

TRANSCRIPT

Open Thanatology - What is it like to research death and loss?

ERICA BORGSTROM:

Welcome to this Open Learn and Open Thanatology podcast recording about what it's like to research death and loss. I'm Erica Borgstrom and I'm a professor of medical anthropology at the Open University and one of the directors for the Center for Open Thanatology at the university. This podcast recording has been inspired by many of the conversations I've had with members and colleagues of the Center for Open Thanatology and that is around what is it like to actually research death and loss. It's not uncommon for people to think it must be morbid or always sad but we know from our research and the day-to-day life that it can be much more varied than that and full of connections between peoples and ideas and very inspirational.

Researching death and loss is well established at the Open University and now via the Center for Open Thanatology there's a wide variety of research and education on death and loss across many contexts, subjects and disciplines.

For those unfamiliar with the word thanatology it literally just means the study of dying death and bereavement related losses and grief and the interdisciplinary field is sometimes called death studies.

I'm joined today on this panel by colleagues from the Center, Sophie and Sara and they're each going to briefly introduce themselves now.

SOPHIE MICHELL:

Hi, my name is Sophie Michell. I'm a postgraduate researcher in the history department. I research in quest in the 19th century.

SARA MACKIAN:

Hi, I'm Sara Mackian and I'm a senior lecturer in health and wellbeing at the Open University. I'm a geographer by training and my research is driven by a curiosity for how people's experiences of health, illness and wellbeing impact on their engagement with the world and how they navigate their daily life. But I'm also an artist on the side and I've been trying to draw more of that into my research in recent years and I'm really inspired by the idea that the world is more mysterious and enchanted than we think and I use social science and art combined to explore the relationship between the real and the imaginary, the body and the spirit, this world and the otherworldly and ultimately life and death.

ERICA BORGSTROM:

Wow, awesome. Thank you both so much for joining me in this conversation and I think it's quite intriguing to hear a bit about your backgrounds and where you're at in your careers and how you approach your research and to think about that also in combination with my background as an anthropologist who tends to study palliative and end-of-life care but also grief and loss, particularly since COVID-19.

Now we know it can be a bit cliche to say this but learning about death can actually teach us about life, people and society and our own reactions to grief and loss. So today we'll share some of those experiences and thoughts about what that's like and ask each other different questions. I'm going to turn to Sara who's going to ask the first question.

SARA MACKIAN:

Thanks Erica. Yeah, I wanted to ask you, you've written about how people can sometimes assume that death-related research is inherently sensitive. Why do you think this is?

ERICA BORGSTROM:

Thanks for bringing that up. I've had lots of different responses from people when I tell them what I do for a job or the type of research I do, whether they think it is always very sad and upsetting or particularly sensitive research. And this notion that research on end-of-life is inherently sensitive comes across in a lot of different ways. I found it comes up when I put in applications about the ethics of my research so I can get approval to do the type of work I have. So people assuming that because it's about end-of-life care, about death, it automatically is sensitive research so that implies different types of paperwork one has to fill out. I've had people respond that this research is sensitive when I present my work at conferences or to the public and also when I'm supporting students and postdoctoral researchers in their projects, they've had this come up as well. And I also have it when you know I'm at the hairdresser and getting my hair done and people ask you what you do for a job. Now I've tried to understand a little bit more about why people think not just that death and end-of-life care related research is somehow inherently setting but particularly sensitive. Like what does it mean to be sensitive? And that is because people think that those who are the subjects of such research, so people who might be dying or caring for those who are dying or who are recently bereaved, are somehow inherently vulnerable because death and loss and grief make them somehow vulnerable. And that research in this has the risk of upsetting them or hurting them further because of this vulnerability. And rightfully so, we have ethics committees looking out for research projects to make sure that they don't harm people and to try to protect them from them. It's interesting to think about why people assume talking about end-of-life might inherently be hurtful to someone or upsetting. And I think actually when I explore this a bit further with people in their assumptions, it's sometimes based on their own experience or lack of experience with death.

Now in my experience of doing research on end-of-life care and on grief, I don't necessarily see that for all people talking about end-of-life care as inherently upsetting. And so I don't argue that it's necessarily sensitive per se.

And I also argue in some of the work that I've written around this topic that if we always frame research on death and dying as inherently sensitive, it frames the work in particular ways both in terms of how we think death and dying means certain things in society, but also about what the research participants may or may not be able to do. And it can actually really disempower people from their own perspectives where they might want to share other experiences and actually want to engage with this research.

