through a process of reading about the person, exploring what happened to them and sharing information about them in the public domain people who have died lone deaths were given new social identities (Caswell and O'Connor, 2015). We endeavoured to be fair to all participants, both living and deceased and to take a balanced view throughout our process of decision making. However, we were keen to undertake the research and inevitably this influenced the choices we made and our belief that the understanding we gained would justify the inclusion of deceased individuals who were given no choice.

Reporting research on the recently dead

The second issue concerns the reporting of our research. The usual practice in our work is to offer living participants anonymity, and to disguise their identities in publications through the use of pseudonyms and the anonymisation of their data. Living participants receive information sheets telling them about the research, they sign consent forms and they talk with the researcher about what is involved in taking part in the research. A relationship is established between participant and researcher, and this is the basis upon which data collection and the reporting of findings are built.

Clearly a mutual relationship cannot be established when the 'participant' is deceased, and the ethics committee which gave approval for the study laid no specific requirements on us in relation to how we should report the research. It is also the case that the General Data Protection Regulations, which came into force in the UK in 2018, do not apply to people who are dead (Information Commissioner's Office, 2018). There is therefore a sense in which our responsibilities to our deceased participants were entirely in our hands and on our consciences.

Exploring the options

The first question we asked when thinking through how to handle these ethical issues was whether the dead can be harmed. If they can, then this would have ramifications for how we approached both the conduct of the research and its reporting.

Harming the dead

The question of whether or not the dead can be harmed is not, however, straightforward to address. In relation to the use of bodies after death, for example, Wilkinson (2002, 2012, 2014) argues that people who have died retain the interests they had while alive in the form of posthumous interests. This means that the person who existed before death can be harmed if the dead body is used in ways which are contrary to their posthumous interests. Fisher (2001) supports the view that the dead can be harmed, arguing that they can be both harmed and benefited, as the interests which they held while alive can be ‘thwarted or promoted posthumously’ (p. 558). This capacity to be harmed or benefited exists because, Fisher (2001) states, the interests that the deceased had whilst alive continue to exert a claim after death. For example, Fisher (2001) suggests that the accidental death of one of their children may be harmful to an individual, whether or not the individual becomes aware of the child’s death or is even dead when the accident occurs (p. 563).

Other scholars argue, however, that it is not possible to harm the dead. Harris (2013), for example, makes the strong suggestion that it is nonsensical to pay attention to the possibility of posthumous harm to the dead; there is no person left to be harmed. Taylor (2005), on the other hand, suggests more cautiously that the thesis that the dead can be harmed has not been proved. It has not been disproved, either, so we were left uncertain on this question of harm.

It seemed to make sense, as an intellectual exercise, to say that the interests that someone has while alive can continue to exert a claim once they have died (Fisher, 2001). However, this was not helpful as a way of making decisions about ethical behaviour towards a deceased person, and it raised more questions than it answered. Which interests, for example, could remain important and relevant? How could we know which interests were important for a deceased person whom we had not known when they were alive? Reference to someone who had known the deceased person might have been a key element in the process of evaluating their interests, but for most of the people whose deaths we were interested in we were unaware of whether there was such a person to whom we could refer.

Some commentators make the case that actions which appear to hold the capacity to harm a person who has died may, instead, be experienced as harm by those

who knew and cared about the deceased person. Tomasini (2008, 2009), for example, makes such an argument in relation to the parents of children whose organs were retained in what became known as the Alder Hey scandal, when organs from babies were retained illegally at Alder Hey Hospital.² The possibility of harm to the living from the research involvement of the dead was something that the research ethics committee had considered, as had we, and our recruitment and data collection processes were designed to limit the risks.

Overall, this did not appear to be a very helpful line of enquiry in practical terms, as we both struggled to comprehend, in everyday terms, how someone who was dead could have their interests harmed. Perhaps through philosophical naivety we did not find ourselves convinced by either side of the argument, particularly when it came to deciding how to apply the principles to our empirical work. My personal feeling (GC) was that it would be wrong to behave without constraint in relation to our deceased ‘participants’, and, as project lead, I felt from the beginning that they should be considered as participants. The research could not exist without them and their stories, yet I was unable to justify the implicit wrongness of publicly displaying the life and death of a private person, with all its personal details, inviting readers to make judgements. My colleague concurred. As Scarre (2013) writes ‘The puzzle is then to reconcile the moral intuitions which posit the existence of obligations towards the dead with the seemingly reasonable thought that there can be no obligations towards the non-existent’ (p. 2).

When working with our living participants we would make decisions in the field, should an apparent dilemma arise. Often this might be through discussion with the participant in a process that ‘. . . recognizes and values mutual respect, dignity, and connectedness between researcher and researched. . .’ (Ellis, 2007: 4). This would not work with our deceased ‘participants’, so perhaps we were simply asking the wrong question; might it be better to ask whether the dead have rights and, if they do, how might this affect our research? For if the dead have rights, then it behoves us to treat them in our research in accordance with those rights.

