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Using an ethnographic approach to study end-of-life care: reflections from research encounters in England

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Abstract

This chapter is based on reflections about the various kinds of explanatory work that I had to do to legitimise and negotiate studying end-of-life care in England ethnographically with various stakeholders. By examining the responses I received, I comment on how this explanatory work and framing shaped what I could ultimately study, the knowledge that could be produced, and my relationship to the project. Ultimately, this chapter invites ethnographers to be reflexive about the ways we position our methodological stances and ourselves as researchers within health-related fields and how this constructs our subjects of study.

Introduction

This chapter was inspired by the reflections on the various kinds of explanatory work that I had to do to legitimise and negotiate studying end-of-life care in England ethnographically. This was often on the fringes of the ‘actual fieldwork’ – in outlining and justifying the methods to colleagues, to the ethics review board, and to potential participants – and in doing, it shaped the study and what could be known. In this chapter, I alternate between reflections on my experiences (written in italics) and how these relate to developing understandings of what doing ethnographic research is in the contemporary (Rabinow et al. 2008), one of not just ‘being-in-the-world’ of our research sites (Cooley 1997) but of being in particular kinds of ways in relation to the wider research endeavour. I use these reflections to make connections between adopting an ethnographic approach and what I was able to observe, hear, and later know and say, certain things about end-of-life care in England that spanned beyond a healthcare-perspective of the dying.

Rather than get entangled in debates about what ethnography is, and who can do it – despite such claims to method being important within anthropology (Rabinow et al. 2008; Ingold 2014) – I argue for talking about the ethnographic approach. I adopted ‘an ethnographic approach’ that encapsulates the techniques of data collection, and more importantly, how these are grounded within a wider understanding of the research endeavour, which can be lost when ethnography is reduced to method. For this, I define an ethnographic approach as entailing: a commitment to make sense of people’s lives from their points of view; engagement with the field, however constructed by the researcher and through the project and not limited to a geographical area (Kisliuk 1997); flexible in the kinds of engagement involved in research, recognising that people who are ‘participants’ have their own lives outside of the scope of the project; most likely multi-modal in that observations often includes listening and interviews note-taking; seek to place issues within wider context, but acknowledging that researchers shape what is considered context (Hammersley & Atkinson 1983); analysis that invokes working through descriptions even if these do

not always feature as ‘thick descriptions’ in the various outputs produced by research. In doing so, I am aligning my argument with Law’s (2004) encouragement to think and write about (social science) methods as ways of being.

The Study on End-of-Life Care

It was not uncommon to see absent looks when I told people I was an anthropologist or that I wanted to do ‘an ethnography’ about end-of-life care...simplistic understandings of anthropology rolled off my tongue to fill the silence... ‘traditionally, anthropologists would go off to far away, exotic places to live with people for long periods of time to observe and write about how they see the world’. And with an uncomfortable chuckle, I’d add: ‘of course, that’s not always appropriate now or in the UK, so what I do is watch and talk with people to understand what they do, etc’ ... by this point, most people would smile and nod, saying ‘how interesting’ or ‘how useful’. Reassured, I was often given the chance to then listen to them or invited to tell more about specific elements of my project, a sign that they could entertain me studying end-of-life care in this way. Perhaps we could have a mutual understanding that watching and listening were important means of studying this topic.

For my doctoral research on end-of-life care in England, due to the prominence of the concept of ‘choice’ in policy, I wanted to examine what ‘choice’ was and how it was done as people approached the end of their life, linking together policy discourses, healthcare practices, and people’s everyday experiences (Borgstrom 2014). The National Institute of Health Research funded the research, and because of this I was part of a university department focused on primary care and public health. In part, the funding mechanism determined that end-of-life care was primarily a health issue, or could be understood through health research.

