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The state of dying

Carol Komaromy

Dr. Riley¹ told me that Elsie was in what he considered to be ‘a state of dying’. He added that she had surprised everyone by pulling through on Thursday night, but ‘she won’t recover. She may last a few more weeks, but she’s terminally ill. She’s had a CVA² and this is the cause of her sudden deterioration last week’.

This chapter is based on the findings of an ethnographic study into the management of death and dying in care homes for older people. The quote above sets the scene for the discussion that follows on how ‘dying’ was diagnosed. The data were drawn from participant observations over a 12-month period and interviews with care staff, general practitioners, care home residents and relatives of deceased residents in eight care homes in England.

Glaser and Strauss (1976) highlight the importance of being able to make temporal predictions of death for those people who work in the area of death and dying. They claim that this is explained by the need to reduce the uncertainty associated with death. Certainly

¹ The names of care home staff, residents and care homes have been changed to pseudonyms to protect their identity.

² CVA – Cerebro-vascular accident refers to either a clot in the brain which deprives a large area of brain tissue of oxygen and causes this to die, or a bleed which can have the same effect. Both types of CVA are more commonly called a stroke and result in a one-sided paralysis and depending on the site of the cerebral event, a loss of speech.

my findings showed that such 'temporal predictions of dying trajectories' enabled care home staff to prepare for death and, this preparation included the expressed aim of affording the benefit of terminal care to residents. Senior home staff members with experience of death and dying were more likely than less experienced colleagues to be able to assess whether or not a resident was 'dying' and, if so, how imminent the death might be. However, while staff often speculated about the significance of particular signs of dying, this dying status had to be confirmed, or conferred onto specific residents by a doctor, most often the resident's GP. I would argue that by formalising the period of dying, doctors acted as imprimaturs. They also decided whether or not to launch a rescue for those residents whose lives were considered to be worthy or capable of being 'saved'. As a last resort, general practitioners might also decide to transfer residents when it was agreed that it was beyond the home's capacity to care for them in this terminal phase. However, in my study, despite the fact that it was usually the resident's general practitioner who made any formal diagnosis of dying, the senior staff members were the people who orchestrated the management of death and dying. In practice this meant setting up a routine of terminal care, usually through a care plan. The privileged status of dying afforded a routine of care that was distinct from other forms of care. This involved residents being nursed in the private space of their own bedroom and no longer sharing the communal spaces of the home.

The rhetoric of a 'good' death, expressed so often at interviews, was not always the reality. My observations revealed that the main focus of end-of-life care was on the physical needs of residents. In particular, keeping residents clean and free from pressure sores was the main aspect of this care. For example, the matron of Regis House set up a care plan for Alice (one of the residents whose dying and death I observed), that included the need to

avoid pressure sores by changing Alice's position every two hours and also offer her liquids. I observed that the staff visited at least every hour, and when the fore mentioned two-hourly care was due, care staff spent longer with Alice (but not ever more ten minutes) performing the tasks of physical care-giving. Therefore, while staff expressed the aim of avoiding a 'lonely' death by sitting with dying residents, this seemed to be compromised by staff shortages and different priorities. If relatives were not available to keep a bedside vigil, then I noted from observations that care staff would look in on a dying resident at regular intervals.

In what follows I explore in more depth how the status of dying was awarded to residents. Throughout, I argue that the way in which the category of dying was constructed served to produce a good death as it was interpreted within institutional life.

Awarding a status of dying

The combination of changes in policy that result in later admission to care homes, and the shift away from the dangers of institutional care (Booth, 1985), have resulted in the need to 'keep residents going' in care homes. Therefore, despite their frailty and chronic illnesses this has resulted in a blurred boundary between living and dying, and, within this, I argue that the dying phase is narrowly defined as days or weeks. I argue further that a narrow dying trajectory minimised the risk of identifying dying too early and inappropriately.

While the transition into the category of dying allowed for material privileges associated with terminal care to be awarded to residents such as being kept in bed and receiving bodily care and pain-relieving drugs (often tokenistic) my data showed that, as with 'living', the 'dying' period also fulfilled symbolic functions. For example, fieldwork

observations revealed the extent to which the boundaries between life and death were maintained and the strategies that staff deployed in order to do so. The literature on boundaries and rituals is useful to this type of exploration and van Gennep (1960) identified crucial stages of life as rites of passage, including birth, puberty, marriage and death. He argued further that, through ageing and illness, individuals withdraw from active life and social contact. The arguments by Douglas (1984) also help to explain the symbolic significance of boundaries and thus the need to categorise and keep distinct and separate living and dying residents. Douglas argues that by maintaining boundaries that carry high levels of significance such as that between life and death, the rituals and actions that maintain a distinct boundary can as in this case serve to avoid contamination of life by death. It seemed to me that in care homes rites and customs served important psychological, sociological and symbolic functions that contributed to the need to separate living and dying residents.