And in some of the writing I've done further on that, I also focus on how this framing as this type of research is sensitive can actually really impact the researcher about how it might make them think about their project, about how they must feel they always need to be really protective of their participants in certain ways, and how also sometimes that focus on what does it mean for the potential participants can actually ignore what it means for the researcher to be researching these topics and what we might want to do to support them to help make sense of death and loss and grief, as well as how we want help with them make sense of why this research may or may not be upsetting or sensitive in different ways.

SOPHIE MICHELL:

Sara, you've taken the insights from your research and considered them in a healthcare context to develop a dramatised film and an interactive resource on Open Learn, which is called Beyond Belief. Why did you create Beyond Belief and what's been the response to it?

SARA MACKIAN:

Well, I was invited to do it by someone who really loved my research, which was great, and I thought long and hard about what to include in it. I wanted it to feel relevant to people working in healthcare, but also to anybody who has faced their own mortality or that of a loved one. So I decided it should follow the story of someone who has terminal cancer and is seeking spiritual healing as a means of support to cope in that situation, and I wanted to explore how the people around them react to that.

So Darren is the patient and his wife Joan isn't so keen on the angel healing that he's been having. She's more of a traditional Christian, but his nurse Phoebe, she's fairly open-minded, but she encounters hostility from a colleague. During one of the healing sessions in the film, Darren meets his deceased grandmother and is really comforted by that and the idea that she'll be there for him when he dies. And we use that storyline to open up learning around different attitudes to life, death and the afterlife, as well as to the role of religion and tolerance in society more broadly. The film won an award at an international film festival for Best Message, which I'm particularly proud of, and that

makes me think that talking about these things is a good thing to do. I also wanted to do it because end-of-life visions or experiences like Darren's are actually very common and many people working in end-of-life care will have their own experiences to share if asked about it, but on the whole people don't tend to talk about them and they're not really covered in formal medical training.

As they're common and can be incredibly therapeutic, I think this should be covered in training and I'm keen to use the Beyond Belief interactive in that way in the future. I recently met a nurse educator from Spain and she wanted to share it with her students because she agrees it can be a really powerful tool to help practitioners learn from, to reflect on and to have an opportunity to share their own experiences of these sorts of encounters. So that's something I'm really keen to do more of, so watch this space.

ERICA BORGSTROM:

Sophie, I've got a question for you. Reflecting on how you approach your research as a historian, what's it actually like studying deaths that have happened in the past?

SOPHIE MICHELL:

I think the most important thing about researching death is how much it tells you about life in the past. Inquests were really called after a sudden death, so the witnesses come together, usually in the pub, to talk about what was happening immediately before the fatal incident happened.

This can be doing the washing, you know, cooking tea or walking home from the pub, as well as more industrial accidents like getting hit by a train.

I've been able to use my inquest data to reconstruct practical things like how emergency care was managed in the 19th century long before we had ambulances and more pragmatic things like how many trains run through the centre of Peterborough every day. It is the most amazing source.

I don't get to talk to anyone who knew my subjects. I work on death from the entire modern era, which is a strange term meaning everything from 1800 onward, but my thesis is on 1856 to 1905 and it's well outside living memory. Most of my inquest subjects were working class and I don't have anything to personalise them. I don't have photographs, I don't have belongings, I don't get to ask their family what they were like.

So it's really weird when you do find something that personalises the subjects and a great example of that is suicide notes. All suicides are subject to an inquest in the 19th century and they are looking at the inquest to find out whether or not the suicide was criminal, so it's more of a legal inquiry than a social inquiry. But the originals of suicide notes are usually preserved with the inquest documentation and they have such an

immediate and emotional link to the people that I'm researching. They can be tear stained, they can be scribbled at the end as people are losing consciousness as they write them.

I'm not the kind of historian that thinks it's imperative to be detached from my work. I think the lack of personal connection and interaction does make the work easier. I'm not developing a relationship with these people in any meaningful way, but I still have to reconstruct the physical, social and emotional context of each inquest and that can be really emotional for me. I'm best known for talking about homicide but I work on all types of death. When I was collecting data I found it really hard to transcribe accidents on children that were the same age as my children at the time. So although I am quite removed from my subjects it doesn't mean that I'm not a little bit emotionally involved.

ERICA BORGSTROM:

Thank you so much for that Sophie. As I reflect already around some of our conversations so far there's a few different things about what it's like to talk about the research we're doing and engaging people with it in different ways and also different people's attitudes to death and dying either over time or in different contexts. Now I know based on your research that you're actually publishing weekly accounts about what you found in the archives in your sub-stack and on social media and that's been a great way of doing like a version of public history. What have you found the response to have been from others about these stories and how has that shaped your thoughts about people's engagement with death?