Nevertheless, I sought to view end-of-life care as something inherently social and to be understood from a cultural perspective – both in terms of how policy is understood and how end of life care is done. I also wanted to maintain my identity as an anthropologist within a multidisciplinary department, so without much hesitation I began to define my project as having an ethnographic approach, both in terms of how I did the actual data collection and analysis, but more importantly for me, how I approached the wider project of conducting research. During my Masters in anthropology we had learned how ‘ethnography’ could be used as a short-hand for saying something greater about one’s epistemological and moral stance about research. I did so even though it was evident that the project I was proposing did not fit the trope of traditional anthropological ethnography. Moreover, I did so not always appreciating the subtle slips between anthropology, ethnography, and ethnographic approach that I was making (see Hockey & Forsey 2012).

The project had three main parts focusing on end-of-life care: policy, practice, and everyday experiences of living with life-limiting conditions. The data collection was between 2010 and 2012 and primarily within one county of England. In total, the project consisted of over 300 hours of observations (of policy events; of professional team meetings and patient care provided in hospitals, hospices, doctors’ offices, and in people’s homes), 100 semi-structured interviews, textual analysis and further

longitudinal fieldwork with 10 people, which contained more time of observations and informal interviewing. I wrote the research as a single doctoral thesis that combined, juxtaposed and spoke across the three elements (Borgstrom 2014).

The first part was an analysis of local and national policy discourse to examine the use of the word ‘choice’ and what it was referring to, and what values and practices it was associated with, such as advance care planning. This included studying the text within policy documents, observations at policy events, as well as interviews with policy makers to elicit their understanding of the concepts used and how they came into being within the policy-making process. My focus on policy here was to understand how the discourses set values for care, influenced how healthcare professionals viewed and did their work, and how policy values intersected with people’s experiences of their own lives in the context of life-limiting illness. My analysis of policy illustrated how end-of-life care created dying and certain kinds of death as problems that could be solved through managed (and predominately medically-supported) care (Borgstrom 2015c; Borgstrom 2016).

The second element of the project involved observing and talking about clinical practice – how choice, particularly though advance care planning, was done or not done. This included observations and interviews with a wide variety of healthcare professionals, covering: a large teaching hospital; several city and community hospitals, including specialist services; a hospice; three care homes; and several general practice and community nursing services. For example, I spent weeks visiting an out-patient hospice day therapy unit where nurses, allied health professionals, and volunteers worked with patients on managing their symptoms, including anxiety, talked about care planning, and provided general chitchat and social activities as a form of respite. I also shadowed specialist palliative care teams in hospitals and the community to understand their daily work practices and observe when and how they decided to do advance care planning with patients. Where possible, I also collected and analysed documentation used in these places, such as care plans. This approach to research enabled me to see how forms for advance care planning were used, and in some cases, became proforma that marginalised the very person-centredness they were designed to capture (Borgstrom 2015a). Overall, what these interviewees and settings had in common, which an ethnographic approach enabled me to analyse, was how they defined end-of-life care as something that was part of their responsibility as a health and care issue and prioritised care on the basis of a person’s diagnosis and prognosis.

The third element primarily involved interviews with those who could be considered to be towards the end of their life (defined by policy within the last year of life usually related to a life-limiting illness), or caring for someone in this condition, or likely to be considering end-of-life care issues. I ‘recruited’ these participants through condition or caring-related support groups (some of which I visited for several months) or through clinical contacts (such as the hospice and specialist palliative care nurses). Most people I only interviewed once or twice with interviews lasting from 45 minutes to several hours, and I ‘followed’ another 10 people (and their families where possible) for up to 14 months. In the latter cases, I regularly visited them and participated in ‘daily living’, including going shopping, discussing the news, and drinking tea. Where possible and with consent, I accompanied them to clinical appointments and/or had access to their medical records. For this part, the methods I

used were about being with people and to experience, to some extent, their ways of being in the world. This demonstrated analytically that whilst end-of-life care policy is very individualistic in its interpretation of choice, people view it and their health in more relational terms (Borgstrom 2015).

