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Researching death: Some reflections on life

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A Viewpoint Paper

Abstract

Purpose

The paper makes reflections on some ethnographic work undertaken with dying patients. My reflections cover the practical and social implications of doing this work but also the emotional impact it had on me.

Design/methodology

Although this paper is a viewpoint paper, I take my verbatim quotes and observations from an ethnographic review of End of Life services in one London borough in 2009.

Findings

My main findings are to consider the use of open-minded, independent researchers to undertake reviews and assessments, even if it does seem outside their area of 'expertise'. This is because their impartiality from the area may be beneficial. Secondly, I suggest that multi-agency 'politics' can be detrimental with regard to commissioning work which directly informs policy. Lastly, I appeal for there to be greater consideration of ways of allowing frontline workers to listen to patients' and carers' concerns about death and dying.

Originality/value

As far as I can see, there has been little work which has made practical, social and emotional reflections on the area of death and dying.

Key words: death, dying, research, emotional impact, reflexivity.

Introduction

As you begin to read this article you might be thinking 'why is this guy (who teaches criminology) writing about researching death?' You may be right to be curious or even have doubts. I don't mind. In fact, I am used to it. You may question my 'expertise' to undertake any kind of work in this area. While I don't have experience it shouldn't mean that I cannot research this area. On the contrary, the fact that I am a researcher does qualify me and this is what I argue in this viewpoint paper. I offer this through reflections on a project I undertook in 2009 which sought to review of End of Life (EOL) care for terminally-ill patients in one London borough. The reflections I make are as a researcher undertaking this work on three levels: the practical level considers the way in which the review was commissioned and why I was put forward to undertake it; the social level which discusses the consequences of the review despite fears about its impact on the patients and carers; and the emotional level which is more about how it impacted on me as a researcher.

The practical level: Commissioning the EOL review

In October 2008, I was working as a contract researcher. Each month was drastically uncertain. I was working in the Social Policy department in London South Bank University when an email was circulated asking for short tenders to undertake a needs assessment for terminally-ill Chronic Obstructive Pulmonary Disorder (COPD) and cancer patients. It sounded interesting and with potential redundancy looming, I submitted a proposal. To my surprise, and despite no experience in the area, I was shortlisted in November and asked to undertake the work. Over the course of a month, I conducted qualitative interviews with twelve patients with COPD and cancer and four carers, and wrote the report. It was very different to my work with people on the wrong side of the law and I welcomed the change. The assessment was not considered to be 'research', and probably because of the quick requirement of the funder, certain strings had been pulled so they could perhaps say they had done it or fed the findings back into policy. Hopefully it was more the latter.

When I attended into one of their many meetings and presented my findings, it seemed as if I had done something right. Most seniors in the Primary Care Trust (PCT) didn't seem to mind that I wasn't an expert in the area. In fact, maybe being someone outside the bureaucracy and 'expertise' looking into an area with no experience and making sense of it seemed to have been beneficial. During that meeting, I had a decent amount of licence – more than I have ever had with other funders working in the criminal justice sphere. Although I didn't understand all the acronyms and buzz words, I was questioned directly on matters related to my findings. However, when other PCT partners spoke about current issues, I sensed a tension between them. I was, fortunately, outside these dynamics and treated with respect. The report was warmly welcomed and they contacted me shortly after in January 2009 to undertake a larger piece of work reviewing EOL care in the borough.

Having undertaken the previous work, I was quite excited by this new project. It required me visiting care homes, hospitals, patients' homes, and hospices. The only experience I had of some of these institutions was when my grandmother was dying. She was shipped between hospital and care home, from hospice to care home and back again. However, when I sat down with the PCT Commissioner and the EOL Strategic Lead and a few other practitioners relevant to the field, this time there seemed to be a little more curiosity about my 'research ability' in this area. They were also extremely cautious about me interviewing people on their deathbeds. Certainly the EOL Strategic Lead seemed to probe me on my 'experience' in this respect. Once again, I could only concede that apart from my experience on the previous work, I had little other specific experience. I reiterated my commitment to research and studying sensitive areas of social life and this seemed to reassure them somewhat.

The brief was to interview 50 terminally-ill patients and carers representative to the borough, analyse the data and write a full report in three months. Now I am industrious but this was quite ambitious given that I was also still managing a project in Greenwich on mentally ill adults in the community. They agreed to facilitate my access to the relevant agencies to speed up the process. Over the week that followed, they seemed to be able to get most on board; palliative care nurses in hospital, hospice staff, and most of the care home managers (although they seemed careful to hand pick which care homes I was to visit). However, they could not seem to get the voluntary sector on board and two key agencies remained defiant over their involvement. Both were agencies which had frontline contact with terminally-ill patients and carers, predominantly in the high-rise urban estates

in the more deprived areas of the borough. If we could not get these agencies on board, the review might be skewed; that's to say, we would miss key groups in deprived areas.

