5 key points

1 Many family carers have fears and anxieties about coping with the dying process at home.

2 They need information, preparation and guidance about the dying process.

3 Equipment, medication and paid care should be provided at the right time but with sensitivity and explanation.

4 Carers need approachable and accessible health and social care professionals to support them in being there and “letting go”.

5 Professionals and paid carers need training to prepare them for end-of-life conversations with carers.

Method

The study followed a qualitative approach using grounded theory methodology. It focused on carers’ expectations and preparation for the last few days of their family members’ lives. I used a longitudinal design to capture carers’ perspectives, carrying out in-depth, semi-structured interviews with 15 carers in the weeks before the dying phase (current carers) and again three months after the death (bereaved carers).

The sample was from a specialist palliative care service in south-west England. Eleven carers were the patient’s spouse or partner, while four were adult offspring; five were employed full time and two part time, five had suspended work for caring, two were retired and one had part-time voluntary work. Thirteen patients had cancer, five were employed full time and two part-time. The study was approved by the local research ethics committee and the university research ethics approval panel.

Findings and discussion

Through concepts and themes identified from the interviews, it became clear that carers were playing a leading role in the drama of the dying process. This “dramaturgical” perspective, influenced by the work of Goffman (1959) and Harre and Blumberg (1988), provided the study’s theoretical framework.

The scene at the time of dying has been described as a stage (Donnelly et al, 2006), and this theatrical concept underpins the presentation of the findings. Fig 1 outlines the dramaturgical concept of carers’ experiences. Pseudonyms are used to protect confidentiality.

Carers’ “performance”

Carers took on a role they did not want because they wanted their family member to be well, and some alluded to their role as a performance:

Margaret (bereaved carer): “I found it extremely difficult to act as if everything was OK, because it wasn’t.”

Nicola (current): “You’ve got to be strong. Strong is the best thing. Don’t be weak. Try not to cry and just try and laugh. On the telephone you’ve got to try not to crack up because they can tell it in your voice.”

Researchers have identified “pretending” as a coping strategy for carers. Yates and Stetz (1999) found carers acknowledged their relative was dying, but chose to act as though they would continue to live. Carers also feared they would miss their cues:

Jane (bereaved): “I was worried to death... that am I going to know the signs, that am I going to miss him [dying]?”

Setting and props

Most carers saw home as the right place for their family member to die, but all found caring mentally and physically tiring. Some found aids and equipment, such as a hospital bed, helpful, but these also changed the setting:

Margaret (bereaved): “He had his own bed in his own room because it was a special bed that sang and danced and did everything. I did like that actually – he was put in bed and slept a bit because I had to sleep a bit.”

Dying at home is often viewed as synonymous with dying in your own bed. One carer felt under pressure from professionals to have a hospital bed:

Stephen (current): “It wasn’t Sarah’s wish I knew, but at one stage I felt it was being imposed on us... to be put downstairs in a hospital bed was not what she considered to be hospice at home. Hospice at home was to be as close to me as she could be at night, which actually made it easier for me and still does.”

Stephen resisted the pressure and his partner died next to him in their shared bed.

Stephen (bereaved): “At 12 o’clock I made her comfortable. She was gurgling a bit so I put her on her side and I sort of said to her: ‘Well you can go now but I somehow think you’ve got several more days of this,’ I woke up in the night, I don’t know what time, and thought I couldn’t hear her breathing. Then I heard her breathe... And then I woke up at seven o’clock and she was too cold and I’d been right up beside her. It just felt nice.”

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