

Methodology overview

To explore family experiences of living with life-threatening illness, this PhD research involved conducting 39 repeat in-depth interviews with members from nine different families. All the ill individuals involved in the interviews had a cancer diagnosis (in most cases prognosis was terminal). Some also had other illnesses as well - but the cancer diagnosis was essentially the trigger which led to their involvement with hospice care and therefore to them being part of the research sample. In each family a patient attending a hospice day care service was recruited (via hospice staff) and asked to invite their family members to be involved in the research. In total nine patients and 14 family members participated in the interviews which were conducted over a 12 month period. Where possible, by conducting repeat, sequential interviews, a more sustained picture of family life and not just a 'snapshot' was gained.

During the same fieldwork year and over a period of seven months, I conducted participant observation on a hospice inpatient ward where I performed the duties of an inpatient volunteer and participated in informal conversations with patients, their relatives and different staff members. The families I encountered here were not involved in the interview element of the project, though I did visit some of my interview participants when they were admitted onto the hospice ward. The participation observation allowed me to explore what family life is like towards the end of the illness process and when someone is in the very end phases of their life.

Appropriate NHS ethical approval for the study was granted.

Research context & participant info

The people who took part in this research lived in a town in the north of England. Its ethos and character can be described as generally working class - owing in large part to the fact that it was once a strong-hold of heavy industry. In terms of the ages of my participants, the ill interviewees ranged between 51 and 78 years, whilst the age spread for family members interviewed was between 13 and 76 years. None of the individuals living with cancer were in paid employment, though two were of a typical working age - in their 50s. Of the nine family members (from a total of 14) who were of usual employable age all were in employment - paid and unpaid.

Regarding the relationship between the ill person and the other participants in the study, I recruited in total, one husband, three wives, one son, six daughters, one sister, one granddaughter and a close friend, who was described by the ill person as, 'like a daughter' to her. These relationships were important because I approached ill participants as family members first and foremost, and considered

them within a family dynamic rather than seeing their experiences and those of fellow family members as separate.

Interviewing Process

To try and work with families where the ill person had less advanced disease and was likely to live for a length of time which was conducive to participating in repeat interviews over a period of at least three-four months, I approached a hospice day unit team for help with recruitment. It was decided that I would not approach patients directly, but that staff would do so on my behalf. They mentioned the research to patients whom firstly they felt were well enough and would not be adversely affected by taking part, and secondly that fit the research criteria in terms of having regular face-to-face involvement with family members. To keep the family focus of the research I stipulated that by 'family' I was referring to blood relatives or individuals connected to the patient by marriage or partnership. By suggesting that these individuals should be 'close' to the patient, I tried to ensure that relatives interviewed would have a reasonably in-depth involvement with the ill person, if not always daily contact. After a member of the day unit recruitment team made an initial approach and handed over information packs, families who were willing to take part returned reply slips to the hospice and it was at this point that I would make contact to discuss their initial interest. Therefore patients acted as gatekeepers with regard to the recruitment of family members and had initial control over the decision to participate.

I interviewed my 23 participants over 12 months designated for empirical work completing 39 interviews in total across the nine families. Families were recruited at staggered stages across this time to avoid having too many schedules to manage at once. Ultimately, I inevitably fell into closer relationships with certain families and therefore interviewed particular families and family members more often than others, sustaining varying levels of contact over the 12 months of fieldwork.

Inviting families to give their own accounts about everyday life in unstructured, in-depth interviews allowed members to reflect upon and articulate particular understandings of the illness experience. It enabled individuals to share their experiences and understandings, but it also created opportunity to express views about the experiences and understandings of fellow family members and to consider how the family more generally goes about everyday life in the context of life-threatening illness. Moreover returning to re-interview families and to enquire about everyday life as it was actually happening, allowed me to engage with feelings and experiences infused with a sense of immediacy. This concern with everyday experience and the production of accounts or stories to represent it was at the heart of the interviewing phase of the research.

When I first met my interview participants, I explained that I would like to re-interview them over the course of a few months and gave the figure of three interviews as a benchmark. Sadly some of my participants died before three interviews or even a second meeting could be arranged. However by conducting post-death interviews with two family members from different families where the ill participant had died, I managed to gain some understanding of the more protracted effect on family practices when the ill family member was dying, and also when they had actually died.

Therefore, given the potentially sensitive nature of the interviews, location and context was an important consideration. Consequently I suggested in the information sheets that it was down to the individual families to decide how and where they would like to be interviewed. Ultimately all opted to be interviewed in their own homes, apart from one person who I interviewed at their place of work, and whilst I had anticipated that some individuals may wish to speak to me on their own, all the married couples in my sample requested to be interviewed together.

To conduct the interviews I used guides which listed areas of everyday family life to probe around, and some broad questions about family life and the illness. This acted as a prompt, but generally the research was participant lead. At the initial interview I was more concerned with scene-setting; I wanted to get acquainted with the family and to hear an overview of the illness story - for instance how it came about, current prognosis and what the general approach in the family was towards it. I aimed to explore broadly anything salient about the family's past, any general feelings and experiences of family life in the present (especially related to the illness) and to a lesser extent but where appropriate, I sensitively probed around understandings regarding the future. Then the purpose of any further interviews was to encourage the participant/s to describe their experiences of doing family life, day-to-day, at this time and to follow up on some of the issues which were discussed in previous interviews.

The interviews varied in length with the shortest recorded session approximately 35 minutes and the longest three hours and 40 minutes. The interviews were transcribed almost verbatim¹, and I did this personally once the interviewing had started to come to a close.

¹ Occasionally I made a decision to omit some (limited) dialogue from transcription if a passage of conversation was more general 'social chat', or clearly not relevant to the research aims. This has also happened in some cases for anonymisation purposes.