SOPHIE MICHELL:

One of the biggest differences between history and social sciences is that historians don't require ethical clearance to do their research. So I have got a really strong sense of ethical responsibility developed from years of working in the NHS to put these deaths appropriately back into the public domain and respond to people's interaction with them in a way that respects the person who died.

The true crime genre is a massive subculture at the moment and many of my readers engage with my work from a true crime perspective. My aim is to put the victim back into the story because so much historical true crime just slides over the victim. They prefer to focus on investigations, motives, trials, sentencing, executions, whereas I try to keep the focus on the person who died and their life.

Sometimes, not very often, but sometimes the families of the victims or perpetrators that I write about do get in touch with me. I've not had any bad experiences with that yet. I have friends who have been working on the post-1950s murders who have had very difficult exchanges with surviving family members, so I consider myself lucky to have not had anything like that happen yet.

I'm always fascinated by how these stories are told or more importantly not told as part of family history. Most people who get in touch with me were either only dimly aware of what happened in their family or they had no idea at all. Again, this brings me back to the ethics of how you tell these stories, knowing that descendants might read them and that this might be their first contact with some personal dark history.

SARA MACKIAN:

That issue of ethics raises another question in my mind for you, Erica. Much of your research is on palliative and end-of-life care and you work with health and social care professionals, but you're a social scientist yourself. In what ways do you think your non-clinical background helps or hinders you and vice versa for those who may have a professional background and then decide to go and do some research?

ERICA BORGSTROM:

Well, excellent question, Sara, and really thinking about what I've heard so far and being really grateful for my training as an anthropologist in that as part of that training we're taught to really be reflexive about our positionality. How do our beliefs, our relationships, for example, impact how we are doing our research and the way we relate to others that we encounter?

Now, when I'm a social scientist going to study, say, palliative care, whether that's in a hospice setting or a hospital or even in someone's home, I have to learn the environment, the language, what does it mean by people saying certain things or even indicating things as sometimes things aren't said and what happens in those different contexts. Now, my professional health and social care colleagues might have learned all of that through the job, but for me, initially when I'm doing my work, that can feel really bewildering and overwhelming, but it also gives me a bit of a permission to ask what I sometimes call naive questions to others because they know they can't necessarily assume I have the same knowledge that if they say a certain clinical term that I know what it means and that I can't take things for granted. I find that quite helpful also as like an icebreaker sometimes to ask those questions, particularly as someone coming in from a university and there might be power differentials, others might assume I have lots of knowledge. So to show to them that I don't have that knowledge can be really inviting and that we can connect in different ways. But it's also been really helpful for me to then understand through those questions and through all that learning the different ways in which people think about what makes a death or dying experience good or not and what different practices shape how that can unfold for different people.

Now in my experience of working with health and social care professionals or when I'm also supervising the ones who have worked clinically before or worked in social care before and then come to go do some research, I've often found that they might have insights or are able to raise research questions that I might not ever think of because they have certain knowledge already about what's happening or certain

understandings of the world, including death and dying. I've also found that on a practical level sometimes they have much easier access to some of those sites. So someone who's already a nurse might find it easier to engage in an NHS site with research and they might be more readily able to identify and articulate the value of their work or recommendations for changing practice based on their study findings. When I'm acting as a supervisor though for people doing research, I've also witnessed how doing research may challenge the assumptions they might have learned through their professional practice and the knowledge that they have and sometimes that challenging seeing the world in different ways than the way you already knew it can be really unsettling as well as enlightening for them. But whoever it is, it can also be useful to know that what topics one can engage with in such depth. So Sophie mentioned earlier about being mindful of engaging with child homicide for example and I know in my own work thinking about what elements of pallets of an end-of-life care I may or may not find easy to work with due to how they may impact me or knowing. I might be more opinionated or close-minded rather than curious about certain things because of previous experiences I have and or fear I might have around certain topics. So it's quite useful to again be reflecting on what one is and is okay not comfortable with exploring and how one knows the world based on one's experience and what that is doing in terms of shaping the work one is doing.

SOPHIE MICHELL:

Death is interdisciplinary and touches everyone's life. So Sara what's it like studying a topic that may be at the margins of disciplines, fields or even society?