When they initially refused to take part or help in the review, the EOL Strategic Lead coaxed me into trying to set this up myself - after indicating they would facilitate access. I was calling cold and it didn't go down well – especially when I said the review was PCT funded. A series of vociferous email exchanges and phone calls followed between the EOL Strategic Lead and the voluntary agencies. Indeed, both representatives had got quite aggressive and defensive on the phone to me. While one agency refused to meet, when the EOL Strategic Lead and I went to meet the other agency representative, she highlighted the practical and ethical issues associated with the review. She said I was not qualified to be asking questions when I wasn't 'an expert' and protested at the way in which 'her clients' would feel about reflecting on service provision at a sensitive moment in their lives. Once again, I reiterated my experience of sensitive interviewing in the context of prisons, street crack cocaine users and illegal immigrants. This, it seems, was not enough and the agency refused involvement.

The social level: Existential reasoning and dealing with fragility

Perhaps these barriers at the beginning of the research were more about the relations between the PCT and its partners than about the review or me as an 'inexperienced researcher'. I followed the access granted through the hospitals, hospices and care homes and was called when patients and carers consented to interviews. When I started to interview the patients and carers, they could not have been more accommodating. The difficulty was fitting interviews around their fragile state, family commitments and perhaps medical appointments. Sometimes I had a few hours notice to get to the borough and sit down with them. I made sure I was polite when I contacted them. Unfortunately, some, having consented to participate, died before I could reach them. Nevertheless, those who I did get to were very warming to the idea of the interview; not only to reflect on service provision it seems but to also discuss coming to terms with the inevitable:

They gave me a year or two or less. Could be tomorrow. I am frightened. I don't know how it is going to end. I don't sleep at night. I am gasping for breath. Do I die like this in my sleep? Gasping for breath? I could be wrong. I could be here for six years. [Gladys]

Some like Gladys (all names are changed for confidentiality) seemed relieved to talk to me about other issues aside from service provision; perhaps it was some sort of existential reasoning. One man who I interviewed said he had just been diagnosed with liver cancer and had "*days to live.*" At the beginning of our interview, he was defensive and towards the end he seemed to feel guilty about it and asked me to call back in a few days. When I did return the call, he seemed totally different – "*I am comfortable with the condition*" as he put it.

What impressed me most, regardless of the quality of care these people were receiving was their ability to deal with their fragility. Some found it difficult but wanted to be independent or continue to try and do something to maintain some sense of purpose – to cope with their condition. Ayesha, who was diagnosed with lung fibrosis and confined to her bed with an oxygen mask, found it difficult to not be active: "*I try to do activities by myself, I like to be active but with this sickness I can't do nothing. I don't want to be statistic. This is not my nature so I pray to god*" she reflected. Ruth, who

had recently been diagnosed with cancer, insisted on trying to maintain her independence by rejecting care and support, despite living alone, having difficulty on some days with her arthritic hip and living on the third floor of a council block: *"They said if I need any help cleaning or that I can get it but I prefer to do it myself, its not hard, its only a little small bedroom flat."* In fact, far from the client who would be afraid or upset with talking about services (and even their condition and impending death), most appeared to find the interviews therapeutic.

Even the most vulnerable ones seemed to be taking these steps to deal with their condition, despite the harsh barriers. My field notes recorded a visit to an elderly black man, his wife and two children in their third floor council flat:

It is difficult for Abdul to get around. His feet are severely swollen and he can't move up and down steps. He lives on the third floor of a council block with no lift. He lives and stays in one room. The room, he smiles and says, is a *"living room, pharmacy, bedroom, whatever you want"*. This gets him down and despite frequent letters and bids through the housing system; they are still stuck in this accommodation. They also have to find room for their two sons. They were desperately looking for a way out of their accommodation and, as I left, Polly showed me an old lottery ticket which she had bought in an effort to get out of their situation. *"I tried to win 100,000 but have not had any luck yet."* [Field notes]

Paul, who was diagnosed with cancer and schizophrenia, rarely had family and friends visit. Furthermore, his wheelchair did not fit through the door and he rarely left the flat. Living alone, and only in the brief daily company of carers and district nurses, he reflected on his current situation:

Paul: *The wheelchair does not fit through easily, so if you try to get out, you bang through the doors.*

Dan: *Do you wheel yourself out or try?*

Paul: *No, a carer has to do that – I want to go shopping but they would rather not I do that sort of thing.*