Rights of the dead

It was not easy to make sense of the concept of the rights of the dead in terms of absolute rights which all living and deceased people may have. The dead are not able to exercise those rights nor to claim them, in the manner that living people are; if those rights are breached, how are the dead hurt, when there is no person still alive to experience that hurt? How can they seek redress or ensure that it does not happen again?³

Scarre (2013) suggests that although the dead cannot own material objects, it may be possible for them to hold onto abstract goods such as reputation. Humans

are social beings who care about how they are perceived within their social network. A concern for privacy while alive may extend to a concern for one's reputation after death; an individual may not want their reputation tarnished after death by the revelation of a secret, which could lead to people thinking less well of them than when they were alive (Scarre, 2013). The argument here is that '...privacy interests and rights should be seen as possessions of the living, and that breaches of privacy after their deaths are morally significant for antemortem persons' (Scarre, 2013: 8).

A rule of thumb measure would be that if it were wrong to reveal something about a living person, then it would also be wrong to reveal it about a deceased person (Scarre, 2013). The notion that this is morally significant for the person when they were alive seems less difficult to understand than the notion of harm; although they cannot be directly affected by the damage to their reputation, for example, it makes sense that the view of people has altered towards them and their legacy may have changed because of it. It is, after all, not necessary for a living person to be aware that rumours which may damage their reputation are circulating amongst their social networks for that damage to be real; the reputational damage has occurred whether or not the owner of the reputation is aware of it. Similarly, the reputation of a person who had died may be damaged morally, even if not legally (Scarre, 2013).

Other scholars have explored the idea of the dead having rights. Moon (2016), for example, asserts that the dead may have human rights, despite an inability on their part to claim those rights or to exercise the corresponding responsibilities. This comes about because people treat the dead as if they have rights and, '... insofar as there are social conventions and customs that confer rights (and human rights) upon the dead, and insofar as these conventions shape social practices, then the claim can be sustained' (Moon, 2016: 58). Moon's (2016) research is concerned with the work of forensic anthropologists and the efforts made to identify bodies discovered in unmarked graves and return them to their families.⁴ The existence of human rights depends upon action; they only exist if people act upon them and treat each other as if they have human rights. It appears to make sense, therefore, that the dead can have some measure of human rights conferred upon them through the actions of living people towards them.

Lessons from historians

At this point we turned to the work of historians, to enquire how they handle the ethics of working with the stories of the dead. Without explorations of the past we would have far less understanding of our social world and a much less developed sense of society. Remembering and learning from those who have lived and died before us is key to understanding ourselves and our world (Black and MacRaid,

2007). Historians, who routinely work with the past and its people, may therefore be expected to have experience of navigating the ethical challenges involved in researching the stories of those who have died.

The human dead are marked with symbolic value and while they are less than human, they are more than objects or bodies (De Baets, 2004). De Baets (2004) suggests that the dead are ‘former human beings’ (p. 134) and, as such, they should be treated with respect and dignity, in the same way that people who are still alive are, or should be, treated. This means that we all have responsibilities towards those who have died, just as we have responsibilities to people who are still living (De Baets, 2004).

Having drawn this conclusion, De Baets’ makes a range of recommendations for the responsibilities that the living have towards past generations. These include caring for and disposing of their dead body and possessions, ensuring that their body is identified and their identity preserved, safeguarding their heritage and memory, and being respectful of their privacy. The key element for our work was his recommendation that historians and others whose work is concerned with exploring the past should bear responsibility for doing so in a fashion that, ‘weigh(s) . . . privacy and reputation against the public interest when disclosing or formulating facts. . .’ (De Baets, 2004: 143). The notion is not that disclosures should never be made about individuals who have died, but that their privacy and reputation should be considered and balanced against the public interest.

This perhaps makes most sense in relation to recent history. Moore, for example, carried out archival research exploring stories of women in late 19th century and early 20th century Lancashire with regard to abortion which was, at that time, illegal. Despite all the women involved being deceased by the time of her research, she decided that:

. . . although many of the details of these women’s crimes were now matters of public record as many appeared in newspapers and court records, out of respect for the women involved and their secrets, I decided that it was imperative to change the names of my research subjects to keep their behaviour hidden in accordance with their attitudes decades earlier’ (Moore, 2010: 267).

Accepting that those who have died may have some rights conferred upon them through the behaviour of living people towards them we next had to decide how to put this into practice in the research context.

Addressing the ethical issues

We have outlined the ethical issues we encountered as we began work on this project as two-fold. First, the question as to whether it is ethical to research the lives

and deaths of people who have recently died in circumstances deemed socially undesirable and second how such research should be reported.