For all parts of the project, interviews took place in a location suggested by the participant – sometimes offices, hospital cafes, or in their homes. With consent, interviews were audio-recorded, although for practical reasons longer visits or excursions were not audio-recorded. From all of these encounters, including observations, I made fieldnotes and kept a reflexive field diary. These enabled me to keep a record of things that appeared salient at the time – how a room was laid out, the tone of the encounter, what stuck with me – and feedback to myself on how I may approach questions differently in future encounters. Not only can such notes be useful for future data collection and provide contextual data in analysis, but fieldwork notebooks are also a space to cultivate the ‘imaginative logic of discovery’ (Tausig 2011). Therefore, rather than assume that what I observed and heard was fixed knowledge, such notes helped me see how what I came to know and write about end-of-life care evolved and what could be known when different kinds of data and accounts were juxtaposed with one another.

Clinical colleagues: a critique of method

Within a health department, many of my colleagues had little formal training in ‘social science research methods’, and tended to label me as a ‘qualitative researcher’. But this did not mean they accepted what I was doing... the first line of criticism was the subjective nature of the study. Fieldnotes ‘contaminated’ by my personal filters about what to record and how to do this, as well as my presence (akin to the Hawthorne effect). Colleagues questioned how I intended to minimise or control these elements; at worst, it was suggested that whatever data I collected and regardless of how I analysed it, it would be somehow inferior to ‘more objective’ modes of research. Even those who were ‘sympathetic to qualitative research’ were troubled by the potential variability within ethnography as a method. There were presumptions about the importance of pre-determined interview schedules, the numbers of interviewees (the more the better usually)...I was doing something that felt radically different in this work environment, even if ‘pro-ethnography’ pieces had been published in medical journals before (e.g. Reeves, Kuper, et al. 2008; Savage 2000).

From conversations I have had with social science colleagues, both within the departments where I have worked and at conferences, these types of reactions to doing ethnographic research are not unique to my experience. It is evident that working at the margins, where an ethnographic approach is not the staple method of one’s colleagues, other standards and approaches to knowing that privilege ‘evidence’ and ‘science’ are present, and as such, ethnographic approaches can come across as questionable and somehow ‘lesser’ (see also Dey 1993). My encounters with colleagues suggested that we had different presumptions about what health is and could be, and how it could be known, with their focus on framing research as solving known problems or testing theories. In part, this tension sits at the fault line between qualitative and quantitative methods, and debates about art versus science (Fuller 2002).

In response, I stressed the ability of an ethnographic approach that was able to take a topic – such as choice in end-of-life care – but not predetermine what is important in terms of how it is defined, how it is done, and what the consequences of it might be. I noted that I was seeking to understand something that we did not know how or when it happened, and therefore it was only through the uncovering processes of the methods I was proposing that I could begin to locate the object of study. Anthropologists' own comfort with ambiguity, and to assume that the 'taken-for-granted' can be made visible, allows for the suspension of *a priori* beliefs as part of the research process. I drew on the anthropological trope of 'seeing life from others' points of view' to legitimise this, particularly noting how through engaging with people over time inevitably implied that our encounters would draw on previous discussions and changes in their circumstances since we last spoke. Not only does this mean that an ethnographic approach can be less prescriptive than other methods, but in doing so we accept that our focus of study – and indeed the various kinds of knowledges that a study may produce – can be beyond our current comprehension of the issues at hand.

These encounters with colleagues made me very self-aware of how I was doing 'data collection' as a process, but a different kind of process than just considering it as 'fieldwork' or ethnography as a perspective (c.f. Wolcott 1973). It meant my methods had to be accountable to others even in how I held open the possibility of being flexible and not pre-determining the analysis or findings. For example, I recorded number of hours of observations and number of interviews, creating and structuring metadata in ways I had not originally intended. Overall, working within this multi-disciplinary environment made me appreciate how in order for my research to be taken 'seriously' outside of my own discipline I had to present my research in particular ways, such as quantifying data collection, without compromising my epistemological position.