However, while the short duration of the period of dying, allowed for a more sustained intense period of terminal care, my data showed the arbitrary nature of these categories. In a spiral of gradual but uneven decline, which is the case for many older and frail residents, the boundary between living and dying was not easily demarcated and, therefore, predictions were difficult to make. Furthermore, I argue that making an overt and explicit separation between living and dying residents was problematic in settings where death was viewed as the 'natural' and timely outcome of a long life (Komaromy and Hockey, 2001).

In the following section I consider how the dying trajectory for older people in care homes was narrowly defined and illustrate the qualities of dying and the way certain features

served as signs of the beginning of the dying trajectory. While there was some variation between homes, they all shared the practice of changed routines for a resident once the status of dying was afforded.

The separation of living and dying residents

When residents were considered to be dying, I was keen to explore any existence of the practice of moving them into a separate part of the home, which had been the case in Hockey's study (1990). However, in one interview with Meg Johnson, the head of Poplar Court, she told me that the practice of moving sick residents into bedrooms on the same corridor, so that care staff could more easily observe and attend to their needs, had ceased. She went on to explain how she had discovered that the surviving residents referred to this corridor as 'death row'. In none of the homes in my fieldwork did I observe the transfer or separation of dying residents into special spaces set aside for their care. However, it was clear from talking to care staff that, when a resident who was thought to be dying shared a room, the non-dying resident might be moved out of that bedroom, either at the terminal phase of dying or at the moment of death. Furthermore, several members of staff suggested that having a 'sick bay' would be one way of overcoming the problems of having to care for dying residents in the home.

While my data suggest that the practice of separating living and dying residents by moving such categorised residents into dying spaces had largely ended, living and dying residents continued to be kept spatially apart. For example, I noted that dying residents no longer shared the public spaces of the home and instead were kept in the more private space of their bedrooms. Separating residents categorised as dying from those who were considered to be living was the first significant change in the routines and practices of care homes that

marked the beginning of the dying process. For example, I would argue that the absence of the qualities of living and the exclusion from the community of living residents that followed and sometimes extended into a sustained lack of presence in public spaces of homes could be interpreted by other residents and visitors to the home as a sign of dying. In other words, this transition from the status of living to that of dying was marked by absence rather than being able to observe the physical signs of dying.

During my fieldwork, I heard staff and residents refer to vacant chairs as belonging to a particular resident. In this way, the surviving home residents were marking the space of an absent resident and participating in the activities associated with the production of dying. I argue that the absence of dying residents from public spaces not only separated 'dying' from 'living' residents, but also signalled to those residents who were 'living' what was taking place. Since making predictions about death and dying was in the interests of everyone in care homes, I argue that the interpretation was something that was co-produced by staff and residents. A resident's absence from the public spaces of the home was something that living residents remarked upon. For example, Lucy, a resident in Autumn Lodge, told me about the first time that she noticed something was wrong with another resident, called Mary, with whom she was friends:

She didn't come down to breakfast which was not like her, you know? Then she didn't make it for her lunch and I thought to myself, like, oh erm, there's something wrong here. I asked Jane (the care assistant) and she said, 'She's not so good today Lucy.' I knew it were *more* than that, though!

This brief extract from Lucy suggested to me that Mary's absence from her usual space in the home, in this case, the dining table, was something that Lucy interpreted as being significant and more than 'not so good' as the care assistant explained to her.

It might seem to be self-evident that, part of their task for care staff was distinguishing between living and dying and the outcome would be the development qualities they could be attributed to each living and dying category. However, while there is a clear distinction to be made between those residents who were able to get up and dressed themselves, and those whom the staff had to help, this degree of ability did not in itself define one of the qualities of living. The reality was that for a resident who usually got up out of bed and who could no longer do so, this change could be interpreted as a sign of dying, as the following quote by Lin, the head of Peacehaven Home, illustrates. I asked Lin how she knew that a particular resident – Florence – was dying:

Possibly about a month before she actually died. She just lay in bed really; she didn't want to do anything. It was just a case of wanting to keep her fluid intake up. We just didn't want to get her into hospital because we didn't feel she would benefit from that. We did speak to the niece and say that she was deteriorating; do you want us to get her into hospital? And she said, 'No. She's been here so long.' Obviously we called the doctor in.

The head of home indicated that because Florence 'just lay in bed' she was dying. This was significant as it marked a change for someone who had been a relatively active participant in living activities. Also in that account, the head of home used the word 'obviously' as if sending for the doctor was an uncontested part of confirming the process

of dying, even though, from what she had told me, she did not think that the hospital could do anything for Florence. I would argue that, for Florence, the medical diagnosis served to confirm the staff's own prediction of the beginning of the dying phase.

