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Appendix: Research and Methods

The stories in this book have come out of encounters and relationships – interviews, ethnographic observation and anecdotes – drawn mainly from a hospice ethnography and a narrative-based project called ‘Stories That Matter’ run by the voluntary organization *Priae* (The Policy Research Institute in Ageing and Ethnicity). I have also drawn upon my teaching experiences in palliative care and from my membership of various working groups in palliative care organizations.

The hospice ethnography was a three-year doctoral research study that began in 1995.¹ I had started off trying to research and compare two sites: a hospice and a local teaching hospital. I spent one-day a week for six months accompanying two Macmillan nurses at the hospital. I also carried out five group interviews with doctors and nurses there. I had wanted to interview patients, but towards the end of my fieldwork I had conducted only four interviews and there were few people from ethnically minoritized groups on the nurses’ case load at the time. With the advice of the nurses I decided to focus upon the hospice ethnography.

The ethnography entailed hundreds of hours of being in the hospice and accompanying nurses on visits in the community. I spent three months observing two different home-care teams. I also volunteered in the hospice day centre for six months, working one day a week, helping with a pottery class, making and serving drinks and food, talking to patients and cleaning-up. Whatever it was that I was doing, I made notes everyday of my observations, experiences and feelings. I also organized what I called ‘emotions in fieldwork’ supervision sessions with Colin Murry Parkes, a psychiatrist and global expert in grief and loss, who had worked with Cicely Saunders in the early days of the hospice movement. We met every six weeks or so during my fieldwork, and the sessions became a space

for me to explore my feelings, dilemmas and thoughts. Each session was tape-recorded and transcribed, becoming integrated as a part of the study's 'data'.

The discussions with Colin were important in recognizing and responding to the emotional demands that I was facing in working with dying and loss. They also provided a novel approach to reflexivity in research, as a practice which aims to interrogate how tacit assumptions and one's own social positioning can affect the research process. A shortcoming of reflexivity, is that lone researchers, or indeed research teams, have vested interests and unconscious biases that can lead to blind-spots and collusive tendencies. It is a predicament of modern knowledge production that the philosopher Michel Foucault saw metaphorized in Diego Velázquez's painting *Las Meninas* (painted in 1656), that plays with ideas about perspective and the relationship between inside/outside.² For Foucault, one of the questions posed by *Las Meninas* is whether it is possible to be both inside (subjectively involved) and outside (distant and objective) a social scene, or in Foucauldian terms, a power-knowledge nexus.

A difficulty with critical reflection in research or for care practitioners is its superficial interpretation. Describing and thinking about what you have done, or how you felt at the time, so often becomes an easy stand-in for critical reflective practice. It fails to engage with what we cannot see, or worse still how we negate other experiences by incorporating them into our own experience and viewpoints. 'Any purely reflexive discourse runs the risk of leading the experience of the outside back to the dimension of interiority' Foucault argues, continuing

reflection tends irresistibly to repatriate it to the side of consciousness . . . it risks setting down readymade meanings that stitch the old fabric of interiority back together in the form of an imagined outside.³

Opening up the research process to those who are independent from the research and who also bring with them very different worldviews is something that I found valuable in helping to question and contest my interpretations. Towards the end of the hospice research, I also experimented with setting up a 'talking wall' type installation in the hospice, where I summarized and displayed key findings, together with blank sheets of paper where responses to the research could be recorded.

The hospice study involved: 33 interviews with 23 patients; migrants mainly from South Asia, Africa and the Caribbean; and 14 group interviews with 38 members of staff. Five of these discussion groups were held with three white women social workers over a 12-month period, giving me a deeper insight into the quotidian unfolding of hospice life. All of the hospice interviews were in English, tape-recorded and fully transcribed by me.

When I began the research I knew nothing about narrative methods and was nudged towards them by the patients that I was interviewing. After listening to the first of my five pilot, semi-structured interviews, I realized that my interview schedule was being skilfully by-passed. I was being given wide-ranging biographical narratives. Following some haphazard discoveries of literature and training in the Biographical Narrative Interpretive Method,⁴ I moved towards a more open, non-directive approach and this is what I used in the *Stories that Matter* project. The basic idea in biographical narrative interviewing is to start with an open question, some variation of ‘Tell me about the story of your life’ or as I phrased it more narrowly ‘Tell me something about yourself and your experiences of illness and care’. After this first question, the interviewer listens, noting down in chronological order the topics as they are narrated, asking for more narrative about each topic and in the order in which they were raised, but only after the initial freely-associated narrative has been completed.⁵

The single most important lesson that I have learned as an interviewer is that in order to elicit narrative and stories you need to ask narrative-inducing questions. These are open ‘Do you remember what happened?’ type questions, rather than questions that ask directly for opinion, rationalization or feelings. This is because opinions and rationalized accounts of behaviour or emotions can be constrained by what is felt to be socially acceptable or desirable. Some people can find questions about what they think or feel threatening. Opinions are also often pre-formulated and rehearsed, providing insight into autobiographical theory but remaining somewhat distant from experience.