The Ethics Committee: ethnographic approach as sensitive

When preparing my applications, many of the questions on the standardised forms pertained to the randomised-controlled trial (RCT) model of research, presuming health research is focused on a prescribed intervention intended to affect someone's health and that effects of this can be observed and measured. The trick to completing these forms it seemed was to be detailed enough about my intentions of actions –breaking it down into components of participant-observation, interview, document analysis, and potential sites – but vague enough to enable me to change direction during the study as it unfolded, and to justify this. I was lucky to have a committee member who was familiar with participant-observation who could vouch for 'the method' during the ethics committee's three-hour long deliberation of my study. Moreover, they were 'relieved' upon meeting me to see I could be sensitive enough not only to handle the topic and 'vulnerable patients' appropriately, but also to manage the flexibility inherent in the project I was proposing.

I will address three issues about my experience with these formal requirements. One is the lack of awareness about what ethnographic research is, and the importance in being able to make claims about it. The second, which is related, is how these kinds of committees and governance structure knowledge, and how as ethnographers we can

promote the kinds of research we do within these frameworks. Lastly, I will comment on the role of identity in these encounters.

Justifying an ethnographic approach can become about claiming it is '*a practical choice from one of several alternatives*' (Taylor 2002:3). As I note above, I was 'lucky' that one of the ethics committee members knew about participant-observation prior to my application, and could 'vouch' for it as a 'legitimate and appropriate' method. Bracketing the collapsing of participant-observation with the entire project (even though I outlined other methods), without this person I would have probably had to spend more time in the meeting than I did describing not only the specific methods and study rationale, but the deeper methodological and epistemological commitment the research was based on. Not only were most of the members unfamiliar with the kinds of methods I was proposing, they were also less familiar with inductive styles of research, open questioning and the prospect of flexible research encounters, and therefore felt under-qualified to pass judgement on the relative 'riskiness' of the proposal, as one member told me during the panel meeting.

This was a particular issue because of their concern that, being a study about end-of-life care, participants would be inherently vulnerable (see Koffman, Morgan et al. 2009). Whilst my research was not the first to interview people during this phase of life or to even do observations on dying (see also Lawton 2000), the ethics of doing death-related research is still discussed (Cook & Bosley 2007; Kendall, Harris et al. 2007; Borgstrom & Ellis 2017). It was therefore important that I could make substantiated claims about not only the suitability of the match between research questions and methods, but also the ability of my research approach to be 'sensitive' to this potential vulnerability and, for example, 'meet' participants where they were at emotionally. This flexibility also meant I did not presume what would be important to people to discuss about end-of-life care. One of the defining features of social theory is its ability to be sensitising – to point out areas to examine but not claim to be definitive about them (Blumber 1954), and I argued that an ethnographic approach can be both sensitising and sensitive through seeking to follow potential participants' perspectives and lives, and negotiating the research process with them. This is important because ultimately my research on choice and advance care planning contrasts with most of the research on the topic, which seeks to identify barriers and facilitators, rather than, as this ethnographic research suggested, we should rethink what choice is and how it operates in this context.

Now, I realise that for many anthropologists and ethnographers, what I am saying may seem redundant. Yet, it is important to note how they can be deployed strategically as these encounters are moments in which the value of different kinds of ways to produce knowledge are adjudicated on. And that we are actually in many cases in a position of authority to make claims about the method we are proposing. Research ethics committees are supposedly about a risk/benefit analysis of the method within the remit of the particular study (Tolich & Fitzgerald 2006). This is a false impression as the feedback and 'opinions' (as they are not strictly called approvals) that they provide pass judgement on the value of the study (and components within it) to 'science', clinical practice, the potential participants, and overall societal value. Their comments can effectively change the nature of a project.