Medical diagnosis as a marker of dying

By contrast, Danny, a comparatively young male resident aged 67 years, at Regis House had been considered to be dying over a period of months. Eight months after Danny died, I visited Danny's wife, Lauren, at her own home and talked to her there about his death. There were several events during his illness trajectory that made Lauren think that Danny was dying. The following example from Lauren describes the first of a series of markers which she interpreted as significant:

And I thought then, I don't know he's going, you know, and that he was going down. And I thought, 'Oh golly, you do look frail', you know, because he was a strong person. But I thought then that he wasn't getting much better, you know? But he seemed to go down from then.

Lauren described how Danny had changed his routine from sitting in the residents' lounge to going to bed to lie down in the afternoon, marking a change in his routine behaviour. She followed this account with a description of the moment at which she knew that Danny was definitely going to die and used pneumonia as a metaphor for death. Lauren's retrospective account of Danny's death in the nursing home also shows how the signs that marked dying were not universal since the staff and Lauren placed different interpretations on their significance as features of dying:

Well, I didn't think he was getting any better because they said he had a chest infection. But when I looked at him, I thought it was pneumonia and I thought, 'Oh golly, I bet he's – you know – this is the end – or the beginning of the end. Because, you know, people that are ill, or been ill for a long time, they don't always die of the – of what they're ill with. They die of pneumonia, don't they?

And I sort of guessed that he hadn't long to live, you know. But they made him very comfortable. In the last period, they came up every half hour. And they were feeding him liquid drinks.

This account from Lauren conflicted with those accounts from the home staff who considered that Danny might live. For example, home staff told me that they did not think that Danny was dying because, as the youngest resident in the home, he was *too* young. Chronological age, as timeliness, was an essential feature of a 'natural' death at the end of a long life. Lauren's translation of the term 'chest infection' into 'pneumonia' and, for her, its associations with death, suggested to me that there were different signs being read from similar information. I would emphasise the difference in opinion between the staff and the wife of a resident about what counted as a sign of the beginning of the dying period, and the power which conferring a medical diagnosis had on confirming bad news as Lauren anticipated.

For many residents, it was difficult to discover many clear bodily signs that they were dying since theirs was a path of general deterioration. I argued earlier that the deaths that occurred in homes often followed a slow deterioration and, as such, residents were not

subjected to the diagnostic medical tests that a younger person might receive. The pronouncement of a doctor, even in the absence of any medical evidence was a common marker of the beginning of a period of dying. In this way, for Lauren, it seemed that she was part of the negotiation of dying in that the interaction between the information which she received, combined with her own interpretation of what she looked for, persuaded her that her husband was dying. This suggests that on one level, information, although carrying a high level of significance, was still subject to interpretation. On another level, the medical information, in the form of the doctors' announcement, seemed to carry a lot of weight and made Lauren use the information to confirm her fears.

The following example is taken from an interview with the head of Church House. She described a medical diagnosis that she interpreted as a marker of dying:

She had a stroke, CVA and – a very large one – and unfortunately she lingered for about a month. Full nursing care, similar to Ted.

There are several interesting points about this brief extract. First, while it is the case that many people make a recovery from a stroke, for this resident the stroke, which was called 'a very large one', served to indicate that a catastrophic event had occurred. The head of home's assertion was underpinned by an assumption that after a 'large' stroke, which qualified as an acute episode and, as such, a clear marker of dying, there would be a rapid decline into death. Second, the use of the word 'unfortunately' suggests regret that this resident's period of dying was protracted. The regret could also refer to the amount of care that this resident required, 'full nursing care', which would have been difficult to sustain in a small home such as Peacehaven. Furthermore, because this death followed Ted's death,

another resident who also needed a lot of nursing care, there would have been no respite for the staff. Deaths in care homes were not necessarily spaced over a period of time and even in small homes, with a comparatively low death rate, two deaths close together could make considerable resource demands. The need to be able to marshal scarce resources, and the timing of deaths so that they did not consume all of the resource, further explains the staff's reasons for their pre-occupation with the prediction of dying and their desire to avoid defining dying 'too early' and thus have a more extensive period of giving terminal care.

Conclusion

The examples of markers of dying discussed above which included being absent from the public spaces of the home, having a care plan, becoming immobile and having a medical diagnosis confirmed, have provided brief illustrations of how the period of 'dying' was negotiated. The markers also include not eating and other withdrawals from activities associated with living, which were likewise negotiated and not intrinsic signs. In my data I noted how in the retrospective accounts from staff and other residents, those residents who had been able to move around and who were no longer capable of independent moving were marked as having suffered a severe and possibly irreversible change. I argue that this change from an established way of behaving served as a marker of dying. Furthermore, the way in which dying was produced could be seen as a circular process whereby certain qualities of dying were attributed to individual residents and their condition was then interpreted on this basis. The boundary between life and death which is maintained through such practices requires care home staff to make complex and seemingly arbitrary judgements. The price for getting this wrong is high. Predicting dying sets in motion activities that are difficult and embarrassing to reverse.

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