I now see the role of the interviewer, in similar ways to Pierre Bourdieu,⁶ as a midwife to narrative, with questions and attentiveness helping and coaxing a fragile narrative into the world.

My hospice study was followed by three other related projects:

1. ‘Stories That Matter’ – a narrative project for the Policy Research Institute on Ageing and Ethnicity, with ‘minority ethnic’ elders and carers, and health and social care professionals in cities in England (2003–7).⁷
2. ‘The Listening Study’ – on patient priorities for cancer research in the United Kingdom using focus group and nominal group techniques for Macmillan Cancer Support (2004–6).⁸
3. ‘Involving people of diverse ethnicities in cancer research’ – a project using semi-structured and narrative interviews with patients and research nurses in England for Macmillan Cancer Support (2008–10).⁹

All of these three projects have contributed to the writing of this book, especially the narrative interviews in the *Stories That Matter* project. The project involved

33 interviews with elders and carers from racialized minorities and 11 group interviews with 56 health and social care professionals in London, Berkshire, Bradford, Hertfordshire, Nottingham and Leicester. The older people and carers who were interviewed came from a range of ethnic and cultural backgrounds (broadly speaking South Asian, African, Caribbean, Portuguese and Chinese). Fifteen interviews were conducted in English and 17 in the preferred language of the older person/carer. Twelve of the interviews conducted in a language other than English were conducted through an interpreter (Cantonese, Portuguese, Gujarati, Hinkoo). The remaining five interviews were done in Hindi, Punjabi and Urdu by the project worker, Neera Deepak. All of the interviews were audio-recorded (except for one spontaneous and elder-initiated telephone interview with his daughter) and transcribed verbatim by an external transcriber.

There is certainly a difference between what people tell you in interviews and what you can take in when you see them interacting with others or in their home environments *au naturel*, with a grandchild clamped onto a waist, an aroma of spices in the air or neighbours popping in and out for a chat and a spliff. And there is always more going on in interviews than what is being said. Contrary valences and nuances can be conveyed in the tonality of a voice, gestures and switches to dialect. And because most of the interviews took place in homes – and in the case of professionals, in the institutions in which they worked – I was able to see localities, kitchens, bathrooms, institutional cultures and architecture. So as an ethnographer I am not entirely convinced or happy about the often derogatory differentiations that are made between ethnography and interviews (where ethnography is always superior), or the claims that ethnography is ‘naturalistic’ and interviews are not. It very much depends on what sort of ethnography and what sort of interviews you are doing.

Stories, writing, care

The writer and environmental activist Arundhati Roy describes the relationship between stories and human life as a zone of contact where the forces of volition and choice can flow in unconventional directions ‘a kind of reverse colonization’ as Avery Gordon might describe it.¹⁰ Although ‘Writers imagine that they cull stories from the world’ Roy asserts,

I’m beginning to believe that vanity makes them think so. That it’s actually the other way around. Stories cull writers from the world. Stories reveal themselves

to us. The public narrative, the private narrative – they colonize us. They commission us. They insist on being told.¹¹

Roy's poetic observation is not the hyperbole of the artist. Can we not also think of the objects, events, sights, sounds, tastes and smells that we encounter in research (and in life) in this way? Research 'materials' as much as stories can animate and inhabit us. At times they seem to choose us and carry us away with them, revealing their demands and messages at a pace that has little respect for place or mechanical clock time, for whether you are waiting at a bus stop or trying to meet a book deadline.

For Arthur Frank, stories are our companion species. 'Stories work with people, for people, and always stories work *on* people' Frank writes in his book *Letting Stories Breathe*.¹² Yet the way in which stories (read also research materials) work on us, their power over us, is not as one-sided as Arundhati Roy would seem to suggest. The power of stories in the jargon of the social sciences is said to be 'relational'. The meanings and impacts that a story has on those who participate in it and receive it are a part of continually moving properties, energies and connections. Mariam Motamedi Fraser makes this point so clearly with regard to stories as research methods, materials and as relationships, 'for what are methods, after all, but different modes of relating?' she asks.¹³ What is so valuable in these discussions of the relationality of stories and research methods is the restoring of vitality to research and to writing.