There is a bias within the forms one must complete as part of process towards certain ways of thinking and doing research; they frame health as something to be intervened upon and social aspects to be controlled for. Others have commented on how these do not necessarily fit a more qualitative or even mixed methods approach (Ramcharan & Cutcliffe 2001; Wynn 2011). The ways in which the forms are constructed suggest particular ways of doing a project – usually in the framework of an RCT – are the preferred ways of conducting high-quality research. What is important then for those like me having to complete these forms is to not only justifying the method, but the kinds of knowledge that this kind of approach can produce. In this instance, as with clinical colleagues, I had to shift their focus from presuming knowledge production should be about how to best do advance care planning or measuring the most effective ways of doing care planning. Instead I demonstrated how anthropological interests in how policy, healthcare practice and people’s experiences interact to enable an understanding of how ‘choice’ is understood and operationalised in the context of end-of-life care.

Lastly, the committee were also passing judgement on my character as part of their assessment in my ability to conduct this study. Writing about his research with Jewish communities, Shaffir notes how *‘the way we are perceived can greatly influence how others respond to our work’*, with the most critical response being to *‘the researcher’s human qualities’* (Shaffir 1998:58). In my example, as with Shaffir’s work, the assessments of the researcher’s human qualities are intertwined with how the research objectives are understood by others. Since I wanted to study end-of-life care, both my answers in the boxes of the forms and my personal presence had to ‘convince’ the committee that I was “sensitive and sensible” (as stated in the meeting) and therefore considered to be less of a risk to the (potentially) ‘vulnerable’ people I would be spending time with. As part of their role as ‘protectors’ of potential participants, they wanted to be ‘reassured’ that both the methods would not be blunt, but that the instrument conducting the study (me) would be ‘sensitive’. I think that in this instance, my ability to display characteristics that ‘reassured’ them about how I would do the study was as important as justifying the methodological fit and procedural decisions that are detailed in the forms. In essence, they were making a decision about who could do this kind of research: someone with the methodological rationale, technical expertise, and interpersonal sensitivity. The consequence this has for understanding ethnography in this context is that it is more than just method, it is also about the ethnographer, and therefore methods are not just about a way of being but also of how being is perceived.

Recruiting: describing fieldwork

Unlike how I was taught about traditional fieldwork, where the anthropologist showed up and lived in a village, serendipitously encountering people and learning about how they lived, I had to actively recruit people to my study. I visited different support groups and hospices, giving short talks about my research to gauge interest and enlist potential interviewees and people ‘to follow’. To foreground the ethnographic approach, I highlighted how I was interested in them as people and what their lives were like.

As part of the study, I had to formally recruit people to interview and ‘to follow’. To do this, I deployed the trope of traditional anthropological fieldwork as a means to

outline the kinds and variety of methods used, particularly the ‘hanging out’ aspect of the longitudinal element. I also highlighted the wider commitment to not pre-determining what the main issues are and therefore being adaptable to both people and circumstances. In this section I reflect on what the use of this trope allowed for but also limited in terms of how the study unfolded.

Firstly, I noticed how the use of this way of describing the research, rather than employing only technical terms with predefined number of research encounters, affected who was considered ‘an appropriate participant’ either by themselves or others (e.g. institutional gatekeepers in care settings, see also Witham, Beddow et al. 2013). For those that were interested in the longitudinal element – that is more than a single research interview – they often cited their willingness to talk about anything as a quality that qualified them for the role of participant. Some of them admitted that they wanted the social company that regular research participation seemed to offer, and this was particularly noticeable towards the end of the study when people were upset that our visits would soon stop. In addition to welcoming my presence and listening ear, people had to be to various extents, willing to open up aspects of their lives to a stranger, including elements that are rarely viewed by themselves (such as their medical record). How the ‘fieldwork’ was described meant that there was an element of (self) selection of what a ‘participant’ should be like and be willing to do. It also reflects wider issues in end-of-life care about how ‘choice’ is often perceived only through verbal and active responses from people who have the willingness to share these elements of their lives and perspectives with others after being asked to by a person in authority.