SARA MACKIAN:

Great question, well I think being a geographer has probably prepared me perfectly for that. Geographers study everything and anything, the connecting theme being how it relates to space and place and our experiences of that. It also means I can draw on a lot of different things, I'm not confined to disciplinary rules or boundaries, we're really a very eclectic bunch of geographers and I like that and it also plays to my creative side. My research on spiritualism could certainly be seen as being at the margins of society, it's a very small religion and its core belief is that death is not the end, the soul lives on in spirit. So it could be described as being fairly peripheral in modern Britain I guess but being human is all about making connections and learning from those that we might consider to be different to ourselves. It can help us to look at the world in new ways and challenge our preconceptions and sometimes it might force us as well to reevaluate our own ideas and experiences in light of what we've learnt, just like Erica was saying, our previous experiences feed into what we then go on and do in future.

So an example of that is that we used an interactive museum exhibition with our spiritualism project in Stoke-on-Trent and this was to try and encourage people to reflect on their own spirituality as a result of what they learnt from the exhibition. So it really spoke not just to the spiritualist community there but also to the wider city itself. It

helped to celebrate a really vibrant but hidden side to Stoke and shining a light on it helped others to learn something about themselves as well even if they had no personal connection to spiritualism.

But my research also looked at things which many wouldn't even consider to be a legitimate part of this world, things like spirits, angels, tarot, other worlds and that can be challenging. It can get ridiculed by the public and I had personal experience of this in a Twitter Q&A I did a few years ago that was hosted by the OU marketing team and there was quite a bit of a trolling negative reaction as a result of that. But I've also experienced prejudice amongst academics. It seems they're happy to accept these sorts of things if they're in far off countries seen as buried culturally different to the UK. But when I talk about the otherworldly in a UK context people seem to be quite happy to ridicule it, even academics, especially I think because a lot of women are involved in these practices.

So I've even been asked if I've been tempted over to the dark side as a result of the research I do. So I think there's a bit of a colonial hangover there and also an element of misogyny probably.

ERICA BORGSTROM:

What Sara's just said reminds me that people sometimes claim that death is universal, like it's the only certainty in life. We hear that often or also around tax and yet may have very different expectations about what death is like and people's relationships to death and the dead depending on cultural, geographical or historical context. This notion that you brought up there Sara about accepting it if it happens in far away places but not here is really reminiscent of that. Now Sophie, I'm thinking about your research which has been based in Peterborough, England. Have you noticed a difference between how deaths were dealt with then and now and does that matter?

SOPHIE MICHELL:

Yeah, I mean my mum died in 2016 and she died at home and it was a very raw experience, very little medical intervention which was shocking to a lot of our friends and family. They assumed that she would be in a hospice, they assumed she'd be drugged up to the eyeballs at the end.

In the Victorian era that kind of death was absolutely normal, death was part of everyday life. It was increasingly medicalised as the century went on, people wanted to know why someone had died but it was also domestic. You got sick, your family looked after you at home, you died in the house, everyone came to see your body before the funeral, the funeral ended, you went back to the house and you got drunk.

Hospitals were not interested in caring for the dying. Peterborough's hospital staff got quite angry when dying people were taken there.

There was an almost religious fatalism around death in both the way that people dealt with that at home and also in law. Visitation of God was a common verdict in early and mid 19th century inquests and it was a kind of acceptance that sometimes we just die and we don't know why.

The Victorians developed the idea of the good death and as most people know they had a highly performative grief culture. The coroner's court by definition examined the bad deaths, the ones that happened outside normal and acceptable dying. Victorian inquests were designed to minimise disruption, they were held very very quickly after the death, sometimes hours after the death, and they were held as close to the family home as possible but they were still considered shameful and unwelcome, a kind of judgment on the family that someone had dared to die in an unexpected way.

My work doesn't just tell us what the coroner's court did, it tells us what the court didn't do and I think the oddest thing is how many deaths that we would now consider shocking and preventable were entirely normal. Almost no deaths in childbirth needed an inquest, very few neonatal deaths needed an inquest unless the child was illegitimate, infant death was completely normal. Children died of infectious diseases all the time but again this was completely normal.

Getting hit by a train was a tragic accident with no lessons to be learned, it's quite the culture shock compared to today's society.

Sara, my work has brought up notions of good and bad deaths. I know for some researchers engaging with this field shapes how they see deaths in their own lives. How was your work on death and dying and loss impacted your own experience of it?

SARA MACKIAN:

Well when my mother-in-law died a few years back and then my dad died a little over a year ago it prompted a lot of reflection for me because being involved in research around death and dying meant I knew a lot of strange things that I wouldn't have known about otherwise. Very practical things like dead bodies can move and the cremation remains may have fragments of bone in them, things I just wouldn't have had any idea about before.

And it also meant I knew the theory about the important role that a funeral can play in the grieving process as a ritual with meaning but also that it's something that has to be negotiated very carefully at a difficult time for everyone involved.