The notion that those who have died can be harmed was challenging for us and did not offer a conceptual approach that could help us decide how to manage our ethical duties, if we had any such duties, towards our deceased research ‘participants’. The idea that those who are dead may have a reduced set of rights did, on the other hand, seem to be more easily comprehended. The right to be treated with respect and dignity, and not to be subjected to reputational damage seemed to be a good starting point (Moon, 2016; Scarre, 2013).

How to enact this in our research was the next question. De Baets’ (2004) codification of responsibilities of the living towards the dead was helpful here.

Whether we drew individuals into the project or not, records and reports will exist about them. It is unlikely that anyone will come across coroner records about them accidentally, but news media reports which are online are easily found and accessed. It was our belief that through the exploration of different cases where people have undergone lone deaths, we could learn about such a manner of dying, and come to understand more about how human differences manifest at the end of life. We could also increase our knowledge of the social processes we use to manage death, and the limits we place on socially acceptable choices in relation to how we die. This, we came to believe, justified bringing people who were already dead into the research.

That still left the question as to how we should report our findings. As we confer rights upon the dead by treating them as if they have rights, and this requires us to treat them with respect for their dignity as former human beings, their involvement must be reported in such a way that their personal privacy is respected and their reputation safeguarded. The easiest way in which to do this was to approach the reporting as we would for a study involving living participants. As Moore (2010) did, we made the decision that when we wrote or spoke about any of our case study ‘participants’, we would follow the practices of anonymisation and pseudonymisation that we use when reporting research about living participants. If necessary, we would change small details in order to obscure who they were during life.

Concluding thoughts

Conducting qualitative research involving, as it does, people as participants, can present researchers with ethical challenges when working in the field (Pollock, 2012). When this occurs, it is often necessary for the researcher to make a judgement about what to do in that moment (Robinson, 2020). However comprehensive the ethical review process and however carefully researchers have considered

potential ethical issues it is not possible to think of everything; there are times when researchers must rely on their own judgement (Guillemin and Gillam, 2004).

In research involving living participants this process of judgement may be assisted and informed by the nascent relationship building between participant and researcher in the interview process. It may also be one of those ‘. . . “ethically important moments” in doing research – the difficult, often subtle, and usually unpredictable situations that arise in the practice of doing research’ (Guillemin and Gillam, 2004: 262). Robinson (2020) suggests that such moments may also lead researchers to look again at a research setting and may enhance the process of data collection and the relationship with participants. One of us has experienced this in a previous research study whilst engaging with a participant in a discussion about the need, declared on the participant information sheet and consent form, for any suggestion of harm to be reported. The participant was open about the nature of what he might say, relative to future plans to end his life in certain specific circumstances. We were able to come to a satisfactorily mutual conclusion that did not result in sharing what he had to say with anyone in a position of authority. Instead of following procedural ethics, we used a form of relational ethics, borne of mutual respect, which enabled us to navigate our way to an appropriate conclusion which satisfied us both and allowed the research encounter to go ahead (Ellis, 2007). The process added to and enhanced data generated on the project (Robinson, 2020).

In the case of our research involving people who had already died, it was not possible to involve them in a process of discussion and debate about what would be appropriate. We did not have clear guidance from the ethics committee which gave us approval for the study, so we therefore needed to consider the wider context, within which we gathered data about our case study ‘participants’, in terms of what to disclose about them. This was particularly important because in most cases we did not have access to a living individual who had known the deceased person, and who was able to advise us about their likely preferences (Crossen-White, 2015).

The decisions that we made relative to the ethics of our research exploring the lone deaths of people who lived alone may seem excessively cautious to some readers. We believed that, as researchers, we should be ‘. . . governed by what feels appropriate in a specific setting. . .’ (Perez, 2019: 148–149), but also believed that we should have rational grounds for doing so. The decision to treat our ‘participants’ who were former human beings in the same way that we treat our living participants felt right, and it also honoured their rights and reputations.

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Notes

1. Link to project website: <https://www.nottingham.ac.uk/research/groups/ncare/projects/exploring-the-social-management-of-lone-deaths.aspx>
2. Report on scandal, which related to the retention, without parental consent, of organs from children's bodies: <https://www.gov.uk/government/publications/the-royal-liverpool-childrens-inquiry-report>
3. There is a similarity in the position of those who have died to those who are in a coma or a vegetative state in terms of a lack of ability to exercise rights. However, there are also dissimilarities in that there is no expectation that someone who has died will return to life, whereas this may be a possibility for someone in a coma. We made the decision, therefore, to focus on the literature concerned with the rights of those who are dead.
4. Human rights human remains project website: <https://humanrightshumanremains.com/>

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