In some instances, nurses recommended patients who they felt ‘needed to talk’ or who would ‘benefit from talking’ to me, viewing the research engagement as a potential extension to the care provided. The healthcare professionals viewed what the ethics committee considered as the ‘sensitive’ nature as ‘therapeutic’. This selection of patients as potential participants suggests that the healthcare professionals presumed that there are certain issues that people should process before death, especially through talking, and that perhaps there was not always adequate time or resources to accommodate this talking within the services they provided. Viewing talking about end-of-life care as beneficial shows a shift in care values since the 1960s where many patients were not even told they were dying (Glaser & Strauss 1965); however, the structural spaces of care may not always allow for this as implied by using research to fulfil this need to talk.

There were limits to adopting the ethnographic approach as I did. For example, although we joked that as an anthropologist in Britain (with a husband and a ‘job’ as they saw it), it was perhaps not as socially appropriate for me to ‘live with them’ as the traditional trope suggests (see Hockey and Forsey 2012), this lack of on-going presence meant that there were often gaps in my ability to know about developments in their care (i.e. emergency hospital admissions). These omissions were sometimes willing on their part or they thought I might not be interested. This was further articulated by the ways in which people restricted the engagement of other family members or friends in the project (i.e. suggesting we meet only when spouse was not at home) and the spaces in which I was made to feel welcome. In this way, these boundaries of the research were set by the participants, and shed some light on how issues of dying and sharing personal perspectives may be similarly hidden or revealed

within families and between families and healthcare professionals. Yet, due to my reliance on and joking about the traditional trope of ethnography to initially explain my research intentions, they may not have always fully appreciated the extent of my interest in their lives more generally as part of my attempts to understand end-of-life care in the widest context possible. The flexibility that had been built in by trying to tap into the mythical ethnographic ability to know the lives of those under study also enabled the very same people to shape what could be the subject and course of the research. This ability to shape what could be known and documented paralleled how people did not always engage with advance care planning documents as policy intended – the gaps, impartial context, and incomplete forms mirrored the inability to capture all and the necessity of responsiveness in engaging with the person.

Discussion

By adopting an ethnographic approach, I sought to talk about a ‘way of being’ within our research contexts (Law 2004), in a way that talking about research as a noun does not allow for. This way of being can include how one wants to do research, how one positions themselves and their identities in relation to others in research endeavours, and how ‘*being with*’ and ‘*being there*’ as part of one’s research engagements (Hockey and Forsey 2012:75).

When I present my research to different audiences, I try to often incorporate these different elements of being alongside the different kinds of data collection and knowledges that the study produced. Through this I become part of the story I tell. Each (re)telling risks the critiques and comments that I experienced on the way – subjective research, concerns about rigour, bias in sample – as well as the risk that it may not be viewed strictly as ‘ethnography’. Yet, I have found that by being able to make links between healthcare policy, practice, and people’s everyday experiences, what I write and talk about ‘makes sense’ to people in a new way. For example, hospice workers have told me that hearing how I interweave policy understandings of choice, structural limitations of healthcare provision for advance care planning, and accounts of how people live enables them to think differently about how they see patients, and themselves, as people. Not only as people but people whose lives can be influenced by things (e.g. policy, hospital culture) that are not always within their control despite the choice rhetoric. An ethnographic approach, although not always well understood or accepted as a methodology, has the ability to ‘speak to’ different audiences through the connections it makes and the positionality of the ethnographer.

Adopting an ethnographic approach enabled me to explore facets of English end-of-life care and present different kinds of knowledges about it. Firstly, it enabled me to argue for seeing end-of-life care not only as an element of healthcare, where biology of dying determines patterns of death, but as a social and cultural construction and process. Through an analysis that juxtaposed policy, healthcare practices, and people’s everyday lives, I was able to write about how the values, actions and experiences interacted. In this study, I was able to demonstrate how dying and end-of-life care became defined within policy as ‘problems’ for the English healthcare system and what solutions were proposed – pre-dominantly patient choice and advance care planning. I was able to observe where, how, and when ‘choice’ was done – but more often not done – and how people lived relational lives outside of the

health constructions of end-of-life care. Such an approach brings to the fore and challenges the normative assumptions within healthcare systems and policy about what the focus of end-of-life care should be.

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