Deathbed phenomena and palliative care workers

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Our deathbed research project is in answer to a plea from palliative carers who want to understand how they can provide better support for patients dining the dying process.

Irrespective of sceptical comment, deathbed phenomena happen. They are witnessed by people from all walks of life and in all kinds of situations. They inspire what I would describe as 'awe' in those who talk about them.

Let me give a few examples which have come to light in the course of the research I have been doing:

- A work colleague told me that her aunt talked of seeing and smelling flowers just before she died. This provided immense comfort to her aunt.

- The manager of a counselling centre with which I am associated recounted a couple of days before her mother died that her mother repeatedly called out, 'I'm coming! I'm coming!' to a blank wall. At the time, the manager put it down to a lack of oxygen, but now thinks there may be more to it.

- A more disturbing story I heard was about a young woman who was to be admitted to hospital for a routine operation. A couple of weeks before she went into hospital, she told her mother she had seen

the 'Angel *of* Death'. Her mother thought she was making it up, so ignored it. The girl died on the operating table.

• On the other hand, I was told this story by a friend. Her friend had a three-year-old daughter who was critically ill. The night before her daughter died, the mother saw an angel standing at the end of the child' s bed. This soothed and reassured the mother, because she believed her daughter had been collected by the angel and was being cared for in death.

Traditionally, deathbed phenomena are not addressed during medical or nursing training. Within the medical fraternity, death is normally viewed as a failure. In fact, one of the interviewees referred to death as 'the enemy' — so medical professionals have to find their own way of dealing with death and of making sense of what they are witnessing as the patient dies.

Nevertheless, there is now a growing realisation amongst medical practitioners and nursing staff that deathbed phenomena do happen. The problem is that physicians and carers often do not know how to support their patients, or what to say to them. But come back to that in a minute.

We decided to conduct a pilot study with the Camden Palliative Care Team (CPCT), to explore the impact that witnessing deathbed phenomena may have on them. Our findings were fascinating. The CPCT agreed that deathbed phenomena are virtually impossible to explain. One doctor described them as 'things that cannot be explained by science.' The team were also agreed that deathbed phenomena not only occur, but they are an intrinsic part of the dying process.

When questioned about the difference between drug-induced hallucinations and deathbed phenomena, all the interviewees made the same distinctions. Those patients who experience drug-induced hallucinations report seeing things like animals walking around the floor, children running in and out of the room, devils and dragons dancing in the light, insects moving on the wallpaper, or patterns undulating on the carpet. Patients also tend to 'pluck' at the air, or shiver violently. These hallucinations are vivid to the patient — some patients tell their carer what they are seeing and ask if it is real. However, the hallucinations tend to be annoying rather than frightening, and medical staff can usually control them by changing drugs or drug dosages.

On the other hand, deathbed phenomena hold some kind of profound meaning for the patient. According to one nurse, the patient's language changes when they are describing them. She said 'it's like a switch has been thrown'. Some patients will talk about seeing a loved one who has already died. Others, as I outlined earlier, will call out to someone whom their relatives or carers cannot see. Some patients talk about being surrounded by a warmth and a light which is comforting and secure. The interviewee who experienced such a phenomenon described it as, 'it's really nice; it's a bit like the smell of fresh bread'.

Other patients feel compelled to make some kind of reconciliation with estranged family members or friends. An interviewee explained it as patients are processing their lives and looking towards where they are going and who may be there and what spiritual aspects of life they are going to have. They are definitely taking stock of what is going on, and dealing with their inner selves, facing themselves, maybe for the first time, because they haven't done it before. There's nowhere to go — no escape when you are dying.'

Interviewees reported other deathbed phenomena, such as waking dreams which are different from ordinary dreams. An interviewee told me that one of her patients who was close to death dreamt that he was being judged by a higher power; but in this dream there was also temptation. So, in a way the interviewee believed that, through his dream time, the patient was trying to resolve whatever was going on for him.

Some people will start writing poetry or singing religious songs. Others report synchronistic events at the precise moment of death, such as the dying or dead person appearing to a relative, or clocks stopping, or a sudden appearance of a bird or a butterfly.

But the most important aspect to come out of the research was that the interviewees felt put into the position, as one nurse described it, of being the 'new priest at the bedside'. Patients often want answers that physicians or carers are unable or unwilling to provide.

All the interviewees stated that that they had little or no training to deal with these existential issues. Therefore they believe that many deathbed phenomena go unreported. Few of them are encouraged to talk about it at their team meetings, nor do they have appropriate supervision.

The upshot of this is that the interviewees made a request for pastoral care training, workshops on deathbed phenomena, and opportunities for time to discuss what they had witnessed, in order to provide better support for their patients, as well as making sense of it for themselves.

Whilst Sue's study was carried out in a Community Palliative Care Team, my study took place in a hospice, where I interviewed nurses, doctors, chaplains, and a complementary therapist.

What came out of this immediately was the fact that different disciplines within the hospice had totally different attitudes to deathbed phenomena.

The chaplains were very eloquent on the subject. They had had a lot of experience of deathbed phenomena, as they were often called in at the time of death. They had vocabulary for it and were very excited by it. They also felt able to interact with the situation quite easily, as it was no mystery to them.