Dan: *Why?*

Paul: *It seems a bit of a hassle for them, so they go and bring it back to me.*

Dan: *Would you like to do those things?*

Paul: *Yes, but I need a person to push me.*

After the interview, he asked me to do a few favours for him. I closed the window, put the TV on, turned on the heater and passed him a book. For me, looking into this area of social life was rewarding. I felt I was gaining experience. In other examples, Edith, who lived alone and had cancer, frequently burned herself on her cooker as her eyesight deteriorated. She had convinced herself that she was still *"self sufficient"* and that the burns didn't matter. Bob, who had bladder cancer, lived alone in a basement flat. From time to time he got depressed, but had tried to 'get out and about' to live his life. My field notes recorded the moments entering his flat:

When I arrived, as with a few other elderly gentlemen, the flat was very messy and dusty. It was dark and damp. Bob was also heavily medicated and, at times, found it difficult to put words in order. He found it difficult to get out of the flat because of the steep stairs from the basement to ground level. He had tried to get out to the front garden to be active outside but had fallen quite a few times. [Field notes]

When I arrived at PCT meetings, gave them interim reports and even after they had fed back from the final report, they seemed surprised at my findings. Not because they confirmed anything they perhaps didn't know, but the accounts and stories were graphic. The people were not numbers, graphs or figures in statistical reports and performance reviews. Nor were they all helplessly lying on beds, with their arm out about to utter deep words of wisdom on their last breath of air. The people I had written about were alive and were dealing with their condition (or at least trying to). They weren't pushing any self destruct buttons but were looking for meaning in their last days. PCT providers probed me less on the report findings but more on Paul's concerns or the condition in Bob's flat. They asked me what the flats and patients were like. Surely they should know. It gave me the distinct impression they hadn't been out of their offices much because of various meetings. This seemed to be confirmed when one policymaker confessed to have never been in a care home. I wondered what qualified them to be making policy if they hadn't met people such as Paul and Bob. What experience did they actually have?

The emotional level: Reflexivity gone wrong

It was only after I handed the final report to the PCT that the review and what it meant to me emotionally started to catch up with me. It wasn't a depressing feeling as such, perhaps almost comforting in a way. That is, to meet people who are dying, to listen to them about their experiences – whatever they divulge - and maybe help them in some way. Even if it is to allow them to unload their concerns and feelings about their conditions, their family politics or ask me to do a few favours around the flat before I go. At least, it seemed like I was acting as an ambassador for their thoughts and feelings because I got the impression that most patients had not even discussed these issues of death and dying with their families. They had certainly not approached the professionals about it and were reluctant to do so since most, as they saw it, 'dropped by' to do practical day-to-day duties for them.

I certainly think differently about life now as I see ironies of dying and death. For example, in one north London town centre, there is a tobacconist next door to a cancer research shop, and two doors down a funeral directors; it is a one-way street. On a deeper note, the review did stimulate another personal 'adjustment period'. When I undertook my first research project in prison in 2001, I was listening to accounts of murder, abuses, destructive drug use and various forms of suffering. I guess I was adjusting to the research narratives because during the fieldwork I started to have vivid dreams of waking up with corpses in my bed and robbing people. When I started undertaking ethnographic work with crack cocaine users in 2004, a similar adjustment period followed. I dreamt of all-night crack binges and waking up in police and prison cells. A similar adjustment seemed to happen when I undertook this work, except this time it was my death I was visualising. Dreams and thoughts of how I would die, where I would be, who would be at my funeral. It was like reflexivity gone wrong. Up until this point in my life, I was able to rewind and revisit past memories and

thoughts but now I was fast forwarding to the end. It's OK by me though because now I am prepared for the worst which is why I am always at my best.

Discussion

In this short article, I have tried to highlight how some professionals had concerns about me undertaking a review in an area which was outside my expertise. I hope that I have shown that it is possible for such a researcher to undertake this kind of work; someone who is perhaps outside the dynamics, tensions and pressures of PCT life but not entirely aloof to what is going on. Indeed, it seemed that at times I was being used as a political pawn – contacting agencies where the PCT had poor relations and left to try to secure interest and support for the review. However, I still managed to get the job done and despite concerns about my 'experience' and 'qualifications', the report seemed to resonate both with the patients and carers I was able to revisit as well as the PCT members and other practitioners sitting around the table. I concede I have no relevant formal qualifications in this area; only my interest in *helping* people *help* the people who need most help as they leave this life. At least I have now gained some experience, so maybe this makes me 'qualified'.

Implications for practice

- Consider the use of open-minded, independent researchers to undertake reviews and assessments, even if it does seem outside their area of 'expertise' – their impartiality from the area may be beneficial
- Try to avoid letting 'politics' interfere with commissioning work which will inform policy – this can potentially skew the findings and future provision for the populations which are missed
- Consider ways of allowing frontline workers to listen to patients' and carers' concerns about death and dying – after all, we are all human

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