So I knew those kind of things, the practical and theoretical side, but it also brought home to me just how much I really didn't know about death and dying when it comes to dealing with it on a personal level.

That research knowledge kind of gave me practical tools and insight which helped me be prepared for some aspects but it left me feeling completely hopeless emotionally because my logical side was saying you know how this works but my grieving self was of course having none of that.

After dad died something else strange happened as well which links to my research on after-death communications and I'm currently in the process of writing an autoethnographic article around that. So I've been reflecting a lot in recent months about what happens when our research worlds and real life worlds collide and when it's all about death that generates a lot of food for thought. And it's thrown up methodological challenges for me to try and learn about autoethnography for example but it's also deepened my understanding of the subject that I research and I think that will hold me in good stead in future projects. And as researchers I've recognised really that we have a certain power to share stories, to generate knowledge, to change the conversation and to give voice to the voiceless. So my own experiences of grief have really helped me to reflect on what I do as a researcher too and how I tell those stories.

ERICA BORGSTROM:

Thank you both so much for sharing such amazing insights and I'm really struck by also how you've both mentioned personal experiences of death and loss and how that has shaped ways of understanding either the material you work with or also how your research and knowledge that you gain through research has helped you make sense of and sometimes not make sense of what goes on in your own life. And it really strikes me that there is still so much to learn about death and loss. It is one of those areas of research that feels like we will never know everything because it's always shifting slightly, it varies so much and there's always that meaning making that is happening in our societies.

With that in mind that there is so much that can still be learned about and researched and understood, what would you recommend to others who want to get into researching these topics or are already doing so?

SOPHIE MICHELL:

I don't think anyone gets into studying difficult history without having a reasonable idea that they can handle the challenging content but it does get hard, it can be relentless. So take breaks from archival work but more importantly look for structural support. Universities and research bodies are increasingly acknowledging that historical work can be emotionally demanding and they are providing support accordingly.

SARA MACKIAN:

I think what I would recommend is to first of all make sure you feel comfortable with death or at least as comfortable as you possibly can be but be accepting the fact that a lot of other people won't really want to talk about it and won't be that comfortable. So

it's really trying to recognise that difference that you might come across. growth of things like death cafes shows that there's an appetite to talk more openly about death but we still have to tread really lightly sometimes.

ERICA BORGSTROM:

That's great, you both have some practical ideas or tips as well but also reflecting some of the conversations we had about sensitive research and how people might respond to your work when you present about it in different contexts so it's really great advice. If I were to add something really reflecting on my role as I have as an editor on research about death and dying and also as a doctoral supervisor I sometimes come across people who are really keen to explore an idea thinking that maybe no one else has done it before you know to ask certain questions about death or people's experiences of end of life. Now when I come across those I'd actually really recommend that people look at what's already been done about those things. Search engines may not always bring up research so you might need to look at research databases for example and so that you understand that if you're keen to do research in this area and you think you have this novel question that you're really building on the work that's already been out there and in that I'd also really recommend looking beyond your own discipline because death studies and thanatology has so many different perspectives within it and hearing today you know from historian and geographer and anthropologist but also you know reflecting on medical research that's out there and much much more it's good to take those different perspectives into account when shaping your research question and project.

Before we wrap up is there anything else that either of you'd like to add?

SARA MACKIAN:

I'd just like to say thank you as well it's it may sound strange but I find talking about death strangely life affirming because it is something that we do so thoughtfully and carefully and gently and so it's been a really lovely experience to talk about death with you both.

SOPHIE MICHELL:

Yeah I'd echo that there are not a lot of historians of death around and the Open Thanatology Group has been a great place to talk about my research at the OU when I don't have a lot of like-minded colleagues in the history department.

ERICA BORGSTROM:

Well thank you both and I also want to thank other members of the Centre for Open Thanatology for sharing their thoughts and ideas with this as well. Thank you to all who are listening and hopefully this has inspired you to learn more about the Centre for Open Thanatology and learning about death and dying more generally and possibly doing research in this area. I also want to thank our Open Learn colleagues for helping us make this podcast. If you are interested in learning more about the Centre for Open

Thanatology and the free educational resources produced such as Sara's Beyond Belief Interactive, visit the Open Thanatology Hub on the Open Learn website or search for Open Thanatology in your preferred web browser. If you'd like to learn more about death and dying, you're curious to see what's out there, you can study with us at the Open University. For example, via our free courses that are on Open Learn in our undergraduate level module called Death Dying Abreavement or by applying to be a postgraduate research student with us. Follow the links provided with this recording for more information.