By contrast the doctors had very little experience of deathbed phenomena and were awkward about it. There was a sense of professional embarrassment; of going into a taboo area. After all, where do deathbed phenomena fit in the reductionist medical model?

Between these two parties fell the nurses and complementary therapist who had a wealth of experiences, nurses most often being there when the patient died. They were in total awe of the experience, but didn't see how they could interact with it. It wasn't really within their remit and they were not trained in this area. They saw themselves merely as witnesses. So it is interesting that just one discipline felt able to do something with all this.

The second thing that came out of this study was that there was a wealth of experiences: deathbed phenomena *do* happen. Some of these phenomena seem to perform a particular function. They are generally helpful to the patient, and very comforting. They are also helpful to the relatives, who are often around that patient at the time of death.

Let me give you some examples of phenomena helpful to the patients:

There was a Thai lady, who was reported to have come into the hospice to die. She had married an Englishman, so she was very anglicised, having been in England for some years. As she approached death she wanted to take on her Buddhist faith again. She asked her children, who were from Thailand, to bring a Buddhist monk to her, so she could resolve some issues before she died. To a Buddhist this is very important. However, the monk never came. One night, a nurse went to settle this lady, who at this stage was unable to move, unable to get out of bed, and not speaking very much — in that state just before you die — almost unconscious. She found the lady was kneeling on the floor and bowing to her three jade Buddha figures which were arranged on the floor.

She was talking to them and waiting for answers and nodding. The nurse said she became involved in it as a witness because, although she didn't speak Thai, she understood every word of the exchange. Then the lady looked up and said to the nurse, 'Now you know why I wanted a monk here', and she got back into bed, rolled on to her side, and didn't move or speak until she died about twenty minutes later. So this experience can be seen to have helped this lady resolve issues that were unresolved before she got to the moment of death.

A second example: a thirty-eight year-old man was dying. Too young to die, he thought, and he was resisting; he was denying. Then his mother and his own eight-year-old son, both of whom were dead, appeared to him in a vision and after that he said to the nurses, 'Now I feel that I can die with peace, because I know I'm going to join my loved ones.' So another example of how these visions can be helpful.

These visions can also comfort the relatives. A man was dying in a hospice with his family around him and a little robin suddenly appeared on the window-sill outside the room. The daughter said, 'Look! There's the robin!', and it turned out that within this family there was a tradition that if anyone was about to die, a bird — usually a robin — would appear very close by as a portent of the death. It was a very positive thing in that family, and here was the robin, coming 'as ordered' as it were. Then the father who was dying opened his eyes from his 'unconscious' state and said, 'That bird will take any soul'. The family were grieving; they were going to miss this man, but were hugely comforted to know that in the presence of death (about which we can do nothing, as we are not in control) here was an example of order, of things going as expected — and it gave the relatives a coping mechanism to get through this very difficult period.

Another instance: a lady said to the chaplain of the hospice, and to her husband, 'I'm so scared that I'm going to go alone.' The husband said to her, 'Look, don't worry, ducky, I'll be with you; I'll hold your hand'. She said, 'Oh, no, I don't want *you;* I want someone to collect me from the other side'. When her husband and the chaplain were sitting with her at the moment of her death, in the middle of the night, the door of the room swung open, and nobody came in. They took notice of this and at that moment the lady's hand went into the air, as if grasping another offered hand, and then fell down as she died peacefully. The husband said, 'Gosh —it looks like she got what she wanted; it looks like someone came to meet her'. And

he felt hugely comforted by this — though we shall never know whether *she* was comforted!

So the last category is that people may get what they need, as I have just illustrated, but also here is one last example. A lady was frightened of the dark. Death to her was darkness, a snuffing-out, a great black abyss. As she was dying, she said to the nurse, 'A light! A light!' The nurse couldn't see anything, but she said, 'O.K.; you're seeing a light'. And the patient replied 'Yes and it's a *good* light', and then she died. The nurse remembered how frightened this patient had been of the dark, so it seems that we may get what we need — and that's hugely comforting for us as carers because *we* are going to face death ourselves and we need to know too, we need to have *our* issues resolved.

So a conclusion from this hospice study is that there is an enormous unmet need in palliative care. There are all these experiences going on and they are very much 'under the table', very taboo. We want to bring them out into the open. Interestingly, the very act of coming into the hospice, talking about these things and doing the study, affected the culture in a subtle way. One doctor who had formerly been reticent about these phenomena is considering changing her practice in this area as a result of being in contact with the study. One of the chaplains is also going to develop her practice further within the hospice. By this study happening, we are influencing the culture in a very subtle way.

This unmet need in palliative care could be addressed by setting up workshops, fora for discussion, educational literature, and even a publication on the importance of recognising the existential issues that arise in the dying process.

Sue Brayne, Chris Farnham, and Peter Fenwick have published a paper in the January 2006 issue of the *American Journal of Hospice and Palliative Medicine,* entitled 'An understanding of the occurrence of deathbed phenomena and its effect on palliative care clinicians' and I hope that my own study will be written up and published in 2007.

We know there's a lot of interest; the Princess Alice Hospice in Esher is taking on our study, so we are going to do more interviews with palliative care professionals, and we are very excited about that. A Gloucester nursing home and an oncology unit in Cheltenham have also registered interest. Gradually we are becoming 'respectable' as we uncover something which has been very much hidden in our medical and social culture.