Trying to understand, write and assemble the stories that I have gathered here has been slow. Very, very slow. I have produced academic articles along the way. I have also written poems and short stories. And all the while I have found myself returning time and again to the same materials, re-reading transcripts and fieldnotes, listening to the recordings of interviews, picking up sensory clues that I had missed before, understanding the research materials in new ways as my life and thinking changed. There is also something specific in all of this about working with people at the end of their lives and who are often in pain.

I interviewed Ibrahim, a 46-year-old Ghanaian refugee with kidney cancer in his hospice bed, ten days before he died (see *Sweet Chariot*). Ibrahim's pain filled-up the room, pushing itself under the skin of the interview. There were the frequent recuperative pauses that he took when speaking. The restless shifting of his body as he tried to find a comfortable position, the rhythmic whirring of a syringe driver delivering his morphine. All of these sounds burrowed into the audio-record of our conversation that I would return to, layering more detail into the transcript of the interview that is heavily punctured by ellipses – [. . .] – the

transcription code used for pauses. Was that a spasm of pain in the rise and fall of his intonation? Why does that sentence trail off? What was that half-formed word?

During the interview I became increasingly unsure of how to tell the difference between ordinary bodily movements and pain-relieving adjustments. Even the smallest, most innocuous of movements unnerved me.

Do you want to lie down at all?

No it's all right, I am just lifting my leg away.

And then shortly before I took the decision to end the interview there were two more variations on the following type of exchange,

You seem to be in a bit of discomfort now though is it –?

No.

No? You're OK?

If I am, I will let you know.

But would he let me know? At what point would that be? And what sort of pain were we talking about? How to carry on talking and listening when pain is evident but someone wants to carry on with an interview and to tell you their story? How to write a story that is true to the amiguities of sensuality and spirit and to what cannot be known? 'Undecidability . . . names the condition of impossibility that underwrites decisive action', the geographer Clive Barnett has explained of Jacques Derrida's use of the term ' . . . in the sense that what is impossible is founding action on a saturation of knowledge'.¹⁴ Working with the undecidable is what ethics in research and in writing has come to mean for me.

Ethics is not only about what we do (and what we fail to do). It is also about the timing of what we do. It is about responding to and negotiating two distinct but related times: the compelling urgency of acting in the now together with a patient respect and openness to a future that can never be adequately known or planned for, but must still be cared for and oriented to.

This long-drawn-out time of thinking, digesting, being acted upon and hesitant writing, concerns situations and qualities that I think are a trans-methodological excess – a surplus value reaching beyond what any method was designed and intended for. By 'situation' I mean something that happens during research (and in everyday life) that has a punctal¹⁵ quality, a piercing donated by convention that alters the ebb and flow of the routinized processes of research – the question-putting, the listening, the transcribing, the writing-up. A situation is a disturbance that reminds you of, or reaffirms, the indeterminacy of life and meaning. It is space of chora: enigmatic, provocative, generative, spirited.

Despite rigorous, sometimes arduous methodological training, we cannot control or prepare for how such situations will unfurl or makes themselves felt. They can be immediate, such as in those real-time electric intensities in an interview or interaction. They can also accrue and emerge much later as ghostly disturbances, where despite concerted effort and collaborations, a story or event continues to elude and trouble interpretation and analysis. It just keeps coming back, wanting more. It says ‘I’m not finished with you yet’.

I have taken to calling this strange unsettlement and *longue durée* of understanding and writing ‘vital time’; my colleague Nirmal Puwar in one of her profound, off-the-cuff comments has called it a ‘In your own time’. It is a temporality that breaches linear clock time and far exceeds the research cycle that is timetabled and funded accordingly. It incites thinking about how creativity inheres in life and in research materials themselves.¹⁶

The voluptuous curly Sinhalese alphabet is an example of what I am talking about, about how materials can cultivate and draw out thinking and writing. Michael Ondaatje

I still believe the most beautiful alphabet was created by the Sinhalese. The insect of ink curves into a shape that is almost sickle, spoon, eyelid. The letters are washed blunt glass which betray no jaggedness. Sanskrit was governed by verticles, but its sharp grid features were not possible in Ceylon. Here the Ola leaves which people wrote on were too brittle. A straight line would cut apart the leaf and so a curling alphabet was derived from its Indian cousin.¹⁷

I started off writing this with stories and methods in mind and I have found myself thinking about good care in this way, as being pulled and inspired by the bodies, objects and spaces that it encounters. I hope that this movement between what is good care and what is good research and writing flows throughout the book.